

UNIVERSITY *of*
INDIANAPOLIS[®]

School of Occupational Therapy

Occupational Therapy's Role in Pediatric Oncology Care: The Transition Home

MacKenzie Sauer

May 3, 2019



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

Under the direction of the faculty capstone advisor:

Taylor McGann, OTR, MS, OTD

A Capstone Project Entitled

Title: Occupational Therapy's Role in Pediatric Oncology Care: The Transition Home

Submitted to the School of Occupational Therapy at University of Indianapolis in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree.

By

MacKenzie Sauer

OTS

Approved by:

Faculty Capstone Advisor

Date

Doctoral Capstone Coordinator

Date

Accepted on this date by the Chair of the School of Occupational Therapy:

Chair, School of Occupational Therapy

Date

Abstract

Background: With strict rules on isolation following a bone marrow transplant, the pediatric cancer population suffers from delayed social interaction and developmental skills, impacting their roles and occupations (Connelly, 2015). Follow-up care after transplant is essential for successful recovery but occupational therapy is currently not included within the follow-up planning team.

DCE Aim: The purpose of this DCE was to determine the role that occupational therapists could play in easing the transition of families leaving Brent's Place, a non-profit organization that provides clean-safe living for families undergoing immune-compromising medical treatment, to decrease occupational deprivation.

Needs Assessment: A survey was created and sent to past families to identify the gaps in supports currently offered to families returning home. Results showed that families would benefit from increased emotional and social support and indicated a need for validation in their feelings and experiences when attempting to return to a normal routine.

Implementation: A check-out process was created for families leaving Brent's Place that included necessary resources addressing national and local organizations for support, home maintenance tips, and advice for returning to a normal routine. Families would also be given the opportunity for closure by adding their thumbprint to a mural, which would be displayed yearly at the facility.

Conclusion: When transitioning home, families should be aware of the impact treatment has on their future. OT's have the skills necessary to fill this role. It is important that oncology teams consider OT's ability to support families affected by chronic disease.

Literature Review

Stem cell transplant (SCT) is one procedure used to treat invasive conditions such as cancer (Connelly, 2015). A SCT is completed when an individual's healthy blood or bone marrow cells have been completely consumed by more common forms of treatment including radiation and chemotherapy (Connelly, 2015). SCT procedures are able to restore cells through either blood marrow, peripheral blood stream, or umbilical cord blood (Connelly, 2015). The procedures used vary depending on the source of the blood. If blood is taken from the client themselves, the transplant is called *autologous*, if the blood comes from a donor, it is called *allogeneic* (Connelly, 2015).

When taken from a donor, the blood is processed through multiple tests to check for matching proteins and antigens (Connelly, 2015). The blood is further prepared with T-cell depletion to decrease the chance of graft-versus-host disease (GVHD), where the transplanted cells identify the body as a foreign substance and attack it (Connelly, 2015). Prior to a SCT procedure, the body is exposed to highly concentrated chemotherapy to kill any unwanted or diseased cells to make room for the new cells. The goal of the SCT process is to achieve *engraftment* which occurs when new healthy cells attach and begin to grow in the patient's bone marrow (Connelly, 2015).

Symptoms of Oncology Treatment

The SCT process is long and taxing on the body and requires frequent hospital visits, as well as strict rules related to food and living environments in order to ensure safety (Connelly, 2015). This process can leave the individual fatigued and deconditioned, due to deficits of decreased strength and range of motion, decreased skin integrity, and psychosocial symptoms such as anxiety and depression. These symptoms impede one's performance in ADL and IADL

participation (i.e. self-care, home maintenance, work, and leisure) and impact their roles as a student, friend, or caregiver (Connelly, 2015). Reported symptoms from SCT and its' associated medications that commonly impede one's participation in occupations include nausea, vomiting, fatigue, skin burns, mouth sores, decreased sensation, and deconditioning (Connelly, 2015).

During treatment, isolation is important in order to maintain the individual's health by reducing exposure to environmental bacteria's while the immune system is compromised (Connelly, 2015). Depending on the situation, isolation may last for years following treatment which can be especially devastating to children who are forced to withdraw from school. This mandatory withdrawal impedes the development of important skills for social interaction with peers including problem solving, adaptability, and pragmatic skills (Connelly, 2015).

