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## The Occupational Therapy Process in Pediatric Oncology

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The Occupational Therapy Process in Pediatric Oncology

By

Olivia Lee

This thesis is submitted in partial fulfillment of the requirements for the  
Elizabethtown College Honors Program

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**Abstract**

An average of 15,000 individuals under the age of 20 are diagnosed with cancer in the United States each year (Siegel, Miller, & Jemal, 2018). The need for occupational therapy services to optimize quality of life persists in current practices (Baxter, Newman, Longpré, & Polo, 2017). Such practitioners may intervene to help remediate, compensate, or adapt pediatric patients' abilities to assist them achieve maximum levels of independence. Children progressively learn to become more independent as they grow older in order to function in self-care tasks, educational responsibilities, and other meaningful occupations; those with a cancer diagnosis may experience physical, social, and cognitive symptoms that could hinder such performances.

Studies have found an underutilization of occupational therapy services within cancer-related care (Baxter et al., 2017). This study sought to understand the occupational therapy process utilized in pediatric oncology. Results indicated a scarcity of occupational therapists and necessary standardized assessments provided in inpatient acute care hospitals. More resources can be found within the outpatient therapy setting for children seeking services after or in between treatment, however, challenges to obtaining this type of care prevail for families due to numerous stressors. Benefits of the study include increasing awareness of pediatric oncology and the role of occupational therapy in the highly specialized area of care.

## **Review of Literature**

Individuals identify themselves with the occupations and activities they perceive as most meaningful, and then revolve their lives around those specific interests (American Occupational Therapy Association [AOTA], 2019a). However, certain challenges may develop throughout the lifespan, hindering people from participating in these activities to any extent. Such obstacles may include accidents, diseases, congenital disorders, injuries, sensory disorders, and other health issues. Occupational therapists aim to help those who face this hindrance to their quality of life and help them do the things they want to do and need to do through the therapeutic use of daily activities (AOTA, 2019a).

Occupations are considered to be the center of a client's identity, having particular meaning and value to that person (AOTA, 2014). Occupational therapy services can extend to any age range and exist in a variety of settings: schools, inpatient hospitals, outpatient centers, workplaces, etc. The occupational therapy process is useful to clients of all ages and in many different contexts. A variety of factors could be responsible for interfering with a person's daily performance. For example, cancer remains to be a prevalent life-threatening disease to anyone across the lifespan (Armstrong et al., 2014). The various side effects of the disease are unique for each person and can be a result of the disease itself or from treatment.

There appears to be a scarcity of occupational therapy services in cancer-related care (Baxter et al., 2017). In regard to adolescents with cancer, the need for occupational therapy services is associated with poorer functioning in health-related quality of life (Smith et al., 2013). The focus of this study is to therefore direct an analysis solely on pediatric oncology, and the occupational therapy process behind it. "A childhood cancer diagnosis means living with disruptions to daily roles and routines," (Mohammadi, Mehraban, & Damavandi, 2017).

Children have important occupations as well and need the skills necessary to participate in them and to develop into independent adults.

### **The Occupational Therapy Process**

People enduring health conditions are at risk of facing barriers and limitations on their physical, mental, and social wellbeing. Occupational therapy focuses on rehabilitating individuals back to meaningful or necessary occupations through the therapeutic use of daily activities (AOTA, 2019a). Occupational therapy practitioners can thus provide interventions to encourage community participation, help restore abilities and skills, prevent problems affecting activity involvement, and promote the health of those in need (Schell, Gillen, & Scaffa, 2014).

The *Occupational Therapy Practice Framework: Domain and Process*, 3rd edition (OTPF-III), guides practitioners through the general principles of the profession and the central concepts that support clinical reasoning (AOTA, 2014). Best clinical decision making is accomplished when an occupational therapist considers client values and circumstances, the treatment environment, and current best evidence (Taylor, 2017). Merging these aspects together establishes evidence-based practice (EBP), an important method to support the decision-making of the profession and to ensure clients are receiving the best possible treatment (Tomlin & Borgetto, 2011). Utilizing EBP has increasingly become a priority in health care professions for the interest of the client (Lin, Murphy, & Robinson, 2010).

Incorporating appropriate intervention methods within practice settings allows for clients to receive relevant care that has been supported by recent research. In order to understand the needs and desires of a client, the occupational therapist gathers prevalent information to build an occupational profile of the client's occupation history and experiences, patterns of daily living, interests, values, and needs (AOTA, 2014). This data can be collected throughout the evaluation

process, which is comprehensive in obtaining and interpreting the data necessary to understand the client and the situation (Asher, 2014).

Occupational therapists are expected to incorporate clients and their family members into the sessions by involving them in establishing goals, creating a plan of care, and determining how to measure progress (AOTA, 2018). Developing an intervention plan should be occupation-based and include the measurable goals within the given time frame. Theories, models of practice, and frames of reference provide a lens for occupational therapists to utilize assessments and to choose intervention methods and approaches to once again ensure evidence-based practice (Schell et al., 2014).

The use of models of practice can support the development of long-term, sustainable improvements from occupational therapy services (Sirikka, Zingmark, & Larsson-Lund, 2014). When interventions have been determined and carried out, the occupational therapist should continuously monitor the client's response through standardized outcome measures and assessments to ensure the client is making progress and improving. Outcome measures relate to performance during interventions and client impressions regarding goal attainment (AOTA, 2014).

Based on outcomes, interventions can be modified to accommodate to the changing needs of the client, and act as overall proof that occupational therapy was successful for the client. If outcome measures exhibit a client has reached all goals and is satisfied with the progress, the occupational therapist is required to complete a discharge summary, or a report outlining the occupational therapy journey of the client from the beginning to the end. Within a discharge summary, client information, a summary of interventions, and further recommendations or a reason for discontinuation are included.

