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Building the Screen of Cancer Survivorship - Occupational Therapy Services (SOCS-OTS): A Delphi Study

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A research project submitted in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree from the University of Indianapolis, School of Occupational Therapy.

Under the direction of the research advisor:

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Acknowledgements

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Plan for Dissemination

Our research team has been accepted to present this information at the AOTA Inspire conference in San Antonio, Texas in April of 2022. Our team also plans to disseminate this information at the Scholars Showcase in April of 2022 for those members who were unable to attend the conference.

Literature Review

As of 2016, researchers estimated that there were 15.5 million cancer survivors in the United States and that by the year 2026, that number will rise to 20.3 million (National Cancer Institute, 2018). Researchers define a cancer survivor as anyone with or who had cancer from diagnosis to the end of life (National Cancer Institute, 2019). As the number of cancer survivors increases, it is essential to consider what factors may impact their quality of life following cancer treatment. Researchers indicated that quality of life was inversely related to occupational performance deficits, which can occur due to side effects of cancer treatment such as fatigue, pain, sensory loss, and cognitive impairments (Brekke et al., 2019). Occupational performance is the accomplishment of an occupation, a purposeful activity that has meaning to the individual (American Occupational Therapy Association, 2014).

In 2006, the Institute of Medicine (IOM) called for the implementation of cancer survivorship recommendations to improve care coordination, facilitate follow-up care, and assure patient outcomes (Stricker et al., 2011). The American Society of Clinical Oncology (ASCO) Survivorship Care Plan (SCP) is a document that includes a treatment summary and follow-up care plan to improve communication and coordination of care for cancer survivors. The ASCO SCP assists patients in tracking check-up appointments, reviewing follow-up tests, mapping out possible late side effects of treatment, and providing ideas for staying healthy (Centers for Disease Control and Prevention, 2018). The ASCO SCP addresses concerns related to emotional and mental health, physical functioning, memory or concentration loss, fatigue, parenting, school/work, and sexual functioning. However, the SCP in care coordination does not include various life activities (occupations) that researchers found cancer survivorship impacts (American Society of Clinical Oncology, 2019).

Despite the implementation of the ASCO SCP, researchers have indicated that a lack of coordination in survivorship care can contribute to poor care delivery and adverse patient outcomes (Klabunde et al., 2013). Researchers have recommended an occupational participation approach to address gaps in cancer survivorship care (Yim Loh & Jonsson, 2016). Although survivors face performance deficits resulting from cancer treatment, there is a lack of referral to occupational therapy services. Survivorship care requires an occupational participation approach which includes regular screening for occupational therapy services. Currently, no validated screening tools indicate the need for referral to occupational therapy in survivorship care. However, the Screening of Cancer Survivorship - Occupational Therapy Services (SOCS-OTS) tool is available but requires a true consensus from experts in the field to indicate which items researchers should include in its final rendition. The purpose of this study was to formally validate The Screening of Cancer Survivorship-Occupational Therapy Services (SOCS-OTS), which researchers developed for oncology team members to identify those that need occupational therapy services due to occupational performance limitations in survivorship care.

Side Effects of Cancer Treatment

Although there is currently no developed screening tool indicating the need for referral to occupational therapy in survivorship care, there are many side effects of cancer treatment that may impact survivors' occupational performance. Larkey et al. (2015) performed a quantitative randomized control trial for breast cancer survivors with cancer-related fatigue (CRF). Researchers selected 87 female breast cancer survivors for this study, of which 49 participated in the tai-chi intervention group. Researchers then administered the exercises for a total of 24 weeks for 90-minute supervised periods twice a week for 12 weeks, followed by 30-minute unsupervised periods five times a week for an additional 12 weeks. Researchers utilized the

Fatigue Symptom Inventory (FSI), in which participants rated fatigue on a scale of zero to ten, with a three or higher score considered a meaningful level of fatigue. The intervention group showed a moderate decrease in CRF after the supervised activities. The scores during the individual intervention were consistent with those reported at the end of the supervised portion of the intervention, suggesting a lasting effect for decreased CRF due to tai-chi exercise in cancer survivors (Larkey et al., 2015).

Johansson et al. (2013) similarly performed a quantitative, randomized control trial that utilized water-based intervention measuring shoulder range of motion for breast cancer survivors with chronic lymphedema. Researchers recruited 29 female survivors for participation in the study, with 15 participating in the intervention group and 14 participating in the control group. The intervention group completed water-based exercise three times a week for eight weeks. The participants either swam or performed specific shoulder exercises shown to them by an instructor during the allotted time. The control group received no intervention treatment. Median changes for flexion and external rotation were significantly larger in the intervention group. Flexion median change increased by seven degrees, and external rotation median change increased by thirteen degrees. Researchers did not observe significant increases in the control group (Johansson et al., 2013).

Salerno et al. (2019) performed a randomized crossover trial study to measure the effects of cancer-related cognitive impairment (CRCI) in breast cancer survivors after aerobic exercise training. Researchers recruited 29 participants for this study and conducted three sessions. The first session consisted of determining the max heart rate of participants. In the second session, participants completed a cognitive battery test followed by either 30 minutes of exercise on a treadmill or 30 minutes of sitting. They then completed a second cognitive battery test following the intervention. Out of the recruited participants, 15 performed walking during the second session, while 14 performed sitting during the second session. Researchers reversed the groups for the third and final session. Participants showed a significant improvement in spatial working memory and processing speed upon the conclusion of the exercise intervention (Salerno et al., 2019). Similarly, Baumann et al. (2011) used physical activity to explore the effects of CRCI in breast cancer survivors. Researchers found significant improvements in intelligence and memory in the exercise intervention group (Baumann et al., 2011).

Kneis et al. (2019) incorporated balance and endurance training in a quantitative randomized control designed to study the effect on neuropathic symptoms. The intervention group performed both balance and endurance training, while the control group performed only endurance training. Researchers selected 50 cancer survivors, with 25 participating in one-on-one interventions lasting 60 minutes in length. Participants completed endurance training for 30 minutes on a stationary bicycle and 30 minutes for balance training. The control group included 25 survivors. Modules in the European Organization for Research and Treatment of Cancer Quality of Life (EORTC QLQ-C30) measured chemotherapy-induced peripheral neuropathy (CIPN) severity in sensory, motor, autonomic, and upper and lower extremity categories. Upon conclusion of the study, the intervention group had significantly better scores in the EORTC QLQ-C30 in all categories measured for CIPN purposes, indicating a significant reduction in reporting the symptoms of CIPN reported (Kneis et al., 2019). These common side effects of cancer treatment, including CIPN, CRF, CRCI, and lymphedema, can impact the occupational performance of cancer survivors.

Jung et al. (2017) used the Brief Fatigue Inventory (BFI) to measure the severity of fatigue, the Hospital Anxiety and Depression Scale (HADS) to measure levels of anxiety and depression, and the EORTC QLQ-C30 to target the patients' emotional, cognitive, social and role functionalities of lung cancer survivors. Researchers reported that approximately 332 individuals of their initial outreach of 830 survivors agreed to complete the questionnaires (Jung et al., 2017). Researchers utilized a univariate analysis of sociodemographic factors to record the impacts on fatigue and anxiety, such as comorbidities, age, and educational level. The researchers concluded that fatigue and depression had the most significant effect on lung cancer survivors (Jung et al., 2017).

Fitch et al. (2020) surveyed a total of 13,258 Canadian respondents in a transitional study asking about unmet needs and experiences between the first and third year post-cancer treatment. The researchers' survey contained open and closed-ended questions focused on the participants' health, medical history with cancer, follow-up cancer care, and additional topics. Following the survey, researchers initiated interviews to gain information on the understandability and meaningfulness of the survivorship experience (Fitch et al., 2020). Roughly 87% of the respondents experienced at least one physical symptom post-treatment, and 58% indicated three or more. Of the participants, 33% were under the impression that their symptoms were expected with no solution, which led to not seeking additional help (Fitch et al., 2020). Those that expressed physical concerns noted the following:

> sexual function/activity (45%), hormonal/menopause or fertility (37%), and fatigue/tiredness (33%). Gastrointestinal problems (63%) and pain (61%) were the symptoms for which respondents most frequently sought help. However, more than one-third of respondents who sought help indicated that it was difficult to obtain for most of their symptoms. Seeking help for changes in concentration and memory was particularly challenging (48% experienced difficulty) (Fitch et al., 2019, p. 2980)

Krok-Schoen et al. (2018) utilized a survey design to explore the influences that inhibited fear of cancer recurrence (FCR) among older female cancer survivors. A total of 4,259 participants with different types of cancer completed an online-based survey that recorded cancer type and treatment data (Krok-Schoen et al., 2018). Researchers measured participants' FCR using an eight-item Cancer Worry Scale (CWS). Participants reported general psychological well-being, physical symptoms, and quality of life. Researchers found that nearly 16% of the participants reported a high FCR based on factors like chemotherapy, high symptom scores, and older age (Krok-Schoen et al., 2018).