Psychosocial symptoms are another factor that hinder an individual's participation in their daily occupations. Children have reported decreased self-esteem, emotional wellbeing, and social interactions, which impact overall quality of life following cancer treatment (Thorsteinsson et al., 2013). The entire family unit can be affected by a family member's battle with cancer as well. In fact, the study of psychosocial support for caregivers with a child with a life-threatening disease has been identified as one of the most important research topics in pediatric palliative care (Baker et al., 2015).

Some of the burdens faced by children undergoing oncology treatment include guilt, anxiety, or fear due to the demands placed on their family members (Stowell, 1987). When family members are able to identify these feelings, they tend to do more for their child in efforts to decrease the stress on their child. In turn, this increases the dependability of the child on their caregiver, decreasing skill development in autonomy, motivation, and initiation, all of which are needed to transition successfully into adulthood (Stowell, 1987).

One area largely impacted by a diagnosis of cancer is one's relationships. In one study completed by Manav and Ocakci (2016), children reported their parents and siblings as their closest social relationships, taking the place of their peers. The children rated these relationships as important. The study showed that the nature of a chronic condition strained these relationships, impacting their development (Manav & Ocakci, 2016).

Late-onset and long-term deficits. Many childhood cancer survivors will experience "late effects," defined as: "complications, disabilities, or adverse outcomes that are the result of the disease process, the treatment, or both" (NRC, 2003, pg. 49). The National Research Council (2003) reviewed the literature and found that late onset deficits are commonly experienced by almost $\frac{2}{3}$ of survivors as late as 5 years following their diagnosis (Garre et al., 1994; Oeffinger et al., 2000; Stevens et al., 1998; and Vonderweid et al., 1996). Many families are unaware of such effects and do not take the necessary follow up procedures suggested by research to decrease the presentation of these losses. The most common deficits experienced by this population include decreased cognition, learning disabilities, social skills deficits, behavioral issues, and educational/vocational difficulties (NRC, 2003). Other physical deficits reported by childhood cancer survivors include organ dysfunction, decreased musculoskeletal functioning/strength, infertility, stunted growth, weight gain, relapse, decreased sensation, and poor dental health (NRC, 2003).

The deficits presented in each patient are dependent on the location of the diagnosed cancer as well as the dose and location of treatment. These deficiencies can be identified early in the recovery process and resolve with little consequences however, some cases develop into chronic disabilities that are further worsened by normal deficits associated with aging (NRC, 2003). Research specifically focusing on children with CNS oncology diagnoses show that

patients do not lose information or skills prior to their treatment but rather require more time and effort to learn new skills afterwards, impeding the child's ability to meet developmental milestones at the same time as their healthy peers. For many children, these deficits may not present until the onset of puberty due to the body's rapid change and growth (NRC, 2003).

Fortunately, studies have shown that families often adjust well to their new reality regardless of what they have been through. However, all survivors report feelings of worry or anxiety about the recurrence of symptoms, treatment, and remission for the long-term (NRC, 2003). It is therefore important that OT involve themselves in providing coping mechanisms for decreased stress through use of skilled emotional and social interventions.

Other psychological effects studied among childhood cancer survivors overall show mixed results. Some adolescents/adults choose to make up for lost time and take more risks than their healthy peers in effort to celebrate life. Others choose to take less risks to preserve the life they fought so hard to keep (NRC, 2003).

Symptoms of Stem Cell Transplant

Through the advancement of modern medicine, patients who receive a SCT as part of their intervention for nonmalignant conditions, are living longer (Socie, 2003). This supports the need to better prepare for and understand the associated effects that can result from this treatment process (Socie, 2003). Although there are similarities in the way SCT affects an oncology patient, there are also some significant differences associated with the treatment of nonmalignant conditions (Socie, 2003). Of greatest concern is the development of *chronic* graft-versus-host disease (cGVHD), which increases the mortality rate by 15% when compared to survivors of SCT without cGVHD. Late onset effects most commonly reported by survivors of SCT include

deficits in vision, lung functioning, liver complications (related to increases of iron in the body), decreased bone composition, dental decay, decreased growth, and fertility issues (Socie, 2003).

