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Interventions for Cancer Survivors in Occupational Therapy: A National Survey

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A Research Project Entitled

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By

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Abstract

This study aims to describe how occupational therapy (OT) practitioners are addressing side effects and occupational performance deficits of cancer survivors in order to analyze current practice trends. Survey methodology with non-probability purposive sampling was used to recruit OT practitioners that work with adult cancer survivors. A total of 267 surveys were distributed and 70 surveys returned (26.20% response rate). Participants reported treating the following side effects of cancer: fatigue (98.57%), pain (84.29%), cognitive impairments (80.0%), and neuropathy (78.57%), more frequently than psychosocial (68.57%), lymphedema (50.0%), and sexual dysfunction (20.29%). Practitioners indicated addressing occupational performance deficits in basic activities of daily living (BADLs) more often than instrumental activities of daily living (IADLs). A low referral rate to OT services was found from primary care physicians. Respondents reported treating survivors most frequently in the acute care setting. Increasing education to cancer survivors and healthcare professionals is imperative to ensure that survivors receive access to holistic and quality OT services across the continuum of care.

Interventions for Cancer Survivors in Occupational Therapy: A National Survey

There were approximately 15.5 million cancer survivors in 2016 within the United States, and that number is expected to increase to 20.3 million by 2026 (National Cancer Institute, 2018). An individual is considered to be a cancer survivor from the moment of diagnosis until the end of life (National Cancer Institute, 2014b). While the prevalence and incidence of cancer continues to increase, the number of cancer related deaths have dramatically lowered in the past 10 years due to more effective diagnosis and treatment (National Cancer Institute, 2014a). Approximately two in three adults diagnosed with cancer are expected to survive more than five years (National Cancer Institute, 2012); therefore, there are more survivors today than previous decades.

While cancer treatment is vital, the side effects associated with treatment decrease survivors' overall quality of life and keep them from fully participating in valued occupations (Hwang, Lokietz, Lozano, & Parke, 2015). These side effects that arise both from cancer and its medical treatment will likely impact a person's ability to participate in activities of daily living (ADLs), instrumental activities of daily living (IADLs), social participation, work, and education (Berg & Hayashi, 2013). Some of these side effects include, cognitive impairments, fatigue, psychosocial issues, sexual dysfunction, lymphedema, pain, and neuropathy (Goncalves & Groninger, 2015; Silver & Gilchrist, 2011). These impairments can be long lasting; therefore, cancer survivorship is now being categorized as a chronic condition (Baxter, Newman, Longpré & Polo, 2017).

During cancer treatment, approximately three out of four survivors experience cognitive impairments and approximately one-third experience issues after completing treatment (American Society of Clinical Oncology, 2015). Cognitive impairments occur when an

individual has difficulty with combined processing functions which can include problem solving, self-regulating, reasoning, strategizing, recalling, concentrating, and performing goal directed behavior (Giles et al., 2013; Radomski & Morrison, 2014). Many survivors that experience cognitive impairments report problems with memory, concentration, attention, and executive functioning (Sleight & Stein-Duker, 2016). These cognitive skills are central to a variety of daily tasks, thus it is clear that cognitive impairments can be a source of distress for many survivors and problematic for participation in valued occupations and roles (Stuss, 2011; Hutchinson, Hosking, Kichenadasse, Mattiske, & Wilson, 2012; Rabinowitz & Levin, 2014). Occupations that can be affected due to cognitive impairments include IADLs such as paying bills, and running errands (Sleight & Stein-Duker, 2016). Additionally, cognitive impairments are associated with decreased community engagement, social role functioning, and productivity (Reid-Arndt, Yee, Perry & Hsieh, 2009). Survivors experiencing cognitive impairments report a greater difficulty maintaining their ability to participate in work (Wefel, Lenzi, Theriault, Davis & Meyers, 2004). Bradley, Neumark, Bednarek, & Schenk (2005) concluded within 6 months after diagnosis, one third of survivors with previous employment were no longer working. Those who returned to work reported working fewer hours per week than previously worked (Bradley et al., 2005). OT practitioners address cognition as it relates to participation and occupational performance (Giles et al., 2013). Therefore, OT practitioners can use their expertise by implementing interventions with “cognitive strategies to address memory, organizational executive function deficits, and low-energy task that focus on restoring engagement in daily occupations” (Longpré & Newman, 2011, p.1). OT practitioners can provide recommendations for strategies to compensate for or adapt to cognitive impairments for the purpose of resuming life roles such as a parent, spouse, worker, etc (Newman, 2011; Polo & Smith, 2017).

Bower & Lamkin (2013) found persistent fatigue affected approximately 30% of survivors for up to 10 years after treatment had finished. Cancer-related fatigue can be defined as “a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer and/or cancer treatment that is not proportional to recent activity and interferes with usual functioning” (Bower, 2014, p. 27). For many survivors, fatigue is treated with pharmacological agents which are chosen based off of the cause of the fatigue (Yennurajalingam & Bruera, 2014; Koornstra, Peters, Donofrio, van den Borne, & de Jong, 2014). OT practitioners commonly implement the following nonpharmacologic interventions education, sleep hygiene, and energy conservation when treating fatigue (Pearson, Morris & McKinstry, 2016). Practitioners can provide interventions for sleep by encouraging proper sleep routines including sleep preparation and participation and modifying daytime activities to increase daytime arousal and decrease nighttime sleeplessness (American Occupational Therapy Association, 2012). Additionally, OT practitioners can assist in implementing energy conservation strategies such as taking additional rest periods, priority setting, delegation, and pacing oneself so that a cancer survivor can manage fatigue during occupational performance over time (Barsevick et al., 2004).

