The Experiences Of Occupational Therapists Working In Oncology Care and the Implications of the Referral Process

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THE EXPERIENCES OF OCCUPATIONAL THERAPISTS WORKING IN ONCOLOGY CARE AND THE IMPLICATIONS OF THE REFERRAL PROCESS

by

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Master of Occupational Therapy, University of North Dakota, 2019

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An Independent Study
Submitted to the Occupational Therapy Department of the University of North Dakota
In partial fulfillment of the requirements for the degree of Master of Occupational Therapy

Grand Forks, North Dakota May 2019
This Independent Study, submitted by Samantha Albrigtson and Jade Clement in partial fulfillment of the requirement for the Degree of Master in Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

____________________________________
Signature of Faculty Advisor

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Title The Experiences of Occupational Therapists Working in Oncology Care and Implications of the Referral Process

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ABSTRACT

**Purpose:** The purpose of this independent study was to explore the current role of occupational therapists working in oncology care and to understand the implications of the referral process for this specific population.

**Methodology:** A phenomenological research design, derived from Giorgi and Giorgi (2008), was used to implement this study. The researchers interviewed 6 occupational therapists, from a variety of settings, in the Midwest region using a semi-structured interview style. The interviews were recorded, transcribed, and broken down into key constituents (Giorgi & Giorgi, 2008).

**Results:** The subsequent results from the 6 interviews were developed from 11 key constituents that related back to current occupational therapists’ experiences working with oncology patients. From the key constituents, the three elements that came forward were (1) Occupational therapists experiences within the process of working with oncology patients, (2) the impact of the referral system on the OT process, and (3) therapist’s reflections on how the Oncology Occupational Performance Screening Tool (OOPST) can shift occupational therapy’s overall experience within the healthcare system. These three elements of the general structure have important implications for the future of occupational therapy in oncology care.

**Conclusions:** In order to increase referrals for occupational therapy services in oncology care, occupational therapists have to advocate their skill set to the medical team, the patients, and other occupational therapists. Current occupational therapists are already implementing evidence-based practice that fit the need of patients in oncology care, and it’s time to apply this knowledge to a population who would benefit so deeply from occupational therapy’s unique skill set.
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CHAPTER I
INTRODUCTION

Rationale

According to the World Health Organization (2018) cancer is the second leading cause of death globally. It is estimated that approximately 15.5 million Americans have a history of cancer and that 1.7 million new cancer cases are expected to be diagnosed this year alone (American Cancer Society, 2018). In addition, there has been an estimated 4,110 new cases of cancer reported in the state of North Dakota for the year 2018 (American Cancer Society, 2018). With this growing population of cases coming into the medical field, practitioners of every specialization need to step forward and identify their unique role in caring for individuals diagnosed with cancer. The researchers are taking on this responsibility to understand the current expectations required of occupational therapists working within this area as well as seeking to understand areas to grow to meet the needs of cancer patients.

Theoretical Framework

The framework guiding this qualitative research study is phenomenology. Phenomenology is a form of interpretation where the key of understanding the world is through human consciousness (Shank, 2002). The aim of phenomenology is not to control the context, but to remain as faithful to the phenomenon as possible (Giorgi & Giorgi, 2008). By following this framework, researchers are ensured that the experiences of occupational therapists working in oncology care can be encompassed within the semi-
structured interview. Researchers used Giorgi and Giorgi's (2008) phenomenological approach to analyze and interpret the data gathered, furthering the use of the theoretical framework.

**Statement of Problem**

Oncology is a new and evolving area of occupational therapy and new research is being published on the need to implement occupational therapy intervention within this population. A variety of occupations are impacted by cancer, including activities of daily living, instrumental activities of daily living, social participation, and so forth (Hwang et al., 2015). Occupational therapists have the ability to address these multifaceted needs by the use of a collaborative, client-centered approach towards treatment that can assist clients in participating in everyday activities to improve or maintain their overall quality of life (Longpre & Newman, 2011). However, due to the lack of research and understanding of what occupational therapy can provide for patients in oncology, a limited number of referrals are being made (Pergolotti et al., 2016). As described above, cancer is a growing concern for the public at large and bringing additional resources and professions into this area of medicine is important to explore further.

**Assumptions**

The researchers anticipate the results to expand the understanding of occupational therapy service’s role in oncology care and support the notion that occupational therapy services can benefit patients during all stages of cancer. In addition, the results will guide how to modify the Oncology Occupational Performance Screening Tool (OOPST) to best measure occupational performance in patients facing cancer diagnosis.
Scope and Delimitation

The purpose of this independent study was to understand the experiences of occupational therapists working in oncology care, specifically the referral process for occupational therapy services. In order to understand this phenomenon, occupational therapists were interviewed on his or her experiences within oncology care and also asked to provide feedback on the OOPST from a clinical standpoint (see Appendix A and B). By conducting a participant guided interview, researchers were able to gather an understanding of occupational therapist’s perspective within oncology care, and their overall experience with the referral process.

Participants consisted of six occupational therapy practitioners who have experiences with working with patients diagnosed with cancer. The participants were obtained from the Midwest region, specifically the North Dakota and Minnesota area. Participants worked in a variety of settings including acute care, hospice, outpatient, and home health and had 6-22 years of experience in occupational therapy (see Appendix C). Delimitation from the study included not being able to speak English and only having 6 months of working experience with oncology patients.

Importance of the Study

The importance of this study was to understand the current standing occupational therapy has within oncology care and further explore where the gaps are occurring through a literature review and qualitative study. The phenomenological study emphasizes understanding the experiences of participants, and the researchers used this method to understand the experiences of occupational therapists working within this area of medicine. Researchers discovered, through this two-part exploration; the literature
review and the subsequent study, that were gaps occurring that limited occupational therapists involvement within oncology care. Within the literature, there was not a clear reason as to why patients diagnosed with cancer did not receive occupational therapy referrals throughout their continuum of care.

The key constituents developed from the interviews with participants provided insight into obstacles and welfares that are commonly experienced by occupational therapists within oncology care, specifically in regard to the referral process. This information can inform professionals about steps to take in order to increase occupational therapists role in oncology care through the increase of referrals.

This study contributed to new knowledge by providing important insight into occupational therapy's role in oncology care, along with the barriers within the healthcare system’s current referral process. Using a phenomenological approach, allowed the researchers to obtain the lived experience of the occupational therapists within oncology care. An in-depth analysis on this information helped the researchers to identify the common barriers, throughout a variety of settings that was impacting occupational therapy’s presence in oncology care.

In the chapters following, the researchers conducted a thorough literature review on occupational therapy’s role in oncology care. The literature review is a synthesis of evidenced-based literature that the researchers subsequently organized into a concise narrative format involving how an oncology diagnosis impacts occupational performance, evidence-based OT interventions in oncology care, and current referral processes. Researchers will break down the methodology used to guide the study, the results found, and the implications the study has on occupational therapy process in oncology care.
CHAPTER II
LITERATURE REVIEW

The American Cancer Society released a 2018 document outlining cancer related statistics for the United States. It is estimated that approximately 15.5 million Americans have a history of cancer and that 1.7 million new cancer cases are expected to be diagnosed this year alone (American Cancer Society, 2018). With the numbers reaching well into the millions, there is a significant need to ensure that this growing population’s deficits are being addressed.

According to Taylor (2018), cancer is the term used to describe “a collection of diseases in which there is uncontrolled, abnormal growth of cells that have the ability to invade other tissues. As abnormal cells continue to divide uncontrollably, a neoplasm, also known as a tumor is formed.” (p. 1) Various medical treatments have been utilized to treat cancer, including surgery, radiation therapy, and chemotherapy (Taylor, 2018). The subsequent impact of cancer treatment can lead to changes in one’s physical, cognitive, and emotional well-being (Longpre & Newman, 2011). With this diagnosis impacting multiple areas of an individual's life, an equally multifaceted approach must be utilized to have any positive impact on the patient’s overall treatment. For example, occupational performance issues related to activities of daily living, instrumental activities of daily living, work, and social participation increase for cancer survivors (Polo & Smith, 2017). Occupational therapists have the ability to address these multifaceted needs with the use of a collaborative, client-centered approach towards treatment that can assist patients in participating in everyday activities to improve or maintain their overall quality of life.
Recognition of the impact occupational therapy services can have on those affected by cancer needs to be established. In order to begin establishing occupational therapy’s role in oncology, an increase in referrals need to occur.

The American Occupational Therapy Association (AOTA) has defined our profession’s role in this emerging area of practice; “to facilitate and enable an individual patient to achieve maximum functional performance, both physically and psychologically, in everyday living skills regardless of his or her life expectancy” (Penfold, 1996, p. 75). Suggested intervention approaches for this population include managing ADLs, lifestyle management, sleep and fatigue, cognitive strategies, therapeutic exercises, and lymphedema management (Longpre & Newman, 2011). AOTA has directly outlined a comprehensive document of our role within oncology but the translation into practice has continued to see gaps. With this clear outline, what is deterring occupational therapy from expanding its services for patients in oncology care and how can we increase the referral rate?

**Needs of Cancer Patients**

As an individual faces’ cancer treatment, there was a significant change in that individual’s physical, sensory, and/or cognitive functioning that directly impacts their occupational engagement (Baxter, Newman, Longrè, & Polo, 2017). According to Longpre and Newman (2011), each patient with cancer will experience different limitations in his or her various occupations and/or roles, along with different restrictions in participation throughout the course of the disease. Deficits in self-care, work, leisure, or social activities are areas in which cancer and cancer treatment affects a patient
(Longpre & Newman, 2011). Occupational therapy’s approach to use a collaborative, client-centered treatment will help promote those occupations and roles that the patient no longer can participate in (Longpre & Newman, 2011) and can help overcome the physical, cognitive, and psychosocial deficits connected to cancer treatment.

**Care Along the Continuum**

Patient’s face challenges in each stage of the cancer process. It is important to understand these deficits in order to implement interventions at each stage. A national questionnaire survey of all adult residents in Denmark diagnosed with cancer was used to collect the patient’s perspective of unmet needs of rehabilitation during the early stages of diagnosis and treatment (Veloso et al., 2013). Veloso et al. (2013) concluded a strong correlation between unmet needs and impaired quality of life. These patient-perceived unmet needs indicate the need for clinical attention. Both sociodemographic and clinical characteristics were associated with unmet needs. More specifically, young age, male sex, low educational level, and living alone increased the probability of an individual facing unmet needs. Overall, the results support recommendations to integrate cancer rehabilitation from the beginning of the cancer trajectory (Veloso et al., 2013).

Hwang, Lokietz, Lozano, and Parke (2015) explored functional deficits and perceived quality of life among cancer survivors. The researchers found that participants reported deficits across the aspects of occupations, body functions, performance skills, and psychosocial well-being. Furthermore, the study revealed that participants suffered from psychosocial complications such as social avoidance, depression, and anxiety after treatment (Hwang, Lokietz, Lozano, & Parke, 2015). Occupational therapy services can help support patients for these deficits during each stage of treatment. These findings
support the importance of addressing the need for ongoing services upon completion of primary cancer treatment (Hwang, Lokietz, Lozano, & Parke, 2015).

Baxter, Newman, Longrè, and Polo (2017) examined how common symptoms experienced by cancer survivors can be addressed through occupational therapy intervention. Occupational wellbeing is not addressed in current cancer treatment and is often overlooked (Baxter, Newman, Longrè, & Polo, 2017). Occupational therapy can play a significant role in bringing holistic treatment into these challenges faced by cancer survivors, but there is a need to develop a model to unify practice (Baxter, Newman, Longrè, & Polo, 2017). A uniform model can bring structure to help pave the way towards holistic practice when working with oncology patients.

**Occupational Therapy Interventions**

**Physical**

Occupational therapy is unique in the sense that there is versatility to the interventions that can be provided to a variety of individuals, and this versatility can be brought to serve individuals facing cancer diagnosis. Occupational therapists focus on adaptive and compensatory strategies to optimize health and well-being through the facilitation of meaningful activities (Polo & Smith, 2017). Buckland and Mackenzie (2017) found that the most common issues being addressed by occupational therapists for patients diagnosed with cancer included equipment needs, fatigue and energy conservation, pressure area prevention and management, return to meaningful activities, lifestyle adjustment, lymphedema, education, stress management, cognitive changes, and pain. Prescribing equipment, teaching energy conservation and fatigue management, and addressing pressure care needs were perceived as the most routine aspects of
occupational therapy care (Buckland & Mackenzie, 2017). Farley, McCarthy, and Pergolotti (2017) provided evidenced-based interventions used by both occupational therapists and physical therapists including: fall prevention through mitigation of fatigue and neuropathy, cognitive declines, psychosocial needs, lymphedema management, physical activity, range of motion, and pain. Ensuring that occupational therapy interventions addressing the physical needs of patients diagnosed with cancer are backed by research is vital to the growth in this area of practice.