Theoretical Guide

Under the direction of Maslow's Hierarchy of Needs, one must first meet their most basic human needs (including food and shelter) before they are able to consider their more complex needs (such as love and belonging) (McLeod, 2018). The goal is to reach *self-actualization*. Self-actualization is a state in which a person who has reached their full potential. Maslow believed that everyone is capable of obtaining self-actualization, however life circumstances often hinder them from reaching their goals (Cole & Tufano, 2008; McLeod, 2018).

Brent's Place is a non-profit that provides clean, safe housing for children and their families while the child receives treatment for a life-threatening condition. Oftentimes, the child has traveled far from home to receive a SCT for oncology treatment. Brent's Place website states, "when a child is faced with a life-threatening crisis like cancer, it impacts the whole family...it devastates finances, impacts emotional health, and on the most basic level, affects day to day life for every member of the family" (Brent's Place, 2019). The families in this situation are demonstrating Maslow's Hierarchy of Needs theory and are void of housing, food, and transportation needs. The staff members at Brent's Place provides families with programs and resources that fit these basic needs so that families can advance the hierarchy and focus their attention on their more complex medical needs (Cole & Tufano, 2008; McLeod, 2018).

When addressing a major change, occupational therapists must consider the impact that the environment has on the client's ability to engage in their meaningful occupations. While in an unfamiliar environment, children and their families may find it difficult to maintain their normal lifestyle. The Ecology of Human Performance (EHP) model discusses this relationship

by suggesting that when in the appropriate context, the client will be able to successfully function using their skills (Cole & Tufano, 2008). Once a family has moved out of Brent's Place and has returned home, occupational therapists can use the above-mentioned theory and model to structure a program to specifically meet the client's changing needs. Utilizing structure and establishing relationships between all involved variables is one advantage in using theory to guide practice (Bonnell & Smith, 2018).

OT's Role in Oncology Care

During treatment, families are likely to encounter a disruption in their normal schedule of functioning both during and after oncology treatment, supporting the need for skilled occupational therapy services in all stages of the disease (Palmadottir, 2010). Following a traumatic event, one may reconsider their definition of meaningful and change their needs and interests, requiring direction, which can be provided by an occupational therapist (Palmadottir, 2010).

Occupations themselves can be used as therapeutic agents. As stated by Palmadottir (cited in Unruh, & Elvin, 2004; Vrkljan, & Miller-Polgar, 2001; Unruh, Smith, & Scammell, 2000), current literature shows that among patients with breast cancer, continued participation in occupations increased women's personal perceptions of health, wellness, and feelings of normalcy and capability despite their prognosis. As described in Palmadottir's (2010) results, when patients were able to maintain control and stability within their daily schedule, they were able to decrease negative feelings about their wellness. The same was shown to be true among children diagnosed with cancer, as shown by Mohammadi and colleagues in 2017 (cited in Hassani, Hasani, & Amini, 2016), occupations not only provided mental, social, and physical benefits but also taught the children important skills needed for adulthood. In the same study,

both groups of children (those who were healthy versus those diagnosed with cancer) reported enjoyment in completing their daily occupations and both groups accepted help equally (Mohammadi et al., 2017). This supports the need to continue independent participation in daily occupations throughout treatment.

Identified Barriers

One of the barriers to OT's participation in oncology rehab is the current lack of training available for this specific practice area, categorizing oncology care as an emerging area of practice in occupational therapy (Silver & Gilchrist, 2011). This is expected as statistics show that childhood cancer makes up only 1% of all new cancers diagnosed in the United States (American Cancer Society, 2018). It is important that OT's involve themselves in oncology care as childhood cancer is the second leading cause of death for children ages 0-14 (American Cancer Society, 2018). This presents with an important job for the healthcare professional: to advocate for their scope of practice and encourage others' understanding for more appropriate and necessary referrals (Silver & Gilchrist, 2011). One article highlights the importance of oncology rehabilitation by stating, "In effect, the medical system creates a situation where high functioning individuals are given life-prolonging treatments and then left to struggle with how to recover from the toxic adverse effects of these therapies" (Silver & Gilchrist, 2011, p. S7).

Survivorship

In more recent medical research, topics have focused on developing a follow-up plan for delivering care to childhood cancer survivors following their treatment (National Research Council [NRC], 2003). This is significant as the number of childhood cancer cases is increasing (NRC, 2003) however, developing an effective plan is difficult as each case, diagnosis, treatment plan, and family genetics vary.