The experience of pain for survivors can occur at the time of diagnosis, during treatment, or after treatment is finished (American Cancer Society, 2016). Researchers have found for 30 to 60% of survivors pain shifts from a short-term problem during treatment to a chronic problem, potentially lasting a lifetime (Brown, Ramirez, & Farquhar-Smith, 2014; Levy, Chwistek & Mehta, 2008). Cancer related pain can be treated through pharmacological and nonpharmacological interventions. Pharmacologic interventions primarily consist of opioids to treat pain however antidepressants, anticonvulsants, and nonsteroidal anti-inflammatory drugs

may also be prescribed (Taverner, 2015). OT practitioners can work with survivors so that pain interferes less with their meaningful activities through cognitive behavioral strategies such as relaxation and visualization, or through more physical intervention such as electrocutaneous nerve stimulation (Hofmann, 2015). Specifically, for peripheral neuropathy, electrocutaneous nerve stimulation have been found to be an effective treatment intervention (Coyne, Wan, Dodson, Swainey & Smith, 2013). Education based interventions are found to improve knowledge, reduce unfavorable attitudes toward cancer pain, and decrease average pain intensity (Urlic & Hoffmann, 2010). Finally, OT practitioners can work with clients experiencing cancer related pain to teach coping strategies, identify painful activities and recommend adaptive equipment to decrease pain with these identified tasks (American Occupational Therapy Association, 2002).

Psychosocial issues associated with survivorship include depression, anxiety, decreased self-esteem, and distress (Olesen et al., 2016). Pitman, Suleman, Hyde, & Hodgkiss (2018) estimated that 20% of survivors experience depression and 10% experience anxiety. These issues can continue long after the client is cancer-free and in remission, affecting quality of life and willingness to engage in meaningful occupations (Gossain & Miller, 2013; Hwang et al., 2015). The most common occupations that are affected by these psychosocial issues include bathing/showering, sleep, education, work, social participation, and leisure participation (Hwang et al., 2015). It is important for OT practitioners to help clients who may be dealing with psychosocial issues, such as depression, anxiety, and decreased self-esteem (Hwang et al., 2015). OT practitioners have the skills to help survivors with psychosocial issues by taking a client-centered approach to modifying activities and the environment to improve quality of life (Longpré & Newman, 2011).

Sexual dysfunction associated with survivorship can be found in any cancer type, stage and in both men and women (Brotto et al., 2012). In the United States, almost two-thirds of survivors received treatment for pelvic or breast tumors, and at least 50% of these individuals presented with severe and long-lasting sexual dysfunction (Schover et al., 2014). Sexual dysfunction decreases the sexual and overall quality of life for survivors (Barsky Reese et al., 2014). Some of the physical aspects that affect sexual dysfunction in survivors are fatigue, nerve damage, pain, dryness, discomfort and many other side effects from cancer related surgeries (Barsky Reese et al., 2014; DuHamel et al., 2016). Decreased body image, self-esteem, self-efficacy and partner communication are some of the psychosocial aspects that negatively affect sexual dysfunction (Jun et al., 2011; Krychman & Katz, 2012). OT practitioners can implement interventions using relaxation techniques and stress management, such as mindfulness-based interventions, to help clients with psychosocial problems associated with sexual dysfunction and survivorship (Newman, 2011). Additionally, OT practitioners can recommend alternate methods for sexual intimacy while managing symptoms to allow the client to return to their activities associated with their role as a partner (Newman, 2011).

Lymphedema is a common side effect that can appear within days or years following cancer and/or treatment (Petrek, Senie, Peters, & Rossen, 2001; Shaw, Mortimer, & Judd, 2007). Researchers have found that an onset of lymphedema happens in approximately 80% of survivors following surgery (Petrek et al., 2001). Lymphedema is a progressive condition that can cause dysfunction in daily life, emotions, and cause stress (Gautam, Maiya, & Vidyasagar, 2011; Vojáčková, Fialová & Hercogová, 2011). Rehabilitation is used to decrease the negative effects of lymphedema and increase quality of life (Gautam et al., 2011). OT interventions aid

survivors in managing lymphedema in order to resume meaningful occupations (Hwang et al., 2015; Wigg, 2012).

The American Occupational Therapy Association (AOTA) has deemed cancer care and oncology as an emerging area of practice in OT (American Occupational Therapy Association, 2011). Therefore, it is imperative to examine literature that supports evidenced-based OT interventions to maximize therapeutic outcomes for survivors.

Review of Literature

There is limited research on interventions for survivors facing cognitive impairments and a paucity specifically in OT literature. Support was found for OT interventions for cognitive impairments with conditions other than cancer. Medicare and insurance companies provide reimbursement for evidence-based interventions for cognitive impairment following traumatic brain injuries and strokes (Giles et al., 2013).

There are moderate amounts of literature to support compensatory strategies to improve occupational performance of individuals with cognitive impairments, and multiple clinical trials demonstrating the effectiveness of interventions for this side effect (Radomski, Anheluk, Bartzen, & Zola, 2016; Gillen et al., 2015). Level I randomized control trials support compensatory strategies and cognitive training programs with people who had suffered a traumatic brain injury; time pressure management and cognitive strategy training with people who had suffered a stroke; and memory training in people with multiple sclerosis for cognitive impairments interventions (Cantor et. al., 2013; Winkens, Van Heugten, Wade, Habets, & Fasotti, 2009; Guesgens et al., 2006; Solari et al., 2004). Additionally, the effectiveness of group-based Cognitive Strategy Training (CST) was demonstrated in a level III pilot study with

veterans with persistent mild cognitive disorder and history of traumatic brain injury (Huckans et al., 2010).

Most studies with cognitive impairments were conducted by researchers from disciplines other than OT and much of the research does not explore cognitive impairments in terms of occupational performance. Therefore, it is unknown as to whether any study-related improvements can be generalized to the real world (Yu & Mathiowetz, 2014). The OT profession has the potential to grow its role with survivors experiencing cognitive impairments (Sleight & Stein-Duker, 2016) and there is a need to for evidence-based, client-centered interventions supporting occupational performance for survivors throughout life (Newman & Campbell, 2013).

Research focuses on populations facing chronic fatigue other than cancer including rheumatoid arthritis, multiple sclerosis, pulmonary diseases, chronic fatigue syndrome, and postpolio syndrome (Barsevick et al., 2004). Interventions that have proven to be effective in reducing and managing clients' chronic fatigue include education, support groups, sleep therapy, light exercise, and mindfulness (Reif, de Vries, Petermann & Görres, 2013; Purcell, Fleming, Burmeister, Bennett & Haines, 2011; Björneklett et al., 2012; Saarik & Hartley, 2010; Wanachi, Armer, & Stewart, 2011; Ritterband et al., 2012; Huether, Abbott, Cullen, Cullen & Gaarde, 2016; Barsevick et al., 2004; Yuen, Mitcham & Morgan, 2006; Santorelli & Kabat-Zinn, 2013; Johns et al., 2015).