**Cognitive**

Evidence-based intervention must also carry through with cognitive interventions. Patients diagnosed with cancer may experience certain side effects from treatment that affect their everyday life. An example of this includes ‘chemobrain.’ ‘Chemobrain’ is a change in cognitive functioning for individuals going through chemotherapy (Player, Mackenzie, Willis, & Loh, 2014). This change in cognition may allow for simple functional tasks to become more complex. Player, Mackenzie, Willis, and Loh (2014) conclude that occupational therapy can play an important role in assisting women experiencing ‘chemobrain’ by addressing these cognitive deficits along with emotional and psychological wellbeing.

Munoz, Cambell, and Bowyer (2015) examined the unique role occupational therapy can bring to older cancer patients who are facing cognitive impairments. Cognitive impairments directly impact all aspects of occupation and can significantly decrease a client’s quality of life if not addressed. Occupational therapy brings the ability to adapt the environment to the specific needs of the client; meeting them where they are in a holistic way (Munoz, Cambell, & Bowyer, 2015). Munoz, Cambell, and Bowyer
(2015) used an example of an occupational therapy intervention by utilizing metacognition strategies such as Goal-Plan-Do-Check. This is just one example of a cognitive intervention approach occupational therapy can apply. The collaborative nature of occupational therapy practice brings the client into making these decisions and helps them feel motivated to follow through with these strategies (Munoz, Cambell, & Bowyer, 2015). This collaborative engagement with the client helps bring meaning into their lives and ensures quality of life by participating in occupations that are meaningful to them (Munoz, Cambell, & Bowyer, 2015).

**Psychosocial**

When collaborating with an individual patient, an occupational therapist must also take into consideration the psychosocial components. Taylor (2018) defines ‘psychosocial disruption’ as a disturbance or situation negatively affecting the interrelationship of the individual and their social environment. If disturbances from cancer treatment are changing the client’s mood or interpersonal relationships, their ability to engage in activities may decrease (Taylor, 2018). Braveman, Hunter, Nicholson, Arbesman, and Lieberman (2017) examined how to apply occupational therapy interventions to one individual. This study was significant because the field of occupational therapy examines each case on an individualistic and holistic nature and viewing one case can help guide the profession into molding these interventions to the needs of their patients. The study included the most evidence-based interventions such as energy conservation, problem solving for task analysis, monitoring signs and symptoms, and strategies for reducing anxiety and depression (Braveman, Hunter, Nicholson,
Arbesman, & Lieberman, 2017). Keeping the methodology evidence-based and client-centered is what will drive our profession forward into this emerging area of medicine.

Funk and Lackie (2017) created the Oncology Occupational Performance Screening Tool (OOPST) as a means to increase the referral process towards occupational therapy services for individuals diagnosed cancer. This screening tool was developed to increase awareness among the oncology medical team of symptoms patients with cancer may be experiencing that could be addressed by occupational therapy interventions (Funk & Lackie, 2017). The OOPST has been designed to quickly screen potential occupational performance issues a patient with cancer may be experiencing to signal out areas the oncology team could identify and amend through occupational therapy services (Funk & Lackie, 2017). Through this independent study, we hope to contribute to the development of the OOPST by applying feedback from practicing occupational therapists working in oncology care to further promote occupational therapy’s role within oncology.

Who is Receiving OT Services Now?

Even though expanding occupational services is the ultimate goal, there are currently individuals receiving occupational services throughout their cancer treatment. Pergolotti, Cutchin, Weinberger, and Meyer (2014) examined how occupational therapy services are being utilized within the North Carolina area. Specifically, the researchers focused on the use of occupational therapy services for older adults with cancer diagnosis. Of the 27,131 adults examined in this study within a two-year period, only 32% of the population used occupational therapy services, and the majority of whom were women (Pergolotti, Cutchin, Weinberger, & Meyer, 2014). Socioeconomic
variables and comparing rural versus urban characteristics did not have a significant impact on whether individuals received occupational therapy services, but this may be specific to the North Carolina population (Pergolotti, Cutchin, Weinberger, & Meyer, 2014). Two groups identified through this study to be least likely to receive occupational therapy services where participants diagnosed with lung cancer and those with a stage IV diagnosis. The study recognized that those receiving occupational therapy services reported a desire to continue with these services in the future (Pergolotti, Cutchin, Weinberger, & Meyer, 2014). These findings, though regionally specific, reveal future growth opportunities for occupational therapy. Most importantly, this study illustrated that occupational therapists need to advocate for the interventions their professional services can provide for this population.

In a follow-up study, Pergolotti, Deal, Lavery, Reeve, and Muss (2015) researched older adults with cancer and the impact both physical and occupational therapy can have in their treatment. Researchers discovered that even after participants underwent the geriatric assessment, which identified functional deficits, they were still not receiving OT/PT services (Pergolotti, Deal, Lavery, Reeve, & Muss, 2015). The statistics revealed only 1.8% of those individuals receive OT/PT within the first month after the assessment, and 9% of participants received services within one year (Pergolotti el al., 2015). Regardless of whether patient’s needs are being assessed, cancer patients are still not receiving the care they need; further identifying the need for the occupational therapy profession to advocate for the services that can be provided for individuals battling cancer.
Why are Referrals not Occurring?

The lack of referrals to occupational therapy services stem from both a healthcare professional perspective and a patient perspective. According to Sleight and Duker (2016) there are a number of reasons physicians may not refer their oncology patients to occupational therapy services. Examples of potential rationales included the model of care cancer treatment was based on, physicians hesitation to engage in rehabilitation services when anticipating a full recovery after treatment, and the high cost associated with care, including lack of insurance coverage. From the patient perspective, the barriers include not understanding what services occupational therapy and other health professions can provide and increasing anxiety in relation to unknown factors of their treatment (Sleight & Duker, 2016). By bringing forward the component of client-centered intervention that is at the core of occupational therapy practice, therapists can reduce these factors.

Hwang, Lokietz, Lozano, and Parke (2015), reported that only 4.5% of participants received an occupational therapy referral for treatment during survivorship care. In order to address the lack of referrals to occupational therapy services for cancer survivorship, there needs to be a focus on occupation rather than the management of cancer symptoms to help other disciplines recognize what is unique in occupational therapy interventions (Buckland & Mackenzie, 2017).

Chan, Xiong, and Colantonio (2015) reviewed the referral process in Canada for occupational therapy working with clients diagnosed with a brain tumor, whether the tumor was malignant or benign. The researchers used data gathered from the Discharge Abstract Database (DAD) as well as the Home Care Reporting System (HCRS) to
understand what processes occurred after a patient was discharged from the hospital and whether or not those individuals were receiving OT services. These individuals were either receiving occupational therapy services within their private home, in a long-term care facility, or in educational facilities (Chan, Xiong, & Colantonio, 2015). The results showed percentages at 90% and above of individuals diagnosed with various stages of tumors were receiving occupational therapy services (Chan, Xiong, & Colantonio, 2015). This was a substantial finding for the referral process and the researchers identified that the gap for those without occupational therapy services was due to the type of insurance agency an individual is a part of for their treatment (Chan, Xiong, & Colantonio, 2015). Therefore, if the insurance agency did not include or refer to occupational therapy services, an individual does not receive needed occupational therapy services (Chan Xiong, & Colantonio, 2015). Although this study comes from the Canadian system, it gives insight into another disconnect occupational therapists are facing in practice. If insurance companies are unaware of the benefits occupational therapists can provide clients then there services will not be reimbursed and physicians will not refer to occupational therapy services.

Challenges for OT’s working in Oncology Care

In addition to the external barriers occupational therapy services face regarding referrals, there are internal challenges the profession has to overcome. Baxter, Newman, Longpre, and Polo (2017) reported that occupational therapists are unsure of the reimbursement coverage for cancer survivors. This lack of knowledge prevents therapists from advocating for their role for cancer survivors. As occupational therapists, the skill set of helping patients with cancer re-engage in their daily life within the circumstances
of a cancer diagnosis should be motivation enough to advocate for our services within this area of medicine (Baxter, Newman, Longrè, & Polo, 2017).

The research done by Ulfers and Berg (2017) surveyed occupational therapists regarding their knowledge on cancer-related cognitive impairments (CRCI) and their preference of utilizing the programs to increase competency in knowledge on CRCI. The results of the study indicated that occupational therapists would like to learn more information about CRCI programs and how to apply them to the cancer population (Ulfers & Berg, 2017). In order to remain engaged within this emerging field of medicine, occupational therapists must seek out updated information to best serve our clients in a holistic view. This study was an initial analysis of the limitations seen within occupational therapy’s scope of practice and how we need to advocate for additional resources and knowledge to apply to our unique practice (Ulfers & Berg, 2017). Occupational therapy practitioners lack of understanding in reimbursement coverage and programs for cancer treatment leads to decreased confidence in advocating for the profession in this area.

Moving Forward in Oncology through Research

In addition to advocating for occupational therapy services, therapists must dedicate time to review and implement research into their practice to continue building the credibility of this profession. According to Hunter, Gibson, Arbesman, and D’Amico (2017), the strongest and most current intervention evidence for cancer survivors involve multidisciplinary rehabilitation programs, psychosocial interventions, sexuality supports, and supports for returning to work. These results fall within the scope of occupational therapy, therefore, interventions need to be applied to these challenges for cancer
survivors. To further build occupational therapy’s presence within this scope of practice, more rigorous studies need to be conducted in order to understand which interventions would best support the needs of cancer survivors and patients (Hunter, Gibson, Arbesman, & D’Amico, 2017).

Stout et al. (2016) recognized the gap rehabilitation spectrum for cancer patients and sought to pursue oncology care within the area of medicine. One area of focus indicated that a shift needs to be made towards promoting “health-related quality of life;” that comes from a failure to recognize the shifts that inevitably occur for an individual battling cancer that may lose functional abilities. This article examined post-acute care, home care, and outpatient ambulatory care while measuring function through physical, cognitive, and functional performances to best understand the needs of each individual cancer patient. Due to the significant gaps seen within this area of rehabilitation, the researchers concluded that using an interdisciplinary approach can cover these gaps seen within this population. The main objective of this approach was to ensure all health professionals are connected and progressing forward in treating the needs of patients through the patient’s identified goals (Stout et al., 2016).

Maher and Mendonca (2018) examined the effectiveness of activity-based programing and self-identified goals for women diagnosed with cancer. To measure occupational performance and satisfaction in community-based programs, the study utilized three assessments: functional health measure, Quality of Life (QOL) measure, and Canadian Occupational Performance Measure (COPM) (Maher & Mendonca, 2018). Sessions were guided by the occupational therapy framework and included physical, emotional, spiritual, sensory, and educational types of activities (Maher & Mendonca,
2018). The results of the research indicated that COPM scores on performance and satisfaction were significantly improved (Maher & Mendonca, 2018). This indicates that self-identified goals lead to improvement in performance and satisfaction and may translate into occupational functioning (Maher & Mendonca, 2018). The researchers indicated that future studies should address how intervention should be implemented in practice and include “assessments that are more sensitive to participants’ diagnosis” (Maher & Mendonca, 2018).

Asserting OT’s Role in Oncology Care Through Referral Process

In response to the formation of a national program that excluded occupational therapy, Polo and Smith (2017) wrote an article providing examples of treatment interventions ranging from energy conservation, cognitive adaptations, lymphedema specialization, and mental health interventions that could have been implemented into this program. Polo and Smith (2017) identified ways for occupational therapists to advocate for our role and developed interventions specific for treating cancer survivors. Failing to advocate for our roles was a huge disservice to survivors because of the variety of tools and knowledge that can be offered to those who have battled cancer.

Increasing the number of referrals to occupational therapy services of patients diagnosed with cancer is a key component in expanding occupational therapy’s role in oncology care. To advocate for this increase, occupational therapy practitioners need to educate other health professionals on the interventions used to treat cancer deficits. This can be demonstrated through interdisciplinary conversations, or a screening tool that flags deficits occupational therapists can address. The role of occupational therapy in oncology care will not expand if patients are not being referred to occupational therapy services.
Seeking out more referrals through advocacy can build the momentum in showing the impact occupational therapy can have on closing the gap in care so clearly seen throughout the research for those battling cancer.