Similarly, Galica et al. (2021) found that as the number of cancer survivors continues to increase, FCR is the most significant factor limiting this population. FCR is associated with an overall decrease in quality of life, increased anxiety, and higher rates of depression (Galica et al., 2021). The researchers indicate that previous findings show cancer survivors want help to cope with their FCR; however, this concept is still under-recognized, and the needs remain unmet (Galica et al., 2021). The researchers found that survivors within this population are experiencing unmet and unrecognized needs, warranting oncology nurses to assess, care for, and provide intervention for these increasing numbers of patients (Galica et al., 2021).

Impact on Occupational Performance

Side effects of cancer treatment impact every category of occupation, including ADLs (Activities of Daily Living), IADLs (Instrumental Activities of Daily Living), rest and sleep, work, leisure, and social participation (American Occupational Therapy Association, 2014). First, experts define ADLs as activities directed at taking care of one's own body, such as sexual activity, toileting and toilet hygiene, feeding, functional mobility, and personal hygiene and grooming (American Occupational Therapy Association, 2014). Hwang and colleagues (2015) investigated cancer survivors' functional deficits and their impact on quality of life. The researchers conducted a one-group, nonrandomized study. They had 68 cancer survivors respond to the Post Cancer Outcome Survey (PCOS) and Cantril's Self-Anchoring Striving Scale to measure perceived functional deficits and quality of life. On the PCOS, cancer survivors frequently reported that sexual activity was an occupation in which they experienced difficulty due to a lack of sexual enjoyment from decreased sexual drive, negative body image, and discomfort during sex following cancer treatment. Researchers found that the occupational performance limitations survivors faced were associated with reduced quality of life (Hwang et al., 2015).

Cancer survivors also listed toileting and toilet hygiene as an occupational performance deficit in research conducted by Marciniak et al. (1996). Researchers identified functional impairments resulting from cancer and its treatment among 159 cancer survivors using the Functional Independence Measure (FIM) in a non-experimental, retrospective study at the Rehabilitation Institute of Chicago. Cancer survivors indicated that they experienced gastrointestinal problems such as constipation, diarrhea, and incontinence following treatment which impacted their toileting occupations (Marciniak et al., 1996).

Lastly, cancer survivors reported that another area of occupational performance deficit was functional mobility. Lyons and colleagues (2018) used a mixed-methods sequential explanatory approach to identify and reduce disability among cancer survivors. Participants in the study were 65 years and older and were cancer survivors who were experiencing disability due to cancer treatment. Researchers used the Health Through Activity Program intervention, which required participants to reflect on pleasurable and beneficial activities to their physical and mental health, create goals to engage in said activities, and then reflect on their experience and success with those weekly activities with an occupational therapist. During the completion of the intervention, survivors reported that functional mobility, such as walking, was an area of performance deficit due to side effects such as sensory loss, pain, and edema (Lyons et al., 2018). These findings indicate that survivors face occupational performance deficits in the occupational category of ADLs due to the side effects of cancer treatment.

ADLs are impacted by the effects of intensive cancer treatment, but IADLs are also negatively influenced. IADLs are activities that benefit daily living throughout the community and home and involve more complex interactions such as child-rearing, home establishment and management, health management and maintenance, and driving and community mobility (American Occupational Therapy Association, 2014). Hwang et al. (2015) and Lyons et al. (2018) found that side effects negatively influence ADLs. Researchers also discovered performance issues in health management and maintenance, an IADL. Cancer survivors indicated difficulties exercising/working out due to treatment effects such as fatigue, decreased energy levels, nausea, and pain (Hwang et al., 2015; Lyons et al., 2018).

Another IADL that drastically changes for survivors following cancer treatment is home establishment and management. In a cross-sectional, descriptive survey study with 368 participants in Iran and Canada, researchers found that survivors reported limitations in home establishment and management (Shahidi et al., 2014). Survivors reported that constraints were present in their abilities to complete house chores such as laundry and cleaning following treatment due to muscle weakness, fatigue, and sensory loss (Shahidi et al., 2014). Not only have performance deficits in ADLs and IADLs been found in cancer survivors due to the side effects of treatment, but researchers discovered that the occupation of rest and sleep also suffers.

Individuals reported rest and sleep activities restore engagement in other occupations (American Occupational Therapy Association, 2014). Researchers found that survivors' side effects hinder sleep participation during or after cancer treatment. Engstrom et al. (1999) used a qualitative, multi-institutional sleep study to explore the impact, type, frequency, and severity of sleep disturbances among 150 cancer survivors. Participants completed interviews and phone surveys using an 82-item sleep questionnaire to obtain data regarding cancer survivors' sleep participation following cancer treatment. Survivors reported that sleep participation was disturbed by side effects such as insomnia, sleeping at unusual times, having trouble with dreams or nightmares, and psychological distress following cancer treatment (Engstrom et al., 1999).

Carpenter et al. (2004) further explored sleep participation limitations among cancer survivors in a cross-sectional, descriptive, comparative pilot study using questionnaires and monitoring sessions to compare differences in sleep quality and disturbance between cancer survivors and healthy women who have hot flashes. Researchers discovered that cancer survivors experience poor sleep quality and high levels of sleep disturbance (Carpenter et al., 2004). As sleep participation limitations can lead to symptoms such as fatigue, poor cognition, and depression, which can impact other areas of occupation, it is essential to consider how sleep participation can be affected by the side effects of cancer treatment (Durmer & Dinges, 2005).

The occupation of work includes labor, construction, organizing and planning services or processes, and committed occupations which may consist of financial reward (American Occupational Therapy Association, 2014). Many cancer survivors reported that the side effects of cancer treatment negate job performance. Groeneveld de Boer and Frings-Dresen (2013) used interviews in a qualitative, phenomenological study to evaluate how cancer treatment had impacted 10 participants’ work participation. Researchers explored survivors’ experiences with returning to work and work performance, a physical exercise intervention, and the link between physical exercise and work. Survivors reported that their job performance and work productivity had declined following treatment due to side effects such as fatigue, feeling sick, cognitive deficits, impairments in concentration, memory deficits, and increased stress levels. Survivors also explained that absenteeism increased following treatment due to feeling ill, overly tired, or unmotivated to go to work (Groeneveld et al., 2013). Fangel and colleagues (2013) further explored cancer survivorship's influence on job performance in a descriptive, exploratory, cross-sectional, and qualitative study using Katz's index and Lawton's index to assess functional capability and its correlation with the quality of life among 42 cancer survivors. Participants reported difficulties with work performance due to decreased independence, limited functional capability, and the presence of psychosocial issues following cancer treatment (Fangel et al., 2013).

Leisure participation is another area of occupation hindered by the presence of cancer treatment side effects. Experts define leisure activity as an activity that is not an obligation but is intrinsically motivated and completed during a discretionary time (American Occupational Therapy Association, 2014). Keesing et al. (2018) conducted a mixed-methods Delphi study to explore the possible role of occupational therapists in the care of female cancer survivors. The researchers found survivors faced many challenges engaging in and resuming meaningful leisure occupations following treatment because of functional, emotional, and psychosocial side effects. Further, researchers supported the idea that occupational therapists could play a significant role in helping survivors address these occupational performance limitations. Occupational performance limitations related to leisure participation can also occur among survivors due to arm morbidities, such as pain, limited range of motion, and lymphedema of the arm following cancer treatment. These side effects are especially common among breast cancer survivors (Thomas-Maclean et al., 2008). In a longitudinal, qualitative cohort study conducted by Thomas et al. (2015), 40 cancer survivors reported in interviews that side effects including arm morbidity, physical discomfort, and psychological distress reduced their abilities to engage in leisure activities. Researchers have identified specific forms of leisure participation limitations in the literature that involve difficulties engaging in travel and active leisure participation (Thomas et al., 2015).

