Building the Screening of Cancer Survivorship - Occupational Therapy Services (SOCS-OTS)

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Abstract

Purpose: The purpose of this study was to identify the occupational performance deficits experienced by cancer survivors in order to help develop a screening tool that would indicate a need for occupational therapy services in cancer survivorship care (before, during, and after being diagnosed with cancer). Methods: The delphi technique was used to develop a screening tool aimed to determine the need for occupational therapy services among cancer survivors. Multiple rounds were used to obtain feedback from content experts to continuously refine the screening tool (Keeney, Hasson, & McKenna, 2011). Researchers gathered ideas from survivors about their occupational performance deficits as well as information from current literature to inform and build and enhance screening tool items. Results: The most prominent occupational performance deficits indicated in the screening tool included rest and sleep, sexuality and intimacy, health and wellness, and performing job duties. Discussion: The current study validated occupational performance limitations found in current oncology literature, providing further insight into the relevance of these limitations in a group of cancer survivor content experts in order to inform the SOCS-OTS. Conclusion: Researchers of this study developed items for the SOCS-OTS based on issues faced by survivors validated by experts' personal experiences as well as supporting literature. This study drew on the experiences of content experts with cancer to determine occupational performance deficits that could deem occupational therapy services necessary for cancer survivors. Further development of the SOCS-OTS is necessary to create an occupation-focused screening tool.

Keywords. cancer survivorship, oncology, occupational therapy, screening tool

Introduction

In 2019 there were over 16.9 million cancer survivors in the United States (National Cancer Institute, 2020; Alfano et al., 2011). It is projected that this number will increase to 22.2 million by 2030, due to advanced medical treatments thus, creating a better life prognosis (National Cancer Institute, 2020; Alfano et al., 2011). With an increase in individuals surviving cancer, researchers note that there is an increased number of long term side effects including physical, emotional, and cognitive impairments creating barriers for survivors return to daily living (Alfano et al., 2012; Morrison & Thomas, 2014; Schmidt, Wiskemann, & Steindorf, 2018). Therefore, cancer survivorship is now defined as a chronic condition (Baxter, Newman, Longpré, & Polo, 2017), because these side effects can occur for more than ten years after treatment (Ness et al., 2013).

Cancer survivors have many problems with some occurring more commonly than others. Common issues found in the literature consist of fatigue, sleep disturbances/insomnia, lack of education, psychosocial issues, cognitive impairments, and returning to work/daily activities all of which can significantly impact cancer survivors' occupational performance and quality of life (Zhou et al., 2017; Crist, 2013; Haun, 2014; Burg et al., 2015). Brennan, Butow, Spillane, & Boyle (2016), found at least one problem in more than 76% of cancer survivors, with the average number of problems per cancer survivor being 6.2.

Literature Review

Fatigue

Fatigue is one of the most common problems of cancer survivors (Crist, 2013; Hauken et al., 2013; Le et al., 2017; Palmer et al., 2017; Schmidt, Wiskemann, & Steindorf, 2018; Stergiou-Kita et al., 2016). A study conducted by Crist (2013) concluded that fatigue, aches and pains, and sleep changes are side effects that impact quality of life for cancer survivors most often.

Zhou et al. (2017) highlighted how the lack of acknowledgment of factors such as education on

diet, exercise, and sleep can lead to a range of physical consequences like fatigue and pain.

Palmer et al. (2017) concluded that the quality of life of cancer survivors was lower than that of the general population due to physical side effects such as fatigue. Survivors dealing with fatigue find it to be one of the most difficult late effects because it is a different type of tired than what they experienced prior to their diagnosis, according to Hauken et al. (2013).

Sleep Disturbances/Insomnia

Difficulty sleeping or insomnia is another common problem that is either going untreated or is treated ineffectively (Jakobsen et al., 2018; Palmer et al., 2017; Schmidt, Wiskemann, & Steindorf, 2018; Zhou et al., 2017). Without proper care, sleep disturbances may become a chronic issue that can add to other issues such as fatigue, pain, and depression (Zhou et al., 2017). In a qualitative study looking at the everyday life of breast cancer survivors participants reported difficulty falling asleep and staying asleep which in turn reduced their energy throughout the day (Jakobsen et al., 2018). Survivors found ways to cope with their lack of energy by searching for occupations that give them a meaningful and active lifestyle (Jakobsen et al., 2018). Zhou and colleagues (2017) described how cancer diagnosis and treatments can cause pre-existing sleep problems to worsen, or give rise to new sleep disturbances, yet reported that most survivors were not receiving effective treatment for insomnia. This could be due to the healthcare providers not being trained sufficiently in evaluating and treating these types of issues (Zhou et al., 2017). Because the gap in identification and treatment of sleep disturbances in cancer patients, a more in-depth screening tool is needed to further investigate and attend to this issue for these individuals.

Lack of Education

Another common issue found in the literature is lack of education about cancer survivorship care provided to cancer survivors by health care providers (Burg et al., 2015; Hauken et al., 2013; Jakobsen et al., 2018; Morrison & Thomas, 2014). In a study by Crist (2013), only 17.8% of cancer survivors reported having received information regarding survivorfocused care post-treatment. Palmer et al. (2017) found the number of concerns for cancer survivors can be decreased if they are advised early on how to communicate their concerns. Furthermore, participants in a study conducted by Jakobsen et al. (2018) expressed concern about not having their questions answered. Survivors knew their symptoms were problematic, but they did not understand why they were happening because they were not informed (Jakobsen et al., 2018). According to Schmidt & Steindorf (2018), cancer survivors felt that their needs for counseling and support were unmet. Morrison & Thomas (2014) found that participants were left to decide when was an acceptable time to return to work, as well as what accommodations should be available to them due to lack of advice given by health care providers. According to a study by Hardcastle, Maxwell-Smith, Hagger, O'Connor, and Platell (2018), there is a lack of healthy lifestyle promotion, such as healthy eating, physical activity, and strategies to stay healthy in colorectal cancer survivors following treatment. Participants desired support but received conflicting information (Hardcastle et al., 2018). A qualitative study conducted by Hauken et al. (2013) described young adult cancer survivors experiences reentering everyday life and uncovered four recurring themes among the participants: (1) lack of preparation, (2) late effects pervading entire life, (3) lack of understanding, and (4) being neither sick nor healthy (Hauken et al., 2013). The participants felt alone and unprepared, which they attributed to a lack of knowledge or communication from the physician about the issues related to their survivorship (Hauken et al., 2013).