**Summary**

Oncology care is an emerging area in the field of occupational therapy. Occupational therapy can address the physical, cognitive, and psychosocial needs of patients diagnosed with cancer (Baxter, Newman, Longre, & Polo, 2017; Longpre & Newman, 2011). The stages and level of care patients need vary by their diagnosis and where he or she may be on the cancer care continuum. Occupational therapists are qualified to interject at any stage or time of care, to be a part of the interdisciplinary team, and ensure the patient is receiving holistic care to improve quality of life (Veloso et al., 2013; Hwang, Lokietz, Lozano, & Parke, 2015; Baxter, Newman, Longre, & Polo, 2017). Evidence supported occupational therapy interventions in addressing the physical, cognitive, and psychosocial deficits of patients with cancer face (Braveman et al., 2017; Buckland & Mackenzie, 2017; Farley, McCarthy, & Pergolotti, 2017; Munoz, Cambell, & Bowyer, 2015). However, it is important to continue gathering evidence to support OT’s role in oncology care. Patients who could benefit from occupational therapy services are not receiving referrals for treatment (Pergolotti, Williams, Campell, Munoz, & Muss, 2016; Pergolotti, Cutchin, Weinberger, & Meyer, 2014). Through this independent study, we hope to learn from occupational therapy practitioners experiences in oncology care. In addition, we hope to learn how we can advocate for occupational therapy services through collaboration with other medical professions to serve and meet the goals of those battling cancer.
CHAPTER III

RESEARCH METHODOLOGY

Research Design

This research study followed a qualitative research design to find meaning to connected experiences or phenomenon from a group of individuals (Berg & Lune, 2012). The purpose of this study was to understand the experiences of occupational therapists working in oncology care, specifically regarding the referral process for occupational therapy services. The results of this project provide an understanding of occupational therapist’s perspectives to advocate for the role occupational therapy within oncology care.

The framework guiding this qualitative research study was phenomenology. Phenomenology is a form of interpretation where the key of understanding the world is through human consciousness (Shank, 2002). We asked the participants to articulate their own experiences working with oncology patients using open-ended questions. According to Giorgi and Giorgi (2008), a phenomenological research aims to clarify lived situations of persons in everyday life. The aim of phenomenology was not to control the context, but to remain as faithful to the phenomenon as possible (Giorgi & Giorgi, 2008). By using this research design and framework, we sought to understand occupational therapists experiences when working with patients in oncology care.
Sources of Data

The participants were occupational therapy practitioners who had experiences with working with patients diagnosed with cancer. The participants were obtained from the Midwest region, specifically the North Dakota and Minnesota area. Six participants were selected to be interviewed through purposive, snowball, and convenience sampling methods (see Appendix C).

Locale of the Study

The researchers conducted the interviews via telephone or face-to-face interviews within the University of North Dakota’s School of Medicine and Health Sciences. The interviews were virtually conducted for participants with differing demographics. Participants who could come into UND’s Medical School participated in a face-to-face interview.

Population/Sampling

The inclusion criteria for the population recruited included occupational therapists that primarily speak English and had at least 6 months of working experience with oncology patients. Recruitment was conducted through purposive, convenience, and snowball sampling. The researchers had two gatekeepers who contacted potential participants for the study. The gatekeepers were asked to contact the potential participants who met the inclusion criteria, via email (see Appendix D). Six participants were selected to take part in the interviewing process.

Instrumentation and Data Collection

Semi-structured interviews were administered to collect data (see Appendix E). Once the University of North Dakota’s Institutional Review Board approved the study
(see Appendix F), potential participants were emailed and invited to participate in the study. Six participants agreed to participate. An informed consent document was given prior to the interviews and participants were asked to provide verbal consent upon the start of the interview (see Appendix G). In addition, a copy of the OOPST was sent to the participants to review prior to the interview (see Appendix A). Interviews were audio recorded using QuickTime Player on a MacBook Air and transcribed verbatim. Once the data was transcribed, the audio recordings were deleted permanently. Data was stored in a password protected folder where only the researchers and the researcher’s advisor could access the recordings to protect the confidentiality of the participants.

We are occupational therapy students completing this independent study as a requirement to obtain a Master’s degree. We have completed a qualitative research course as part of our program’s curriculum. During this course, we conducted a qualitative research study that included the use of semi-structured interviews. We have completed a physical dysfunction and a mental health level II fieldwork. During this experience, we gained experience with interviewing clients and collecting data. In addition, our advisor, Dr. Julie Grabanski completed a dissertation using Giorgi and Giorgi’s phenomenological approach.

We used triangulation methods to assess the data collected. This method required us to collect data from multiple sources in three main categories; person, researchers, and theory (Berg & Lune, 2012). We gathered data from the literature prior to conducting interviews with the participants for the first section (Berg & Lune, 2012). Both of us reviewed and assessed the data obtained throughout the study. Finally, we used Giorgi and Giorgi’s (2008) phenomenological approach to guide our research. The
phenomenological approach allowed us to examine the experiences of occupational therapists working in oncology care to ensure an accurate depiction of participant information (Gonzalex & Forister, 2016). Additionally, we used member checking when assessing the gathered data during the interviews. The interview itself was semi-structured and allowed us to ask clarification questions throughout the interview to ensure that the meaning of the experience was understood accurately (Gonzalex & Forister, 2016).

Reliability ensures that the measurements are consistent over time to ensure the data was accurate (Bork, Jarski, & Forister, 2016). Reliability can be broken into three forms; instrumental, intrarater, and interrater reliability (Bork, Jarski, & Forister, 2016). For instrumental reliability, the researchers utilized the same tools to record and transcribe the interviews to remain consistent across each interview. For the intrarater reliability, the researchers utilized the same format to structure the interviews to guide the conversation consistently across each interview. For interrater reliability, the researchers were together for each interview which ensured consistency between the researchers throughout each interview.

**Tools for Data Analysis**

The researchers collected, analyzed, and interpreted the data. Interviews were recorded and transcribed verbatim. Once the interviews were transcribed, summaries of interviews were sent back to the individual participants to review and to ensure accuracy.

Giorgi and Giorgi's (2008) phenomenological approach was used to complete the data analysis. This four-step approach began with reviewing each description thoroughly. This step was needed to understand the global sense of the description before proceeding.
to the next step. The second step was the "constitution of the parts of the description" (p. 34). This step allowed clarifications of implicit matters. By carefully rereading the description, 'meaning units' were identified. These ‘meaning units’ were then transformed from implicit to the explicit statements; this allowed the analysis to reveal meaning that were lived but not necessarily articulated (Giorgi & Giorgi, 2008).

In the final step, we generalized the 'meaning units' and reviewed their transformations to gain an overall understanding of the participant's experiences. During this synthesis step, we determined which constituents were essential to gain a full understanding of the experience (Giorgi & Giorgi, 2008). We used a grid format to organize the data during the process of data analysis (see Appendix H and I).

The steps described above outlined the process that was used through the course of this study to ensure that quality data was produced. Each member of this research team took significant time to process through the details of this study from start to finish to ensure that the resulting data could be used to explore and expand occupational therapist’s role within the oncology field.
CHAPTER IV
DATA ANALYSIS

The purpose of this study was to understand occupational therapy’s involvement within oncology care and understand how the referral process impacted patient’s ability to receive occupational therapy services. In addition, participants provided recommendations for the OOPST to further increase referrals to occupational therapy through the use of a screening tool. The Giorgi and Giorgi (2008) method for phenomenological research was implemented for gathering data. The data was derived from each semi-structured interview. ‘Meaning units’ were identified, transformed and synthesized into common themes (Berg & Lune, 2012). We began by reading through each transcription in full. During the second read through, we identified ‘meaning units’ within each interview and inputted the data into an analysis grid (see Appendix H and I). ‘Meaning units’ are data expressed in the participant's own words that we found to be significant. Each ‘meaning unit’ was established from re-reading the interviews and seeing a transition in conversation to identify individual units of information (Berg & Lune, 2012). Next, we took the divided meaning units and focused on the contextual meaning within the meaning unit to draw out the experiences described by the participants (Berg & Lune, 2012). Through this process, we were able to see patterns emerge from sequential meaning units into a synthesis of data written in the final column (Berg & Lune, 2012).
Presentation of Data

Through the semi-structured interviews, we gathered information connected to oncology and occupational therapy within practice. We discovered connections within occupational therapists experiences within the process of working with oncology patients, the impact of the referral system on the OT process, and therapist’s reflection on how the OOPST can shift occupational therapy’s overall experience within the healthcare system. Each participant provided their own perspective based on the setting where they worked and the experiences they had within that system to inform the researchers on the current practice within the Minnesota and North Dakota medical systems. What follows is an depth analysis of the cumulative data compiled of these findings.

Individual Interview Summaries

Participant 1

Within the acute care setting, participant (P1) prioritized activity tolerance as the main intervention goal. Additional interventions included were energy conservation, recommendations, compensatory education techniques, and management of cares. As interventions with oncology patients were implemented, P1 emphasized the importance of taking more time to work with this population to support them in a way that was uniquely their own. P1 stressed that the qualities of versatility were important to keep a client-centered approach while implementing treatment plans. Addressing the unique characteristics for each individual, understanding those differences, and adjusting accordingly were important to provide the best interventions and outcomes for that patient. On the other hand, as an OT, P1 did not want to overwhelm or add stress to the patient with another appointment but provided appropriate care. Time and space available
to implement intervention within the acute care setting was limited. New regulations on sanitation procedures have further limited OT approaches compared to years past. P1 reflected that the shift has made current intervention approaches less functional due to these changes. P1 identified one challenging situation with discharge plans in the acute care setting was that discharge was determined on a person’s level of independence with walking and was dependent on PT recommendations. P1 reported that this often led OT’s to seek referrals for PT evaluation in order to obtain the appropriate discharge plan for the patient. P1 reported that it was important to have a team work together to better serve the individual patient to ensure that the right care was provided. Despite the challenges, P1 emphasized that the therapist must follow the lead of the patient and take the time to listen and understand their perspective. P1 further explained that this included being flexible to an oncology patient’s schedule and understand that within treatment there may be psychosocial components to consider and evaluate when working with this population.

P1 emphasized that OT’s need to advocate for the unique perspective brought to the medical team through the quality of evaluation an OT invests within each session to understand holistically what is best for the patient. P1 emphasized the importance of advocating this skill set and that the lack of advocacy directly impacts medical professionals from not understanding the involvement OT can have within oncology care. P1 speculated that the lack of OT referrals may be due to new specializations being part of the hospital team and the shift towards a more medical model versus a more holistic model.

P1 reflected that implementing a tool into the normal routine of a doctor’s appointment process aids in the flow of services and provided the medical staff with vital
information related to the patient’s daily routines. P1 stated that more functional tasks should be included within the screening tool, for example getting in/out of the bath or bed. P1 reflected that the tool allowed patients to input unique challenges they have experienced. P1 identified that the tool should provide an opportunity for the patient to concisely communicate the challenges without overwhelming the patient or overburdening the medical staff. P1 reflected that physicians may not take the time to score the OOPST but believes they would quickly reference the scores and apply the information to treatment. Therefore, P1 emphasized that the tool must be easy to read and interpret by both the patient and the physician.

**Participant 2**

In home health care, especially hospice, there tends to be more of a focus on how to make the patient’s life easier and more comfortable, instead of focusing on getting them back to baseline. Participant (P2) believed home health care allowed her to take as much time needed with the patient and didn’t put her on a time restraint. OT in home health was very client-centered and occupation-based due to being in the patient’s natural context. P2 described a wide variety of interventions OT’s provided to patients who had been diagnosed with cancer. Pressure ulcer prevention, providing adaptive equipment, and ADLs/IADLs were the most common interventions in home health care for oncology patients. P2 also discussed the difficulty in working with patients at the end of their life, however, emphasized that with experience she has learned to make it as positive of a situation as possible for the patient. Oncology patients sometimes lacked the motivation for therapy if they are having a hard day or are fatigued, which added to the challenge. No matter what emotion the patient may be experiencing, it was important to let them
talk about it and validate their feelings. P2 emphasized the importance of making sure the patient felt heard when expressing intense emotions. Therefore, P2 allowed more time for the session and focused on the patient’s emotional needs to help with coping.

As a practicing OT in home care, P2 discussed how it was unlikely to ever see or talk to the doctors. That being said, P2 believed it would be beneficial to see more education given to physicians in order to increase their understanding of what OT can do for oncology, and therefore, increase referrals. P2 also emphasized the importance of advocating for referrals in home care services by having someone represent OT at meetings, and in addition, educating the patients of what OT can do. An example of this includes having brochures of what OT can work on at the Cancer Center.

P2 thought the OOPST may be depressing for a patient to fill out, due to having to disclose what he or she is struggling with. However, P2 stated that it would give them a chance to be heard and address aspects of their lives that are affected by the cancer but not being talked about. P2 reported that relationships (such as significant others) and role changes should also be addressed in the OOPST.