There is strong evidence within the literature to support the role and intervention strategies of OT practitioners working with survivors experiencing pain. Practitioners work with survivors to reduce the interference of pain with meaningful activities through cognitive behavioral strategies such as relaxation and visualization (Hofmann, 2015). Informational

education based interventions on pain improve knowledge and reduce unfavorable attitudes toward cancer pain in addition to reducing average pain intensity (Urlic & Hoffmann, 2010). Finally, OT practitioners can work with clients with chronic pain to identify painful activities, teach coping strategies, and recommend adaptive equipment to decrease pain with identified tasks (AOTA, 2002).

There is moderate Level I evidence for interventions regarding guided self-determination and psychoeducation/health education (Olessen et al., 2016; Badger et al., 2013; Guo et al., 2013). Guided self-determination interventions demonstrate improvement in physical well-being and quality of life in cancer survivors (Olessen et al., 2016). Psychoeducation and health education interventions decrease depression and anxiety levels along with improved emotional functioning in survivors (Guo et al., 2013; Badger et al., 2013). There is moderate evidence regarding self-management and cognitive behavioral therapy specific to survivorship (Liu, 2012; Loh, Packer, Chinna, & Quek, 2013), however other disciplines use these interventions. O'Toole, Connolly, & Smith (2013) implemented an occupation-based self-management program for chronic disease management as a whole, not specific to survivorship, and found the program to be effective in lowering anxiety and depression. Hwang et al. (2015) call for Level I evidence in OT practice regarding psychosocial issues and cancer.

Due to stigma around the topic, there is little research on interventions addressing sexual dysfunction with survivors (Brotto et al., 2012). Few research articles are present within the OT profession, however the evidence from other professions falls within the OT scope of practice. There is research to support the use of modifications and adaptive tools for sexual intimacy (Iavazzo et al., 2015; Perz, Ussher, & The Australian Cancer and Sexuality Study Team, 2015). A limited number of articles support using psychological interventions, such as mindfulness-

based cognitive therapy and psycho-educational therapy to educate the client on sexual dysfunction and how to address these concerns (Baker, Costa, Guarino & Nygaard, 2014; Brotto et al., 2012; DuHamel et al., 2016). Overall, interventions for sexual dysfunction is an area that is lacking in OT research and falls within the OT scope of practice due to this side effect decreasing a client's quality of life (American Occupational Therapy Association, 2014b; Newman, 2011).

Lymphedema can be treated by OT practitioners certified in complete decongestive therapy (National Lymphedema Network, 2013). There is strong evidence to support complete decongestive therapy as an intervention, which includes manual lymphatic drainage, pneumatic pump drainage, and compression (Mioc & Pantea, 2013; Morgan, Murray, Moffatt, & Young, 2011; Todd, 2011; Uzkeser Karatay, Erdemci, Koc, & Senel, 2015; Wigg, 2012). In addition, there is moderate evidence to support exercise as an effective intervention to improve the quality of life of an individual with lymphedema (Bloomquist, Karlsmark, Christensen & Adamsen, 2014; Gautam et al., 2011). Weak evidence was found to support acupuncture as an effective treatment for lymphedema; however, it is not a traditional intervention implemented in OT practice (Yao et al., 2015).

The OT profession is now encouraging therapists to view cancer as a chronic condition due to the above-mentioned side effects (Baxter et al., 2017). Researchers indicated the impact of physical activity, symptom management, multidisciplinary rehabilitation, psychosocial, sexuality, and return-to-work OT interventions in a recent systematic review (Hunter, Gibson, Arbesman, & D'Amico, 2017a & 2017b). Researchers also indicated that there is a need for further research exploring occupation-based interventions with integration of participation outcomes during various points in the survivorship continuum (Hunter et al., 2017b).

Researchers in this study uncovered a paucity of evidence exploring current OT intervention practices with survivors, which is necessary for the OT profession to reflect upon so that survivors' occupational needs are being met. Therefore, the purpose of this study is to describe how OT practitioners are addressing survivors' side effects and occupational performance deficits in order to analyze current OT practice trends.

Methods

Research Design

Researchers utilized survey methodology in the form of an anonymous electronic questionnaire to collect information about the current interventions OT practitioners are using during service provision with survivors. This method was chosen to allow for low costs, convenient data gathering, and to recruit a large number of participants (Creswell, 2009). Researchers incorporated a pilot and pivotal phase. A pilot phase is recommended for web survey development to maximize response and minimize measurement error, as it allows for review of the entire survey process and assesses the surveys success, including what is working and what needs improvement (Dillman, Smyth, & Christian, 2014; Portney & Watkins, 2015). This study was approved by the University of Indianapolis' institutional review board. All participants indicated consent prior to completing the survey.

Recruitment

Inclusion criteria consisted of participants that were English speaking OT practitioners, OTRs or OTAs, working with adult (18+) cancer survivors. There was no indicated exclusion criteria.

Both phases of recruitment included sending an electronic survey link to professional contacts. Non-probability purposive sampling was utilized to recruit participants for the pivotal phase of the study, this is an effective way to generate a sufficient sample with populations that

represent insight towards the purpose of the study (Carter & Lubinsky, 2015; DePoy & Gitlin, 2015). Potential participants were asked to provide the researchers with email contacts of their connections who met the inclusion criteria or to distribute the survey to these connections and indicate the number of connections contacted in order to calculate a response rate.

Procedures and Data Collection

Survey development. Based on a thorough review of the literature, the researchers developed a 19-item novel questionnaire. Questions were developed specific to pain, fatigue, neuropathy, cognitive impairments, sexual dysfunction, psychosocial issues, and lymphedema. Themes derived from the OT Practice Framework: 3rd Edition guided occupations included in the survey. Since there are no established psychometric properties, expert reviewers were utilized to establish content validity to identify and correct technical issues within the survey that the researchers may have missed (Carter, Lubinsky, & Domholdt, 2011; Dillman et al., 2014). The researchers obtained feedback from five experts in the area of survivorship from diverse OT practice settings: inpatient, outpatient, home health, and skilled nursing facility. Changes made to the original survey based on the expert's feedback resulted in a 25-item pilot questionnaire.