Although some of the disconnect could be due to lack of communication or knowledge by the physicians (Hauken et al., 2013), the divide could also be due to physicians not being sufficiently trained in treating certain needs such as sleep disorders (Zhou et al., 2017). Because there is a lack of information and education provided to cancer survivors in regards to their survivorship, they have a harder time adjusting to their life changes, previous roles, and responsibilities (Keesing, Rosenwax, & McNamara, 2016). Occupational therapy can play a role in addressing these issues; however, the findings from a retrospective cohort study imply survivors and oncology practitioners lack awareness of occupational therapy, hindering access to beneficial services for cancer survivors (Pergolotti, Cutchin, Weinberger, & Meyer, 2014).

Psychosocial Issues

Mental and emotional health conditions such as depression, anxiety, feeling down, and feelings of helplessness are common problems among cancer survivors in the literature (Burg et al., 2015; Crist, 2013; Hauken et al., 2013; Le et al., Mitchell, Ferguson, Gill, Paul, & Symonds, 2013; 2017; Palmer et al., 2017). Haun et al. (2014) learned that cancer survivors had a higher rate of depression and anxiety when compared to the general population. A study by Palmer et a.l (2017) found that close to one-third of their participants reported issues with anxiety and some reported concerns about experiencing depression. In a study concerning an evaluation of current referral practice, Zimmermann-Schlegel et al. (2017) found most physicians agreed there are not enough psycho-oncologic services for cancer survivors. Nearly fifteen percent of physicians evaluated reported not referring survivors to psychosocial services nor providing services themselves; although, most agreed that survivors would benefit from these services (Zimmermann-Schlegel et al., 2017). Hauken et al. (2013) and Crist et al. (2013) also concluded psychosocial issues, such as depression and anxiety, were main themes of concern in

participants. Schmidt, Wiskemann, and Steindor (2018) documented that families, employers, peers, and friends of breast cancer survivors possess high expectations for them to quickly return to the same performance levels as before diagnosis, after minimal recovery time. This can cause stress and frustration for survivors as they may be unable to meet these expectations due to decreased cognitive and emotional function (Schmidt, Wiskemann, & Steindorf, 2018).

Cognitive Impairments

Cancer survivors report concerns of having cognitive impairments after treatment such as problems with concentration and memorization (Jakobsen et al., 2018; Palmer et al., 2017; Player et al., 2014). Vordermair (2009) found that following treatment 30-60% of women with breast cancer will experience chemo brain, a term used for cognitive impairments after receiving cancer treatment. Cognitive impairments negatively affected participants in areas of daily routines, employment duties, and hobbies to the point that they tended to avoid these tasks (Player et al., 2014). Although participants used strategies to deal with cognitive difficulties, none of the strategies were provided by a health professional (Player et al., 2014). The lack of ability to cope with cognitive impairments can decrease cancer survivors' quality of life (Player et al., 2014).

Return to Work/Daily Activities

Returning to work and/or other daily activities is another area of need that is unmet in the cancer survivorship population (Crist, 2013; Hauken et al., 2013; Jakobsen et al., 2018; Le et al., 2017; Morrison & Thomas, 2014). A study by Crist (2013) found that participants diagnosed thirteen years prior to the study were still experiencing issues in work productivity caused by problems such as fatigue and cognitive impairments. Many of the participants in a study by Jakobsen et al. (2018) were unable to continue working or had to significantly cut back their

hours. Those who were not employed prior to their diagnosis also found it difficult to return to their daily routines (Jakobsen et al., 2018). A study conducted by Le et al. (2017) concluded that being able to perform day-to-day activities such as preparing meals and light yard or housework were within the most common problems of participants. While some participants reported sadness because of the inability to fully engage in prior occupations, others noted that not working allowed them time to participate in different, but still important, occupations (Jakobsen et al., 2018).

Occupational therapists can play a role in survivorship care, because it is "the only profession that helps people across the lifespan to do the things they want and need to do through the therapeutic use of daily activities (occupations)" (AOTA, 2019). According to Hwang, Lokietz, Lozano, and Parke (2015) only 4.5% of cancer survivors are currently referred to occupational therapy services. Research by Hwang et al. (2015) supported that cancer survivors believed occupational therapy services would have been beneficial during ongoing changes affecting quality of life following treatment.

Although literature highlights many changes in quality of life, there is currently no reliable and valid occupation-focused screening tool to aid healthcare providers in referral to occupational therapy in order to address these needs. This gap in care warrants the need for a tool focusing on the problems of cancer survivors that can be addressed by occupational therapy.

Thus, the purpose of this study is to develop an occupation-focused screening tool (SOCS-OTS) that will indicate a need for occupational therapy services in cancer survivorship care.

Method

Research Design

The delphi technique was used to develop a screening tool aimed to determine the need for occupational therapy services among cancer survivors. The basis of the Delphi method is that a group opinion is more reliable than an individual's and is selected when subjective opinions are needed on a relevant issues (Keeney, Hasson, & McKenna, 2011). Multiple rounds are used to obtain feedback from content experts to continuously refine the screening tool (Keeney, Hasson, & McKenna, 2011). Researchers therefore gathered ideas from survivors about their occupational performance experiences in order to develop and enhance screening tool items.

We used the first two steps of the guidelines in scale development to determine the specificity of the construct for the screening tool and the generation of an item pool, respectively (DeVellis, 2017). In step one, we gathered information about cancer survivors' occupational performance limitations, for example fatigue, memory/cognition, anxiety/depression, and pain/peripheral neuropathy, that impact occupational participation indicating the possible need for occupational therapy services. In step two, we used a deductive approach to gather data and themes within the literature to write items for the screening tool. This approach is recommended because it involves logically acquiring evidence to support a general idea (Taylor, 2017). This was done by comparing the constructs of occupation from the Occupational Therapy Practice Framework (OTPF) with the existing literature for inclusion of items in developing the first draft of the screening tool. The Model of Occupational-Participation for Cancer Survivorship (MOPCS) helped guide the development by providing an occupational participation perspective, which facilitated a holistic approach (Loh & Jonsson, 2016).