## **Pediatrics**

The study of child development concentrates on the chronological appearance of physical qualities, psychological traits, behaviors, and capabilities of adapting to the demands of life as they emerge over time (Rathus, 2014). As children age, they progress through different stages and gain these particular traits and skills. Infants focus on exploring their environment to learn about their surroundings; eventually their actions that originally occurred by chance become purposeful and children become able to participate in meaningful occupations (Kuhaneck, Spitzauer, & Miller, 2010).

Children engage in daily occupations as adults do, though their occupations typically fall under play, education, and socialization (AOTA, 2019b). Children across the globe and of all ages participate in play, no matter their socioeconomic status or available resources (Kuhaneck et al., 2010). Not only is play utilized for the purpose of fun, but it is also necessary for the development of gross and fine motor control, social skills, awareness of the environment, cognition skills, and more (Nijhof et al., 2018). Occupational therapy therefore views play as an important occupation in childhood development (Kuhaneck et al., 2010).

Many types of play exist, including sensorimotor, exploratory, constructive, symbolic, and social (Pendleton & Schultz-Krohn, 2013). Each category calls for different behaviors and demands, and presents specific roles in the skill development of a learning child. Certain types of play in which children and adolescents are able to participate allow them to develop motor skills that ultimately enable them to engage in important occupations.

Physical play progresses from understanding the effects movements have on the environment to obtaining foundational motor skills seen in free play at school recess (Yogman, Garner, Hutchinson, Hirsch-Pasek, & Golinkoff, 2018). As children gain control of their

movements, they can gain the strength and confidence to engage in more complex activities (Frost, 2017). Individual and contextual factors are responsible for the acquisition of gross motor coordination in children, which is important to consider as these skills are of great relevance to their long-term health, habits, and behaviors (Chaves et al., 2015).

Fine motor skills encompass those of manual dexterity and the use of smaller muscles for the purpose of movement. With improvements in fine motor coordination, the child can advance to more demanding tasks that may involve more intricate manipulation and form a solid foundation of the finer skills needed for future everyday tasks (Moyses, 2016). Gaining control over the wrists and fingers allows a child to execute certain school or self-care tasks such as holding a pencil, dressing, and eating (Rathus, 2014).

In addition to motor skills, cognitive processes are involved with motor activity, including motor coordination, executive function, and visuospatial skills (Cameron, Cottone, Murrah, & Grissmer, 2016). Coordinating body movements is necessary when achieving goal-related actions, whether it be between individual muscles or between joints and limbs (Diedrichsen, Shadmehr, & Ivry, 2010). Therefore, high levels of physical activity in school-aged children can be beneficial to not only the physical, social, and emotional development, but the cognitive as well (Zeng et al., 2017).

Cognitive development in children refers to the way in which they learn, solve problems, and acquire knowledge about their environment and how to interact with it. Certain cognitive skills can be seen through a variety of childhood occupations such as symbolic play, which exhibits their ability to project an idea onto an object (Scott & Cogburn, 2019). Participating in pretend play, which can be done with others or alone, also allows children to engage in pretense and therefore rich, collaborative dialogue. Opportunities for a child to partake in such play

classifies as an environmental experience and allows for him or her to gain cognitive and social benefits (Paes & Ellefson, 2018).

Proficiency in areas of motor, cognitive, and social competencies and the coordination of the skill sets are necessary for self-care and school performance, two other occupations children engage in (Cameron et al., 2012). The ability to manipulate the hands, wrist, and fingers allows for the completion of youth daily activities. Independent self-care is a crucial aspect to childhood development and successful participation in life (Chen et al., 2018). Children can learn to tie their own shoes, dress themselves, bathe themselves, and feed themselves, all of which can enhance their self-esteem and coping skills necessary for adulthood.

Proper school education allows for a learning process that is instrumental in shaping one's personality and behavior also seen in adulthood (Bissoli, 2014). Children are able to learn basic skills such as reading and writing, and gain knowledge on different subjects of history, biology, arts, literature, mathematics, and more. Through this they can develop interests that can shape into future occupations. The education system throughout the grade levels encompass the several aspects of childhood development: social, physical, and mental (National Research Council, 2015).

Peer play is a primary context for acquiring social and linguistic competencies, preparing children for school and success (Kenney, 2012). Schools provide physical education programs that enable students to develop fundamental gross motor skills, which in turn advance into more complex and sophisticated skills involved in daily movement activities as well as improvements in self-confidence and social bonding (Burns, Fu, Hannon, & Brusseau, 2017; Pantzer, Dorwart, & Woodson-Smith, 2018). School lectures and additional work assignments enhance the mental skills needed for attention, memory, logic and reasoning, auditory and visual processing, and

much more. Cognitive enrichment in the early stages of childhood development may account for the cognitive ability seen in adulthood (Parisi et al., 2012). Fine motor skills are more associated with academic achievement, such as writing and completing projects. All of these skills are profitable in the independence and daily functioning of a developing child.

Throughout child development, play becomes a creative outlet that integrates reality with imagination, which altogether is fun and absorbing. As this happens, the therapeutic relationship in play deepens (Kool & Lawver, 2010). Being able to accomplish play, education, and self-care tasks is an integral element to the independent functioning of a child. Reduced participation in such activities could lead to health complications (e.g. obesity, high blood pressure, etc.) as well as secondary psychosocial issues, including low self-esteem, depression, and victimization (Kennedy-Behr, Rodger, & Mickan, 2011).