The final occupation that cancer survivors have reported experiencing deficits in following cancer treatment is social participation. Social participation involves activities supporting social engagement and interdependence with community members, family, peers, and friends (American Occupational Therapy Association, 2014). Johnson et al. (2017) conducted a quality improvement study focusing on multidisciplinary management of distress that survivors face. Researchers also explored survivors' satisfaction with the distress management they received. Data was collected from electronic health records using a convenience sample of 65 gynecologic cancer survivors. Using the National Comprehensive Cancer Network Distress Thermometer and Patient Related Outcome Measures Information Systems QOL, researchers found that survivors experienced great psychosocial distress following treatment that hindered their social participation. Side effects of treatment that negatively influenced survivors' social support were anxiety, depression, emotional distress, and feelings of psychological isolation (Johnson et al., 2017). Not only does psychosocial distress negatively influence cancer survivors' social activities and social function, but survivors have also reported that physical functioning has impacted their social participation. In a cohort study completed by Syrjala et al. (2010), researchers used the Social Activity Log (SAL) to explore the social activities of 100 cancer survivors following hematopoietic stem cell transplantation. Researchers found that survivors face many physical challenges such as fatigue, incontinence, and increased functional dependence due to muscle weakness following treatment that negatively impact one's desire to engage in social participation (Syrjala et al., 2010). Hair loss is another common physical side effect following treatment that many cancer survivors state has negatively influenced their desire to engage in social participation. Survivors report being embarrassed and upset by hair loss, limiting their willingness to participate in social activities with family, friends, and peers (Petruseviciene, 2018). These occupational performance deficits impact the quality of life of cancer survivors; therefore, it is essential to utilize screening tools to evaluate the need for rehabilitation services such as occupational therapy.

Current Survivorship Screening Tools

While none currently screen for the specific need for occupational therapy, screening tools are available that screen for side effects of cancer treatment and the need for rehabilitation services. In an observational study, Henneghan et al. (2018) implemented the Patient-Reported Outcomes Measurement Information System (PROMIS) Item Bank, perceived stress scale (PSS), UCLA Loneliness scale, Pittsburgh sleep quality index (PSQI), and the functional assessment of cancer therapy-cognitive function instrument (FACT-Cog) to measure anxiety, depression, fatigue, stress, loneliness, and sleep quality on perceived cognitive function. There were ninety female breast cancer survivors three years post-chemotherapy treatment that participated in the study. The researchers reported that breast cancer survivors who felt high stress levels, social isolation, and poor sleep quality might also have a lower perceived cognitive function (Henneghan et al., 2018).

Boronowski et al. (2012) conducted a research study to determine the interrater reliability, intrarater reliability, predictive validity, and concurrent validity of the Occupational Therapy Discharge Needs Screen (OTDNS). Professionals use this screening tool to identify clients with more complex discharge needs (Boronowski et al., 2012). The hospital discharge-planning process for complex needs often includes a home assessment conducted by an occupational therapist before being discharged. Pre-discharge home visits lead to quicker discharge times and play a role in fall prevention post-discharge. The researchers conducted a prospective study in a convenience sample of 89 participants in a community hospital's rehabilitation and transitional care unit that were about to be discharged. Categories on the OTDNS include functioning, disability, and contextual factors. Functioning and disability include items related to medical condition, mobility, and activities of daily living. Contextual factors included items related to social support, physical/environmental barriers, and perceived readiness for discharge (Boronowski et al., 2012). Researchers found that the OTDNS can contribute to the efficiency of the discharge-planning process (Boronowski et al., 2012).

Many individuals affected by stroke(s) often have physical, cognitive, psychosocial, or behavioral challenges (Jaber et al., 2018). Identifying self-perceived challenges to daily participation helps occupational therapists create client-centered goals and support long-term community engagement after stroke. According to Jaber et al. (2018), strokes impact several different areas of occupation including activities of daily living, instrumental activities of daily living, work, leisure, and social participation. Researchers recruited 25 participants receiving occupational therapy services from the American Stroke Foundation and had met the inclusion criteria. Researchers implemented a demographic questionnaire, the Canadian Occupational Performance Measure (COPM), and the Montreal Cognitive Assessment (MOCA). Researchers used the COPM to identify patients' self-perception of performance in everyday living, and the MOCA was used to identify mild cognitive impairments. Patients reported IADLs, leisure participation, and ADLs as the top three challenges on the COPM. Survivors frequently report that driving and community mobility are challenging IADLs. They also noted that employment seeking and functional mobility are challenging. The participants' self-efficacy indicated that they were not yet satisfied with their occupational performance. (Jaber et al., 2018). Not only is there a lack of an occupational therapy screening tool available in survivorship care, but there are other gaps in survivorship care that impact the overall quality of life for survivors.

Gaps in Survivorship Care

Some gaps in survivorship care include lack of education of the healthcare provider, survivors' lack of knowledge about the SCP, lack of communication between the survivor and the healthcare provider, and poor care coordination. The gaps in care can lead to the needs of survivors being left unmet. First, healthcare providers lack education, which can make them feel unconfident in treating survivors' late side effects or managing their symptoms. Many providers do not understand what late side effects are and how survivors still experience deficits even after remission. Researchers identified these issues with both PCPs and nurses. Barton (2014) investigated oncologists and PCPs infrequently providing SCPs. Researchers used data from the Survey of Physician Attitudes Regarding the Care of Cancer Survivors, a 2009 national poll of 1,020 PCPs and 1,130 oncologists. The researchers looked at post-treatment follow-up care for patients surviving breast or colon cancer. Researchers used four outcome variables: how often oncologists supply survivors with a written SCP, how much oncologists discuss the SCP with patients and who will be providing care for them, PCPs discussion of recommendations, and how often oncologists supply the written SCP and discuss the plan with patients. The researchers found that PCPs with less training in survivorship care were 43% less likely to have discussions with survivors. Only 12% of PCPs reported having full conversations of survivorship care with their patients. The author suggested a low percentage of PCPs having full discussions because of the lack of physician training and care coordination (Barton, 2014).

Similarly, in 2014, Lester et al. studied nurses' knowledge of cancer survivorship care through a descriptive, cross-sectional study in a Midwestern comprehensive cancer center. This study included 223 registered and advanced practice nurses and used an online survey with 50 questions created from the Institute of Medicine report and related publications (Lester et al., 2014). The researchers found that less than 50% of the nurses felt knowledgeable about the impact cancer could have on survivors and their families, how to prevent certain conditions after cancer treatment, and the side effects survivors may face (Lester et al., 2014). The authors concluded that there are definite gaps in knowledge regarding cancer survivorship care with nurses (Lester et al., 2014).

Cheung et al. (2013) conducted a quantitative cross-section study that surveyed PCPs and oncologists in 2013. The researchers looked at PCP and oncologists’ views on self-efficacy regarding the follow-up care of cancer survivors, such as their ability to detect recurrence and manage the effects of cancer and various treatments (Cheung et al., 2013). They designed survey questions to assess both the PCP and oncologists' views, knowledge, and care coordination methods regarding post-treatment care in cancer survivors (Cheung et al., 2013). The researchers also listed questions regarding PCPs' attitudes and preferences. In this study, participants identified their preferred survivorship care model regarding who has the most responsibility in the care plan. Their options in the final survey about who they preferred for the responsibility of care included PCPs having the primary responsibility, PCPs sharing the responsibility with other cancer specialists, or oncologists having the primary responsibility. Researchers utilized the initial survey to determine which participants were eligible through a telephone screening process and followed up with a survey in the mail for the eligible participants. In this study, there were 2,026 total participants. Out of these participants, 938 were PCPs, and the other 1,088 were oncologists. The study found that 51% of PCPs supported a PCP/shared model of care, 59% of cancer specialists preferred an oncologist's model of care, and 23% of physicians favored the specialized clinic models (Cheung et al., 2013). The study also found 70% of oncologists were confident in their ability to manage long-term effects in cancer survivors, while only 19% of PCPs felt confident in their ability to provide adequate care (Cheung et al., 2013). Overall, the authors concluded that PCPs and oncologists have different model preferences for cancer survivorship care. These preferences can affect communication and role delineation, affecting the survivors' care (Cheung et al., 2013).

Another issue with the current SCP is that survivors do not have knowledge of what a SCP is, and they do not know how to understand the plan if they do have one. Casillas and colleagues (2011) explored how confident young adult cancer survivors are in managing their care. Researchers recruited 376 participants from the LIVESTRONG™ Survivorship Center of Excellence Network sites aged 18-39 years old. This self-report survey study looked at 57 items in six domains. The six domains included sociodemographic information, cancer diagnosis and treatment, experiences with doctors, survivors' knowledge of late side effects, current health status, and opinions regarding the availability of resources for survivors. Researchers found that one-third of participants did not have copies of their medical records, 48% did not have a written treatment summary, and 55% did not have a written survivorship care plan (Casillas et al., 2011). The researchers found that patients lack the knowledge they need when it comes to their medical records and SCPs, which leads to them not being able to get the care they need. The authors of this study concluded that if survivors receive the SCPs, they will better manage their care and understand their past medical history. If provided with a SCP, survivors would likely better understand their past medical history and have more information on late side effects that they may experience, which could lead to improved communication with their healthcare providers.