We utilized an inductive approach to analyze the data and feedback received from the questionnaire. Inductive reasoning is important to generalize statements from specific observations (Taylor, 2017) thus, we used this approach to refine the screening tool after

receiving feedback from the content experts. Specifically, in each round it allowed for us to find redundancy of items expressed in similar content but stated in different ways. The use of the deductive and inductive approach ensures content validity within this study. The visual diagram displays the number of rounds and provides information on questionnaire formation (See Figure 1).

Content Experts

Thirteen content experts for the inductive round, 44 for round 1, and 45 for round 1B were recruited using snowball sampling through social media sites and personal/professional contacts, and willing national cancer support organizations. Inclusion criteria consisted of individuals: (a) diagnosed with cancer at or after 18 years of age, (b) fluent in English, and (c) have access to a computer/smartphone with the internet. Content experts varied in age, cancer type, and occupational performance limitations. Many similar studies use 15 to 35 experts to gain evidence to support claims (Gordon, 1994); therefore, we initially aimed for 45 content experts to account for attrition. This study was exempt from the process of being reviewed by the Institutional Review Board at the University of Indianapolis because it was not human subject research.

Data Collection

An online questionnaire platform, Qualtrics, was used to administer the questionnaire, collect data, and analyze the data. Content experts completed the questionnaire in their respective locations.

Inductive Round

The inductive round served as a pilot study for content experts. Ten adult cancer survivors and two occupational therapy oncology experts comprised the participants of the pilot

study and served to inform changes for the questionnaire. The demographic questions were presented to content experts to screen for the inclusion criteria. The questionnaire was administered to ensure the content validity of the tool. The questionnaire entails questions for participants to rate occupational performance deficits they may experience, such as "How severely is/has your sexual activity/intimacy been impacted?" See Appendix A for the Inductive Round Screening Tool.

Round 1 instrument

The first round aimed to gather demographic information about the panel and determine if the items in the questionnaire were relevant by asking opinions on potential included items. The demographic questions asked experts to provide the following information: name, phone number, cancer diagnosis, and years since the most recent cancer diagnosis. Content experts were asked to respond to yes or no questions about whether their cancer has made it difficult for them to perform certain daily activities. At the end of the questionnaire, experts could provide overall feedback on the format of the screening tool. See Appendix B for Round 1 Screening Tool.

Round 1B instrument

The statements were re-formatted based on feedback from Round 1 from the phrase "I have difficulty performing..." to "My cancer diagnosis has made it difficult to..." A priori consensus agreement was set at 80% among experts for each item to be included (Keeney et al., 2011). The content experts were also asked to provide overall feedback on the structure of the tool in an open-ended question at the end of the questionnaire. See Appendix C for Round 1B Screening Tool.

Data Analysis

Qualtrics was used to analyze demographic and item response data of the content experts by descriptive statistics. The descriptive statistics include sample size and percentage of content experts who selected each answer determining if items reached 80% consensus. Initial items were refined and reformulated based on the patterns that emerged from the thematic analysis of the open-ended questions in the Delphi Round 1.

Results

All content experts met the inclusion criteria for our research. Thirteen content experts participated in the inductive round, 44 content experts participated in Delphi Round 1, and 45 content experts participated in Delphi Round 1B. Throughout each round, content experts represented a variety of cancer types. The types of cancer represented in each round are displayed in Table 1.

In the inductive round, content experts rated the following items as most severely impacted by their cancer diagnosis: sex and intimacy, care for others, health and wellness routines, maintaining the home, rest and sleep, leisure activities, and social participation. Content experts were then asked to provide symptoms that predominantly affected the activities above. According to the content expert's responses on the questionnaire, these activities were affected predominantly by fatigue and pain, however, anxiety and depression also impacted multiple activities. Results from the inductive round are displayed in Table 2.

In the Delphi Round 1, content experts answered from a nominal scale of 'yes' or 'no' if the item was relevant to difficulties they experienced when performing occupations during their cancer survivorship. After Round 1, no items met a priori of 80% consensus; however, we found the following items were most relevant to content experts due to receiving 40% or higher

consensus: rest and sleep, sex and intimacy, and work performance. The next most relevant items reached between 30% and 39% consensus: maintaining the home, meal preparation, shopping, caring for others, transportation, and health and wellness management. Results from the Delphi Round 1 are displayed in Table 3. We used a thematic analysis from the open-ended questions in the Delphi Round 1 to inform changes to the tool that included adding education as an item, breaking down items into more specific tasks, the wording of the items, and the format of the tool.

In the Delphi Round 1B, no items reached a priori consensus of 80%; however, several items reached 40% or higher consensus: engaging in sexual activity with myself or a partner, maintaining closeness and intimacy with a romantic partner, maintaining health and wellness routine, rest and sleep, and performing job duties at prior level of expectation. The items that reached between 30% and 39% consensus include: providing care for other people and/or pets, doing yard work, fully returning to work, and participating in leisure activities. Results from the Delphi Round 1B are displayed in Table 4.

Discussion

The purpose of this study was to identify the occupational performance deficits experienced by cancer survivors in order to help develop a screening tool that would indicate a need for occupational therapy services in cancer survivorship care. After reviewing the literature, the most common performance difficulties of survivors included fatigue, sleep disturbances/insomnia, lack of education, psychosocial issues, cognitive impairments, and returning to work/daily activities. We theorized that cancer survivors would benefit from the development of an occupational therapy oncology screening tool. We began phase one for

developing a screening tool that would indicate a need for occupational therapy services in cancer survivorship care plans.