Pilot. Data collection through the pilot and pivotal phase of this study consisted of a survey through Qualtrics, an online survey platform used to collect and analyze data (Qualtrics, 2017). This questionnaire was estimated to take ten minutes to complete and consisted of closed ended and partially closed-ended questions. Eleven participants completed the survey for the pilot phase. Data was analyzed, and questions were improved based off of responses in order to enhance survey success.

Pivotal. Based on changes made from the pilot survey, researchers finalized a 34-item questionnaire that included closed and partially closed-ended questions. In order to allow

participants to only answer questions relevant to the side effects they directly address, the survey used skip logic to determine the flow of questions presented to each participant. Skip logic allows the survey creator to dictate how questions are presented based on the answers given for previous questions. An example of skip logic in this survey occurs when a participant selects the option 'are not addressing' to a specific side effect then the questionnaire skips to the next section. If the participant selects that they are addressing the side effect then this skip logic allows the researchers to go deeper and collect more information on interventions and referrals for that side effect. Due to this skip logic, not all of the 34 questions were asked of every participant. Overall, this is a strength of the survey because it allows for more information to be gathered on side effects being addressed and saves participants time from answering questions about side effects, they have previously stated they are not addressing. See Appendix A for the complete pivotal survey questionnaire and Appendix B (table 1B) for question distribution.

An initial email with study-related information and a request to participate was emailed to potential participants, posted on social networking sites, American Occupational Therapy Organization forums, and willing state professional organization websites. For the pivotal phase, the aim was to generate a 26% response rate. This response rate is approximately midpoint to the recommended liberal (5%) and stringent conditions (58%) for survey response rates (Nulty, 2008).

Data Analysis

Results were collected and data analyzed using descriptive statistics through Qualtrics (Qualtrics, 2017).

Results

Participants

The survey was sent to 267 potential participants. Eighty-two surveys were returned, two lacked informed consent, and 10 were partially completed resulting in 12 surveys being discarded. Therefore, 70 completed surveys were entered in the data set resulting in a response rate of 26.20%. Table 2B presents respondents' practice setting based on single or multiple settings. Respondents indicated treating survivors across the cancer care continuum. See Figure 1 for further details. Table 3B describes respondent's caseload of survivors.

Current Practice Trends

Respondents identified the top three referral sources to be medical oncologist (17.79%, $f=58$), medical doctor/hospitalist/physiatrist (15.03%, $f=49$), and primary care physician (14.11%, $f=46$). See Table 4B for further information on referral sources.

Occupations. Respondents reported addressing the following ADLs among all side effects: dressing (median 17.20%), functional mobility (median 17.11%), bathing/showering (median 15.57%), and personal hygiene and grooming (median 15.45%). Health management and maintenance was the only IADLs that respondents identified as addressing with the side effect of sexual dysfunction. The three main IADLs being addressed were health management and maintenance (median 16.97%), home establishment and management (median 13.93%), and meal prep and clean up (median 11.72%). Leisure is addressed across all side effects (median 23.12%), more so than return to work (median 19.22%). Occupations in the community such as shopping (median 7.50%) and driving/community mobility (median 8.33%) are infrequently addressed. Across the side effects, financial management is not frequently being addressed (median 2.08%). See Table 3B for side effects addressed in occupation(s).

Pain. Fifty-nine respondents, (84.29%) reported directly addressing pain when working with survivors. Participants reported using interventions such as education and problem-solving (18.21%, f=59), cognitive-behavioral interventions (15.12%, f=49), and promotion of self-management of pain flare-ups (14.81%, f=48). One respondent (1.43%) reported not addressing pain in practice and ten (14.29%) reported not addressing pain but referring to another health care professional including medical doctors (60.00%, f=9), physical therapists (20.00%, f=3), and/or professionals in complementary and alternative medicine (20.00%, f=3).

Neuropathy. Fifty-five respondents (78.57%) reported directly addressing neuropathy when working with survivors. Participants reported using interventions such as compensatory and adaptive strategies (46.55%, f=54), cognitive-behavioral interventions (22.41%, f=26) and sensory stimulation (19.83%, f=23). Nine respondents (12.86%) reported not addressing neuropathy in practice and six (8.57%) reported referring to another health care professional including medical doctors (58.33%, f=7) and physical therapists (33.33%, f=4).

Fatigue. Sixty-nine respondents (98.57%) reported directly addressing fatigue when working with survivors. Participants reported using interventions such as energy conservation (21.10%, f=65), education (20.78%, f=64), and light exercise (18.18%, f=56). Those OT practitioners not addressing fatigue in practice reported referring clients to other OT practitioners (100%, n=1).

Psychosocial. Forty-eight respondents (68.57%) reported directly addressing psychosocial issues when working with survivors. Participants reported using interventions such as self-management (23.04%, f=44), problem-solving therapy (16.23%, f=31), and mindfulness based therapy (14.14%, f=27). Those OT practitioners not addressing psychosocial issues in practice were often referring clients to psychologists (38.46%, f=10), psychiatrists (26.92%,

f=7), and other health professionals (social workers, nurse case managers, and physicians [34.62%, f=9]). Eight respondents (11.43%) respondents reported that not addressing psychosocial issues with cancer survivors.

Cognitive impairments. Fifty-six respondents (80%) reported directly addressing cognitive impairments when working with survivors. Participants reported using interventions such as compensatory strategies (36.08%, f=57), cognitive strategy training programs (25.32%, f=40), memory training (21.52%, f=34), and cognitive behavioral interventions (15.82%, f=25). Six respondents (8.56%) reported referring cancer survivors with cognitive impairments to the following other healthcare professionals speech language pathologist (62.50%, n=5), neuropsychologist (25.00%, n=2), and OT specialist (12.50%, n=1). Eight respondents (11.43%) reported not addressing cognitive impairments with survivors.