The final issue is the lack of communication between the healthcare provider and the survivor. Benci et al. (2018) conducted research to identify cancer survivors' barriers when sharing their SCP with their healthcare provider. The researchers in this quantitative study used data from 3231 cancer survivors who used the OncoLink SCP resource between the years 2009-2016. Researchers found that 87% of users rated their satisfaction with their SCP good or better; however, only 70% of survivors planned to share their SCP with their health care provider (HCP) due to the feeling that they would not care (Benci et al., 2018). The researchers found that some survivors are not communicating their SCP and their needs with their HCP because they feel that their needs will be ignored. The researchers in this study concluded that the primary goals of the SCP are to facilitate the transmission of information from the oncologist to survivor to the long-term care team and serve as a communication bridge between survivors and providers. However, there is an alarming disconnect with survivors feeling comfortable sharing their SCP with their healthcare provider (Benci et al., 2018).

The lack of role delineation for treating the long-term effects of cancer in the cancer survivorship stage is another detriment that substantially impacts overall cancer care (Cheung et al., 2013). Some believe ongoing cancer survivorship care falls under the role of oncologists, who specialize in cancer, while others think primary care physicians (PCPs) should monitor this care (Greenfield et al., 2009). There are currently no guidelines stating what health care professionals are in charge of cancer survivors; therefore, there are disparities because people do not have adequate follow-up care. Some oncologists feel monitoring and treating long-term effects resulting from cancer treatments is their role, while others believe they do not have time for this portion of cancer care and think it should be in the hands of primary care physicians (Klabunde et al., 2013). Similarly, some PCPs feel they should oversee follow-up cancer survivorship care, whereas others do not feel comfortable treating the adverse effects of cancer (Cheung et al., 2013).

Cheung et al. (2013) conducted a quantitative cross-section study that surveyed primary care physicians (PCPs) and oncologists' views on self-efficacy regarding the follow-up care of cancer survivors. In this study, researchers also examined what cancer survivorship model PCPs and oncologists preferred to develop new strategies for follow-up cancer care. They designed survey questions to assess both the PCP and oncologists' views, knowledge, and care coordination methods regarding post-treatment care in cancer survivors (Cheung et al., 2013). The three possible survivorship model preferences were a shared model involving PCPs and oncologists together, care only by oncologists, or specialized survivor clinics that include physicians that exclusively focus on cancer care with skilled nurses, physician assistants, and nurse practitioners. Researchers examined participants' attitudes regarding their views on personal self-efficacy related to detecting cancer recurrence and the ability to manage cancer and its effects. The initial survey determined eligible participants through a telephone screening process, followed by a mailed version of the formal survey packet to eligible participants. In total, 2,026 participants consisted of 938 PCPs and 1,088 oncologists. The study found that 51% of PCPs supported a PCP/shared model of care, 59% of cancer specialists preferred an oncologist lead model of care, and 23% of physicians favored the specialized survivor clinic models

(Cheung et al., 2013). Researchers found that 70% of oncologists were confident in their ability to manage long-term effects in cancer survivors. However, PCP’s were less optimistic in their ability to provide adequate care, with only 19% reporting high self-efficacy (Cheung et al., 2013). Researchers concluded that the discrepancy in preference of PCP or oncological care in treating cancer survivors might fail to coordinate care between providers adequately.

A 2016 qualitative study, conducted by Smidt et al. (2016), focused on the perceptions of Australian oncologists in terms of cancer-related cognitive changes (CRCC) in patients and the impact of their views on patient care. The main questions researchers addressed in this study include how oncologists perceive CRCC and address these issues with their patients during the survivorship phase (Smidt et al., 2016). After receiving verbal consent, the researchers used telephone interviews, where interviews were audio-recorded and then transcribed verbatim. The interviews ranged from 15 to 30-minute intervals on average and consisted of 18 oncologists. The critical points asked in the interview were: (1) the beliefs about the impact of cognitive function among cancer survivors, (2) perceptions of which party is more likely to address cognitive changes, (3) uncertainty of how to manage CRCC, and (4) the role of oncologists in CRCC (Smidt et al., 2016). The researchers discovered that the participating oncologists treat cancer survivors that have side effects of cancer treatment. However, the patients indicated that they were given little information from their oncologists regarding CRCC. Researchers showed a minimal number of oncologists in this study referred patients to other healthcare professionals, including nurses, occupational therapists, and social workers (Smidt et al., 2016). They concluded that the lack of guidelines for cancer survivor treatment, and the number of survivors not experiencing the CRCC, has created a barrier in practice that has prevented survivors from the best care possible. This study successfully highlighted the barriers Australian oncologists face when delivering survivorship care, which can impact the patient's care and overall quality of life (Smidt et al., 2016).

Similarly, Klabunde et al. (2013) also investigated PCPs’ and oncologists' self-reported roles in follow-up care of cancer patients. Their focus was to assess the roles of PCP's and oncologists in the follow-up cancer care process. Researchers also determined what factors are involved in follow-up care and how clinicians utilize care coordination and communication (Klabunde et al., 2013). The researchers in this cohort study used data from the 2009 Survey of Physicians' Attitudes Regarding the Care of Cancer Survivors (SPARCCS), which surveys both PCPs and oncologists. The researchers primarily focused on the follow-up care of breast and colon cancer survivors; therefore, they excluded physicians who reported to never, or not in the past year, care for patients with these forms of cancers (Klabunde et al., 2013). The final study sample included 1,014 PCPs and 1,125 oncologists. Researchers assessed the physician's roles by asking how often treatment services were provided in their practice and evaluated the participants' beliefs on the role of PCPs in cancer survivorship (Klabunde et al., 2013). They specifically asked PCPs how often they received a summary of the patient's cancer treatment or recommendations for future care from the treating oncologists. Researchers found that many PCPs reported co-managing survivor care with other oncologists unless screening for new primary cancers in patients. The PCPs that reported receiving summaries from the treating oncologists were also more likely to prefer the co-managing role pattern (Klabunde et al., 2013). These researchers found that many PCPs feel that they have an active role in cancer survivorship but often accompany co-management of oncologists. However, oncologists reported they directly provide follow-up care without assistance from the PCPs. The authors noted the discrepancies of reports in co-management care from PCPs and oncologists and believe this emphasizes the need for a shared-care model when treating cancer survivors to meet the patient's needs (Klabunde et al., 2013).

Finally, a mixed-method study, conducted by Suija et al. (2016) focused on the current role general practitioners play in caring for cancer patients and the unmet needs that cancer patients in primary care face. Researchers conducted a study at general practice locations in Estonia that included patients with various stages of cancer but excluded patients with terminal diagnoses (Suija et al., 2016). Researchers (2016) used the qualitative portion to understand the current phenomenon through interviews, where patients expressed their personal experiences. Ten interviews lasted from 35 to 120 minutes and were recorded, transcribed verbatim, and analyzed using thematic analysis. A questionnaire was later developed as a form of quantitative research to collect data based on previous findings. The questionnaire focused on demographics, illness, treatment methods, follow-up care, and statements related to their diagnosis and their medical professional's role (Suija et al., 2016). There were 300 questionnaires distributed to eligible participants throughout Estonia, and 113 participants responded. The researchers found that 92% of survivor participants were satisfied with the GP's work, 77% felt their GP was competent in cancer care, and 79.5% reported their oncologists thoroughly investigated them (Suija et al., 2016). The most common unmet need reported by patients was poor communication, where 19.5% had negative attitudes toward communication with their physicians, and 30% stated they could not understand the doctor's explanations. Finally, 39.9% of participants reported that they felt their oncologists and general practitioners did not collaborate in shared survivorship care (Suija et al., 2016).