Currently, there is a lack of known, reliable, and valid occupational therapy screening tools for cancer survivors. Funk & Lackie (2017) conducted a study to expand screening of occupational therapy services in oncology, yet the researchers only utilized a deductive approach from literature to develop their tool; thus, they did not seek critical feedback from cancer survivors (Funk & Lackie, 2017). Although we appreciate Funk & Lackies' (2017) results as they aid greatly in the expansion of screening tools in oncology, their research was limited due to the lack of validity and reliability that may have been gained through use of blending inductive and deductive approaches. According to Boyatzis, (1998), Crabtree & Miller, (1999), and Day & Bobeva, (2005), using a deductive approach alone isn't always sufficient for high validity and reliability due to the strong support researchers give to the use of blending inductive and deductive approaches in the development of screening tools. Therefore, we used both a deductive and inductive approach to develop and refine the tool by using content experts to increase rigor and validity (Day & Bobeva, 2005)

The current study validated performance limitations found in current oncology literature and provided further insight into the relevance of these limitations in a panel of cancer survivors. Throughout literature, cancer survivors report occupational performance deficits in rest and sleep, physical wellness, work, sexuality and intimacy, and in daily activities (Jakobsen et al., 2018; Hardcastle, Maxwell-Smith, Hagger, O'Connor, and Platell, 2018; Palmer et al., 2017; Schmidt, Wiskemann, & Steindorf, 2018; Zhou et al., 2017). Our study findings aligned with the literature as the cancer survivor content experts experience difficulties with rest and sleep (Jakobsen et al., 2018; Palmer et al., 2017; Schmidt, Wiskemann, & Steindorf, 2018; Zhou et al.,

2017) and difficulty returning to work (Jakobsen et al., 2018), therefore, these items should still be included in the SOCS-OTS. Although there is literature to support issues related to sexuality and intimacy in survivorship (Jun et al., 2011; Hwang, Lokietz, Lozano, & Parke, 2015), researchers show that sexuality and intimacy are areas of practice that therapists do not feel comfortable discussing (Areskoug-Josefsson et al., 2016). Content experts reported sexuality and intimacy as one of their top performance deficits supporting the inclusion of the sexuality and intimacy items in the SOCS-OTS. Our content experts reported difficulty maintaining wellness routines and participating in leisure activities. Previous researchers have found a correlation between leisure activities and increased quality of life in cancer survivors (Schlesinger et al., 2014), therefore, supporting the inclusion of this item on the SOCS-OTS. Our content experts also reported difficulty caring for others which is supported by past researchers. Implications for future studies include completion of the Delphi method (Rounds 2-4) to continue with refinement of the screening tool and development of a Likert scale for rating ability of performance. Additionally, further research is necessary to determine reliability and validity of the tool. (Muriel et al., 2012). As a result, this item was important to include on our screening tool. This study provides relative information on the occupational performance concerns of cancer survivors that can be applied to an occupational therapy screening tool.

Limitations

Study limitations in the development of the SOCS-OTS are present. The panel consisted of over 50% breast cancer survivors, which could create a bias towards occupational performance deficits specific to that cancer type. We were not able to verify inclusion of the screening tool items by traditional consensus value of 80% with the content experts, however,

our results support inclusion of the items by aligning content experts' occupational performance experiences with those found in literature.

Conclusion

This study drew on the experiences of content experts with cancer to determine occupational performance deficits that could deem occupational therapy services necessary for cancer survivors. This entailed a deductive and inductive approach that aligned the literature on the issues of our content experts. Our findings indicate that some survivors have difficulty engaging in sexual activity and intimacy, maintaining health and wellness routines, rest and sleep, and performing job duties at prior levels of expectation. Although we fulfilled phase one of the Delphi method, further development is necessary including reaching item consensus through content experts of oncology occupational therapists and researchers to finalize an occupational therapy screening tool. It is our hope that once the Delphi process is completed and the screening tool is validated, the SOCS-OTS will aid in the referral to the emerging practice of occupational therapy in oncology.

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Table 1

Percentage of Content Experts with Each Type of Cancer

	Inductive Approach	Delphi Round 1	Round 1B
Type	n (%)	n (%)	n (%)
Blood	2 (15)	5 (10)	3 (5)
Brain	2 (15)	0 (0)	0 (0)
Breast	4 (31)	29 (54)	33 (59)
GI	3 (23)	2 (4)	2 (4)
Gynecological	2 (15)	3 (6)	3 (5)
Head/Neck	2 (15)	2 (4)	1 (2)
Lung	2 (15)	0 (0)	0 (0)
Prostate	2 (15)	3 (6)	3 (5)
Skin	3 (23)	4 (8)	5 (9)
Soft Tissue Sarcoma	2 (15)	1 (2)	1 (2)
Thyroid	2 (15)	3 (6)	3 (5)
Urinary/Renal	3 (23)	0 (0)	1 (2)
Other	1 (8)	1 (2)	1 (2)

Note. The total sample size (N) for the Inductive Approach, Delphi Round 1, and Round 1B are N= 13, N=44, and N=45 respectively. n = number of content experts with each type of cancer, (%) = the percentage of content experts with each corresponding cancer type. Content experts could select more than one cancer type; one person could be contributing to multiple cancer type percentages.

Table 2

Inductive phase: Occupations Most Severely Impacted by Cancer Diagnosis

Occupation	Extremely (n)	Very (n)	Moderately (n)	Slightly (n)	N/A (n)
Self-care	1	1	0	4	7
Sexual Activity/Intimacy	2	1	0	3	5
Care for Others	0	2	1	3	6
Transportation	0	1	1	2	7
Managing Finances	0	0	0	2	10
Health and Wellness Routines	1	1	2	2	6
Maintaining the Home	1	2	1	2	6
Meal Preparation	0	2	1	1	8
Shopping	1	0	1	1	9
Rest and Sleep	0	3	2	1	6
Job Performance	0	1	2	2	7
Leisure Activities	1	2	2	1	6
Social Participation	0	2	1	3	6

Note. The total sample size (N) for the Inductive Approach, N= 13. (n) = number of content experts indicating Extremely, Very, Moderately, Slightly, or N/A.

Table 3

Delphi Round 1: Relevancy of Occupations to Occupational Performance Difficulties

Occupation	Yes	No
Occupation	n (%)	n (%)
Self-care	12 (27)	32 (73)
Maintaining Home	17 (39)	27 (61)
Meal Preparation	14 (32)	30 (68)
Shopping	17 (39)	27 (61)
Rest and Sleep	24 (55)	20 (45)
Caring for Others	15 (34)	29 (66)
Transportation	13 (30)	31 (70)
Managing Finances	5 (11)	39 (89)
Health/Wellness Routines	15 (34)	29 (66)
Sex/Intimacy	18 (41)	26 (59)
Work Performance	18 (41)	26 (59)
Leisure Activities	12 (27)	32 (73)
Social Participation	12 (27)	32 (73)

Note. The total sample size (N) for the Delphi Round 1, N=44. n = number of content experts indicating yes or no (%) = the percentage of total content experts from Round 1.