**Participant 3**

Participant (P3) emphasized that a goal utilized more frequently in oncology care included training family members on transfers. Overall, P3 identified that OT’s are focused on promotion of function and independence in occupational activities. P3 reflected that oncology patients have a more complex medical background and OT’s have more data to assess before heading into treatment. P3 has experienced that patients may be resistant to services due to fear of exerting too much energy on interventions. As a therapist, P3 stated that it is important to understand when to push for therapy and when
to hold back services to avoid overworking patients. P3 emphasized finding a balance and just right challenge was difficult initially but developed with experience. P3 included how important it was to understand the patient’s treatment schedule to predict potential side-effects and ensure that when family comes to visit that that time is valued and prioritized. P3 reflected that it was most rewarding when a patient was central to practice and was able to accomplish their goal through the OT intervention, through adaptation or modification approaches. With new research surfacing, P3 identified a goal of having more OT presence within oncology treatment and become a valued asset to the medical team in the same way other professionals and procedures are valued.

P3 identified most commonly implemented interventions were functional movements and transfers, exercises, education, and discharge planning. P3 reported that the therapist assessed level of independence with toileting, standing at the sink, dressing, and sitting at the edge of the bed. With exercises, P3 reported that therapists often used TheraBand or occasionally weights if there were no precautions/restrictions. Additionally, education covered a wide range of areas and were specific to the client’s diagnosis and the individual needs. P3 reflected that patients aren’t often seeking OT services but are admitted for different reasons and OT’s must take time to explain the purpose of incorporating OT services to treatment. Once explained, P3 carried out treatment in the patient’s room, the therapy gym, or the nurse’s station. Often the gym wasn’t used due to its location on different floors then the oncology floor and thus caused a barrier for patients who have oxygen, chest tubes, or lines from moving to different floors. P3 reflected that the majority of time was spent in the patient’s room completing functional tasks from materials patients brought from home such as toothbrush or
deodorant, which promoted meaningful intervention to services. Through treatment, OT’s often encountered psychosocial components to treatment and P3 identified that it was important to take the time to listen to participants during this time and often this paralleled with intervention services. There are layers to every intervention approach and P3 emphasized that the psychosocial component is a piece that shouldn’t be ignored. Two modifications identified by P3 was changing the environment to provide more opportunity to expand upon current intervention approaches and conduct group sessions where patients had the opportunity to connect within a community to share experiences. P3 hoped that the first identified recommendation may happen after the new hospital was built and the second would be a challenge to complete in the hospital due to the overlapping medical schedules that would make set times difficult to establish.

P3 reflected that an obtained OT referral within the acute care setting were often completed using two methods and both required the doctor’s input. One method was a blanket referral from the doctor and the other was a nurse recommendation that the doctor make the referral to OT. P3 identified that when referrals come through the screening from nurses there was more of a need for OT and through the blanket referral, it often led to unnecessary evaluations. P3 stated that when working with clients, the whole team was informed of the client’s progress and the OT was responsible for providing the rationale for discharge recommendations and adaptations/equipment that should be added within the home. P3 reported that when discussing oncology patients there was often more stress involved due to the complicated medical history and the time constraints placed on therapists. If more time were allotted to OT’s, more interventions would be implemented to complete a full assessment on level of assist needed and the OT would have a fuller
description of discharge recommendations. P3 stated that discharge was often decided between home, a swing bed, or rehab with oncology patients.

P3 liked the idea of patients filling out the information prior to a session to help the therapist understand and prepare for a session without taking any time away from the session. P3’s recommended that the OOPST tool should be shifted into vertical versus horizontal columns to make the process flow more readily with completing the assessment and scoring the information. P3 also recommended that the number values be spread down along the columns so patients wouldn’t have to waste time flipping papers back and forth. P3 identified that the score and colored numbers may mislead against an OT referral. The example provided by P3 was that some people may be doing well in many occupations but struggle significantly in a handful which the scoring would not indicate the necessity of an OT evaluation. This could potentially prevent some individuals from obtaining a needed referral and P3 suggested that having any score of 5 should warrant further assessment by OT.

**Participant 4**

Overall, participant (P4) believed the goals of oncology patients were similar to other diagnoses. However, oncology patients did not always get better, therefore, therapy focused on maintaining their current independence. Lymphedema, energy conservation/adaptation strategies, and home safety were the most common interventions P4 used in outpatient occupational therapy services for oncology patients. P4 added that outpatient therapy allowed for the opportunity of having therapy in the most natural context (the home). In addition, it was important as a therapist to be emotionally stable and strong to work with individuals who were dying, in order to maintain mental health.
P4 described how it was rewarding to improve a patient’s quality of life, however, the most challenging part of OT in oncology care was that not every patient survived. The amount of emotional support the patient needed was also challenging (due to time constraints). From a psychosocial aspect, it was important to P4 to put herself into her patients’ shoes and validate whatever he or she may be feeling.

P4 described the referral process as a challenge. Patients fell through the cracks, getting referred too late and ended up having problems with ROM that could have been avoided. P4 discussed how home evaluations should be protocol for individuals diagnosed with cancer to evaluate safety and quality of life, especially if needing end of life care. In addition, every woman should be referred to OT after a mastectomy to review the risk of lymphedema. P4 continued by stating that it is important to advocate for the benefits of OT for oncology patients. Examples P4 provided included going to events, lunch meet and greets, developing an in-service, and trying to get your face out there so that doctors/health professionals know what OT is all about. P4 emphasized how showing other disciplines what OT can offer patients with cancer, will increase overall understanding of OT, therefore increase referrals.

P4 believed that understanding the referral process and educating the doctors, to increase their confidence if they were intimidated by this process, would increase referrals. If not educated on what OT can provide for a patient, doctors may feel like they are abusing the system. It is important to advocate for the benefits of OT for oncology patients by building rapport with the doctor, for it will increase their referral to you. P4 provided other ideas for improving professional relationships including communicating
with the doctor, such as sending a personal note thanking them for the referral, and not understanding that the doctors may not have time to read the OT note.

P4 believed the OOPST is a holistic tool, covering the major ADLs. However, due to chemotherapy side effects, the questionnaire should ask "When do you feel the worst? And how long does it take you to recover and get back to your baseline?" instead of "On average, how many days in a week?" or, "How do you feel?" P4 emphasized how this would allow the scorer to get a glimpse of what a hard day may be for the patient. In addition, P4 thought adding questions such as: "When was your last chemo? How do you feel after chemo? How many days does it take you to feel better?" would be beneficial. This may make it more complicated, but these are common questions the OT will be asking once the patient is referred. Also, if a patient is going through chemo treatment, the patient may have a hard time rating how they are feeling on particular days. However, according to P4, if you worded the questions, "On a chemo week, versus a non-chemo week," the tool would be more accurate. Lastly, P4 disclosed that this may not be a good population to have a rating scale to measure the outcome of therapy because the chemo could interfere with the patient’s rating of how he or she may be feeling.

**Participant 5**

According to participant five (P5), acute care goals for patients in oncology care did not differ much from other patients. In acute care, treatment and assessment looked very similar for all patients, including oncology patients. P5 provided examples such as, range of motion, post-surgery precautions, upper extremity function, and fatigue as the main interventions used to treat oncology patients in a rural setting. In addition, ADL training, strengthening, and endurance were the most common interventions for oncology
patients that P5 used in acute care. P5 discussed how being able to see patients make improvements was rewarding, however, the variety of cancers made it challenging to treat patients. In oncology care, a treatment session may have involved just discussing the patient’s emotions and letting them process his or her feelings. P5 emphasized how a diagnosis of cancer turned patient’s worlds upside down. It was important to let patients process through the emotions they were feeling, in order for them to prepare for the long road ahead. This required a therapist to peel back a lot of layers, to find out what’s going on with a patient.

P5 described oncology care in OT as reactive. Referrals were only happening once the symptoms from the cancer significantly affected a person’s daily activity. This issue could have been prevented if the patient was referred initially. P5 discussed the trend that oncology patients were not being seen for leisure, social participation, and IADLs. Sexual activity, child care, community involvement were all important aspects of a patient’s life that were also not being addressed from P5’s perspective. People needed to continue working, they had children, they had hobbies, whatever it may have been, they had activities they needed to keep participating in. P5 believes this needs to be emphasized in order to increase referrals in the future.

The STAR program, a program utilized by P5, is an interdisciplinary program that educates all disciplines on how to get an oncology patient back to functioning the best they can. It navigates the referral process so patients do not fall through the cracks, and are seen by the correct disciplines. The STAR program is a very expensive program and was never implemented completely. P5 explained how patients were not getting caught, and falling through the cracks, not getting the referrals they needed. P5 believed each
patient who is diagnosed with cancer should be assigned a ‘gatekeeper’ or someone to follow his or her case and make sure they do not fall through the cracks from a rehabilitation standpoint. In addition, P5 believed the continuance of care from one setting to another (acute, TCU, outpatient, etc.) needs to be enforced. P5 reported that an issue in most facilities, was making sure that patients received continued referral/care. In addition, patients may have been falling through the cracks because referrals were being sent on weekends, or holidays and not getting scheduled. Another barrier that P5 recognized was not receiving the proper referral because it was hard to get patients to admit they had problems. The deficits in their daily activities appeared to be the norm for them now, and patients began to believe it could not be addressed. In addition, patients may be embarrassed to admit deficits, therefore, you may not capture the severity of their impairments.

As a profession, P5 believed that occupational therapists need to expand our role and stop living in the shadows. A change in the referral process needs to include an increase in education on what OT can provide in order to receive proper referrals. According to P5, having something in place to educate all professions, having a system to allow the patients to identify problems, and understanding how physicians can refer them to the right disciplines would help increase referrals. To increase referrals, occupational therapists have to sell the services provided to the patient by educating the patient on the importance of continuing care through OT services. In addition, nursing staff are just as important to educate about the referral process and role of OT. In acute care, protocol included ordering therapy on each patient. P5 reported no barrier in receiving OT
referrals in the hospital. However, as an acute therapist, there were not always ways to confirm that the recommendations made were implemented into that patient’s treatment.

Overall, P5 believed the referral process was, and continues to be, a challenge in oncology care. The biggest barrier identified by P5 in the hospital setting, included therapists not recognizing that their patient was an oncology patient, and how treatment may vary because of this. P5 emphasized that physicians were not against referring to other disciplines, the barrier involves them not knowing what service we can provide to their patients. Understanding how to refer through the computer system was also a barrier for some physicians. Knowing who is appropriate to refer to for certain deficits was an additional barrier in the referral process. Another barrier included explaining to the provider that their patient needed therapy. Face-to-face time with a physician may increase the likelihood they will refer to OT services. If you wanted to improve the referral process, P5 reported that it needed to be easy and quick. Everyone is busy, not just physicians, so the process needs to be efficient.

P5 stated that the OOPST needs to either stay within the scope of OT or include an interdisciplinary approach. For example, is nausea and vomiting really within the scope of OT? How about anxiety and depression? It may be more appropriate for them to be referred to a psychologist or psychiatrist. The OOPST seemed great from an OT perspective and standpoint, however, what about an interdisciplinary approach? P5 believed that if each profession had their own unique screening tool, the patients would be filling out 600 questions every visit. Condensing all these questions into one screening tool would be the end goal. P5 expressed how it would be ideal to have a tool that is really fast and quick, and can be done before the physician comes in. It might be
beneficial for a nurse or other health profession to go through the screening tool prior to the patient seeing the physician, so that the physician only has to look at the bottom line. P5 also stated that if the OOPST was scored and then handed to the physicians with the “Referral strongly recommended,” marked, it would not take very long for a physician to decide if he or she wanted to refer that patient. A barrier with the OOPST, is that because it is a paper form, it is less likely that the survey will be put into the patient’s electronic chart for the physician to see. In the future, P5 believed this tool could be developed onto an iPad form and their answers would go straight to their chart. Lastly, P5 believed the OOPST would benefit from using a 3 point Likert scale. P5 discussed how patients usually struggle with self-reports, so decreasing the options will hopefully decrease hesitation. Using extremely difficult, moderate difficulty, or no difficulty could be the rating scale.

**Participant 6**

There aren’t significant differences in goals/treatment with oncology patients, but participant six (P6) identified that more education was implemented in practice on symptomatology of a diagnosis. When working with oncology patients, P6 identified the importance of using therapeutic use of self during interventions including understanding the dynamics amongst the patient’s supports systems. P6 reflected that having an impact in improving quality of life will look drastically different with each individual but may have an equally powerful impact over that individual’s happiness. P6 emphasized client-centered treatment to ensure that the true desires and aspirations for occupational fulfillment are met. P6 identified the four main challenges in working with oncology patients are pain management, recognizing that you can’t always help during the end of
life, facing the lack of education provided to some patients, and creatively involving the family when implementing interventions. P6 reported that the most important interventions were modifications of occupations and appropriately involving support systems with intervention planning. P6 also identified that the education component was vital when working within oncology from explaining medical terminology or explaining how to adapt/modify potential changes that often come with treatment. P6 reported that the modifications to occupations and education often intertwined during interventions and OT’s are responsible for helping oncology patients. In addition, P6 provided insight on OT settings discussing how acute care was a quick education/intervention with focus on discharge; outpatient provided time to have interventions focused on adaptations needed for the client; home settings focused on safety and making adjustments to the environment; and treatment in hospice involved both the patient and family and ensure transfer skills are learned effectively with safety as the top priority with energy conservation methods.