Unmet Needs of Survivors

Due to gaps in care and a lack of referral to rehabilitation services such as occupational therapy, survivors live with unmet needs. Thorsen et al. (2011) published a cross-sectional study where researchers focused on assessing the rehabilitation needs of cancer survivors and exploring factors that are associated with these needs. The other aims of the study were to estimate the need for complex rehabilitation and its associated factors, address unmet needs in rehabilitation services, and assess the factors related to these needs (Thorsen et al., 2011). The researchers used a questionnaire to determine the patient's need for certain rehabilitation services relating to their type of cancer and what patients had been offered and utilized the rehabilitation services. The final number of participants was 1,325, where 37% reported no need for therapy, and 63% needed at least one form of rehabilitation that was listed (Thorsen et al., 2011). The highest reported need was physical therapy at 43%, followed by the need for more than one form of therapy at 40% (Thorsen et al., 2011). The authors concluded that most patients reported the need for some form of rehabilitation service, and physical therapy was the most indicated need. They believe the results from the study help to enforce that cancer patients need rehabilitation services in each phase of treatment, and that rehabilitation is often only offered after initial treatment (Thorsen et al., 2011). They also concluded that the need for rehabilitation remains present for the first few years after diagnosis and often remains relatively constant for years after (Thorsen et al., 2011).

Binkley et al. (2012) conducted a mixed-methods study that focused on the unmet needs of breast cancer patients. The researchers hypothesized that the frequency of unmet needs could result from the lack of awareness of the potential long-term effects of cancer treatments. Researchers used a prospective surveillance model to explore various articles that included issues regarding lymphedema, fatigue, upper extremity dysfunction, neuropathy, etc. (Binkley et al., 2012). The data was collected through systematic reviews, focus groups, and questionnaires to obtain the primary data sources (Binkley et al., 2012). The qualitative results suggest that patients need long-term attention, specifically shoulder and trunk strength and range of motion. The researchers also found few women are referred for rehabilitation services while receiving or after the conclusion of treatment for breast cancer (Binkley et al., 2012). They concluded that patients need consistent care, such as rehabilitation services, to treat short- and long-term effects of breast cancer (Binkley et al., 2012).

Jang and Jeong (2021) performed a cross-sectional descriptive study focusing on the unmet needs of cancer patients and their families following diagnosis. Researchers hypothesized that these unmet needs would lead to a decreased quality of life in the patients (Jang & Jeong, 2021). The researchers utilized a questionnaire to collect patients' demographics, disease-related characteristics, unmet needs, and quality of life. Both cancer patients and family members completed the questionnaire, with 115 patient-family dyads participating in the study (Jang & Jeong, 2021). Researchers found that the patients’ unmet needs decreased their physical function and overall quality of life. Researchers also found that the patients’ unmet needs led to decreased mental quality of life in patients’ families (Jang & Jeong, 2021). The authors concluded that intervention programs are necessary to improve cancer patients' and their families’ quality of life (Jang & Jeong, 2021).

In summary, researchers have indicated the need for an occupational therapy screening tool in cancer survivorship care. Survivors experience many side effects of treatment, such as fatigue, pain, sensory loss, and cognitive impairment that may impact occupational performance and overall quality of life (Brekke et al., 2019). These side effects can result in deficits in areas of occupation such as personal hygiene and grooming, toileting, sleep, work, and sexual activity (Hwang et al., 2015; Marciniak et al., 1996; Petruseviciene et al., 2018). Although survivors face performance deficits resulting from cancer treatment, many do not receive referrals to occupational therapy. Occupational therapy practitioners are skilled in addressing these late side effects and occupational performance deficits for improved overall quality of life in cancer survivors. However, Pergolotti et al. (2014) found that only 32% of their total sample received referrals to occupational therapy within the first two years of their cancer diagnosis. Survivorship care requires an occupational participation approach which includes regular screening for occupational therapy services. Currently, no developed screening tools are indicating the need for referral to occupational therapy in survivorship care. Researchers previously developed the SOCS-OTS to screen for occupational performance deficits and the need for occupational therapy services in cancer survivors. The purpose of this study is to identify the level of consensus on which items should be included in this tool using a Delphi technique. Researchers will explore which items on the SOCS-OTS reach 80% consensus for inclusion, which do not reach a level of 80% consensus for exclusion, and additional items to include in the tool.

Building the Screen of Cancer Survivorship - Occupational Therapy Services (SOCS-OTS): A Delphi Study

Abstract

Background: Occupational therapy is needed in cancer survivorship care to bridge the gaps in care and treat the unaddressed life activities experienced by this population. The Screening of Cancer Survivorship - Occupational Therapy Services (SOCS-OTS) tool is available but requires a true consensus from experts in the field to indicate which items to include in its final rendition. The researchers in this study aim to identify the level of consensus on which items should be included in the final rendition of the SOCS-OTS tool. The purpose of the tool is to survey cancer survivors to assess their need for occupational therapy.

Introduction: This paper reviews the lack of occupational therapy services provided to cancer survivors post-treatment. The researchers of this study set out to create a screening tool that depicted the need for therapeutic interventions for these individuals. The Model of Occupational-Participation for Cancer Survivorship (MOPCS) helped guide the development of this study and the screening tool.

Methods: Researchers used a classical Delphi methodology to assess 14 expert opinions and indicate which items meet consensus for inclusion on the SOCS-OT tool through an online survey development software program. Researchers used thematic analysis and open, axial, and selective coding to interpret experts' comments and feedback and guide appropriate modifications to the survey before sending it out for subsequent rounds. Researchers removed items not reaching 80% consensus from the tool. In each round, participants received an overview of participants' feedback from the previous round.

Results: At the conclusion of the Delphi methodology process, 20 items met consensus for the final rendition of the SOCS-OT tool. Researchers modified several items throughout the process and removed three items from the tool.

Conclusions: With the given information, the need for occupational therapy services in oncology is prevalent and requires additional research and assessment tools. The development of the SOCS-OTS provides a rise for further investigation.

Recommendations/Implications: It is imperative that individuals in the field of oncology adopt and implement the SOCS-OTS into standard cancer survivor treatment. Researchers will utilize validity and reliability tests to confirm the tool's psychometric properties.

Keywords: Cancer survivorship, Occupational Therapy, Screening Tool, Delphi Method

Introduction

As of 2016, experts estimated that there were 15.5 million cancer survivors in the United States, and they predicted that by the year 2026, that number will rise to 20.3 million (National Cancer Institute, 2018). A cancer survivor is anyone with or who had cancer from the time of diagnosis to the end of life (National Cancer Institute, 2019). As the number of cancer survivors increases, it is essential to consider what factors may impact their quality of life following cancer treatment. Quality of life is inversely related to occupational performance deficits, which can occur due to side effects of cancer treatment such as fatigue, pain, sensory loss, and cognitive impairments (Brekke et al., 2019). Occupational performance is the accomplishment of an occupation which is a purposeful activity that has meaning to the individual (American Occupational Therapy Association, 2014).

In 2006, the Institute of Medicine (IOM) called for the implementation of cancer survivorship recommendations and plans to improve care coordination and follow-up care and assure patient outcomes. The American Society of Clinical Oncology (ASCO) Survivorship Care Plan (SCP) is a document that includes a treatment summary and follow-up care plan to improve communication and coordination of care for cancer survivors. It helps patients track check-ups or follow-up tests, maps out possible late side effects of treatment, and provides ideas for staying healthy (Centers for Disease Control and Prevention, 2018). Researchers have indicated that a lack of coordination in survivorship care can contribute to poor care delivery and adverse patient outcomes (Klabunde et al., 2013).

The ASCO SCP addresses concerns related to emotional and mental health, physical functioning, memory or concentration loss, fatigue, parenting, school/work, and sexual functioning. However, the SCP in care coordination does not include various kinds of life activities (occupations) found which impact cancer survivorship in the literature (American Society of Clinical Oncology, 2019). Researchers have recommended an occupational participation approach to cancer survivorship care to address gaps in care (Yim Loh & Jonsson, 2016). Although survivors face performance deficits resulting from cancer treatment, many do not receive referrals to occupational therapy. An occupational participation approach is necessary in survivorship care, including regular screening for occupational therapy services. Currently, no developed screening tools indicate the need for referral to occupational therapy in survivorship care. However, a previously developed Screening of Cancer Survivorship - Occupational Therapy Services (SOCS-OTS) tool is available but requires a true consensus from experts in the field to indicate which items are necessary in its final rendition. The researchers in the study aim to identify the level of consensus on which items should be included in the SOCS-OTS tool.