Table 4

Delphi Round 1B

Delphi Round IB		
Occupation	Yes	No
Occupation	n (%)	n (%)
Bathe/Shower	6 (13)	39 (87)
Engage in Sexual Activity	21 (48)	23 (52)
Maintain Intimacy	18 (41)	25 (59)
Care for Others	15 (33)	30 (67)
Move from One Position/Place to Another	9 (20)	36 (80)
Manage Finances	5 (11)	40 (89)
Maintain Wellness Routine	22 (49)	23 (51)
Manage Medications	5 (11)	40 (89)
Clean my Home	13 (29)	32 (71)
Do Yard Work	14 (31)	31 (45)
Home Maintenance/Repairs	13 (29)	32 (71)
Meal Preparation	13 (29)	32 (71)
Grocery Shop	13 (29)	32 (71)
Rest/Sleep	23 (51)	22 (49)
Fully Return to Work	16 (36)	28 (64)
Perform Job Duties at Prior Level	18 (41)	26 (59)
Engage in Educational Activities	10 (22)	35 (78)
Participate in Leisure Activities	15 (33)	30 (67)
Socialize with Family/Friends	12 (27)	32 (73)
Participate in Community Events	11 (25)	33 (75)

Note. The total sample size (N) for the Delphi Round 1B, N=45. n = number of content experts indicating yes or no (%) = the percentage of total content experts from Round 1B.

Figure 1

Deductive Approach

OTPF framework & existing literature to inform item development

Formulate inclusion criteria for participants

Inductive Approach

Collect qualitative data for questionnaire

Alter the design and item

Delphi Round 1 and 1B

Sample size: 44 and 45 respectively

Objective: To determine the significance and feasibility of the items included from the deductive and inductive approaches.

Data collected: Nominal scale of yes or no was used with additional space for feedback on each item.

Qualtrics email reminders

Major revisions done to the item structure of the questionnaire as per recommendations from participants

Decision on Delphi progress

Analyze the items return from Round 1 and 1B

Subjective misinterpretation from the participants led to termination of the Delphi questionnaire

$Appendix\,A$

In	ductive	Round:	Cancer	Survivor	Survey

Start of Block: Demographics
Q1.1 Are you fluent in English?
O Yes (1)
O No (2)
Skip To: End of Survey If Are you fluent in English? = No
Q1.2 Current age
O 18-35 (1)
O 36-55 (2)
O 55+ (3)
Q1.3 Gender
O Male (1)
Female (2)
Other, please specify (3)

Q1.4 Ethnicity
O American Indian or Alaskan Native (1)
O Asian (2)
O Black or African American (3)
O Hispanic/Latino (4)
White (5)
Two or more ethnicities (6)
O I prefer not to answer (7)
Q1.5 Age of initial diagnosis
O 18-35 (1)
O 36-55 (2)
O 55+ (3)

Q1.6 Please indicate the type of cancer(s) you were diagnosed with by selecting which stage(s) with which you were diagnosed (check all that apply throughout your survivorship journey)

	Does not apply (4)	Stage 1 (13)	Stage 2 (5)	Stage 3 (9)	Stage 4 (10)	Noninvasive Ductal Carcinoma (DCIS) *breast cancer only (11)
⊗Blood related cancers (i.e. Leukemia, Lymphoma, Multiple Myeloma) (1)						
⊗Brain cancer (2)						
⊗Breast cancer (3)						
⊗Gastrointestinal cancers (i.e. oesophagus, gallbladder, biliary tract, liver, pancreas, stomach, small/large intestine, rectum, anal) (4)						
©Gynecological cancer (5)						
[®] Head and neck cancers (i.e. larynx, throat, lips, mouth, nose, salivary glands) (6)						
⊗Lung cancer (7)						
⊗Prostate cancer (8)						
⊗Skin cancer (9)						
Soft tissue sarcoma (i.e. muscle, tendon, fat, nerves, blood vessels, lymph) (10)						
⊗Thyroid cancer (11)						
⊗Urinary and Renal cancers (i.e. bladder and kidney) (13)						
⊗Other, please specify (12)						

	What treatment have you undergone at any point in your cancer survivorship journey? all that apply)
	Surgery (1)
	Chemotherapy (2)
	Radiation therapy (3)
	Immunotherapy (4)
	Hormone Therapy (5)
	Stem Cell Transplant (6)
	Targeted Therapy (7)
	Precision Medicine (8)
	Complimentary or Alternative medicine (11)
	None (10)
	Other, please specify (9)
Q1.8 A	Are you currently undergoing treatment?
○ Ye	s (1)
O No	(2)
_	Have you ever received occupational therapy services in relation to your cancer orship?
O Ye	s (1)
O No	(2)
_	How severely is/has your ability to perform self-care activities been impacted? (i.e. ing, bathing/showering, toileting)

*Please answer according to the time in your survivorship that was most severely impacted.					
O Extremely severe (1)					
O Very severe (2)					
O Moderately sever	re (3)				
O Slightly severe (4	4)				
O Does not apply (5)				
Skip To: Q2.4 If How (i.e. grooming, b =			perform self-care ac	tivities been impa	cted?
_		•	ing or have impacted acted) (check all that a	•	s can
*Please answer accor	rding to th	ne time in your surviv	vorship that was most	severely impacte	d.
*Please answer accor	rding to the Fatigu e (1)	Memory/Cognitio n (2)	vorship that was most Anxiety/Depressio n (3)	Pain/Peripher al neuropathy	d. Othe r (5)
*Please answer according Bathing/Showering (1)	Fatigu	Memory/Cognitio	Anxiety/Depressio	Pain/Peripher	Othe
Bathing/Showerin	Fatigu	Memory/Cognitio	Anxiety/Depressio	Pain/Peripher al neuropathy	Othe
Bathing/Showerin g (1) Toileting (2) Dressing (3)	Fatigu	Memory/Cognitio	Anxiety/Depressio	Pain/Peripher al neuropathy	Othe
Bathing/Showerin g (1) Toileting (2)	Fatigu	Memory/Cognitio	Anxiety/Depressio	Pain/Peripher al neuropathy	Othe