During certain psychosocial challenges, P6 reported how important it was to advocate for patients to seek services from a counselor or psychologist; especially those with specialized knowledge of oncology. P6 reflected that OT’s then reinforced that treatment and apply strategies from the professional into treatment. P6 emphasized that it was important to take time and slow down for patients to process oncology diagnosis and give them opportunities to process end of life conversations and always be conscious of being sensitive to the situation. P6 emphasized the importance of asking additional questions to ensure clients are supported. P6 cautioned that some OT’s may be too quick to discharge patients and should take time to dive further into other important questions
that can directly impact a person’s ability to be independent in all occupations within the home.

With new research, P6 hoped that this encouraged more referrals so OT’s can prioritize program development and create a clinic where patients can be evaluated and treated. P6 identified that a barrier would be getting doctors on board with this. With research showing that OT’s reduce readmission rates, P6 emphasized how important it was to complete OT evaluations to its entirety in order to maintain and expand this.

Within each setting, referrals come differently. In acute care, P6 reported that referrals are completed more readily where in home health and outpatient relied on specific referrals which led to less referrals. P6 reflected that doctors often only refer when significant deficits occur and not proactively. P6 reported that doctors who are more likely to refer to OT often spend more time with patients and have a more holistic understanding of that patient. Within current Medicare systems, OT’s are able to take more proactive approaches to evaluations to prevent future deficits and it is P6’s hoped that this approach becomes more accepted within the medical field. Two barriers P6 identified when working with doctors and oncology patients is advocating for blood work to be conducted for the older population and discussing end of life matters. P6 reported that at times, doctors do not want to run blood panels on patients who are older and this can prolong symptomology and delay a cancer diagnosis. P6 reported that in Wisconsin the doctors make conscious efforts to discuss end of life wishes with patients, but overall this remains a conversation that many doctors do not readily have with patients. P6 emphasized that OT’s have many skills to offer medical teams and need to take progressive steps towards communicating those qualities; often times doctors are open to
hear OT’s perspectives due to the wide range of assessments that are conducted and information gathered to support plans of care. P6 suggested that OT’s take time to contact the physicians regarding treatment plans, and to share observations from therapy sessions that may assist the doctors in making appropriate referrals. P6 recommended that OT’s need to focus on asking the doctor for their interpretation of the observations shared and asking if they feel certain treatment approaches are appropriate. P6 identified developing relationships amongst different departments had also aided in referrals to OT services because the communication flows much more effectively and benefits the patient and team.

P6 had a positive outlook for the tool and suggested that a supportive staff or nurse be included in the process to ensure accuracy within home life. P6 recommended changing the order from easy to difficult tasks to make it easier for patients to fill out. P6 made the following suggestion of order: getting dressed, bathing, showering, getting on/off the toilet. P6 also suggested that pain and weakness should be combined to one score and have an additional score for numbness or tingling in fingers or toes. For the grading system, P6 recommended including a zero mark to make it clear that a referral was not warranted. Anything scored at the middle mark and above should warrant a referral. These changes will help make decisions easy and ensures that unnecessary time wasn’t spent weighing on a decision to refer or not to OT. P6 added that with collecting the data, each point should be numbered 1-20 to make tallying easier for scores to be computed and simplifying the process within the clinic.
Key Constituents

Eleven key constituents or themes were derived from the descriptions provided by the participants in regard to occupational therapists experiences in oncology care and the implications of the referral process to these services. The key constituents were:

Goals within Oncology Intervention

Interventions Implemented for Oncology Patients

Challenges faced for Oncology Patients within OT Treatment

Modifications Made to Therapeutic Approach

Psychosocial Barriers Experienced in Treatment

Environmental Differences Between Settings

Establishing and Advocating for OT’s Role within the Medical Team

Implications of New Research to OT’s in Oncology

Advocating for OT services to increase referrals

Patients falling through the cracks

Relationship with physicians to increase referrals

Goals within Oncology Intervention

Participants working with oncology patients identified that goals are often similar across settings for oncology patients and often don’t vary away from goals set for other patients. Common goals identified by the participants include increasing activity tolerance, maintaining current independence, and training family members on appropriate techniques to complete a safe transfer with an oncology patient. One difference within oncology treatment identified by participants was that occupational therapists often provide more education with this population then with other populations. Specifically, P6
identified that education was often facilitated to help patients connect the challenges they face in completing daily tasks with the symptoms experienced from oncology medical treatment.

**Interventions Implemented for Oncology Patients**

For interventions, participants identified common interventions including education on modifications for energy conservation to manage fatigue, compensatory techniques, how to accommodate/adapt to new symptoms, helping patients understand how new post-surgery precautions impact daily life, and modifications to current occupations that are meaningful to the patient. P1 reflected that within the acute care setting, interventions are built around energy conservation, providing education to oncology patients coming out of surgery, and applying new precautions to patient’s functional tasks. When it comes to end of life matters, P2 reflected that the focus was on understanding “how to make the patient’s life easier” and using equipment and energy conservation to facilitate that. Additionally, participants identified ROM, upper extremity function, pressure ulcer prevention, ADL/IADLs, lymphedema, and home safety as important interventions worked on within this population. P4 reported that lymphedema and home safety evaluations are the most common interventions, but saw an opportunity to grow. P4 reported a desire to have every woman with a breast related cancer to undergo a preventative intervention screen as well as implement more home evaluations for this population of patients. This demonstrated that there was more opportunity to grow in the areas that occupational therapists are already engaged in.
Challenges faced for Oncology Patients within OT Treatment

Within these interventions, the participants also identified challenges connected with oncology patients. Energy was a common struggle with facilitating interventions identified by the participants because oncology patients were acutely aware and cautious with their movements and prioritized when to excerpt energy in their day to day life. P6 identified challenges connected with patients being uneducated about their diagnosis and treatment and addressing that within treatment as well as seeing the reluctancy some patients were to admit deficiencies experienced in life. P5 reported that when working with patients at end of life, a therapist has to “know that you can’t push them because it’s not going to make their cancer go away.” P5 further reported that a therapist has to recognize the reality of the situation the patient was going through and not make the intervention uncomfortable. Participants also identified pain management as a challenging component to treatment for oncology patients. P6 reflected on one case where it was challenging to “not be able to take that pain away.” For the therapists participating in the study, they reported that recognizing that not every patient will survive, and that the therapist can’t always help are challenging realities that occupational therapists have to confront when working with oncology patients.

Modifications Made to Therapeutic Approach

The participants identified different approaches to interventions that were important within this population that included not overwhelming patients with too much information or moving too fast with the interventions described above. Participants also emphasized that the therapist must understand the unique characteristics of each individual when facilitating interventions with patients. P6 recognized that the healthcare
system was overwhelming and as a profession OT’s don’t want to add to this stress. P6 also identified that modifying therapeutic use of self was important for occupational therapists when facilitating interventions. P3 identified that for the initial evaluation, therapists should modify their approach to include taking more time to review the medical history as well as understanding the patient’s treatment schedule to better prepare for interventions. For the treatment itself, the participants emphasized that interventions may require more time to work through with oncology patients and that therapists have to apply the just right challenge for oncology patients to not over challenge them in treatment. P3 reported that “the more you work in OT, the more you understand what the just right challenge is, and you can figure it out more by working with patients.”

**Psychosocial Barriers Experienced in Treatment**

A separate challenge that the participants identified was the psychosocial aspects that parallels treatment. There are layers of emotions that surface when engaging in therapeutic intervention. P2 emphasized the importance of allowing patients to express their emotions and that “part of working with a patient is listening to them, hearing them.” P6 emphasized that therapists should be advocating for patients to seek a professional counselor or psychologist to fully process these emotions. P4 reported that therapists must also show mental strength through these challenges because “the hard part sometimes, is that saying goodbye to your patients.”

**Environmental Differences Between Settings**

Participants 1, 3, and 6 identified challenges within the acute care setting to be difficult when working with oncology patients. These included that interventions were often limited to patient’s rooms, there were significant time constraints when working
through interventions, and P3 identified that a barrier within acute care can be moving patients to different floors to get to the gym who have oxygen, chest tubes, or lines. P6 identified that the acute care setting focuses on discharge, and P1 identified that these challenges and limitations occurred with new regulations and sanitation procedures and inhibits functional intervention. These were identified challenges within the acute care setting.

P2 identified that within the home health environment, there can be more focus on making the patient’s life easier and more comfortable, then helping them return to their baseline. P2’s approach within home health was patient driven, reporting that “you’re kind of following their lead because it’s their house.” P2 reflected that time was not restricted within this setting and that this setting was very client-centered and occupation-based due to being within the patient’s natural context.

P6 also provided insight within the outpatient setting as focusing on adaptations needed for the patient and for the patient’s home environment to ensure safety in all contexts. Within hospice treatment, P6 identified that the priorities shifted to involve the family to ensure safe transfers. Additionally, P6 reported focusing on modifications to establish energy conservation methods for the oncology patient were also prioritized.

**Establishing and Advocating for OT Roles within the Medical Team**

When working with oncology patients, occupational therapists are not working alone, but are a part of a team of medical professionals to provide the best care. P1 reflected that working together was an important part of treatment and reflected that with more specializations occurring in oncology, professionals were less focused on what occupational therapy could provide for oncology patients. P2 described a disconnect in
the amount of communication between physicians and oncology patients. P4 reported seeking out and engaging in more opportunities to speak with doctors to advocate for occupational therapy services. P5 described using the STAR program as a platform for interdisciplinary communication in relation to oncology patients and reported that in P5’s experience, doctors were often unaware of what occupational therapists could do. Therefore, P5 recommended utilizing the STAR program to facilitate opportunities to have all members of the team engaged in understanding each other’s roles. Even without this program, the participants emphasized that occupational therapists needed to be better at voicing what occupational therapy brought to the table within the medical team in oncology care. P6 identified ways to advocate for OT services through attending meetings and in-services.

**Implications of New Research to OT’s Services in Oncology**

P2 and P3 identified that with new research looking at occupational therapy’s role within oncology, each desired that the results of these studies lead to more referrals and a greater presence within the medical team. P3 reported the hope that new research would help OT stand as an equally important aspect to treatment instead of overlooked which was often the case. P6 reported the hope that more research would lead to more immediate referrals to OT services for oncology patients. Overall, the participants were seeking growth in this field of occupational therapy with the backbone of new research facilitating that change.

**Advocating for OT services to increase referrals**

The majority of participants felt that it was important to not only advocate for OT services as a whole, but also the services OT can specifically provide for oncology
patients. P1 believed that the OT profession needed to advocate for the unique perspective that occupational therapists can bring to the medical team, while P4 discussed the importance of advocating what OT can do for oncology care patients. More specifically, P1 emphasized the importance of advocating for our specific skill sets, including OT evaluations which enabled understanding of the patient in a holistic way to find out what was best for the patient.

According to P2 and P5, educating other health professionals on how OT could benefit patients was the most efficient way to achieve this. As a profession, P5 believed that occupational therapy practitioners need to expand our role and stop living in the shadows. In order to receive the proper referrals, P5 recommended educating on what OT services can provide in oncology care. P5 also suggested having something in place to educate all professions, where there was a system of how the patient identified problems, so physicians could refer them to the right disciplines. It was important to advocate for the benefits of OT for oncology patients by going to events, lunch meet and greets, developing an in-service, and trying and get your face out there so that physicians/health professionals know what OT was about. Participants felt that showing other disciplines what OT could offer patients with cancer would increase their understanding of OT, therefore increase referrals. Nursing staff were just as important to be educated on the referral process and role of OT. In addition, P2 emphasized how having someone to represent OT at meetings was a great way to advocate for referrals to home care services. Educating the patients about what OT can do may also increase referrals. An example provided by P2 was having brochures of what OT can work on at the Cancer Center. P2 also believed that if you want to increase referrals, you have to also sell OT to the patient.
P3 reflected that patients aren’t often seeking OT services but are admitted for different reasons and occupational therapists have to take time to explain the purpose of incorporating OT services to treatment. P6 empathized the need for educating the patient on the importance of continuing care through OT services.

P2 thought it would be nice to see more education given to physicians in order to increase their understanding of what OT can do for oncology, and therefore, increase referrals. According to P4, developing an in-service was a way to advocate for OT services in oncology care but there were barriers including, not having enough interest from physicians. If not educated on what OT can provide for a patient, doctors may feel like they are abusing the system. It was important to advocate for the benefits of OT for oncology patients, even if that meant breaking through these barriers.

The OOPST, in general, was a resource that can be used to advocate for OT as a profession. By taking into consideration the recommendations made by the participants, the OOPST can help educate health professionals and patients on how OT could be a part of oncology treatment (see Appendix J).