Method

Study Design

Researchers used a classical Delphi methodology to assess expert opinion on a screening tool to indicate which items meet consensus for inclusion on the tool. The classical Delphi methodology is a consensus technique used to obtain and evaluate the views of an expert panel who have extensive knowledge and experience in oncology care (Sekayi & Kennedy, 2017). We used an expert panel for the ability to have multiple skillful opinions of how to adapt our screening tool to best address the concerns and problems of the cancer survivorship population. It also allows for knowledge sharing between the panelist and researchers. Lastly, it alters any researchers' bias that may occur throughout the developmental process (Avella, 2016). Our study consisted of four rounds in which experts gave their opinions on whether to include an item in our screening tool or not. Our study included a set of open-ended questions allowing for freedom of response. Sekayi and Kennedy (2017) indicated that a classical Delphi methodology is often used in health and social science research when developing a screening tool due to the ability to converge opinions from a wide variety of experts and reach consensus. Further, the Delphi methodology was appropriate for this study as it allowed researchers to use several rounds of feedback for revision and improvement of the screening tool after each consecutive round (Hasson et al., 2000). Delphi study methodology is used in occupational and physical therapy practice to provide the foundational psychometric testing needed to validate a survey tool in areas where evidence and research are lacking, such as oncology care (Falzarano & Pinto Zipp, 2013).

Previous to this project, a group performed the first round of this Delphi study, including a deductive and inductive approach to item writing and included a set of open-ended questions allowing for freedom of response. The deductive approach was conducted by thematically analyzing oncology literature and using the Occupational Therapy Practice Framework to guide item writing specific to occupational performance limitations in survivorship. Researchers used an inductive approach to verify the items that were issues relevant to cancer survivor panelists.

Participants

While researchers that have used Delphi methodology have not clearly defined an expert, experts may include informed individuals, specialists in the field, or someone who knows about a specific subject (Keeney et al., 2001). An expert can also include an individual who has worked within an area for a certain length of time (Hardy et al., 2004; Jeffery et al., 2009). Qualified expert panelists included occupational therapists (OT), certified occupational therapy assistants (COTA), and OT researchers who practice and study in oncology. The inclusion of OT practitioners required expert panelists to have at least five years of clinical experience with a 30% caseload of adult cancer survivors. OT researchers required a published oncology-related article. Exclusion from this study involved OT practitioners serving the pediatric oncology population because the SOCS-OTS is for the adult population. Purposive and snowball sampling recruitment methods occurred through our professional networks, posting on forums on AOTA.org, and social media platforms.

Instrument

Under the leadership of the principal investigator, a previous group of students developed an electronic questionnaire, *The Screening of Cancer Survivorship-Occupational Therapy Services* (SOCS-OTS), to indicate the need for occupational therapy services in survivorship care. The questions ask about everyday activities of daily living performed by cancer survivors, e.g., “My cancer has made it difficult to engage in sexual activity with a partner or myself.” Survivors indicated their level of agreement with each question on the tool on a five-point scale: ‘I cannot do this,’ ‘I have a lot of problems with doing this,’ ‘I have some problems doing this,’ ‘I can do this well,’ ‘I can do this very well’. A five-point Likert scale is the most commonly utilized Likert scale in empirical research. Researchers indicate that a 5-point Likert scale produces greater validity, reliability, and variance in response than scales with fewer items (Dawes, 2012). The current tool requires a true consensus from experts in the field to indicate item inclusion in its final rendition, which researchers will gather in this study. See Appendix A for an original questionnaire of SOCS-OTS.

Data Collection

Round 2

The second round of the overall classical Delphi study for this project consisted of a survey containing quantitative and qualitative methods that researchers developed from cancer survivors in Round 1. Researchers sent an ordinal questionnaire to participants in Round 2. Expert panelists indicated whether or not to include each item on the tool through a "yes, yes with revisions, or remove" ordinal questionnaire and provided qualitative feedback on improvements for each item. An overall additional qualitative question at the end of the survey asked experts to indicate missing items they felt should be included on the tool. Additionally, expert panelists provided feedback about the scale used in the SOCS-OTS and any additional general feedback. Round 2 concluded after 24 days, with follow-up emails sent to expert panelists on day 7, day 12, and day 14. Due to the limited number of responses, our initial response time frame was changed from 14 days to 24 days to gain more participants.

Round 3

In Round 3, researchers sent out another ordinal questionnaire to panelists to determine which items were essential to include on the SOCS-OTS. The expert panelists rated each item on a 5-point Likert scale of importance, rating 1 (Unimportant) to 5 (Very Important). Additionally, panelists provided feedback on the updated format of the tool itself and any additional general feedback about items. Round 3 concluded after 18 days, with follow-up emails sent out to expert panelists on day 7, day 12, day 14, and day 17. Due to the limited number of responses, our initial response time frame was changed from 14 days to 18 days to gain more participants.

Round 4

In the fourth and final round, researchers sent the revised questionnaire to expert panelists following further adjustment to the tool using expert feedback from Round 3. The final questionnaire consisted of items that met consensus after Round 3. Panelists indicated whether the item must be included or removed from the tool. Round 4 concluded after 35 days. Researchers sent follow-up emails to the panelists after 7 days, 9 days, 11 days, 12 days, 13 days, 24 days, and 29 days. Researchers intended to close Round 4 after 14 days, but due to limited participation was extended to 35 days. Round 4 received 14 responses, and the researchers verified the final version of the SOCS-OTS. On the final version, 20 items remained after researchers removed 2 items due to unmet consensus.

Data Analysis

Panelists' responses were collected and analyzed using Qualtrics (Qualtrics, Provo, UT), which is an online survey development software. Researchers collected these responses after each round to obtain quantitative data. Although there is no set consensus value when using the Classical Delphi technique, many studies use 80% consensus, which was the consensus chosen for this study (Keeney et al., 2006). To be in consideration for the next rendition of the screening tool, items needed to reach the minimum consensus. Researchers used thematic analysis and open, axial, and selective coding to interpret experts' comments and feedback and guide appropriate modifications to the survey before sending it out for subsequent rounds. Researchers analyzed data through all three rounds regardless of the attrition of expert panelists. After the Delphi process, researchers sent the final results to the participating panelists through Qualtrics.

Results

Round 2

In Round 2 of our Delphi study, researchers sent the survey to 75 panelists through Qualtrics and gathered 27 responses. Nine panelists did not meet expert criteria, so researchers only included 18 responses in data collection. See Appendix A for Round 2 screening tool sent for expert feedback. After analysis of feedback provided by participants, researchers made changes to the items on the SOCS-OTS for clarity based on themes generated. Five items did not meet consensus and were modified using expert feedback. Items that did not meet consensus included “Engage in sexual activity with a partner or myself,” “Maintain closeness and intimacy with a romantic partner,” “Move from one position or place to another,” “Do my yard work,” and “Fully return to work.” Six items including “Drive and move around the community,” “Manage my health,” “Toilet and toilet hygiene,” “Engage in religious/spiritual activities, organizations, and/or practices,” “Dress/undress,” and “Personal hygiene and grooming” were added to the screen using expert recommendations. See Table 1 for Round 2 consensus levels. Per expert panelist feedback on the scaling technique, researchers changed the tool to a “check all that apply” format. Instead of having clients rate their difficulty level, this new format allows clients to indicate which items they find difficult and would like assistance completing.

Table 1

Consensus Levels for Round 2

Items	Consensus
Bathe and/or shower	100%
Engaging in sexual activity with a partner or myself	64.70%*
Maintain closeness and intimacy with a romantic partner	70.59%*
Provide care for other people and/ or pets	88.89%
Move from one position or place to another	61.11%*
Manage finances	100%
Maintain my exercise routine and physical fitness	83.33%
Manage my medications	94.44%
Clean my home	83.33%
Do my yard work	77.78%*
Perform home maintenance and repairs	83.33%
Plan, prepare, serve and/or clean up meals	83.33%
Grocery shop	83.33%
Rest and sleep	94.44%
Fully return to work	72.22%*
Perform my job duties at prior level of expectation	88.89%
Engage in educational activities	88.89%
Participate in leisure activities	94.44%
Socialize with my family and friends	100%
Participate in community events	100%

Note. * indicates items that did not meet consensus.

Round 3

In Round 3, researchers collected 15 total responses. Based on the feedback received, two items did not meet consensus, including "Doing my yard work" and "Performing home maintenance and repairs." Researchers removed these two items from the SOCS-OTS entirely and sent out an updated revision in round 4. See Table 2 for Round 3 consensus levels. Researchers modified a few of the items with added clarification, where the experts expressed appreciation for the use of the updated vocabulary. In regards to the “check all that apply” format, the experts provided positive feedback, expressing that the new set-up is “relevant” and “easier for the readers’ comprehension.”