Lymphedema. Thirty-five respondents (50%) reported directly addressing lymphedema with survivors. Respondents reported using interventions such as exercise regimens (19.75%, f=32), compression garments (14.20%, f=23), and manual lymphatic drainage (16.05%, f=26). Those not addressing directly are referring to another health-care professionals (27.14%, n=19) such as certified lymphedema therapist (76.92%, f=20) and medical doctor (23.08%, f=6). Sixteen respondents (22.86%) reported not addressing lymphedema with survivors.

Sexual Dysfunction. Across all side effects, the occupation of sexual activity was rarely being addressed in practice (median 1.46%). Fourteen respondents (20.29%) reported directly addressing sexual dysfunction, and those not addressing reported referring to another health-care professional (7.25%, n=5) such as physical therapist (26.67%, f=4), psychologist (20%, f=3), and gynecologist (20%, f=3). Fifty respondents (72.46%) reported not addressing sexual dysfunction or referring to another healthcare provider. In practice, the interventions participants reported

using include modifying sexual activity (30.77%, f=12), energy conservation strategy (20.51%, f=8), and modifications and adaptive tools such as lubricants, vibrators, or making other activity changes (15.38%, f=6).

Discussion

Respondents reported that 31% of cancer survivors were seen during active medical treatment and similar results were found by Pergolotti, Cutchin, Weinberger, & Meyer (2014), where 32% of older adult cancer survivors received OT services within two years of their cancer diagnosis. This is alarming as seemingly no progress has been made in increasing OT's role in cancer care and oncology despite being an emerging practice area.

Respondents identified treating middle-aged adults at an equal rate to which they are treating older adults. Smith, Smith, Hurria, Hortobagyi & Buchholz, (2009) found that by 2030 there will be an increase in cancer prevalence in older adults from 61% to 70% (a 9% increase). OT practitioners need to prepare for this increase in older adult survivors by providing needed services in the area of oncology and cancer care. Further research is necessary to identify effective interventions for treating chronic conditions related to cancer within this population.

Setting

Acute care was reported as the most frequent practice environment among respondents in both single and multiple settings. Given the chronic nature of side effects, this is problematic for survivors who need OT services beyond the acute setting. Based on these results, survivors may be falling through the cracks in terms of OT service provision in practice settings other than acute care. Polo and Smith (2017) note the effects of cancer and cancer treatments can impact survivors during, shortly after, and more than 20 years after treatment; therefore, survivorship care needs to be redefined beyond the acute phase. This gap in practice settings and point of care

has created a call for OT practitioners in the community setting (Polo & Smith, 2017). OT practitioners need to recognize their potential in the community setting for promoting health and well-being for survivors because many survivors are receiving their medical care in the community setting (Polo & Smith, 2017).

Referrals

Due to the chronic conditions of cancer, survivors will likely still be experiencing side effects after oncology follow-ups are completed. Therefore, primary care physicians play a vital role in identifying late side effects and occupational performance deficits associated with cancer. Respondents of this study reported that primary care physicians that provide follow-up care in the community refer to OT services at a dismal rate. The lack of referral could stem from primary care physicians and cancer survivors not realizing OT's scope of practice in relation to treating cancer survivors with chronic conditions. If lack of referral is due to limited knowledge about OT's scope of practice, education and advocacy efforts can serve to bridge this gap and improve patient care in the primary care setting (Metzler, Hartmann & Lowenthal, 2012). Another potential explanation for the low referral rate may be that survivors do not recognize or report their side effects and occupational performance deficits. If this is the case, survivors may benefit from a survivorship care plan that provides education and resources to address short- and long-term side effects of treatment (McCabe et al., 2013) and screening of occupational performance deficits for OT referrals. A third potential explanation for the low referral rate from primary care physicians may be that their caseload is too saturated to adequately serve oncology patients (Grunfeld & Earle, 2010). Further research should be conducted to identify the source of low referral rate from primary care physicians for OT services. OT practitioners can play an important role in the primary care setting through their expertise in addressing deficits that

impair occupational participation and performance related to chronic conditions (American Occupational Therapy Association, 2014a).

Work

Evidence suggests survivors have a difficult time returning to work and many survivors work less hours or do not return to work at all (Bradley et al., 2005). Hunter et al., (2017b) found limited evidence to support strategies for return to work and declared return to work an emerging intervention area in cancer survivorship (Hunter et al., 2017b). Results of this study, align with Hunter et al., (2017b) as only a small percent of OT practitioners identified addressing work. Future research should focus on effective return to work interventions for survivors.

Functional mobility and community participation

In this study functional mobility was an ADL addressed by OT practitioners across all side effects; however, driving and community mobility were not commonly addressed IADLs.

Fatigue, pain, and neuropathy

Participants' responses of commonly used interventions for fatigue, pain, and neuropathy, include education, energy conservation, and cognitive-behavioral therapy, which align with current evidence (Reif et al., 2013; Barsevick et al., 2004; Ahlberg, Ekman, Gaston-Johansson, & Mock, 2003; Yuen et al., 2006; Santorelli & Kabat-Zinn, 2013; Johns et al., 2013). Therefore, OT practitioners are likely using evidence-based practice to guide their clinical reasoning and intervention planning when treating survivors who face fatigue, pain, and neuropathy.

Sexual activity and sexual dysfunction

Sexual activity is an occupation, within the scope of OT practice, and has been reported as a frequent area of difficulty for cancer survivors within the first-year post-treatment (Hwang et al., 2015). However, findings from this study suggest that sexual activity is infrequently being

addressed in practice. Across all survivorship side effects, sexual activity was the least addressed ADL. There is moderate evidence to support exercise and limited evidence for utilizing psychoeducational intervention to aid in return to sexual activity (Hunter et al., 2017b). Contrary to this evidence, the current study revealed that these interventions are being infrequently utilized in practice. Respondents of this study reported using task modification, energy conservation, and adaptive tools to address sexual dysfunction, yet there is a lack of robust literature to support these interventions. This illustrates a gap in the available research for effective interventions for sexual dysfunction and what is being reported by practitioners addressing sexual dysfunction with survivors.