**Patients falling through the cracks**

The referral process was a challenge. Patients fall through the cracks every day. According to P4, P5, and P6, this was why it was important to seek preventative care and avoid reactive referrals. According to P5, oncology care in OT has always been reactive. Once the symptoms from the cancer significantly affected a person’s daily activity, they were finally being referred, when in reality this issue could have been prevented if the patient was referred right away. There was a trend that oncology patients were not being seen for leisure, social participation, and instrumental activities of daily living (IADLs)
deficits. Sexual activity, child care, and community involvement were also all important aspects of a patient’s life that were not being addressed. P5 stated that, “people need to continue working, they have children, they have hobbies, and whatever it may be they have activities they need to keep doing; this needs to be emphasized to increase referrals.”

An issue in most facilities, according to P5, was making sure that you get continued referral. P4 emphasized that every woman should be referred to OT after a mastectomy to review the risk of lymphedema. Patients get referred too late and develop problems with ROM that could have been avoided. P4 also noted that home evaluations should also be protocol for individuals diagnosed with cancer for safety and quality of life, especially if needing end of life care. P5 suggested that each patient who was diagnosed with cancer should be assigned a ‘gatekeeper’ or someone to follow his or her case and make sure they do not fall through the cracks from a rehabilitation standpoint. In addition, the continuance of care from one setting to another (acute, TCU, outpatient, etc.) needs to be enforced. Lastly, P5 added that patients may be falling through the cracks because referrals are being sent on weekends, or holidays and not getting scheduled.

Everyone was busy, not just physicians, so the referral process needed to be efficient, quick, and easy. That was where the OOPST came in. Changing the formatting of the OOPST would increase the ease of use for patients, and therefore prevent more patients from falling through the cracks (see Appendix J).
Relationship with physicians to increase referrals

In order to increase referrals, P2, P4, P5, and P6 indicated the importance of forming a relationship with potential referring physicians. According to P4, this relationship could be strengthened by helping the physician understand the referral process. In addition, building rapport with the doctor and overall communication with the doctor was important. P4 stated that simple things such as sending a personal note thanking them for the referral increased OT referrals.

P5 emphasized how physicians were not against referring to other disciplines. The barrier was them not knowing what services occupational therapists could provide to their patients. Understanding how to refer through their computer system and who was appropriate to refer to for certain deficits were also barriers for some physicians. P5 also believed that face-to-face time with a physician may increase their likelihood to refer to you.

P6 believed that doctors were open to hearing OT’s perspectives. This was due to the wide range of OT assessments that were implemented to gather and connect information to support plans of care. P6 suggested that during treatment plan discussions with physicians, describing your observations and asking for the physician's opinion, rather than recommending OT options without consulting the physician first, was the best way to successfully communicate recommendations. P6 also recommended to avoid statements during these conversations and focus on asking the physician questions. Even when the relationship may be more virtual, P2 still emphasized the importance of having relationships with physicians. As a practicing occupational therapist in home care, it was unlikely to ever see or talk to the physician. However, this did not decrease the
importance of developing relationships with referring providers or potential referring providers.

The importance of developing relationships with physicians needed to be taken into consideration when creating a screening tool such as the OOPST. P3, P5, and P6 suggested changes within the scoring process of the OOPST, to ease the use for referring physicians and other health care providers. In addition, the importance of the timing of administration of the OOPST was addressed by P1 and P5 (see Appendix J).

**Relationship of Key Constituents**

Through the eleven key constituents that emerged based on the experiences of the six participants, clear relationships were presented. The *goals within oncology intervention* connected with *interventions implemented for oncology patients* by determining the methods used by occupational therapists when initiating treatment with patients diagnosed with cancer. Similarly, *challenges faced for oncology patients within OT treatment* matched with *modifications made to therapeutic approach* when determining OT’s methods of following through with treatment. Additionally, the combined challenges unique to oncology care within the scope of occupational therapy is reflected in *psychosocial barriers experienced in treatment* and *environmental differences between settings* which further connects to the overall treatment interventions discussed above when working with patients diagnosed with cancer. These constituents lead to instill change within the current medical system which was identified in the relationship between *establishing and advocating for OT’s role within the medical team* and the *implications of new research to OT’s in oncology*. To continue growing and
changing OT’s approach to impacting oncology treatment there needs to be further opportunity to grow within this medical model of care.

Additionally, establishing and advocating for OT’s role within the medical team aligned with advocating for OT services to increase referrals when looking towards future growth. Advocating for OT’s role on the medical team is the only way to establish a place at the table, and therefore, begin receiving the proper referrals and connects to prevent patients falling through the cracks overall. Within these constituents, participants discussed the importance of advocacy through education. Another significant relationship that was found with establishing and advocating for OT’s role within the medical team involved relationship with physicians to increase referrals. Many participants highlighted the importance of advocating through the referring provider, however, this advocacy occurs much easier if there has been foundation of a relationship formed between the provider and the occupational therapist.

**General Structure**

Through the course of these interviews, we found that there was not anything profoundly new about occupational therapy working within oncology. The goals and interventions reflect the needs and priorities of the individual patient to obtain occupational fulfillment within their life, which was occupational therapist’s mission with every patient. The occupational therapy process did not change with this oncology population of clientele.

The main barrier was the need for advocacy to increase referrals. Expanding OT’s role into oncology care should come more readily to the forefront of oncology care. Occupational therapy in oncology care should be an established position alongside the
other members of the healthcare team. Occupational therapists must communicate the unique value of occupational therapy and collaborate with healthcare team members to ensure that each individual patient received the best possible care when battling cancer.

Verification of Interpretation

In order to establish triangulation of data, we implemented methods including conducting semi-structured interviews, member checking (see Appendix K), and using a peer review system involving multiple researchers. An audio recorder was used to facilitate the transcription process of each interview and ensure accuracy data. Saturation of themes occurred once all four steps of the research process were completed. By obtaining saturation of themes, we were able to identify key constituents, the relationships between constituents, and determined the general structure of occupational therapists experiences within oncology care.
CHAPTER V

CONCLUSION

Interpretation of Data

Through the interpretation of data using the Giorgi and Giorgi (2008) phenomenological approach, it was evident that participants believed occupational therapy services should have a place at the table with patients diagnosed with cancer throughout their entire continuum of care. Evidence supports occupational therapy interventions in addressing the physical, cognitive, and psychosocial deficits of patients with cancer face (Braveman et al., 2017; Buckland & Mackenzie, 2017; Farley, McCarthy, & Pergolotti, 2017; Munoz, Cambell, & Bowyer, 2015). However, patients who could benefit from occupational therapy services are not receiving referrals for treatment (Pergolotti, Williams, Campell, Munoz, & Muss, 2016; Pergolotti, Cutchin, Weinberger, & Meyer, 2014). In order to address this gap in oncology care participants emphasized the importance of advocating occupational therapist’s established skill sets to patients, other healthcare professionals, and most importantly the referring physician. Participants also believed that establishing relationships with other medical providers would increase referrals to occupational therapy and therefore increase the overall quality of care patients deserve.

Implications of Occupational Therapy

We believed that occupational therapy interventions would be beneficial to patients diagnosed with cancer at various stages throughout their treatment. However,
more evidence-based research is needed. Occupational therapists need to be proactive in their practice and advocate for OT services for patients diagnosed with cancer. Referrals for services would increase opportunities to develop further evidence of the unique value of occupational therapy in oncology care. Overall, having more opportunity with this population will allow for more opportunities to show what occupational therapy services can provide for patients in oncology care.

**Limitations**

There were several limitations of this study. The small sample size of therapists working in the Midwest limited the variability across the U.S. medical system. The participants worked in a variety of settings which impacted the ability to generalize the findings of the study. The number of patients treated for oncology per week varied significantly across participants. Finally, the sample of participants represented a variety of occupational therapy service settings in the Midwest, but did not include specialty services such as a cancer clinic.

**Recommendations**

Future research should be implemented on each step of the care continuum to gain further knowledge on specific barriers/challenges within the referral process for patients diagnosed with cancer. Additional research on occupational therapy interventions within oncology care would further support the current literature aiding in advocacy for OT services.

Modifications to the Oncology Occupational Performance Screening Tool (OOPST) (Funk & Lackie, 2017), will increase referrals to occupational therapy, decreasing the likelihood of patients with cancer falling through the cracks in the
continuum of care. Recommendations of participants include changing content within the tool, the format, scoring, and administration of the tool to increase the efficient use by healthcare team members. We would also recommend testing the reliability and validity of the OOPST tool once the recommended changes have been made to the instrument. There are multiple steps that can be taken to promote OT’s involvement within oncology care, and it’s up to the individual therapist to take that step forward to lead future conversations that promote positive changes for the patient’s we serve.

Summary

To conclude this opportunity in exploring the current experiences of occupational therapists working within oncology care, there are so many opportunities that lie ahead for years to come. The data transcribed from our interviews shows that incorporating OT into oncology care is a natural fit. The core essence of OT is to facilitate occupational engagement for all individuals struggling through a challenge within their lives. This includes patients and their families who are living with cancer and cancer survivors. Occupational therapists have to make use of their voices to advocate for the skills that can be brought to oncology care in order to truly advocate for the needs of patients diagnosed with cancer. Change will not happen if the therapists working in the field do not facilitate some change within themselves.
APPENDIX A
Oncology Occupational Performance Screening tool (OOPST)

Oncology Occupational Performance Screening Tool

Created by Courtney Funk, MOTS & Jessika Lackie, MOTS

Overview & Instructions

Purpose: The purpose of the Oncology Occupational Performance Screening Tool (OOPST) is to assist members of the oncology team to identify patients who would benefit from referral to occupational therapy services. This screening tool identifies common symptoms and functional deficits of those diagnosed with cancer and undergoing various types of cancer treatment that can be addressed by occupational therapy services.

Type: Questionnaire with both subjective and objective information

Population: Individuals diagnosed with cancer and in any stage of the treatment process

Materials: A copy of the OOPST, pen/pencil

Time: 10-15 minutes

Administration: The OOPST can be given to patients by receptionists, nurses, nurse practitioners, or medical doctors. The first category addresses physical, cognitive and emotional symptoms. Instruct the patient to circle a number that corresponds with the severity of the indicated symptoms; 1 meaning “does not disrupt me at all” and 5 meaning “is disruptive to my life, and I cannot manage it”. Invite the patient to use the space at the bottom of the page to further describe their symptoms or add others.

The second category addresses necessary and meaningful life tasks (occupations) that can be impacted by symptoms of cancer and cancer treatment. Instruct the patient to circle a number that corresponds with their ability to complete the activities (occupations) listed; 1 meaning “no difficulty/does not apply” and 5 meaning “extreme difficulty”. Again, invite the patient to use the space at the bottom of the page to further describe what tasks (occupations) they are having difficulty with or add others.

If the patient is unable to complete the assessment themselves, a caregiver or family member may assist or complete it for the patient.

Scoring: Nurses, nurse practitioners, and/or medical doctors can score the OOPST. Once the score has been calculated, conduct a brief interview with the patient and/or family member/caregiver regarding responses, areas of concern, etc. See the attached scoring sheet for further instructions on how to calculate scores and score interpretation.

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Oncology Occupational Performance Screening Tool

This quick screening tool was made to rate how or if side effects of cancer or treatment impact your ability to complete daily activities that are important to you. Based on your responses, you may receive referral to an occupational therapist that can address these specific needs and necessary and/or meaningful daily tasks.

Use the scale below to indicate how severe various symptoms are on an average day.

1 - indicates 'does not disrupt me at all'
3 - indicates 'is disruptive but I can manage it at times'
5 - indicates 'is disruptive to my life, and I cannot manage it'

<table>
<thead>
<tr>
<th>Symptom</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea/Vomiting</td>
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<td></td>
</tr>
<tr>
<td>Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty Finding Words</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxious</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling Sad</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low Confidence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weakness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty Remembering</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling Hopeless</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Numb/Tingling Fingers or Toes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Low Motivation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty Planning Ahead</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appetite Changes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Negative Feelings about Body</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty Multitasking</td>
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<td></td>
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<td></td>
</tr>
</tbody>
</table>

Are there other symptoms related to cancer and cancer treatment that significantly impact your life?


Copyright 2017 Funk & Luckie
Use the scale below to indicate how difficult it is to complete the listed activities on an average day.