Table 2

Consensus Levels for Round 3

Items	**Consensus**
Bathe and/or shower	100%
Manage finances	93.33%
Clean my home	86.67%
Do my yard work	66.67%*
Perform home maintenance and repairs	53%*
Plan, prepare, serve and/or clean up meals	93.33%
Rest and sleep	100%
Engage in educational activities	80%
Participate in leisure activities	100%
Socialize with my family and friends	100%
Participate in community events	86.67%
Engage in sexual activity and/or sexual expression (e.g., hugging, kissing, foreplay, masturbation, oral sex, intercourse)	100%
Engage in activities to give and receive affection needed to successfully interact in close personal relationships (e.g., friends, family members, intimate partners)	93.33%
Provide care for others (e.g., childcare, caring for older parents, etc.)	93.33%
Move self from one position or place to another (e.g., reaching, moving in bed, moving in wheelchair, performing transfers, walking during tasks and transporting items)	100%
Maintain my desired exercise routine and physical fitness	93.33%
Manage my medications (e.g. filling prescriptions at the pharmacy, understanding medication instruction, taking medications on a routine basis, refilling prescriptions in a timely manner)	93.33%
Grocery shop (e.g., prepare grocery list, order online/go to store, bag groceries, unloading groceries, paying)	86.67%
Engage in desired work performance and/or returning to work	93.33%
Drive and move around the community (e.g., using public or private transportation)	93%

Manage my health (e.g., communicate with healthcare providers, understand recommendations for care plan, manage symptoms and conditions, etc.)	93.33%
Toilet and toilet hygiene	100%
Engage in religious/spiritual activities, organizations, and/or practices	86.67%
Dress/undress (e.g., fasten and adjust clothing and shoes, remove personal devices/prosthetic devices/splints)	93.33%
Personal hygiene and grooming	93.33%

Note. * indicates items that did not meet consensus.

Round 4

In Round 4 of our Delphi Study, we collected 14 survey responses from expert panelists. Three items did not meet consensus, which included “Engage in leisure activities,” “Participate in community events,” and “Engage in religious/spiritual activities, organizations, and/or practices.” See Table 3 for Round 4 consensus levels. Researchers removed these three items from the SOCS-OTS entirely. Researchers did not modify any items following the conclusion of this round as the remainder of the items reached consensus. Experts expressed general positive feedback about the SOCS-OTS and that it will be a valuable tool to identify the need for OT services. See Appendix D for the final version of SOCS-OTS.

Table 3

Consensus Levels for Round 4

Items	Consensus
Bathe and/or shower	100%
Manage finances	100%
Clean my home	85.71%
Plan, prepare, serve and/or clean up meals	100%
Rest and sleep	100%
Engage in educational activities	57.14%*
Participate in leisure activities	100%
Socialize with my family and friends	100%

Participate in community events	57.14%*
Engage in sexual activity and/or sexual expression (e.g., hugging, kissing, foreplay, masturbation, oral sex, intercourse)	100%
Engage in activities to give and receive affection needed to successfully interact in close personal relationships (e.g., friends, family members, intimate partners)	100%
Provide care for others (e.g., childcare, caring for older parents, etc.)	92.86%
Move self from one position or place to another (e.g., reaching, moving in bed, moving in wheelchair, performing transfers, walking during tasks and transporting items)	85.71%
Maintain my desired exercise routine and physical fitness	92.86%
Manage my medications (e.g. filling prescriptions at the pharmacy, understanding medication instruction, taking medications on a routine basis, refilling prescriptions in a timely manner)	100%
Grocery shop (e.g., prepare grocery list, order online/go to store, bag groceries, unloading groceries, paying)	85.71%
Engage in desired work performance and/or returning to work	100%
Drive and move around the community (e.g., using public or private transportation)	100%
Manage my health (e.g., communicate with healthcare providers, understand recommendations for care plan, manage symptoms and conditions, etc.)	92.86%
Toilet and toilet hygiene	100%
Engage in religious/spiritual activities, organizations, and/or practices	78.57%*
Dress/undress (e.g., fasten and adjust clothing and shoes, remove personal devices/prosthetic devices/splints)	100%
Personal hygiene and grooming	100%

Note. * indicates items that did not meet consensus.

Discussion

In this modified Delphi study, researchers aimed to identify the level of consensus on which items should appear on the final SOCS-OTS tool. There are currently no developed screening tools used in practice to indicate the need for referral to occupational therapy in survivorship care, despite evidence that occupational performance limitations occur from side effects of cancer treatment. Pergolotti et al. (2020) found in ovarian cancer survivors, functional limitations lead to physical, social, and emotional problems, which occupational therapy can address. Survivors reported deficits in areas of daily living, work, and physical activity, which correlate with decreased quality of life (Pergolotti et al., 2020). Martin et al. (2020) further explored the impact of survivorship on occupational performance. They identified six limited domains of occupation: social activity, physical activity, sexual activity, employment and role functioning, physical functioning, and self-care. Side effects of cancer treatment, including urinary dysfunction, fatigue, anxiety, weakness, and pain, impact these occupational domains (Martin et al., 2020). Per Martin et al. (2020), these limitations can result in depression, anxiety, and reduced quality of life among survivors. Thus, the side effects of cancer treatment can have detrimental implications on occupational performance.

According to Hwang et al. (2015), among 30 of the 68 participants (45.5%) who received referrals, 13 participants (19.7%) reported having a physical therapy referral for survivorship care, yet only 3 (4.5%) received occupational therapy. Similarly, Pergolotti et al. (2014) conducted a population-based survey finding that of the 87% of older cancer survivors in need of occupational therapy, only 32% saw occupational therapy within the first two years of their cancer diagnosis, further reinforcing the underutilization of occupational therapy in cancer survivorship. While survivors continue to experience occupational performance deficits following cancer treatment and occupational therapy services are being underutilized, there is also a lack of referral to occupational therapy services (Martin et al., 2020). The ASCO SCP does not include various kinds of life activities (occupations) inhibited in cancer survivorship and would indicate a referral to needed occupational therapy services (American Society of Clinical Oncology, 2019).

Doucet and Gutman (2013) called for the need for occupational therapy researchers to design measurement tools that provide quantifiable data on function in areas including body impairment, activity limitation, and participation restriction. Using this quantifiable data, practitioners could indicate the need for occupational therapy services, justify their role in the healthcare system, and improve the quality of life among clients with functional impairments (Doucet & Gutman, 2013). Researchers in the current study gathered consensus from experts in oncology to determine item inclusion on the SOCS-OTS' final rendition. The items on the SOCS-OTS include everyday activities of daily living that are frequently stated as participation restrictions by cancer survivors, e.g., "My cancer has made it difficult to engage in sexual activity with a partner or myself."

According to the American Occupational Therapy Association (2014), cancer treatment can negatively impact every aspect of the occupation. The most highly rated items on the final SOCS-OTS addressed the following areas of occupation: bathing and dressing, managing finances, feeding/eating, rest and sleep, social participation, sexual activity and intimacy, medication management, work, and community mobility. Literature shows that cancer survivors experience limitations in social participation, leading to decreased quality of life (Martin et al., 2020). Chemotherapy and other cancer treatments can lead to a decline in strength, fatigue, depression, and pain which influences the ability to return to work (Martin et al., 2020). Occupational therapy can positively impact these factors related to their ability to return to work (Wallis et al., 2020). Hwang et al. (2015) stated that cancer survivors often report experiencing decreased sexual drive, poor body image, and sexual discomfort, which limit their ability to participate in sexual activity. Survivors listed hygiene as one of the most important occupational performance deficits experienced by cancer survivors in a study conducted by Marciniak et al. (1996). Hwang et al. (2015) identified the occupational performance limitations cancer survivors face leading to a decreased quality of life. Items of Engage in education activities," "Participate in community events," and "Engage in spiritual/religious activities, organizations, and/or practices" did not meet consensus. There was limited research to support these items, which may have impacted the experts' recommendations to remove these items from the tool.

Limitations and Future Research

It is important to recognize the limitations of this study. First, we faced attrition in this study with 27 initial panelists in round 2; therefore, we had a small sample size of expert panelists that diminished to 14 by round 4. Literature on Delphi methodology states that 30 panelists are ideal (Hasson et al., 2000; Powell, 2003). In accordance with previous Delphi studies, researchers expected an attrition rate of 20% for a Delphi study of 3 rounds (Henderson & Rubin, 2012). Some possible issues related to this more significant attrition rate were that active data collection happened around a holiday break and during a global pandemic. The first round of the Delphi study included a majority of participants who were breast cancer survivors. Therefore, this may be problematic when considering the development of the screening tool as certain forms of cancer can have different effects on various occupations. Future research supporting the SOCS-OTS should focus on developing its psychometric properties, such as a formal validation of its scale and exploring how many responses indicate the need for an OT referral. Additionally, reliability studies are warranted involving a variety of cancer diagnoses. Future researchers should also explore distress screeners or current survivorship care plans to screen for side effects of cancer and identify which items on these screening tools would trigger the need to use the SOCS-OTS for possible OT referral.