Skip To: Q2.3 If Please select what factors you feel are impacting or have impacted each activity (this can range... = Other

Q2.3 If other please specify.
Page Break
Q2.4 How severely is/has your sexual activity/intimacy been impacted?
*Please answer according to the time in your survivorship that was most severely impacted.
Extremely severe (1)Very severe (2)
 Moderately severe (3) Slightly severe (4) Does not apply (5)
Skip To: Q2.6 If How severely is/has your sexual activity/intimacy been impacted? *Please

Skip To: Q2.6 If How severely is/has your sexual activity/intimacy been impacted? *Please answer according to the... = Does not apply

Q2.5 What factors do you feel are impacting or have impacted your limitations in sexual activity/intimacy? (check all that apply)

*Please	e answer according to the time in your survivorship that was most severely impacted.
	Fatigue (1)
	Memory/Cognition (2)
	Anxiety/Depression (3)
	Pain/Peripheral neuropathy (4)
	Medical treatment (surgery, medication, etc.) (6)
	Other, please specify (5)
spouse	How severely is/has your ability to provide care for others been impacted? (i.e. children, , pets, etc.) e answer according to the time in your survivorship that was most severely impacted.
○ Ex	tremely severe (1)
O Ve	ry severe (2)
Омо	oderately severe (3)
	ghtly severe (4)
O Do	es not apply (5)
_	o: Q2.8 If How severely is/has your ability to provide care for others been impacted? (i.e. en, spouse = Does not apply

Q2.7 What factors do you feel are impacting or have impacted your ability to provide care for others? (check all that apply)

*Please answer according to the time in your survivorship that was most severely impacted.		
Fatigue (1)		
Memory/Cognition (2)		
Anxiety/Depression (3)		
Pain/Peripheral neuropathy (4)		
Other, please specify (5)		
Q2.8 How severely is/has your use of transportation and moving around in the community been impacted? (i.e. driving, walking, biking, use of public transportation)		
*Please answer according to the time in your survivorship that was most severely impacted.		
O Extremely severe (1)		
O Very severe (2)		
O Moderately severe (3)		
O Slightly severe (4)		
O Does not apply (5)		
Skip To: Q2.10 If How severely is/has your use of transportation and moving around in the community been impacted? = Does not apply		

Q2.9 What factors do you feel are impacting or have impacted your use of transportation? (check all that apply)

*Please answer according to the time in your survivorship that was most severely impacted.		
Fatigue (1)		
Memory/Cognition (2)		
Anxiety/Depression (3)		
Pain/Peripheral neuropathy (4)		
Medical treatment (surgery, medication, etc.) (6)		
Other, please specify (5)		
Q2.10 How severely is/has managing your finances been impacted? (i.e. processes of paying bills, budgeting, simple money transaction)		
*Please answer according to the time in your survivorship that was most severely impacted.		
O Extremely severe (1)		
O Very severe (2)		
O Moderately severe (3)		
O Slightly severe (4)		
O Does not apply (5)		
Skip To: Q2.12 If How severely is/has managing your finances been impacted? (i.e. processes		

Q2.11 What factors do you feel are impacting or have impacted your ability to manage your finances? (check all that apply)

*Please	e answer according to the time in your survivorship that was most severely impacted.	
	Fatigue (1)	
	Memory/Cognition (2)	
	Anxiety/Depression (3)	
	Pain/Peripheral neuropathy (4)	
	Other, please specify (5)	
wellne	How severely is/has developing, managing, and maintaining routines for health and ss promotion been impacted? (i.e. physical fitness, nutrition, medication management)	
*Please answer according to the time in your survivorship that was most severely impacted.		
Extremely severe (1)		
O Very severe (2)		
O Moderately severe (3)		
Slightly severe (4)		
O Do	es not apply (5)	
	o: Q2.15 If How severely is/has developing, managing, and maintaining routines for and wellness promot = Does not apply	

Q2.13 Please select what factors you feel are impacting or have impacted each activity. (this can range from slightly impacted to very seriously impacted) (check all that apply)

*Please answer	according	to the time in your su	rvivorship that was mo	st severely impact	ed.
	Fatigue	, ,	Anxiety/Depression	Pain/Peripheral	Other
	(1)	(2)	(3)	nueropathy (4)	(5)
Physical fitness (1)					
Nutrition (2)					
Medication management (3)					
Skip To: Q2.15 activity. (this co			ı feel are impacting or	have impacted ead	ch
Q2.14 If other p	please spec	ify.			
Q2.15 How severely is/has your ability to maintain your home been impacted? (i.e. household cleaning, laundry, yard work, gardening)					
*Please answer	according	to the time in your su	rvivorship that was mo	ost severely impact	ed.
O Extremely s	severe (1)				
O Very severe	(2)				
O Moderately	severe (3)				
O Slightly sev	ere (4)				
O Does not ap	oply (5)				
		verely is/has your abil Does not apply	ity to maintain your ho	ome been impacted	!? (i.e.