1 - indicates ‘no difficulty/does not apply’
3 - indicates ‘moderate difficulty’
5 - indicates ‘extreme difficulty’

Driving ....................................... 1 2 3 4 5
Taking care of children/pets ............ 1 2 3 4 5
Housework ................................. 1 2 3 4 5
Meal Preparation .......................... 1 2 3 4 5
Shopping ...................................... 1 2 3 4 5
Work ............................................ 1 2 3 4 5
Sexual Activity ............................. 1 2 3 4 5
Sleeping ....................................... 1 2 3 4 5
Leisure or Hobbies .......................... 1 2 3 4 5
Socializing with Others ................... 1 2 3 4 5
Managing Finances ........................ 1 2 3 4 5
Education .................................... 1 2 3 4 5
Moving around your home ............... 1 2 3 4 5
Getting around your community ........ 1 2 3 4 5
Getting Dressed .......................... 1 2 3 4 5
Bathing/Showering .......................... 1 2 3 4 5
Getting on or off the Toilet .............. 1 2 3 4 5

Are there other activities in your life that are difficult right now? Such as, gardening, going to religious services, sewing, riding a motorcycle, etc.
Interpretation Sheet

Goal: Identify patients experiencing a decrease in function, independence, satisfaction, and/or quality of life due to the symptoms and functional deficits related to cancer and cancer treatment and connect the patient with occupational therapy services to address their needs.

Determining the Need for Referral: In the provided categories, scores can indicate the following referral suggestions.

<table>
<thead>
<tr>
<th>Score</th>
<th>Referral Not Required at This Time</th>
<th>Potential for Referral</th>
<th>Referral Recommended</th>
<th>Strongly Recommended</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-40</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>41-60</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>61-90</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>91+</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Clinical reasoning is required to judge the areas of patient indicated areas of difficulty as well as make further referral determinations if the patient would benefit from services but does not reach the above scoring thresholds.

Rescreen Timeframe: During active treatment, have the patient complete this form approximately once a month to monitor for decline in function, worsening symptoms, patient questions, and concerns. During breaks in treatment, have the patient complete this form once a month or every other month depending on treatment timeframe. During remission, have the patient complete this form annually.

If unsure about the need for referral, please contact:

Name: __________________________ Email: __________________________
Phone: __________________________
Fw: Consent for OOPST Screening Tool

Albrightson, Samantha
Fri 8/31/2018 3:17 PM
Sent items
To: Grabanski, Julie <julie.grabanski@und.edu>

Samantha and Jade,

You have my full consent from Courtney and I to use the OOPST and all of its components for your research study.

Thank you for your interest in our topic! If you need further consent or information, please let me know.

Sincerely,

Jessika Lackie, MOT, OTR/L

-------- Original message --------
From: "Albrightson, Samantha" <samantha.albrightson@und.edu>
Date: 8/23/18 9:31 PM (GMT-06:00)
To: j.lackie@aol.com
Cc: "Clement, Jade" <jade.clement@und.edu>
Subject: Consent for OOPST Screening Tool

Dear Jessika Lackie,

Through the University of North Dakota, Samantha Albrightson and Jade Clement would like to ask for your permission to utilize the Oncology Occupational Performance Screening Tool (OOPST) for their upcoming Independent Study Project. Our hope is to interview Occupational Therapists with experience in Oncology and understand their experiences with working on oncology patients and understand the referral process for OT services. In addition, the interviews will include questions on the OOPST tool in seeking their insight in ways to modify and adapt the tool for oncology patients.

Your tool and project has inspired our independent study and we would love to take this tool forward through our independent study.

-Samantha Albrightson and Jade Clement

https://outlook.office.com/owa?realm=ndus.edu&xrsurl=1&i=1033&m=06p=01path=mail+inbox

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### APPENDIX C
Demographic Chart

<table>
<thead>
<tr>
<th>Patient Week</th>
<th>Setting</th>
<th>Certifications</th>
<th>Degree</th>
<th>Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>6-7</td>
<td>Acute Care</td>
<td>Lymphedema</td>
<td>Bachelors</td>
<td>22 Years</td>
</tr>
<tr>
<td>2</td>
<td>Home care, hospice</td>
<td>Lymphedema</td>
<td>Masters</td>
<td>6 years</td>
</tr>
<tr>
<td>25 (during 34 month) Acute Care Outpatient Adult Physical Therapy, Neuro Developmental &amp; Treatment Assistant</td>
<td>Degree</td>
<td>13 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Home health, home health, ICU care, sometimes covers outpatient</td>
<td>Lymphedema</td>
<td>Masters</td>
<td>21 years</td>
</tr>
<tr>
<td>23</td>
<td>Acute, Outpatient Adult Home Health</td>
<td>Lymphedema</td>
<td>Masters</td>
<td>5½ years</td>
</tr>
<tr>
<td>Unspecified</td>
<td>Acute Care Outpatient Adult Home Health</td>
<td>Lymphedema</td>
<td>Masters</td>
<td>8 years</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Sex</th>
<th>Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Female</td>
<td>22 Years</td>
</tr>
<tr>
<td>P2</td>
<td>Female</td>
<td>6 years</td>
</tr>
<tr>
<td>P3</td>
<td>Female</td>
<td>13 years</td>
</tr>
<tr>
<td>P4</td>
<td>Female</td>
<td>21 years</td>
</tr>
<tr>
<td>P5</td>
<td>Male</td>
<td>5½ years</td>
</tr>
<tr>
<td>P6</td>
<td>Female</td>
<td>8 years</td>
</tr>
</tbody>
</table>
APPENDIX D

Invitation to Participate in Study

Hello ______________,

This is Samantha Albrigtson, OTS and Jade Clement, OTS from the University of North Dakota’s Occupational Therapy Department. We wanted to say thank-you for agreeing to participate in our study to aid in our qualitative research for our final Masters Independent Study.

The purpose of this study is to understand the experiences of occupational therapists working in oncology care, specifically the referral process for occupational therapy services. More research needs to be done to support occupational therapists role in the oncology field as evidenced by a gap in the literature. The researchers believe that occupational therapy’s role in oncology care is an essential part of a patient’s treatment plan, therefore, research to support this role would be beneficial.

Participation would include an interview via phone or video conferencing that would take approximately 1-2 hours. Topic questions within the interview will include the challenges and benefits of occupational therapists working in oncology care, tools used to increase referrals to OT services and overall communication with the interdisciplinary team, and recommendations for specific questions to address the needs of oncology patients in occupational therapy. Participants will be asked to provide recommendations for changes on the Oncology Occupational Performance Screening Tool (OOPST). The OOPST would be sent to you prior to the interview to ensure you have time to review the tool. The OOPST identifies what occupational deficits a cancer patient is experiencing through treatment and determines how beneficial occupational therapy services may be through their recovery process.

We look forward to interview you on Wednesday, at 3:30 on November 28th. We will send you a text message before the phone call once we have everything set up. If you have any questions please feel free to e-mail or call us with any concerns!

samantha.albrigtson@ndus.edu
jade.clement@ndus.edu

Sincerely
Samantha Albrigtson, OTS
Jade Clement, OTS
APPENDIX E
Semi-Structured Interview

Methodology
This qualitative study is guided by the phenomenological approach where semi-structured interviews will take place via phone or video conferencing. The interviews will be recorded, transcribed, and an open coding process will be used for data analysis.

Purpose of Study
The purpose of this study is to investigate the experiences of occupational therapists working in oncology care. Furthermore, the participants will be asked to provide feedback about the process of receiving referrals for oncology patients in occupational therapy, specifically feedback on the Oncology Occupational Performance Screening Tool (OOPST). This screening tool identifies what occupational deficits a cancer patient is experiencing through treatment and determines how beneficial occupational therapy services may be for their recovery process. The feedback from the occupational therapists will help researchers modify and enhance the screening tool to better serve cancer patients. The researchers predict that the OOPST, once implemented in practice, will increase the amount of occupational therapy referrals patients with cancer receive.

Semi-Structured Interview Draft
Thank you for participating in the interview today; please remember that you are not required to answer any question that you are uncomfortable with. The purpose of this project is to gather information about the benefits occupational therapy services may have for patients diagnosed with cancer. Furthermore, the researchers will be asking the participants for feedback about the OOPST. Do you have any questions before we begin?

Demographic/introduction questions:
1. How many years of experience do you have as an Occupational Therapist?
2. What degrees or certifications do you currently have?
3. What type of setting do you work in? What brought you to this area of OT?
4. On average, how many oncology patients do you see a week?
5. In practice, how are your goals different with oncology patients? How are they the same?
Oncology related questions:

1. Describe your experiences with working in oncology care.
2. Tell me about a rewarding experience when working with an oncology patient.
3. What changes have you seen as an OT working with cancer patients?
4. What changes are you most excited for with new research pointing towards advancing OT’s role within the cancer patients recovery/rehabilitation?
5. Research is stating that OT services are severely underused for cancer patients, what has been your experience with the referral process?
   - How is the referral process different at a regular hospital versus this cancer care clinic?
   - What changes would you like to see with the overall referral process for OT with this population?
   - What do you find most challenging with the referral process?
6. What screening tools have you seen to be beneficial in increasing referrals to occupational therapy.
7. How do you discuss your role as a practicing occupational therapist within oncology to other medical practitioners.
   a. Can you tell us something you did to educate others on the scope of occupational therapy services in oncology?
8. What can we do as OT’s to improve the referral process?

OOPST questions:

1. What are your initial thoughts about the OOPST assessment?
2. Looking at the break down of occupations within this assessment; what occupations were not within this tool that you find appropriate to address? Specific performance skills/patterns? Roles?
   a. What areas were addressed on the tool, that you find unnecessary?
3. What areas of improvement do you recommend the researchers make with this screening tool?
4. What did you find easy about the scoring? Difficult?
   a. What other ways have you seen assessments calculate a final score?
   b. How would you improve the scoring system?
Additional Optional Questions:

What are the 3 most commonly used interventions you use within your practice for oncology patients?

What challenges have you faced within this area of practice?

What are some of the biggest successes you’ve had for a patient?

How does the psychosocial aspect of therapy play a role in your treatment?

a. What do you tend to focus on the most?

b. What do you wish you had more time to focus on?

 c. What psychosocial aspects are you addressing?
APPENDIX F
IRB Approval

October 30, 2018

Principal Investigator: Samantha Albrigtsen and Jade Clement
Project Title: The Experiences of Occupational Therapists Working in Oncology Care and the Implications of the Referral
IRB Project Number: IRB-201809-048
Project Review Level: Expedited 7
Date of IRB Approval: 10/29/2018
Expiration Date of This Approval: 09/13/2019

The Protocol Charge Form and all included documentation for the above-referenced project have been reviewed and approved via the procedures of the University of North Dakota Institutional Review Board.

You have approval for this project through the above-listed expiration date. When this research is completed, please submit a termination form to the IRB. If the research will last longer than one year, an annual review and progress report must be submitted to the IRB prior to the submission deadline to ensure adequate time for IRB review.

The forms to assist you in filing your project termination, annual review and progress report, adverse event/unanticipated problem, protocol change, etc. may be accessed on the IRB website:
http://und.edu/research/resources/human-subjects/

Sincerely,

Michelle L. Bowles, M.P.A., CIP
IRB Manager
MLB/eb
Cc. Dr. Julie Grabanski
September 17, 2019

<table>
<thead>
<tr>
<th>Principal Investigator:</th>
<th>Samantha Albrigson and Jada Clement</th>
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<td>The Experiences of Occupational Therapists Working in Oncology Care and the Implications of the Referral</td>
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<td>IRB-201809-048</td>
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<td>Expedited</td>
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<td>Date of IRB Approval:</td>
<td>09/14/2018</td>
</tr>
<tr>
<td>Expiration Date of This Approval:</td>
<td>09/13/2019</td>
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</tbody>
</table>

The application form and all included documentation for the above-referenced project have been reviewed and approved via the procedures of the University of North Dakota Institutional Review Board.

The waiver of written consent has been approved under 45 CFR 46.117(c)(2) and participants will provide verbal consent using the attached consent form.

Prior to implementation, submit any changes to or departures from the protocol or consent form to the IRB for approval. No changes to approved research may take place without prior IRB approval.

You have approval for this project through the above-listed expiration date. When this research is completed, please submit a termination form to the IRB. If the research will last longer than one year, an annual review and progress report must be submitted to the IRB prior to the submission deadline to ensure adequate time for IRB review.