Cognition

Cognitive impairments impact instrumental activities of daily living such as paying the bills (Sleight & Stein-Duker, 2016), yet the occupation of financial management was infrequently identified by respondents as being addressed in practice.

There is a paucity in research guiding OT practitioners in interventions addressing cognitive impairments with survivors. Respondents identified using compensatory strategies, cognitive strategy training programs, memory training and cognitive behavioral interventions to address impairments despite the limited evidence to support the use of these interventions. Many studies involving cognitive impairments are conducted by researchers from disciplines other than OT and much of the research does not explore cognitive impairments specific to survivors. Future research needs to be completed to validate the use of the above-mentioned interventions to address cognitive impairments among cancer survivors.

Psychosocial issues

According to the literature, there is strong evidence for psychosocial interventions that are effective in reducing anxiety and depression after cancer treatment such as cognitive-behavioral therapy and educational interventions, including problem solving therapy (Hunter et al., 2017b). However, cognitive behavioral therapy was not a frequently reported intervention utilized in practice by the respondents. There is moderate evidence for stress management and life review interventions that are effective in improving quality of life in survivors (Hunter et al., 2017b), however, respondents in this study reported using life review infrequently. Participants reported self-management as the most frequent intervention, however, there is limited evidence specifically related to OT and survivorship to support this intervention in terms of psychosocial issues. Self-management has shown to be effective in improving quality of life in survivors, however, health professionals in disciplines other than OT are using this intervention (Korstjens et al., 2008; Loh et al., 2013; Risendal et al., 2014). There is an opportunity for OT research exploring self-management interventions to address psychosocial issues in survivorship.

Lymphedema

When treating lymphedema, respondents are most commonly utilizing exercise as an intervention, which have been found to have strong evidence in a systematic review (Hunter et al., 2017a). OT practitioners are likely using evidence-based practice to guide their clinical reasoning for the intervention, exercise.

Limitations

This study had several limitations. First, due to purposive sampling and the limited sample size, results are not generalizable. The limited sample size is likely due to the inability of practitioners to professionally identify themselves as specialists within this emerging practice

area. Although the sample size was limited, the response rate fell within the recommended liberal and stringent acceptable conditions. A second limitation of this study is that during the expert review process, practitioners from all areas besides hospice and palliative care provided initial recommendations for change to the survey. However, a thorough literature review that entailed all areas of practice was performed and information gleaned from this informed survey development. Another limitation of the study was the results of one question were not reported. Due to survey design, participants were asked twice about the side effects they are addressing with cancer survivors and after analyzing both questions researchers decided not to report on the first question.

Implications for Practice

Results of this study support a variety of implications for OT practice including:

- Educating healthcare practitioners and survivors on OT's role in cancer care and oncology is imperative to assure survivors receive adequate care for their occupational performance needs. A forecasted increase in the number of survivors with potential performance needs is indicated in current literature.
- Researchers found primary care physicians are referring to OT services at a low rate. Increasing OT's presence in primary care settings is critical to close the gap in access to OT services in order to address survivors occupational performance deficits beyond the acute phase.
- Improving coordination of care so that survivors receive access to holistic and quality services is essential. Therefore, OT practitioners should be an integral part of an interdisciplinary care coordinating team in providing recommendations in building survivorship care plans.

- Across all side effects, sexual activity is the least addressed ADL. Research is needed to explore why practitioners are not addressing sexual dysfunction with cancer survivors during service provision. Additionally, research is required in the field of OT to indicate effective interventions for cancer survivors for the side effects of sexual dysfunction.
- Respondents identified using compensatory strategies, cognitive strategy training programs, memory training and cognitive behavioral interventions despite the limited evidence to support the use of these interventions with this population. Further research in the OT profession is needed to support the efficacy of these interventions.
- Respondents identified self-management of psychosocial issues as a top intervention despite limited evidence specifically related to OT. Further research in the OT profession is needed to support the efficacy these interventions.
- For improved professional connection within this emerging practice area, AOTA should consider the creation of a specialty subsection within a Specialty Interest Section (SIS) that allows further breakdown of practitioners in cancer care and oncology. This will allow for improved professional connections and increased potential for research collaboration within this emerging practice area.

Appendix A

Finalized Pivotal Study Survey Questionnaire

Do you treat cancer survivors?

- Yes
- No

Do you work in multiple practice settings?

- Yes
- No

What types of settings do you work in? (Select all that apply)

- Acute
- Outpatient
- Inpatient
- Skilled Nursing Facility
- Home Health
- Hospice

What type of setting do you work in?

- Acute
- Outpatient
- Inpatient
- Skilled Nursing Facility
- Home Health
- Hospice

What percentage of your case load is cancer survivors?

- <10
- 11-20
- 21-30
- 31-40

- o 41-50
- o 51-60
- o 61-70
- o 71-80
- o 81-90
- o >90

Who typically recommends occupational therapy services for your cancer survivor clients?
(Select all that apply)

- Primary Care Physician
- Neurosurgeon
- Medical Doctor/Hospitalist
- Medical oncologist
- Surgical oncologist
- Radiation oncologist
- Oncology nurse
- Oncology social worker
- Psychiatrist
- Patient navigator/case manager/care coordinator
- Home health aid
- Discharge coordinator
- Speech language pathologist
- Physical Therapy
- Other _____

At what point in time do you typically start seeing cancer survivors? (Select all that apply)

- Prior to receiving active treatment
- Actively receiving life saving treatment
- Receiving sustaining quality of life care
- Post treatment: remission

Ly mph ede ma	<input type="checkbox"/>												
Psy chos ocia l Issu es	<input type="checkbox"/>												
Sex ual Dys func tion	<input type="checkbox"/>												

For each side effect, select the other areas of occupation that you most frequently address within your occupational therapy interventions: (Select all that apply)

	Social Participation	Leisure	Rest/Sleep	Work	Education	N/A
Pain	<input type="checkbox"/>					
Neuropathy	<input type="checkbox"/>					
Fatigue	<input type="checkbox"/>					
Cognitive Impairment	<input type="checkbox"/>					
Lymphedem a	<input type="checkbox"/>					
Psychosocial Issues	<input type="checkbox"/>					
Sexual Dysfunction	<input type="checkbox"/>					

Are you addressing pain as a side effect with your cancer survivor clients?