As defined by the authors of *Childhood Cancer Survivorship: Improving Care and Quality of Life* (2003), a high quality survivorship program would include the following: a wide range of direct services to educate, prevent, and rehabilitate from late onset effects; bridge any gaps and develop appropriate communication between the primary care and specialty care professionals' involved; utilize principles of education and occupational services to coordinate the best possible care; and complete research that describes the effects of cancer to better plan and understand the disease process beginning at diagnosis (NRC, 2003). When provided with the above-mentioned resources, a program would help to decrease the number of survivors who lack in the knowledge needed to obtain proper long-term follow-up care, the current problem faced by this population (NRC, 2003).

DCE Purpose

Even with the use of survivorship programs in recent oncology treatment, occupational therapy is not identified as a part of the interdisciplinary team (Morey, Urbina, & Muenks, 2018). Current programs offer a wide range of services to patients including education, observation, and follow up sessions to monitor for signs of late-onset effects, relapse, and secondary diagnoses of cancer (Morey, Urbina, & Muenks, 2018). Professionals on the team providing the above-mentioned services currently include: an oncologist, nurse practitioner, psychologist, social worker, pharmacists, financial counselor, and dietician (Morey, Urbina, & Muenks, 2018). While most literature works to describe the quality of life in cancer survivors (Mohammadi et al., 2017), there is a current lack in literature describing the effects of rehabilitation services during and following oncology treatment. This project aims to help fill this gap by identifying OT's role in ongoing pediatric oncology care.

Needs Assessment and Evaluation

Through completion of a strengths, weaknesses, opportunities, and threats (SWOT) analysis, an area of improvement of OT interest includes putting into place a transition program for families leaving Brent's Place. This problem aligned with current staff development goals to provide a celebration ceremony to families who are able to move home. In summary, strengths of Brent's Place include the success and support for current programs, high volunteer and community support, and partnerships with the surrounding treating hospitals. Opportunities exist to provide families with continued support after they leave Brent's Place. Weaknesses and threats to program development include space, time, funds, resources, the lack of a medical team, and the lack of a current follow-up or exit program.

The community developed at this home-away-from-home among families going through similar experiences does not tend to leave the walls of Brent's Place which could contribute to increased stress and poor success in the transition home. To gain insight on what role Brent's Place could fill to provide *local* supports to families and ease this transition, a needs assessment was created. Families who returned home following the loss of their family member, or who went home on hospice care were not contacted. The questions and topics addressed were not appropriate for this client-base therefore, a new development goal was constructed: a second needs assessment will be sent out to grieving families to address gaps in areas that Brent's Place could assist in providing emotional support and coping mechanisms after the loss of a child.

The current needs assessment was posted on the Brent's Place Families Facebook page and the client database was used to determine who was appropriate to receive the survey via email. Biannually, Brent's Place sends out satisfaction surveys to address client's needs in terms of programs and supports. To avoid sending out two surveys back-to-back these questions were

used as introductory questions, followed by basic demographic questions regarding the patient's stay and disease experience. Questions included in the need's assessment can be found listed in Figure 1. An incentive was provided with entry to win a \$50 gift card to those who submitted a completed questionnaire within 2 weeks.

Needs Assessment Questions:

1. (*Brent's Place Past Families Satisfaction Questions/"Demographic" Questions*) When did your family stay at Brent's Place?
2. How long was your family's stay at Brent's Place?
3. At which Brent's Place location did your family stay?
 - a. Aurora Campus
 - b. Marion St
 - c. Other (please specify)
4. What was the patient's age during your stay at Brent's Place?
5. What were some of the best things about your stay at Brent's Place?
6. What are some things that could have been changed or added to improve your stay at Brent's Place?
7. Do you currently stay connected to Brent's Place?
 - a. No>>>Why not? Are there ways that are not currently offered that you'd be interested in using to stay connected to Brent's Place? If so, what are some suggestions you have?
 - b. Yes>>>How so? Do you have suggestions for other ways that are not currently offered to help you stay connected to Brent's Place?
8. (*Long-term Care Follow-Up Plan Questions*)Does the patient in your family have a cancer diagnosis?
 - a. Yes>>>Are you familiar with the late onset deficits (effects that show up later in life) associated with recovery from cancer treatment?
 - b. No>>>What was the patient's diagnosis? Continue to #9
 - i. Yes>>>What are they? Continue to ii
 - ii. No>>>Are you familiar with the common long-term effects (effects that show up during treatment and last a long time) of cancer treatment recovery?
 1. Yes>>>What are they? Continue to #9
 2. No>>>Continue to # 9
9. Did the patient receive a bone marrow transplant/stem cell transplant as part of their treatment?
 - a. Yes>>>Are you familiar with the late onset effects (effects that show up later in life) associated with recovery from a bone marrow transplant?
 - i. Yes>>>What are they? Continue to ii
 - ii. No>>> Are you familiar with the common long-term effects (effects that show up during treatment and last a long time) associated with the recovery from a bone marrow/stem cell transplant?
 1. Yes>>> What are they?

2. No>> What treatment(s) did the patient receive?
 - a. Are you aware of any late onset effects (effects that show up later in life) of the treatment(s) the patient received?
 - i. Yes>> What are they?
 - ii. No>>Are you aware of any long-term effects (effects that show up during treatment and last a long time) associated with the patient's treatment(s)?
 1. Yes>>What are they?
 2. No>>Continue to #10
10. What was the most challenging part about moving out of Brent's Place?
11. What was the best part about moving out of Brent's Place?
12. When my family left Brent's Place it was because,
 - a. The patient was healthy enough to leave
 - b. The patient passed away or was placed on hospice care
13. What could Brent's Place do to support other families when they are leaving Brent's Place under these difficult circumstances?
14. What is something that we could do to make the move out of Brent's Place more special? Some examples of celebrations include ringing a bell, staff members line the hallway to clap/cheer as your family walks out the door for the last time, sign a wall/mural, etc.
15. What are some things the patient struggled with most regarding returning to a normal routine (for example, interacting with peers at school or work, eating a normal diet, following a bedtime/morning routine, etc.)?
16. What deficits impacted the patient's ability to participate in their daily routine most?
17. What did they do to overcome these deficits?
18. What resources were/would have been helpful when coping with the mentioned deficits?
19. Before leaving to go home, were you given any information (either from Brent's Place or the hospital) relevant to your circumstance of leaving about what to expect medically, logistically, emotionally, etc.?
 - a. Yes>>What was the most helpful resource you were given? Continue to b
 - b. No>>What is something that would have made your transition to life after Brent's Place easier?
20. (*Emotional Support Questions*) How do the members of your family (including you) deal with stress?
21. Would it be helpful to have resources that provide tips on dealing with stress related specifically to recovery or loss of a loved one?
 - a. Yes>>Please indicate which of your family members are part of a social support group. If none are, please select "none."
 - i. Patient
 - ii. Sibling
 - iii. Caregiver
 - iv. None
 - v. Other (please specify)

- b. No>>Are you or any of your family members interested in joining a social support group?
 - i. Yes>>Are you already aware of any existing support groups relevant to your situation in your community (or online)?
 - 1. Yes>>Do you know the steps you would need to take to sign up for the group(s)?
 - a. Yes or No>> Continue to #22
 - 2. No>>Since you don't already know of any groups available to you but are interested in joining one, do you know how to find out if there are relevant support groups in your area or online?
 - a. Yes or No>>Continue to #22
 - ii. No>>Continue to #22
22. Are you aware of the national organizations that provide survivorship groups/support programs?
 - a. No>>Are you interested in learning more about them?
 - i. Yes or No>> Continue to #23
 - b. Yes>>Are you a member of or does your family receive any type of support from any of these organizations?
 - i. Yes>>Which ones?
 - 1. How are they helpful?
 - ii. No>> Continue to #23
23. What suggestions do you have for Brent's Place specifically to help make the transition to life after Brent's Place easier for families?
24. OPTIONAL: If you indicated that you would like more resources from the topics above please provide a good email address to reach you at. Note: this is optional, the survey is anonymous, your answers cannot be traced back to your email address
25. Any last comments or insights your wish to share regarding the transition out of Brent's Place and back to a new normal? Or long-term follow up care for the patient, if applicable?