Play can have a plethora of benefits on the development of a child. By exploring the types of play, children are developing physical, social, emotional, and cognitive skills through the engagement of fun occupations, which in turn allows them to engage in other occupations of self-care and education. Within occupational therapy, play can be focused on as a goal for a child to return to after an injury or other hindrance and can also be used as an intervention tactic for children to engage in when reaching other goals such as the ability to self-care. Utilizing play in occupational therapy services allows for a specific category of skill development that addresses children's abilities to be actively involved with their environment (Case-Smith, 1998).

## **Children with Cancer**

An average of 15,000 individuals under the age of 20 years are diagnosed with cancer each year in the United States (Siegel et al., 2018). Due to major advancements in cancer treatment, the 5-year survival rate in childhood cancers is now at over 80%, indicating an increase from the 58% 5-year survival rate seen in the mid-1970s (American Cancer Society, 2018). Despite this progress, cancer remains to be the second leading cause of death in children ages 1 to 14, after accidents (cancer.net, 2019). Those who survive continue to be at risk of recurrence or debilitating side effects that could lead to further functional impairments (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). Continued research and focus on health-related quality of life are thus prevalent in pediatric oncology (Racine, Khu, Reynolds, Guilcher, & Schulte, 2018).

Common cancers in children include leukemia, brain and central nervous system tumors, and lymphomas (National Cancer Institute, 2018). The most commonly seen of the forms are acute lymphocytic leukemia (ALL) and acute myelogenous leukemia (AML), which are cancers that occur when bone marrow produces immature white blood cells (American Cancer Society, 2018). As a result, patients may experience bone and joint pain, fatigue, and weakness, which can ultimately affect the way children go about their lives. Studies have shown cancer-related fatigue to be a significant factor in over 60% of patients receiving cancer treatment (Hofman, Ryan, Figueroa-Moseley, Jean-Pierre, & Morrow, 2007). Brain tumors may produce similar symptoms pertaining to fatigue and motor skills, as well as neurologic deficits (Amidei & Kushner, 2015).

Survival rates are increasing for children with cancer, placing a new focus on survivorship and the need for care for those dealing with the aftermath of the disease and

treatment (Stout et al., 2016). Children who survive ALL have a significantly elevated risk for secondary malignancies, typically cardiac issues (Ness, Armenian, Kadan-Lottick, & Gurney, 2011). Survivors of leukemia present gross and fine motor problems, and survivors of childhood cancers overall have reported experiencing mental health symptoms, failure to meet expected social milestones, reduced educational achievement, difficulties in vocational attainment, and engagement in maladaptive health behaviors (Brinkman, Recklitis, Michel, Grootenhuis, & Klosky, 2018; Taverna et al., 2017). Children who experience the trauma of cancer and even the aftermath of surviving the disease need care and attention to deal with the numerous symptoms and side effects.

Treatment of pediatric cancers includes surgery to remove the tumor if possible, radiation to decrease tumor size, and chemotherapy to treat the primary tumor and potential secondary, damaged sites (MacDonald, 2010). Chemotherapy implements strong drugs orally or through infusions or injections for the intention of killing cancer cells. Due to the strength of these drugs, they may damage healthy cells as well, which influences negative side effects.

Because cancer can cause various symptoms unique to each person, some cases may be more difficult to cure than others and therefore require more intensive treatment (Israels, Challinor, Howard, & Arora, 2015). The downside to more intensive treatment is that the patient is more susceptible to short- and long-term side effects, such as associated adverse drug reactions (ADRs), peripheral neuropathy, etc. (American Cancer Society, 2016). Treatment of ALL, while effective, can be toxic as well as it has the potential to damage and interfere with the function of secondary organ systems, such as the heart (Ness et al., 2011).

Children are at a greater risk of these symptoms due to their smaller body sizes (Parande, Anand, Khaparde, & Pawar, 2018). Commonly seen ADRs include hair loss, fatigue, infection,

anemia, nerve and muscle pain, and kidney problems. Children undergoing treatment typically report reduced physical fitness, and psychosocial symptoms of depression and anxiety (Braam et al., 2018). Chemotherapeutic drugs can disrupt motor pathway development; 18% to 66% of children treated with such medications have been reported with fine and/or gross motor difficulties (De Luca et al., 2013). *Chemobrain*, the cognitive impairment associated with chemotherapy, is known to affect attention, concentration, and memory (Blanco-Suarez, 2019). All symptoms must be carefully monitored and treated to ensure the chemotherapy is developing beneficial results and not creating more issues.

Cancer and treatment methods can be debilitating on an individual's cognition along with physical and sensory functioning. Cognitive dysfunction is most commonly seen in survivors of brain tumors and ALL, which altogether affect at least one third of childhood cancer survivors in the U.S. (Castellino, Ullrich, Whelen, & Lange, 2014). These children are at risk of impairment in certain cognitive domains such as processing speed, attention, working memory, and executive function (Hutchinson, Pfeiffer, & Wilson, 2017). Cognitive dysfunction in children can also result from being treated with neck irradiation, hematopoietic stem cell transplantation, and repetitive neurotoxic chemotherapy (Castellino et al., 2014).

Considering the numerous ADRs, healthcare professionals and caregivers must be aware of chemotherapy drug interactions due to potential negative and dangerous reactions. Patients with cancer who are being treated with chemotherapy may also be prescribed to take over-the-counter medicines, vitamins, and supplements. Doctors and other healthcare providers must therefore be aware of how other medications may interact with chemo drugs, whether or not they will create negative side effects or worsen how chemotherapy will work for the patient. Stress is

yet another consequence of the life-threatening disease and should be dealt with immediately and carefully by the healthcare team (Rodriguez et al., 2011).