Q2.16 What factors do you feel are impacting or have impacted your ability to maintain your home? (check all that apply)

*Please	e answer according to the time in your survivorship that was most severely impacted.			
	Fatigue (1)			
	Memory/Cognition (2)			
	Anxiety/Depression (3)			
	Pain/Peripheral neuropathy (4)			
	Other, please specify (5)			
Q2.17 How severely is/has your ability to plan, prepare, serve, and/or clean up meals been impacted?				
*Please	*Please answer according to the time in your survivorship that was most severely impacted.			
O Extremely severe (1)				
O Very severe (2)				
Омо	derately severe (3)			
	ghtly severe (4)			
O Doo	es not apply (5)			
Skip To: Q2.19 If How severely is/has your ability to plan, prepare, serve, and/or clean up meals been impacted? * = Does not apply				

Q2.18 What factors do you feel are impacting or have impacted your ability to plan, prepare, serve, and/or clean up meals? (check all that apply)

*Please answer according to the time in your survivorship that was most severely impacted.		
	Fatigue (1)	
	Memory/Cognition (2)	
	Anxiety/Depression (3)	
	Pain/Peripheral neuropathy (4)	
	Other, please specify (5)	
	How severely is/has shopping been impacted? (i.e. preparing shopping list, selecting, sing, and/or transporting items)	
*Please	e answer according to the time in your survivorship that was most severely impacted.	
O Ext	Extremely severe (1)	
O Ve	ry severe (2)	
Омо	oderately severe (3)	
	ghtly severe (4)	
O Do	es not apply (5)	
	o: Q2.21 If How severely is/has shopping been impacted? (i.e. preparing shopping list, ng, purchasing, = Does not apply	

Q2.20 What factors do you feel are impacting or have impacted your ability to shop? (check all that apply)

*Please answer according to the time in your survivorship that was most severely impacted.		
Fatigue (1)		
Memory/Cognition (2)		
Anxiety/Depression (3)		
Pain/Peripheral neuropathy (4)		
Other, please specify (5)		
Q2.21 How severely is/has your rest, sleep preparation, and/or sleep participation been impacted?		
*Please answer according to the time in your survivorship that was most severely impacted.		
Extremely severe (1)		
O Very severe (2)		
O Moderately severe (3)		
○ Slightly severe (4)		
O Does not apply (5)		
Skip To: Q2.23 If How severely is/has your rest, sleep preparation, and/or sleep participation		

Q2.22 What factors do you feel are impacting or have impacted your rest, sleep preparation, and/or sleep participation? (check all that apply)

*Please answer according to the time in your survivorship that was most severely impacted.		
Fatigue (1)		
Memory/Cognition (2)		
Anxiety/Depression (3)		
Pain/Peripheral neuropathy (4)		
Other, please specify (5)		
Q2.23 How severely is/has your job performance been impacted?		
*Please answer according to the time in your survivorship that was most severely impacted.		
O Extremely severe (1)		
O Very severe (2)		
O Moderately severe (3)		
O Slightly severe (4)		
O Does not apply (5)		
Skip To: Q2.25 If How severely is/has your job performance been impacted? *Please answer according to the time in y = Does not apply		

Q2.24 What factors do you feel are impacting or have impacted your job performance? (check all that apply)

*Please answer according to the time in your survivorship that was most severely impacted.			
	Fatigue (1)		
	Memory/Cognition (2)		
	Anxiety/Depression (3)		
	Pain/Peripheral neuropathy (4)		
	Other, please specify (5)		
Q2.25 F and inte	How severely is/has your participation in leisure activities been impacted? (i.e. hobbies erests)		
*Please	*Please answer according to the time in your survivorship that was most severely impacted.		
O Extremely severe (1)			
O Ver	y severe (2)		
O Mod	derately severe (3)		
	htly severe (4)		
O Doe	es not apply (5)		
	: Q2.27 If How severely is/has your participation in leisure activities been impacted? (i.e. and int = Does not apply		

Q2.26 What factors do you feel are impacting or have impacted your participation in leisure activities? (check all that apply)

*Please answer according to the time in your survivorship that was most severely impacted.	
Fatigue (1)	
Memory/cognition (2)	
Anxiety/Depression (3)	
Pain/Peripheral neuropathy (4)	
Other, please specify (5)	
Q2.27 How severely is/has your social participation been impacted? (i.e. participating in activities in the community or with family and friends)	
*Please answer according to the time in your survivorship that was most severely impacted.	
Extremely severe (1)	
O Very severe (2)	
O Moderately severe (3)	
O Slightly severe (4)	
O Does not apply (5)	
Skip To: End of Survey If How severely is/has your social participation been impacted? (i.e. participating in activities in = Does not apply	

Q2.28 What factors do you feel are impacting or have impacted your social participation? (check all that apply)

*Please answer according to the time in your survivorship that was most severely impacted.		
	Fatigue (1)	
	Memory/Cognition (2)	
	Anxiety/Depression (3)	
	Pain/Peripheral neuropathy (4)	
	Other, please specify (5)	

Appendix B

Screen of Cancer Survivorship - OT Delphi: Round 1

Start of Block: Demographics
Q1 In the first round of this questionnaire, investigators are seeking to understand the relevance of these items in relation to your cancer survivorship experiences. Please complete the demographic questions including your full name and phone number at the beginning of the questionnaire. It is important that the investigators can identify your responses in case we need to reach out to you for further questions.
Q2 First and last name
Q3 Phone Number

	ease indicate the type of cancer(s) you were diagnosed with (check all that apply hout your survivorship journey)
	Blood related cancers (i.e. Leukemia, Lymphoma, Multiple Myeloma) (1)
	Brain cancer (2)
	Breast cancer (3)
sto	Gastrointestinal cancers (i.e. oesophagus, gallbladder, biliary tract, liver, pancreas, bmach, small/large intestine, rectum, anal) (4)
	Gynecological cancer (5)
	Head and neck cancers (i.e. larynx, throat, lips, mouth, nose, salivary glands) (6)
	Lung cancer (7)
	Prostate cancer (8)
	Skin cancer (9)
(10	Sarcoma (i.e. bone or soft tissue such as muscle, tendon, fat, nerves, blood vessels)
	Thyroid cancer (11)
	Urinary and Renal cancers (i.e. bladder and kidney) (13)
	Other, please specify (12)

Q5 How many years has it been since your most recent cancer diagnosis?
O Less than 1 year (1)
O 1 year (2)
O 2 years (3)
○ 3 years (4)
○ 4 years (5)
○ 5 years (6)
○ 6 years (7)
○ 7 years (8)
○ 8 years (9)
O 9 years (10)
O 10+ years (11)
End of Block: Demographics
Start of Block: Survey

Q6

The purpose of this questionnaire is to understand if you have had any trouble engaging in daily activities during your survivorship (from time of diagnosis to present day).

While filling out the questionnaire please indicate "Yes, this item is relevant to a concern I have had at some point in my survivorship journey" if you have ever had an issue with the activity listed or "No, this item is not relevant" if you have never had issues performing that activity.