- Yes - Directly addressing in practice

- Yes - Referring to another health-care professional
- No

What interventions are you utilizing in practice when addressing pain with cancer survivors? (Select all that apply)

- Cognitive-Behavioral Interventions (i.e. distraction, deep breathing, relaxation, etc.)
- Education and problem-solving (i.e. body mechanics, posture, ergonomics etc.)
- Self-management of pain flare-ups
- Using physical agent modalities
- Manual Techniques
- Taping
- Exercising
- Energy conservation
- Other _____

What professionals are you referring cancer survivors to for pain? (List all that apply)

- Physical Therapist
- Medical Doctor
- Other _____

Are you addressing neuropathy as a side effect with your cancer survivor clients?

- Yes - Directly addressing in practice
- Yes - Referring to another health-care professional
- No

What interventions are you utilizing in practice when addressing neuropathy with cancer survivors? (Select all that apply)

- Cognitive-Behavioral Interventions (i.e. distraction, deep breathing, relaxation, etc.)
- Compensatory and adaptive strategies
- Taping
- Sensory stimulation
- Other _____

What professionals are you referring cancer survivors to for neuropathy? (Select and/or list all that apply)

- Physical Therapist
- Medical Doctor
- Other _____

Are you addressing fatigue as a side effect with your cancer survivor clients?

- Yes - Directly addressing in practice
- Yes - Referring to another health-care professional
- No

What interventions are you utilizing in practice when addressing fatigue with cancer survivors? (Select all that apply)

- Cognitive-Behavioral Interventions (i.e. distraction, deep breathing, relaxation, etc.)
- Education
- Support Groups
- Sleep Hygiene therapy
- Light Exercise
- Energy Conservation
- Mindfulness
- Other _____

What professionals are you referring survivors to for fatigue? (Select and/or list all that apply)

- Physical Therapist
- Medical Doctor
- Other _____

Are you addressing cognitive impairment as a side effect with your cancer survivor clients?

- Yes - Directly addressing in practice
- Yes - Referring to another health-care professional
- No

What interventions are you utilizing in practice when addressing cognitive impairment with cancer survivors? (Select all that apply)

- Compensatory strategies
- Cognitive strategy training programs
- Memory training
- Cognitive-Behavioral Interventions (i.e. distraction, deep breathing, relaxation, etc.)
- Other _____

What professionals are you referring cancer survivors to for cognitive impairment? (Select and/or list all that apply)

- Neuropsychologist
- Speech Language Pathologist
- Other _____

Are you addressing sexual dysfunction as a side effect with your cancer survivor clients?

- Yes - Directly addressing in practice
- Yes - Referring to another health-care professional
- No

What interventions are you utilizing in practice when addressing sexual dysfunction with cancer survivors? (Select all that apply)

- Modifications and adaptive tools (i.e. such as using lubricants, vibrators, or making other activity changes)
- Mindfulness-based interventions (i.e. guided imagery)
- Cognitive Behavioral Therapy
- Energy conservation strategy
- Modifying sexual activity
- Exercise
- Other _____

What professionals are you referring cancer survivors to for sexual dysfunction? (Select and/or list all that apply)

- Gynecologist

- Urologist
- Psychiatrist
- Psychologist
- Physical Therapist
- Other _____

Are you addressing psychosocial issues as a side effect with your cancer survivor clients?

- Yes - Directly addressing in practice
- Yes - Referring to another health-care professional
- No

What interventions are you utilizing in practice when addressing psychosocial issues with cancer survivors? (Select all that apply)

- Cognitive-Behavioral therapy
- Self-management
- Guided self-determination
- Psychoeducation/Health education
- Mindfulness based therapy
- Life review (Reminiscence Therapy)
- Expressive or disclosure groups
- Problem-solving therapy
- Other _____

What professionals are you referring cancer survivors to for psychosocial issues? (Select and/or list all that apply)

- Psychiatrist
- Psychologist
- Other _____

Are you addressing lymphedema as a side effect with your cancer survivor clients?

- Yes - Directly addressing in practice
- Yes - Referring to another health-care professional

No

What interventions are you utilizing in practice when addressing lymphedema with cancer survivors? (Select all that apply)

- Exercise regimens
- Complete Decongestive Therapy
- Manual lymphatic drainage
- Pneumatic pump drainage
- Multi-layer bandaging
- Compression garments
- Physical agent modalities
- Other _____

What professionals are you referring cancer survivors to for lymphedema? (Select and/or list all that apply)

- Certified Lymphedema Therapist
- Medical Doctor
- Other _____

Appendix B

Tables and Figures of Study Results

Table 1B*Survey Question Distribution*

No. of Questions	Content Covered
9	Demographics (i.e. practice setting, percentage of cancer survivor patients, age range of patients seen, and which side effects they address)
1	General question to determine which side effects therapists are treating
3	Grid-style questions with each side effect on one axis and occupations on the other. Occupations were based on the Occupational Therapy Practice Framework <ul style="list-style-type: none"> a) The first set of grid questions covers ADLs b) The second set of grid questions covers IADLs c) The third set of grid questions covers the remaining occupations
3	Pain questions: to determine whether the side effect is being treated in practice, what interventions are being used, and/or who therapists are referring patients to for the given side effect
3	Neuropathy questions: to determine whether the side effect is being treated in practice, what interventions are being used, and/or who therapists are referring patients to for the given side effect
3	Fatigue questions: to determine whether the side effect is being treated in practice, what interventions are being used, and/or who therapists are referring patients to for the given side effect
3	Cognitive impairment questions: to determine whether the side effect is being treated in practice, what interventions are being used, and/or who therapists are referring patients to for the given side effect
3	Sexual dysfunction questions: to determine whether the side effect is being treated in practice, what interventions are being used, and/or who therapists are referring patients to for the given side effect
3	Psychosocial issues questions: to determine whether the side effect is being treated in practice, what interventions are being used, and/or who therapists are referring patients to for the given side effect
3	Lymphedema questions: to determine whether the side effect is being treated in practice, what interventions are being used, and/or who therapists are referring patients to for the given side effect

Table 2B*Respondent's Indicated Practice Setting (PS)*

	Multiple PS	Single PS	Average
Acute	34.67%	44.44%	38.18%
Outpatient	26.67%	30.56%	27.27%
Inpatient	25.33%	11.11%	20.91%
Skilled Nursing Facility	5.33%	2.78%	4.55%
Home Health	8.00%	11.11%	8.18%
Hospice	1.33%	0.00%	0.91%

Note. Respondents could report working in multiple or a singular practice setting.