Activities of daily living (ADLs), or tasks of everyday life, are pertinent for the independence of an individual for completing self-care. Such tasks include dressing, eating, and bathing. Children who have survived cancer and its treatment may struggle to perform such tasks. Although children are able to rely on parents and other caregivers to help them with certain self-care tasks, children are progressively learning to become more independent as they get older (Rathus, 2014). Children appeared to be more stressed about their ability to be independent in their daily functioning, while both mothers and fathers found caregiving to be their highest stressors (Rodriguez, et al., 2011). Survivors of pediatric sarcoma in one study resulted in lower ADL functioning than those of an age-matched comparison group (Parks, Rasch, Mansky, & Oakley, 2009).

Students receiving cancer treatment also experience significant challenges with maintaining their education (Donnan et al., 2015). Frequent and continuous hospitalizations result in children missing school. School absenteeism has not only led to difficulties keeping up with schoolwork, but psychosocial issues as well; when children missed critical social time with their peers, their sense of isolation increased (Tsimicalis, Genest, Stevens, Ungar, & Barr, 2018). Overall, prolonged periods of missed school can have a dramatic impact on the physical, cognitive, and social development (Donnan et al., 2015).

The quality of care in pediatric oncology is crucial for the wellbeing of each affected child. Despite great gains in the knowledge of cancer and treatment, gaps in this specific healthcare field remain (Fawcett, 2019). A need to improve the general health of cancer survivors and to increase efforts of improving their physical, psychological, and social

functioning prevails, given the increase in childhood cancer survival rates (Baxter et al., 2017). Accurate and timely diagnosis impact the treatment process and survival rate of cancer patients; if found early, the cancer can be treated, and children can be cared for properly (Sung, 2015).

A variety of impairments can be seen throughout the entire cancer treatment process, even following treatment when the disease has been cured. Changes in physical, sensory, and cognitive functioning lead to a decline in the participation of self-care, social engagement, and school performance (Baxter et al., 2017). These challenges can be long-lasting and debilitating as a result of either cancer or cancer treatment, which can be treated with occupational therapy.

### **Occupational Therapy in Pediatric Oncology**

The need for occupational therapy services to optimize quality of life in patients with cancer persists in current practices (Baxter et al., 2017). The dramatic increase in young adult survivors of childhood cancer has also induced high possibilities of serious health implications, some of which may ultimately disrupt daily functioning (Berg & Hayashi, 2013). The number of existing symptoms and side effects from the disease itself or the treatment of the disease is immense and unique to each and every patient. Not only can occupational therapists assist with the debilitating issues cancer patients go through during treatment, but they can also help those who have completed treatment and are experiencing any later effects or delayed difficulties due to the disease.

According to Longpré and Newman (2011), occupational therapy intervention methods can help remediate, compensate, or adapt patients' abilities to assist them in achieving maximum levels of independence and bettering quality of life. Particular techniques include teaching patients the use of adaptive equipment and assistive technology, suggesting lifestyle management

in means of preventative health and improved fitness, and explaining cognitive strategies to address memory, executive functioning, etc. (AOTA, 2011). Such therapeutic methods may be implemented at any point in the cancer care process.

The ability to complete and engage in activities of daily living during childhood is necessary for the health of all children (Rodger & Ziviani, 2006). Involvement in purposeful activities and life situations allow a child to gain confidence, develop skills, and create a sense of competence (Mehraban, Hasani, & Amini, 2016). However, participation patterns in daily life activities of children with cancer in daily life activities appear to be significantly lower than those of healthy children in criteria involving diversity of activities, intensity of participation, with whom they participate, and enjoyment of daily activities (Mohammadi et al., 2017).

Due to both the need for patients of childhood cancer to achieve independence skills and the role of occupational therapy, practitioners can assist this particular population with regaining function. Children undergoing cancer treatment, specifically for leukemia, can experience symptoms of fatigue, sleep disturbances, pain, nausea, depression, and cognitive impairments (Park & Rosenstein, 2015). Surgical procedures and radiation treatments have opportunity to limit independence by causing the loss of joint range of motion (Bower, 2014). Occupational therapists are educated to design necessary orthoses, understand ergonomic principles, and provide manual and compression therapy that could all assist with improving range of motion (AOTA, 2014). Implications for occupational therapy practice suggest that management of symptoms during treatment may also be an additional strategy for protecting cognitive function (Hooke et al., 2018).

Children who survive cancer remain at risk for developing later effects of the disease, and long-term survivorship has its own distinct challenges (Buckland & Mackenzie, 2017). Fatigue

in particular is one of the most intrusive late effects to participation in daily activities for young adult survivors of childhood cancer, as reported by Berg & Hayashi (2012). Cancer-related fatigue is multi-dimensional in its capacity to affect an individual physically, mentally, and emotionally, and is significant in intensity which causes greater impairment in quality of life (Bower, 2014). Occupational therapists can thus address corresponding issues through exercise training in order to reduce fatigue and improve cardiopulmonary measures and physical function (Silver & Gilchrist, 2015).

Research shows that exercise has been used as a common strategy for this particular population of survivors in countering fatigue and sleep disturbances (Berg & Hayashi, 2012). In addition to exercise, occupational therapists often implement behavioral or environmental changes that can facilitate effective sleep habits and routines (AOTA, 2017). Occupational therapists have various opportunities to help individuals throughout the cancer process given the symptoms that inhibit cancer patients from functioning to their fullest potential.

While there is a scarcity of occupational therapy services within pediatric oncology, occupational therapy practitioners and researchers can immerse themselves in the field to extend the profession's role (Baxter et al., 2017; Buckland & Mackenzie, 2017). Practitioners treating children with cancer can help in advocating for the importance of psychosocial supportive care, analyzing the efficacy of physical and psychosocial function-oriented occupational therapy interventions for the population, establishing accessible and appealing supportive care services, and moving toward function-oriented models of care (Sleight & Duker, 2016). Early developmental screening may help determine whether there is a need for rehabilitation services for children who have been newly diagnosed with cancer and must experience surgery, chemotherapy, hospitalization, and more (Sparrow et al., 2016).