At the end of the questionnaire you will have the opportunity to provide overall feedback for anything else you feel should be included.

Click the next button to get started!

Q7 I have difficulty performing self-care activities (i.e. grooming, bathing/showering, toileting).	
Yes, this item is relevant to a concern I have had at some point in my survivorship journey. (1) No, this item is not relevant. (2) Please provide item specific feedback here (7)	
Q8 I have difficulty maintaining my home (i.e. household cleaning, laundry, yard work, gardening).	
Yes, this item is relevant to a concern I have had at some point in my survivorship journey. (1)	
No, this item is not relevant. (6)	
Please provide item specific feedback here (7)	
Q9 I have difficulty planning, preparing, serving, and/or cleaning up meals. Yes, this item is relevant to a concern I have had at some point in my survivorship journey. (1)	
No, this item is not relevant. (2)	
Please provide item specific feedback here (6)	
O10 I have difficulty chapping (i.e. propering chapping list collecting purchasing and/or	

Q10 I have difficulty shopping (i.e. preparing shopping list, selecting, purchasing, and/or transporting items).

jou	Yes, this item is relevant to a concern I have had at some point in my survivorship irney. (1)
	No, this item is not relevant. (2)
	Please provide item specific feedback here (6)
Q11 I I	nave difficulty engaging in rest and sleep.
jou	Yes, this item is relevant to a concern I have had at some point in my survivorship irney. (1)
	No, this item is not relevant. (2)
	Please provide item specific feedback here (6)
Q12 I I	nave difficulty providing care for others (i.e. children, spouse, pets, etc.).
jou	Yes, this item is relevant to a concern I have had at some point in my survivorship irney. (1)
	No, this item is not relevant. (2)
	Please provide item specific feedback here (6)

Q13 I have difficulty using transportation and moving around in the community (i.e. driving, walking, biking, use of public transportation).

jou	Yes, this item is relevant to a concern I have had at some point in my survivorship urney. (1)
	No, this item is not relevant. (2)
	Please provide item specific feedback here (6)
Q14 I transa	have difficulty managing finances (i.e. processes of paying bills, budgeting, simple money ction).
jou	Yes, this item is relevant to a concern I have had at some point in my survivorship urney. (1)
	No, this item is not relevant. (2)
	Please provide item specific feedback here (6)

promo	tion (i.e. physical fitness, nutrition, medication management).
jou	Yes, this item is relevant to a concern I have had at some point in my survivorship arney. (1)
	No, this item is not relevant. (2)
	Please provide item specific feedback here (6)
Q16 I I	nave difficulty engaging in sexual activity and intimacy.
jou	Yes, this item is relevant to a concern I have had at some point in my survivorship arney. (1)
	No, this item is not relevant. (2)
	Please provide item specific feedback here (6)
Q17 I a	am having difficulty returning to work or performing my job duties.
jou	Yes, this item is relevant to a concern I have had at some point in my survivorship arney. (1)
	No, this item is not relevant. (2)
	Please provide item specific feedback here (6)

Q15 I have difficulty developing, managing, and maintaining routines for health and wellness

Q18 I have difficulty participating in leisure activities (i.e. hobbies and interests).		
jou	Yes, this item is relevant to a concern I have had at some point in my survivorship irney. (1)	
	No, this item is not relevant. (2)	
	Please provide item specific feedback here (6)	
	have difficulty engaging in social participation (i.e. participating in activities in the unity or with family and friends).	
jou	Yes, this item is relevant to a concern I have had at some point in my survivorship irney. (1)	
	No, this item is not relevant. (2)	
	Please provide item specific feedback here (6)	
Q20 Please provide overall feedback or suggested changes for the tool.		

Appendix C

Cancer Survivor Questionnaire: Delphi Round 1B

Start of Block: Survey		
Q1 First and last name		
Q2 Phone Number		

	ease indicate the type of cancer(s) you were diagnosed with (check all that apply hout your survivorship journey)
	Blood related cancers (I.e. leukemia, lymphoma, multiple myeloma) (1)
	Brain cancer (4)
	Breast cancer (5)
sto	Gastrointestinal cancers (I.e. oesophagus, gall bladder, biliary tract, liver, pancreas, mach, small/large intestine, rectum, anal) (6)
	Gynecological cancer (7)
	Head and neck cancer (I.e. larynx, throat, lips, mouth, nose, salivary glands) (8)
	Lung cancer (9)
	Prostate cancer (2)
	Skin cancer (3)
(10	Sarcoma (I.e. bone or soft tissue such as muscle, tendon, fat, nerves, blood vessels)
	Thyroid cancer (11)
	Urinary and renal cancers (I.e. bladder and kidney) (12)
	Other, please specify (13)

Q8 How many years has it been since your most recent cancer diagnosis?
C Less than 1 year (1)
○ 1 year (2)
○ 2 years (3)
○ 3 years (4)
○ 4 years (5)
○ 5 years (6)
○ 6 years (7)
○ 7 years (8)
○ 8 years (9)
○ 9 years (10)
10+ years (11)

Q4 My cancer has made it difficult to...

	Yes (1)	No (2)
Bathe and/or shower (1)	0	0
Engage in sexual activity with a partner or myself (2)	0	\bigcirc
Maintain closeness and intimacy with a romantic partner (3)	0	\bigcirc
Provide care for other people and/or pets (4)	0	\bigcirc
Move from one position or place to another (5)	0	\circ
Manage finances (i.e. processes of paying bills, budgeting, simple money transaction) (6)	0	\bigcirc
Maintain my exercise routine and physical fitness (7)	0	\circ
Manage my medications (8)	0	\circ
Clean my home (9)	0	\circ
Do my yard work (10)	0	\circ
Perform home maintenance and repairs (11)	0	\circ
Plan, prepare, serve, and/or clean up meals. (12)	0	\circ
Grocery shop (13)	0	\circ
Rest and sleep (14)	\circ	\bigcirc
Fully return to work (15)	0	\bigcirc
Perform my job duties at prior level of expectation (16)	0	\circ
Engage in educational activities (17)	0	\circ
Participate in leisure activities (18)	0	\circ
Socialize with my family and friends (19)	0	\circ
Participate in community events (20)	0	\circ

End of Block: Survey