The forms to assist you in filing your project termination, annual review and progress report, adverse event/anticipated problem, protocol changes, etc. may be accessed on the IRB website: http://research.und.edu/research/resources/human-subjects/

Sincerely,

Michelle L. Bowley, M.P.A., CIP
IRB Manager
MLB/05

Cc. Dr. Julie Grabanski

The University of North Dakota is an equal opportunity / affirmative action institution.
APPENDIX G
Participant Consent Form
THE UNIVERSITY OF NORTH DAKOTA

CONSENT TO PARTICIPATE IN RESEARCH

TITLE: The Experiences of Occupational Therapists working in Oncology Care and the Implications of the Referral Process

PROJECT DIRECTOR: Julie Grabanski, PhD, OTR/L

PHONE # 701-777-1740

DEPARTMENT: Occupational Therapy

STATEMENT OF RESEARCH

A person who is to participate in the research must give his or her informed consent to such participation. This consent must be based on an understanding of the nature and risks of the research. This document provides information that is important for this understanding. Research projects include only subjects who choose to take part. Please take your time in making your decision as to whether to participate. If you have questions at any time, please ask.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to understand the experiences of occupational therapists working in oncology care, specifically the referral process for occupational therapy services. More research needs to be done to support occupational therapists role in the oncology field as evidenced by a gap in the literature. Topic questions within the interview will include the challenges and benefits of occupational therapists working in oncology care, tools used to increase referrals to OT services and overall communication with the interdisciplinary team, and recommendations for specific questions to address the needs of oncology patients in occupational therapy. Participants will be asked to provide recommendations for changes on the Oncology Occupational Performance Screening Tool (OOPST). Consent has been obtained from previous authors to review and revise the tool.
The OOPST identifies what occupational deficits a cancer patient may be experiencing during phases of recovery while receiving cancer treatment. The OOPST was designed to assist with increasing referrals to occupational therapy services. The researchers believe that occupational therapy’s role in oncology care is an essential part of a patient's treatment plan, therefore, research to support this role would be beneficial.

**HOW MANY PEOPLE WILL PARTICIPATE?**
Approximately six people will take part in this study for the University of North Dakota.

**HOW LONG WILL I BE IN THIS STUDY?**
Your participation in an interview will take approximately 1-2 hours.

**WHAT WILL HAPPEN DURING THIS STUDY?**
Interviews will be conducted by the researchers, via video or phone conferencing, using semi-structured interview techniques. Each interview will take approximately 1-2 hours of participants time to complete. The interviews will be recorded and transcribed. Researchers will then analyze the information obtained through the interviews and use triangulation to ensure validity within the study. Themes and main points will be pulled from each interview to identify the common trends. Participants can expect the total research process to take approximately 4 months but the participants would only be responsible for participating for their interview time.

**WHAT ARE THE RISKS OF THE STUDY?**
There is minimal risk for participating in this study. The potential risks may include emotional responses or distress when reflecting on their experiences.

**WHAT ARE THE BENEFITS OF THIS STUDY?**
You will not benefit personally from being in this study. However, we hope that, in the future, other people might benefit from this study because your feedback will allow support the role occupational therapy has in oncology care.
WILL IT COST ME ANYTHING TO BE IN THIS STUDY?
You will not have any costs for being in this research study.

WILL I BE PAID FOR PARTICIPATING?
You will not be paid for being in this research study.

WHO IS FUNDING THE STUDY
No funding required. Time is being volunteered from both participants and researchers.

CONFIDENTIALITY
The records of this study will be kept private to the extent permitted by law. In any report about this study that might be published, you will not be identified. Your study record may be reviewed by Government agencies and the University of North Dakota Institutional Review Board.

Any information that is obtained in this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. You should know, however, that there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court or to tell authorities if we believe you have abused a child, or you pose a danger to yourself or someone else. Confidentiality will be maintained by means of number coding participants by removing names or other personal information that may lead to identification. The information will be kept in a secured database and only the main researchers will have access to the information. If we write a report or article about this study, we will describe the study results in a summarized manner so that you cannot be identified.

IS THIS STUDY VOLUNTARY?
Your participation is voluntary. You may choose not to participate or you may discontinue your participation at any time without penalty or loss of benefits to which
you are otherwise entitled. Your decision whether or not to participate will not affect your current or future relations with the University of North Dakota.

CONTACTS AND QUESTIONS?
The researchers conducting this study are Jade Clement, OTS and Samantha Albrigtson, OTS. You may ask any questions you have now. If you later have questions, concerns, or complaints about the research please contact Jade Clement, OTS at (608)-963-0064 and/or Samantha Albrigtson, OTS at (715)-531-7990. The researchers are students and their advisor, Julie Grabanski, PhD, OTR/L can be contacted at (701)-777-1740 during normal business hours.

If you have questions regarding your rights as a research subject, you may contact The University of North Dakota Institutional Review Board at (701) 777-4279 or UND.irb@research.UND.edu.

- You may also call this number about any problems, complaints, or concerns you have about this research study.
- You may also call this number if you cannot reach research staff, or you wish to talk with someone who is independent of the research team.
- General information about being a research subject can be found by clicking “Information for Research Participants” on the web site: http://und.edu/research/resources/human-subjects/research-participants.cfm

Verbal consent will be obtained at the beginning of the interview.

I give consent for my quotes to be used in the research; however I will not be identified.

Please initial: _____ Yes _____ No
______________________________ ________________________

Subject Name Date
## APPENDIX H
Data Analysis Grid

<table>
<thead>
<tr>
<th>Participant X (PX)</th>
<th>I= Interviewer</th>
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<tbody>
<tr>
<td><strong>Meaning Unit</strong></td>
<td><strong>Transformation (to language of researcher)</strong></td>
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## APPENDIX I

### Sample Data Analysis Grid

<table>
<thead>
<tr>
<th>Participant X (PX)</th>
<th>I= Interviewer</th>
<th>Transformation (to language of researcher)</th>
<th>Synthesis, if appropriate</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>8.P2:</strong> I know that in our home care office, we do have someone that goes to the meetings that are going on in the hospitals, like in inpatient rehab and things. And they're really being an advocate for home care. So, if they overhear something that OT can do, they would speak up and say, &quot;Hey, I think they would benefit from an OT referral.&quot; So, maybe even if OTs could go to those meetings and help give their two cents, as well, because people just don't realize that there is home care. And that there's so many different things that we can do.</td>
<td>8. Having someone to represent OT at meetings, is a great way to advocate for referrals to home care services.</td>
<td><strong>8 +9:</strong> Advocate through education. Having someone to represent OT at meetings, is a great way to advocate for referrals to home care services. Educating the patients about OT can do may also increase referrals. An example of this is having brochures of what OT can work on at the Cancer Center.</td>
<td></td>
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<tr>
<td><strong>9. P2:</strong> Maybe if the Cancer Center had information about OT, maybe the patients themselves can know about what OT is and what they can do. Yeah, if there was just information everywhere.</td>
<td>9. Educating the patients about OT can do may also increase referrals. An example of this is having brochures of what OT can work on at the Cancer Center.</td>
<td><strong>7 + 8.3 + 8.4:</strong> Advocating what OT can do for oncology care patients. It is important to advocate for the benefits of OT for oncology patients. Go to events, lunch meet and greets, develop an in-service, and try and get your face out there so that doctors/health professionals know what you're about and what you want to do. Showing other disciplines what OT can offer patients with cancer, will increase their understanding of</td>
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<tr>
<td><strong>7. P4:</strong> Yes. Well, we try and do in services but that is really hard to do because it's been very easy for me to get into the residency program but I've been trying to get into the [inaudible 00:15:35] and doctors, that aren't residents, and I can't get anybody to agree and let me come talk. Yeah. I just can't get in. That's part of the problem too is how do you advertise what you can offer if you can't even get in front of these people?</td>
<td>7. Developing an in-service is a way to advocate for OT services in oncology care but there are barriers including, not having enough interest from the doctors.</td>
<td></td>
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<tr>
<td><strong>8. P4:</strong> You need to get your face out there. Try and get to events, lunch meet and greets, or whatever. You try and get your face out there so that they know what you're about and what you want to do. So, I called and said, &quot;Could I ever come with you on a visit? Just to see what you guys are doing.&quot; &quot;Sure. No problem.&quot; As soon as I did that and I met the nurse, now she's calling me all the time and she's sending referrals to me all the time. It's great. But until we had that meet, I wasn't getting</td>
<td>8.3 Go to events, lunch meet and greets, and try and get your face out there so that doctors know what you're about and what you want to do. 8.4 Showing other disciplines what OT can offer patients with cancer, will increase their understanding of</td>
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</table>

75
any. I wanted her to understand the value of what we could offer in OT. Yeah. And now she's super excited and she promotes OT to everybody. She's like, "Oh." And the resident that was with, he's like, "Oh, we need to have the OT go out.”

<table>
<thead>
<tr>
<th>OT, therefore increasing referrals.</th>
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**APPENDIX J**  
**OOPST Recommendation Chart**  
**Oncology Occupational Performance Screening Tool (OOPST)**  
**Recommendations**

<table>
<thead>
<tr>
<th>Content</th>
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<tr>
<td><strong>Timeline for report of symptoms:</strong> Due to chemotherapy side effects, the questionnaire should ask &quot;When do you feel the worst? And how long does it take you to recover and get back to your baseline?&quot; instead of &quot;On average, how many days in a week?&quot; or, &quot;How do you feel?&quot; This will allow you to get a glimpse of what a hard day may be for the patient, and talk about prevention. In addition, adding questions such as: &quot;When was your last chemo? How do you feel after chemo? How many days does it take you to feel better?&quot; This may make it more complicated, but they are common questions the OT will be asking once the patient is referred. If a patient is having chemo treatment, the patient may have a hard time rating how they are feeling on particular days. But if you worded the questions, &quot;On a chemo week, versus a non-chemo week.&quot;</td>
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<tr>
<td><strong>Physiological effects:</strong> It was suggested that pain and weakness should be combined to one score and have an additional score for numbness or tingling in fingers or toes.</td>
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<tr>
<td><strong>Role changes:</strong> Addressing relationships (such as significant others) and role changes should be added in the OOPST.</td>
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<tr>
<td><strong>Keeping it in our scope/having an interdisciplinary approach:</strong> Is nausea and vomiting really within the scope of OT? Is anxiety and depression in our scope or would it be more appropriate for them to be referred to a psychologist or psychiatrist? The OOPST is great from an OT perspective and standpoint, however, what about an interdisciplinary approach? If each profession had their own unique screening tool, the patients would be filling out 600 questions every visit. Condensing all these questions into one screening tool would be the end goal.</td>
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<th>Format</th>
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<tr>
<td><strong>Create a more user friendly format:</strong> The one main recommendation for the OOPST tool would be to shift the format into vertical versus horizontal columns to make the process flow more readily with completing the assessment and scoring the information. It was also recommended that the number values be spread down along the columns so patients wouldn’t have to waste time flipping papers back and forth.</td>
</tr>
<tr>
<td><strong>Different forms:</strong> A barrier with the OOPST, is that because it is a paper form, the less likely that the survey will be put in the patient’s electronic chart for the physician to see. In the future, this tool could be developed onto an iPad form and their answers would go straight to their chart.</td>
</tr>
<tr>
<td><strong>Rearrange order of content:</strong> Changing the order from easy to difficult tasks will make it easier for patients to fill out. Example of suggestion includes: getting dressed, bathing, showering, getting on/off the toilet.</td>
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</table>
Scoring

**Change the scoring:** The OOPST would benefit from using a 3 point Likert scale. Patients usually struggle with self-reports, so decreasing the options will hopefully decrease hesitation. Using extremely difficult, moderate difficulty, or no difficulty could be the rating scale.

**Exceptions:** It was suggested that having any score of 5 should warrant further assessment by OT. Some patients may be doing well in many occupations but struggle significantly in a certain few. Therefore, the scoring may not indicate the necessity of an OT evaluation. This could potentially prevent some individuals from obtaining a needed referral.

**Calculating scores:** With collecting the data, each point should be numbered 1-20 to make tallying easier for scores to be computed and simplifying the process within the clinic.

**Referring score:** For the grading system, including a zero mark to make it clear that a referral is not warranted. Anything scored at the middle mark and above should warrant a referral. These changes will help make decisions easy and ensures that unnecessary time isn’t spent weighing on a decision to refer or not to OT.

Administration

**Implementation:** Having something be implemented into the normal routine of a doctor’s appointment aids in the flow of services and provides the medical staff with vital information related to the patients daily routines and struggles with them.

**Ease of administration:** Physicians may not take the time to score the OOPST results but would use the scores to glance at and have points of conversation about with the client to make the necessary adjustments to treatment and due to this the tool must be easy to read and interpret by both the patient and the physician.

**Administer prior to seeing the physician:** It would be ideal to have a tool that is really fast and quick, and can be done before the physician comes in. It might be beneficial for a nurse or other health profession to go through the screening tool prior to the patient seeing the physician, so that the physician only has to look at the bottom line. If the OOPST was scored and then handed to the physicians with a “Referral strongly recommended,” it would not take very long for a physician to decide if he or she wants to refer that patient.
APPENDIX K
Interview Follow Up Email

Hello_____,

Thank you again for participating in our research study. We have attached a summary of your interview to give you an opportunity to read it over. The summary captures the main points of the interview. If there is nothing that you would want changed please send a confirmation e-mail saying so. If there are any main points missing, or if there is anything that you feel does not come across the way in which you intended, please also let us know.

We truly appreciate you taking the time out of your busy schedule to share your experiences within OT and oncology care.

Sincerely,

Jade Clement, OTS
Samantha Albrigtson, OTS
References