Numerous modes of care can help children undergoing cancer treatment regain function or help survivors of childhood cancer cope with the late effects of the disease. However, there is an underutilization of occupational therapy services within cancer care and a lack of awareness occupational therapists have on the limitations cancer can pose on patients (Baxter et al., 2017). This research seeks to explain the occupational therapy process in the field of pediatric oncology and potential benefits of services.

## **Methods**

The study used a qualitative exploratory design with two cases that were analyzed. This method was chosen as the goal of the study was to describe basic features of the occupational therapy process and provide insight on its underlying characteristics (Taylor, 2017). Approval from the Elizabethtown College Institutional Review Board (IRB) was obtained, and the study application was granted an expedited review because there were no anticipated risks. Several recruitment methods thus ensued.

The principal investigator obtained permission from the American Occupational Therapy Association (AOTA) to post about the research study through the “Survey Requests” thread on the site’s CommunOT boards. Occupational therapists who are also members of AOTA would then be able to see the post and reply to volunteer. Another similar method involved posting about the study on the Pennsylvania Occupational Therapy Association (POTA) website with the same intention. Members of the POTA could also view the post and then respond to participate.

A final recruitment method involved purposive sampling by directly recruiting therapists at various pediatric hospitals that provide pediatric oncology services. This sampling technique allows for the deliberate selection of participants based on specific, predetermined criteria (Taylor, 2017). The researcher obtained individual hospital approval via their IRBs prior to

contacting their staff members. Many hospitals have their own IRB and other requirements to review and monitor research involving their human subjects. The principal investigator identified several pediatric hospitals throughout the United States that offered oncology treatment as well as occupational therapy services. Once site consent was obtained, the principal investigator contacted occupational therapists in those hospital pediatric centers via phone call and E-mail. After these therapists agreed, a signed informed consent regarding the purpose of the study and participant rights was obtained. Due to privacy reasons, participants' names, hospital employers, and any other identifying information will not be disclosed.

### **Data Collection and Analysis**

Two occupational therapists participated in individual audio taped semi-structured interviews. Questions pertained to the professional development of the practitioners, the occupational therapy process they utilize when treating children with cancer, and the benefits of services for this population. The therapists were asked the same fourteen questions, though each were asked additional questions that were relevant within the conversations. The semi-structured interview questions can be found in Appendix A. A follow-up interview was conducted with one occupational therapist to further clarify some questions by the principal investigator.

The method of a phone interview was chosen in order to comply with potential constraints of participants, such as the time of their jobs and their location. The principal investigator conducted each interview alone in a study room of the college library in order to ensure privacy during the phone calls. Each interview lasted approximately 20 minutes. The calls were recorded and then the researcher transcribed each interview for review and analysis. Transcripts were edited only to remove filler speech (e.g. "um").

Results of the study derive from the responses of the occupational therapists during the phone interviews and follow-ups. The principal investigator and the faculty advisor independently read through the transcripts and met to discuss findings. Together, they recognized common concepts from the two conversations regarding the professional development of the practitioners and the occupational therapy process they use in their respective settings.

## **Results**

Two female occupational therapists working in different acute care hospitals volunteered to participate in the study, both with experience in the hematology-oncology (hem-onc) units at their respective sites where they are the primary and sole occupational therapists. Both hospitals are located in rural areas in the same state. Participants will be classified as occupational therapist 1 (OT 1) and occupational therapist 2 (OT 2) based on when each was interviewed. In the pediatric setting, neither of the therapists exclusively specialize in the field, but they treat children with a variety of diagnoses and challenges. A summary of their reports can be referred to in Table 1.

Table 1. Therapist Interview Responses

	Occupational Therapist #1 (OT 1)	Occupational Therapist #2 (OT 2)
Professional Development	<ul style="list-style-type: none"> <li>- Seeks own educational opportunities</li> <li>- Lack of education in OT schools</li> <li>- Learn in the field</li> <li>- Academic journals</li> <li>- Collaborate with coworkers</li> <li>- Online webinars</li> </ul>	<ul style="list-style-type: none"> <li>- Seeks own educational opportunities</li> <li>- Lack of education in OT schools</li> <li>- Learn in the field</li> <li>- Academic journals</li> <li>- Learn from students</li> <li>- Google</li> </ul>
Acute Care Hospital	<ul style="list-style-type: none"> <li>- Hem-onc unit</li> <li>- Only OT in unit</li> <li>- 10-15% caseload of children with cancer</li> </ul>	<ul style="list-style-type: none"> <li>- Hem-onc unit</li> <li>- Only OT in unit</li> <li>- Small caseload of children with cancer</li> </ul>
Outpatient Therapy	<ul style="list-style-type: none"> <li>- Difficulty accessing services for families</li> <li>- Family finances</li> <li>- Geographic location may limit availability of services</li> <li>- Families have additional stressors (e.g. returning to work, other children to care for, etc.)</li> </ul>	<ul style="list-style-type: none"> <li>- Limited access/utilization to standardized assessments</li> <li>- More older children than younger opt for these services</li> <li>- Longer length of stay</li> </ul>
Evaluation	<ul style="list-style-type: none"> <li>- Model of Human Occupation</li> <li>- Behavioral theory</li> <li>- Limited access/utilization to standardized assessments</li> <li>- Performance observations</li> </ul>	<ul style="list-style-type: none"> <li>- Biomechanical frame of reference</li> <li>- Limited access/utilization to standardized assessments</li> <li>- Performance observations</li> </ul>
Interventions	<ul style="list-style-type: none"> <li>- Importance of play</li> <li>- Therapeutic use of self</li> <li>- Craft-making</li> <li>- Finger painting</li> <li>- Slime</li> <li>- Tummy time</li> <li>- Rolling</li> </ul>	<ul style="list-style-type: none"> <li>- Importance of play</li> <li>- Therapeutic use of self</li> <li>- Basketball</li> <li>- Tetherball</li> <li>- Exercise-based</li> <li>- Anxiety techniques; deep breathing</li> </ul>
Targeting Outcomes	<ul style="list-style-type: none"> <li>- Functional-based</li> <li>- Dynamometer</li> <li>- Manual muscle testing</li> <li>- Nine-hole peg test</li> </ul>	<ul style="list-style-type: none"> <li>- Functional-based</li> </ul>