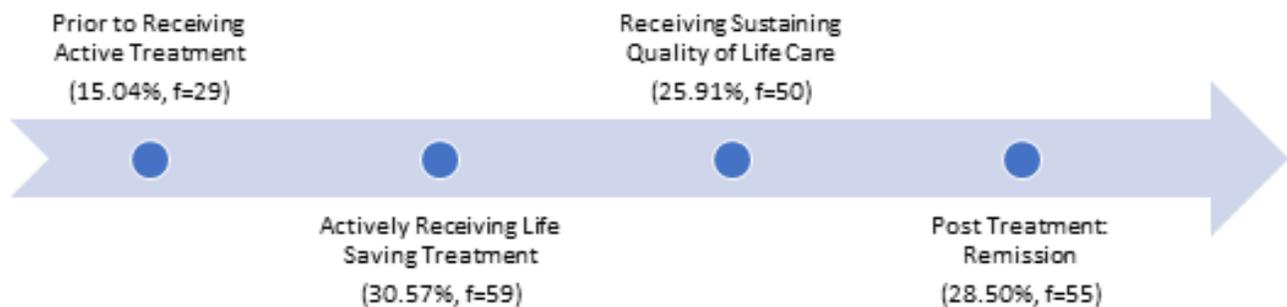


Figure 1B. Cancer survivorship continuum. Point of time when respondents report treating survivors. f = frequency

Table 3B*Respondent's Caseload Demographics*

Caseload	
Cancer Survivor Patients (%)	% of Respondents
Less than 30%	57.14%
31-60%	17.14%
Greater than 61%	25.71%
Age	% of Respondents
Young Adult (18-39)	24.71%
Middle Adult (40-64)	38.51%
Late Adult (65+)	36.78%

Table 4B*Healthcare Professionals Recommending Occupational Therapy Services to Cancer Survivors*

Professional Title	% of Respondents
Medical Oncologist	17.79%
Medical Doctor/Hospitalist/Physiatrist	15.03%
Primary Care Physician	14.11%
Surgical Oncologist	11.96%
Neurosurgeon/Neurologist	8.59%
Rehab Professionals (Speech Language Pathologist, Physical Therapist)	8.28%
Patient Navigator/Case Manager/Care Coordinator	6.44%
Radiation Oncologist	5.83%
Oncology Nurse	5.83%
Oncology/Medical Social Worker	2.76%
Psychiatrist	1.84%
Other: Critical Care, Automatic Order Set from ADL Screening, Palliative Care Nurse Practitioner, Nurse Practitioner, Home Health Aid	1.53%

Table 5B*Occupations Addressed with Each Individual Side Effect*

	Pain	Neuropathy	Fatigue	Cognitive impairments	Lymph edema	Psychosocial Issues	Sexual Dysfunction
Activities of Daily Living							
Bathing/Showering	16.61%	15.42%	17.20%	16.25%	15.57%	14.47%	5.56%
Toileting	12.27%	12.78%	14.58%	15.19%	11.38%	13.82%	11.11%
Dressing	19.49%	18.94%	17.20%	15.19%	19.16%	15.79%	5.56%
Eating	3.25%	0.88%	3.50%	4.59%	4.79%	4.61%	0.00%
Feeding	4.69%	8.81%	7.87%	9.19%	6.59%	5.92%	0.00%
Functional Mobility	20.58%	20.26%	17.78%	15.90%	16.77%	17.11%	5.56%
Device Care	5.42%	4.85%	4.96%	7.77%	8.38%	6.58%	5.56%
Grooming	16.25%	16.74%	15.45%	15.19%	14.97%	16.45%	5.56%
Sexual Activity	1.44%	1.32%	1.46%	0.71%	2.40%	5.26%	61.11%
Instrumental Activities of Daily Living							
Financial Management	0.74%	2.08%	3.62%	10.20%	1.56%	5.42%	0.00%
Health Management	16.97%	17.08%	11.98%	12.83%	24.22%	11.67%	100%
Home Management	15.50%	15.42%	13.93%	11.95%	14.84%	8.75%	0.00%
Care of Others	11.07%	10.00%	10.86%	6.71%	9.38%	10.00%	0.00%
Care of Pets	7.38%	7.08%	9.19%	4.96%	5.47%	6.67%	0.00%
Child Rearing	6.27%	3.75%	5.85%	4.08%	5.47%	7.92%	0.00%
Communication Management	1.85%	2.50%	3.06%	9.04%	1.56%	7.50%	0.00%
Driving/Community Mobility	5.90%	9.58%	7.80%	8.75%	9.38%	8.33%	0.00%
Meal Preparation	16.61%	15.83%	15.60%	10.79%	11.72%	9.58%	0.00%

Religious/Spiritual Activities	2.21%	1.25%	3.34%	3.50%	0.78%	9.58%	0.00%
Safety Maintenance	6.27%	7.92%	6.13%	10.79%	7.03%	8.75%	0.00%
Shopping	9.23%	7.50%	8.64%	6.41%	8.59%	5.83%	0.00%
<hr/>							
Other Occupations							
Social Participation	20.63%	20.33%	21.57%	23.43%	19.09%	25.43%	40.00%
Leisure	23.32%	23.08%	22.35%	23.43%	20.00%	23.12%	26.67%
Rest/Sleep	26.46%	19.23%	23.14%	14.29%	22.73%	16.76%	20.00%
Work	17.49%	21.98%	19.22%	20.00%	22.73%	18.50%	6.67%
Education	12.11%	15.38%	13.73%	18.86%	15.45%	16.18%	6.67%

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