Implications for Occupational Therapy Practice

To address the broad spectrum of occupational performance issues related to survivorship care, health care providers must recognize what clients require an occupational therapy referral at various points in the survivorship continuum. Occupational therapy practitioners can take action with improving screening services for cancer survivors in the following ways:

- Educate referral sources on the distinct value of OT in oncology care. OT has distinct value in oncology care because of the skill set. Occupational therapists work with survivors on their physical and psychosocial needs to improve various occupational performance deficits they face due to cancer treatment. While many healthcare providers focus on the side effects survivors face, OTs focus on how those side effects affect their everyday function and performance in daily tasks (Sleight & Duker, 2016).
- Discuss with oncology teams the importance of screening for occupational performance deficits using screening tools like SOCS-OTS.
- Introduce SOCS-OTS to frontline practitioners in oncology care, including nurse navigators, oncologists, and other members of multidisciplinary oncology teams.
- Adopt and incorporate the SOCS-OTS into screening procedures and care coordination, including its potential implementation into distress screening tools and survivorship care plans.

Conclusion

There is currently no developed screening tool indicating occupational performance deficits and the need for referral to occupational therapy in the cancer survivor population. This gap in screening services led to the development and need for formal validation of the SOCS-OTS. Items included in the final version of the SOCS-OTS tool, following expert consensus, addressed the degree of difficulty clients have performing occupations following cancer treatment. They specifically addressed activities of daily living and instrumental activities of daily living.

In the first round of the Delphi study, researchers used the opinion of cancer survivors for validation of screening tool items they developed from a thorough literature review. In the second round (and current study), researchers used expert panelists, including occupational therapists (OT), occupational therapy assistants (OTA), and OT researchers that practice and contribute to the research in the field of occupational therapy in oncology. In health science research, researchers commonly select a Delphi approach to eliminate biases, allow opinions from a variety of experts, and have the opportunity for revision and feedback following each round of the Delphi until they reach consensus (Avella, 2016; Hasson et al., 2000; Sekayi & Kennedy, 2017).

Practitioners in oncology care can use the SOCS-OTS tool to identify activities that the client cannot perform to their satisfaction. Further work may be needed to refine and test the tool in a clinical setting to ensure its feasibility and effectiveness in client-centered care.

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Appendix A

SOCS-OTS

Please rate your level of functioning as it pertains to each item presented below.

	I cannot do this	I have a lot of problems with doing this	I have some problems with doing this	I can do this well	I can do this very well
Bathe and/or shower					
Engage in sexual activity with a partner or myself					
Maintain closeness and intimacy with a romantic partner					
Provide care for other people and/or pets					
Move from one position or place to another					
Manage finances (i.e. processes of paying bills, budgeting, simple money transaction)					
Maintain my exercise routine and physical fitness					
Manage my medications					
Clean my home					
Do my yard work					
Perform home maintenance and repairs					
Plan, prepare, serve, and/or clean up meals.					
Grocery shop					
Rest and sleep					
Fully return to work					
Perform my job duties at prior level of expectation					
Engage in educational activities					
Participate in leisure activities					
Socialize with my family and friends					
Participate in community events					

Appendix B

Screen of Cancer Survivorship – Occupational Therapy Services (SOCS-OTS)

Instructions: Please check all items that you would like assistance with improving.

Item	Please check all that apply
Bathe and/or shower	
Engage in sexual activity and/or sexual expression (e.g., hugging, kissing, foreplay, masturbation, oral sex, intercourse)	
Engage in activities to give and receive affection needed to successfully interact in close personal relationships (e.g., friends, family members, intimate partners)	
Provide care for others (e.g., childcare, caring for older parents, etc.)	
Move self from one position or place to another (e.g., reaching, moving in bed, moving in wheelchair, performing transfers, walking during tasks and transporting items)	
Drive and move around the community (e.g., using public or private transportation)	
Manage finances	
Maintain my desired exercise routine and physical fitness	
Manage my medications (e.g. filling prescriptions at the pharmacy, understanding medication instruction, taking medications on a routine basis, refilling prescriptions in a timely manner)	
Clean my home	
Do my yard work	
Perform home maintenance and repairs	
Plan, prepare, serve and/or clean up meals	
Grocery shop (e.g., prepare grocery list, order online/go to store, bag groceries, unloading groceries, paying) [modified item	
Rest and sleep	
Engage in desired work performance and/or returning to work	
Engage in educational activities	
Participate in leisure activities	
Socialize with my family and friends	
Participate in community events	
Manage my health (e.g., communicate with healthcare providers, understand recommendations for care plan, manage symptoms and conditions, etc.)	
Toilet and toilet hygiene	
Engage in religious/spiritual activities, organizations, and/or practices	
Dress/undress (e.g., fasten and adjust clothing and shoes, remove personal devices/prosthetic devices/splints)	
Personal hygiene and grooming	

Appendix C

Screen of Cancer Survivorship – Occupational Therapy Services (SOCS-OTS)

<u>Instructions:</u> Please check all items that you would like assistance with improving.

Item	Please check all that apply
Bathe and/or shower	
Engage in sexual activity and/or sexual expression (e.g., hugging, kissing, foreplay, masturbation, oral sex, intercourse)	
Engage in activities to give and receive affection needed to successfully interact in close personal relationships (e.g., friends, family members, intimate partners)	
Provide care for others (e.g., childcare, caring for older parents, etc.)	
Move self from one position or place to another (e.g., reaching, moving in bed, moving in wheelchair, performing transfers, walking during tasks and transporting items)	
Drive and move around the community (e.g., using public or private transportation)	
Manage finances	
Maintain my desired exercise routine and physical fitness	
Manage my medications (e.g. filling prescriptions at the pharmacy, understanding medication instruction, taking medications on a routine basis, refilling prescriptions in a timely manner)	
Clean my home	
Plan, prepare, serve and/or clean up meals	
Grocery shop (e.g., prepare grocery list, order online/go to store, bag groceries, unloading groceries, paying) [modified item	
Rest and sleep	
Engage in desired work performance and/or returning to work	
Engage in educational activities	
Participate in leisure activities	
Socialize with my family and friends	
Participate in community events	
Manage my health (e.g., communicate with healthcare providers, understand recommendations for care plan, manage symptoms and conditions, etc.)	
Toilet and toilet hygiene	
Engage in religious/spiritual activities, organizations, and/or practices	
Dress/undress (e.g., fasten and adjust clothing and shoes, remove personal devices/prosthetic devices/splints)	
Personal hygiene and grooming	

Appendix D

Screen of Cancer Survivorship – Occupational Therapy Services (SOCS-OTS)

Instructions: Please check all items that you would like assistance with improving.

Item	Please check all that apply
Bathe and/or shower	
Engage in sexual activity and/or sexual expression (e.g., hugging, kissing, foreplay, masturbation, oral sex, intercourse)	
Engage in activities to give and receive affection needed to successfully interact in close personal relationships (e.g., friends, family members, intimate partners)	
Provide care for others (e.g., childcare, caring for older parents, etc.)	
Move self from one position or place to another (e.g., reaching, moving in bed, moving in wheelchair, performing transfers, walking during tasks and transporting items)	
Drive and move around the community (e.g., using public or private transportation)	
Manage finances	
Maintain my desired exercise routine and physical fitness	
Manage my medications (e.g. filling prescriptions at the pharmacy, understanding medication instruction, taking medications on a routine basis, refilling prescriptions in a timely manner)	
Clean my home	
Plan, prepare, serve and/or clean up meals	
Grocery shop (e.g., prepare grocery list, order online/go to store, bag groceries, unloading groceries, paying) [modified item	
Rest and sleep	
Engage in desired work performance and/or returning to work	
Participate in leisure activities	
Socialize with my family and friends	
Manage my health (e.g., communicate with healthcare providers, understand recommendations for care plan, manage symptoms and conditions, etc.)	
Toilet and toilet hygiene	
Dress/undress (e.g., fasten and adjust clothing and shoes, remove personal devices/prosthetic devices/splints)	
Personal hygiene and grooming (e.g., using a razor, applying cosmetics, combing or brushing hair, caring for nails, applying deodorant, brushing/flossing teeth, denture care)	

Signature Certificate

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