### **Occupational Therapist 1**

Occupational therapist 1 has worked with children from birth to 17 years of age solely in the inpatient acute care setting. She reported only 10-15% of her caseload consists of children with cancer, exhibiting a small amount receiving occupational therapy services. She revealed having a general knowledge of the different types of childhood cancers, though learned in the field as no courses were offered to her through school or required by their employers prior to working with the population. If she is not familiar with a type of cancer or is unsure of how to approach certain treatments, she seeks out learning from online resources or her colleagues. Such online sources include webinars, academic journals, research articles, and other various websites. She is also able to refer to her colleagues in the physical therapy, music therapy, and the medical departments if she is unfamiliar with a diagnosis or the expectations of one. Other external resources (e.g. continuing education conferences) may be offered occasionally through her employer or during training sessions. Two frames of reference commonly used by OT 1 include the Model of Human Occupation (MOHO) and the behavioral approach. Occupational therapist 1 reports that MOHO allows her to obtain a “bigger picture of the patient” while the behavioral theory is relevant as “children do have behavioral issues at times.”

Occupational therapist 1 measures physical motor skills via assessing “range of motion [and] manual muscle testing” if the client is old enough to understand and follow instructions. Other tools used to test motor skills include the Nine-Hole Peg Test for finger dexterity and upper extremity function as well as the dynamometer for arm and grip strength. Neuropathy is a common physical symptom this occupational therapist notices.

Along with physical symptoms, OT 1 has reported seeing “some cognitive deficits.” However, these symptoms are difficult to tease out due to the young ages of her patients. A

common cognitive symptom is delirium. No standardized assessments are used to measure cognition; OT 1 relies on performance observations when analyzing this aspect. For example, she will have a patient list the materials necessary for a shower and an appropriate order of a shower process.

Within her younger population, the therapist has patients identify toys by color, shapes, and other characteristics, and has them sort these items as such. As for the older children, OT 1 looks at orientation, executive functioning, and sequencing through observations of how they perform certain ADLs. An example of such an assessment had a client identify necessary items for a shower and list an appropriate order of a shower process. Observing clients completing tasks allows the therapist to see clients' current skill levels.

Occupational therapist 1 includes both families and patients with goal-making during the evaluation phase, despite the young ages of the children. Remaining client-centered allows the therapist to understand what goals should be targeted. This tends to create challenges for OT 1 when assessing children as their parents tend to answer evaluation questions for them, such as naming the day it is at the time.

An emphasis on sensory-based and fine motor activities was made when discussing intervention methods with OT 1, such as craft-making, finger painting, and playing with shaving cream. The occupational therapist also completes co-treatments with the music therapists of the unit. Family members are encouraged to participate in the big group session, and are receptive to therapies that get their children moving and happy. With the younger patients, OT 1 implements play in different positions on the floor mat with "Tummy Time" and rolling. The interventions chosen are directed towards the issues seen in patients through the evaluation process, which appears to be mainly physical and motor challenges.

Occupational therapist 1 does not use standardized outcome measures to determine the amount of success patients have had in reaching their desired goals. She documents daily progress based on what she sees in her patients functionally during therapy sessions, though does not formally measure improvements. The functional observations this therapist notes are changes made throughout their admission and hospitalization. Her clinical reasoning is that the patients typically have a short length of stay within the acute care hospital setting.

When asked about discharge summaries, OT 1 reported the medical group was responsible for discharging patients. However, the therapist has recommended families to outpatient therapy services. Challenges of seeking continuous care may appear for them due to numerous stressors. Parents would have to take their children back and forth for outpatient oncology clinic visits with their physicians, which may pose financial strains on families. They may also have other children to care for at home and jobs to return to. Occupational therapist 1 found in particular that geographic location is a challenge when accessing outpatient therapy as there is a lack of outpatient services specifically for pediatric oncology within the larger, rural geographic area of the hospital.

## **Occupational Therapist 2**

Occupational therapist 2 currently works in an inpatient acute care setting and reported that her prior work experience in outpatient therapy services included children with cancer as well. She sees patients from birth to 22 years of age, though in regard to children with cancer, she reported patients being on the younger side around 2 and 3 years old. While OT 2 did not specify a percentage of her caseload of children with cancer, she stated that the number of patients is “more limited” compared to the other patients she sees.

This therapist finds understanding the different types of childhood cancers helpful, and knowing which cancers are more serious versus the types most children recover from. She emphasized the importance of recognizing chemotherapy drugs and knowing what kind of side effects may arise from each. Vincristine, for example, is such a drug that affects distal mobility. Being aware of how both cancer and treatment drugs affect children helps this therapist implement treatment services.

Courses on pediatric oncology were not offered to OT 2 when studying occupational therapy. Instead, she learned through practice. She referred to herself as a researcher when initiating her own learning opportunities to understand the medical background of cancers that allow her to pick and choose what interventions she needs to apply. The sources of knowledge are obtained from different websites, journal articles, and students who intern at the hospital. Her exposure to pediatric oncology began with her fieldwork level II experience at the same hospital where she currently works.

Occupational therapist 2 primarily uses the Biomechanical theory in the hem-onc unit. This frame of reference evaluates the motion, strength, and endurance required to perform an occupation. Similar to OT 1, this therapist tends to focus on the motor skills and physical capacity of her patients. The cognitive deficits she listed seeing in these children with cancer encompass motor planning and processing due to the effect of chemotherapy drugs. Cognition, however, is typically assessed by the speech therapists of the hem-onc unit at this hospital, and OT 2 reported that she does not usually assess cognition.

Occupational therapist 2 also does not use any standardized assessments to evaluate her patients within the acute care setting. She will use muscle testing as appropriate, though no standardized tests are available. All goals are reported to be measured functionally. Such

difficulties she sees in performance include difficulty with motor planning and processing. For instance, she reported that a client may be able to understand instructions to complete a task but lack the motor coordination to do the action. Physical symptoms may also influence this behavior as clients' bodies may be physically unable to do what their mind is telling them to do. Strength is therefore a critical focal point in the evaluation process that helps OT 2 plan interventions.

Interventions vary depending on patients and groups. With younger children, OT 2 implements general play. She will take them to the playroom and get out toys to facilitate whatever needs to be accomplished. Older pediatric patients can do more exercise-based therapies. The therapist emphasized intervention planning is age-dependent to ensure patients are enjoying the session as much as possible.

Exercise-based therapies may involve sets of basic exercises for clients to perform while in their hospital rooms. To make interventions occupation-based, the therapist implements activities such as basketball and tetherball in the hem-onc unit. Physical therapists may collaborate with the occupational therapist in these interventions. She emphasized the importance of making tasks as fun as possible to keep their patients engaged.

Although OT 2 does not typically assess cognition, she will intervene when appropriate. Basketball and tetherball activities can assist with the cognitive aspects as well as the physical skill needed for motor processing. Therefore, both physical and cognitive skills are being worked on through the use of fun and therapeutic activities.

Occupational therapist 2 described the acuity of the inpatient setting. For example, she noted that patients are first finding out about their diagnoses most of the time at this point and are undergoing medical treatment. Emotional liabilities are therefore commonly seen in this setting

given the many stressors and medications. This may pose challenges on the occupational therapist as children therefore are hesitant to participate in therapy services when in the hospital room, especially the younger population. According to OT 2, some of the children she has seen experience depression that hinders their desire to participate. Exercises are therefore implemented to keep patients' strength up.

Depression and psychosocial issues are not assessed by this occupational therapist. However, OT 2 described using basic anxiety techniques and deep breathing for these patients, but she usually refers them to pediatric psychology if she feels as though they are struggling. Therefore, OT 2 focuses more on maintaining strength because the chemotherapy drugs are debilitating children. Managing these skills helps make sure patients have not lost too much ability when they are done with chemotherapy.

Occupational therapist 2 reported that outpatient therapy settings, on the other hand, may exist to aid children who may be free of cancer or are in between stages of medical treatment. The purpose of these services is to help children "rebuild everything." Occupational therapists can implement intervention methods that will allow patients to regain the strength they had before their cancer diagnoses.

Measuring outcomes is all functional with OT 2. Rather than using standardized assessments, the therapist has patients within the inpatient acute care setting complete self-care tasks, such as dressing, and base their performance on how independent they are in doing so. Progress is therefore monitored using functional-based methods.

The outpatient setting OT 2 has experience in does offer standardized intervention assessments. In the past, she has utilized the Bruinicks-Oseretsky Test of Motor Proficiency Second Edition (BOT-2), which measures both fine and gross motor skills. A second assessment

she reported using to measure outcomes within this population is the Peabody Developmental Fine Motor Scales, another mode to measure interrelated abilities in early motor development in young children from birth to five years of age. Both outcome measures assess physical skill levels of these children.

In regard to making progress towards goals, OT 2 claims the process may take much longer in the inpatient side of treatment as children are going through medical treatment and experiencing various side effects, whereas the process of reaching goals within the outpatient side may be shorter in length. Upon discharge, she recommends inpatient rehabilitation first, then outpatient. She believes whether patients seek outpatient therapy services is dependent on the age of the children.

Families of younger children with cancer tend to focus on the recovery process. Parents take the responsibility of learning about their child's diagnosis and treatment to implement the interventions on their own at home, rather than having them see a clinician on a weekly basis. Occupational therapist 2 believes that this is because parents of younger children are more hesitant to allow strangers treat their children as building rapport with them is more difficult. Therapy is therefore a lot more parent-based and consultations are viewed as homework to the parents. Parents of older children are more willing to learn about the benefits of therapy and seek outpatient therapy services for the accurate and necessary care.

## **Discussion**

The purpose of this study was to collect information on the occupational therapy process taken when treating children with cancer and analyze the clinical reasoning behind approaches. Both occupational therapists who participated in the study have current experience with the

population in the inpatient acute care setting, though OT 2 has had prior experience in the outpatient therapy setting as well. The professional development of the two participants involve them initiating their own education opportunities with various formal but also informal learning. The strength of these sources remains unclear.

Understanding the pharmacology and side effects of childhood cancers is crucial for occupational therapists to recognize what patients may be experiencing and to remain client-centered. Neither OT 1 nor OT 2 received academic education or formal training from their employers prior to working with children with cancer. Thus, seeking their own educational opportunities to better understand their clients allows for both occupational therapists to implement appropriate and beneficial interventions, exhibiting the importance of competency in practice.

The results of the study support the claim that there is an underutilization of occupational therapy in general cancer care (Baxter et al., 2017). Both occupational therapists interviewed are the primary and sole occupational therapist in their respective hem-onc units. Occupational therapist 2 mentioned a lack of education within these medical facilities on occupational therapy and the services it provides, which may contribute to the scarcity in occupational therapists and limited time allotted for sessions. Instead, there is a larger focus on the medical treatment of children with cancer within the acute care hospital setting that overshadows the need for therapy services simultaneously.

There is also a lack of standardized assessments the occupational therapists utilize in their acute care hospital settings during evaluations and measuring outcomes. Both occupational therapists rely heavily on performance observations, having patients complete meaningful occupations and task assessments for the therapist to personally witness and score. Instructing

patients to perform such activities allows for services to remain occupation-based and client-centered. The little use of standardized assessments and outcome measures by these occupational therapists may be influenced by a shortage in supplies within the hospitals and the short length of stay for patients.

Intervention methods are similar between the two occupational therapists as they focus mainly on activities and occupation-based services. Both therapists remain client-centered and implement interventions that are specific to clients' ages, goals, and needs. An emphasis on the importance of play based on developmental age is shown within the population, exhibiting the clinical reasoning of the occupational therapists for remaining client-centered.

The listed interventions pertain to the frames of reference the occupational therapists follow. MOHO seeks to understand how occupation is motivated, patterned, and performed, and is intended for use with any individual who is experiencing challenges in their occupational life at any point across the lifespan. Occupational therapists can therefore utilize this with children with cancer and can work through their difficulties to focus on the values and interests of each patient. The Biomechanical frame of reference also focuses on limitations to occupational performance, though due to limitations of physical abilities regarding joint range of motion, muscle strength, endurance, etc. Goals of this theory are to prevent deterioration and maintain or restore existing movements needed for occupational performance. Occupational therapist 2 concentrates on implementing fun activities for the children with cancer she treats in order to retain body functions that may be debilitated during treatment or restore these functions after treatment. Frames of reference are necessary to guide practice and clinical knowledge and allow the two occupational therapists who participated in the study to take action that will facilitate change in their clients with cancer.

Limited length of stay within the acute care hospital setting may hinder the ability for occupational therapists to use standardized outcome measures throughout treatment and for discharge. The average length of hospital stays principally for pediatric cancer in 2009 was 12 days (Price, Strangers, & Elixhauser, 2012). Neither occupational therapist complete discharge summaries, though both are able to recommend patients to outpatient therapy. Discharge summaries are important in occupational therapy as it concludes a patients' stay or series of treatments and includes chief complaints, diagnostic findings, therapy used to tend to it, and recommendations upon discharge. When standardized outcome measures are used to report progress, they can help determine the effectiveness of the treatment, increase reimbursement, decrease denied claims, and articulate the distinct value of occupational therapy. The absence of discharge summaries within occupational therapy services may be a weakness in this practice.

Strengths of the study include the participation of the two occupational therapists, both who have experience within the inpatient acute care setting and one who has had experience in the outpatient setting. A follow-up interview was also conducted with one occupational therapist to clarify additional questions the principal investigator produced after analyzing the interview transcript. Occupational therapist 2 was able to provide insight on the discrepancies between the inpatient and outpatient therapy services, which was then analyzed by the principal investigator to provide more information on how the occupational therapy processes coincide with and differ from one another.

Limitations include the low generalizability of the study given there were only two participants who volunteered to participate. The two occupational therapists who did participate both worked at hospitals in the same state, and both in rural areas. Thus, this study does not confirm that all occupational therapists working with children with cancer experience the same

benefits and challenges. More research with a higher participation rate would be necessary to gather additional information. The participants' processes of evaluation, intervention, and targeting outcomes may not represent all occupational therapy practice in pediatric oncology. With the time constraints of the academic semesters this study took place in, there was a limit to the amount of time utilized to recruit participants.

Challenges surfaced in obtaining IRB or individual approval from several hospitals given their specific requirements prior to contacting its staff members; as such, the researcher was unable to recruit participants from some hospitals. In addition, no therapists responded to the requests for participation through occupational therapy discussion boards. Once site consent was achieved, the principal investigator was able to find occupational therapists in those approved sites to contact and ask if they were willing to participate, which also required time between phone calls and E-mails. In future relevant studies, more time should be allotted for the recruitment phase.

## **Conclusion**

Pediatric cancer presents a plethora of symptoms, both during treatment and after treatment. Therefore, cancer care is beneficial for children throughout the course of the disease. Occupational therapy can offer services to help cancer-related and cancer-treatment-related problems such as pain, fatigue, loss of motor control, etc. (Silver & Gilchrist, 2011). Many factors exist, however, that influence the occupational therapy process used when treating children with cancer. These factors may include type of setting and focus of treatment, access to therapy services, and family stressors. Further research should be conducted to increase generalizability and awareness of the occupational therapy process applied when treating

children with cancer. In addition, more research is recommended regarding the use of assessing outcomes of occupational therapy treatment with this particular population. Occupational therapy has the potential to benefit children with cancer undergoing treatment and during survivorship/across the continuity of care.

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**Appendix A – Semi-Structured Interview Questions**

1. How long have you been an occupational therapist?
2. Do you have experience working in the pediatric oncology field in [insert hospital name]?
3. How long would you say you have been working with children with cancer?
4. Do you work with other patients, or just children with cancer?
5. What age range do you typically see at your hospital?
6. How much information do you have to know about the different types of cancer?
7. How and when did you learn about pediatric oncology when you were an occupational therapy student? Was it something you learned in school, or pursued after college?
8. Did you have to take any additional classes or training programs to learn more about oncology as a registered occupational therapist?
9. Are there other occupational therapists in the hospital with you who also work with pediatrics and cancer?
10. What frames of reference/model do you follow at the hospital?
11. What assessment tools do you use during evaluation and outcome measures?
12. What types of intervention methods do you use with your patients?
13. Do you work with children typically during their treatment or after treatment/survivorship?
14. How do you assess outcome measures, and how effective do you think occupational therapy is for these children?