Figure 1. Needs assessment questions. This figure contains questions asked in the need's assessment with corresponding follow-up questions dependent upon the answer to the previous questions.

Results

Regarding the transition home, families identified the following struggles and concerns: the loss of social support from staff and other understanding families, a lack of physical resources (groceries, gas money, etc.) contributing to overwhelming feelings emotionally, physically, and mentally, worry due to concerns of relapse and the process of disease recovery, and worry from the pressure to fit back into a normal routine and schedule. All 51 participants who responded to the need's assessment reported interest in participating in an exit ceremony or

activity before leaving Brent's Place to assist with closure. Occupational therapy should be involved with follow-up care because they have the skills necessary to provide resources and suggestions for the above-mentioned concerns.

Research suggests that those diagnosed and treated for cancer are likely to be subjected to long term disabilities, affecting their ability to participate in a daily routine (Adler & Page, 2008). Psychological and social skills are also affected but addressed less than the physical disabilities by medical professionals (Adler & Page, 2008). Per past families of Brent's Place, deficits most affecting patients included decreased cognition, endurance, strength, and immune compromised status, affecting participation in school/social engagements, eating/meal prep, and following a daily routine, supporting current literature.

The degree of a mental health disability in patients with cancer and their families vary depending on the situation. Patients and their family members commonly present with symptoms of depression, anxiety, post-traumatic stress disorder (PTSD), and adjustment disorders (Adler & Page, 2008). Stress among all family members including the patient, has been shown to be positively correlated. Worry and stress is particularly high among caregivers of patients with cancer. In fact, parents of children with cancer were shown to have higher rates of PTSD diagnoses than the patient, showing the important role OT can play to keep the entire family happy (Adler & Page, 2008). In turn, when caregivers are emotionally unavailable to support the patient, the patient's stress increases, causing a cyclical effect that is difficult to control (Adler & Page, 2008). 79% of participants in the need's assessment reported that it would be helpful to have resources regarding coping mechanisms for handling the stress specific to recovery.

Traditional Area of Practice

Occupational therapy has been present in mental health since the field was founded in the early 1900's (Castaneda, Olson, & Radley, 2013). OT continues to have a strong presence in mental health as the focus of recovery moves from a medical basis to community integration. Recovery itself has been identified as a long-term process with end results to be independently integrated back into the community (Castaneda, Olson, & Radley, 2013).

Individuals who survive cancer may experience emotional distress resulting from the physical symptoms reported with the disease process such as fatigue, pain, and decreased sensation (Alder & Page, 2008). Roles affected by the physical symptoms of cancer can include an inability to participate in school and work tasks, home maintenance tasks, social and family roles, and leisure participation, decreasing overall morale and quality of life (Adler & Page, 2008).

OT's current role in mental health can utilize skilled services to increase a client's independent participation in their roles within their natural home environment. Skilled interventions to reach this overarching goal can include modifications to the patient's physical environment, providing appropriate education, the identification of leisure activities, and providing resources necessary to request appropriate accommodations for community functioning (Castaneda, Olson, & Radley, 2013). 61% of respondents in the current need's assessment were unaware of the national organizations available to provide support to the entire family, 65% of those respondents reported interest in learning more about them. This area would be important to include in OT interventions to address deficits in mental health and emotional stress.

Emerging Area of Practice

Occupational therapy in oncology care is considered an emerging area of practice, especially when considering the niche of pediatric oncology care. The addition of rehabilitation in oncology care throughout the entire disease process is being considered as recommended by Morey, Urbina, and Muenks' study in 2018. Another identified emerging area of practice in occupational therapy is preventative care. OT has the skills necessary to suggest appropriate lifestyle changes to promote wellness and prevention care through participation in daily, meaningful activities specific to the oncology process (Nielsen & Christensen, 2018).

Current weight loss programs run by occupational therapists aimed to promote health and wellness have shown success through OT-based principles such as setting realistic goals, using occupations as intervention tools, and client-centered practice (Nielsen & Christensen, 2018). These principles could also be used to promote overall well-being among cancer survivors. OT's possess skills in physical disabilities, mental health, and cognition that when used in combination, have shown to produce successful results (Nielsen & Christensen, 2018).

Cancer is more commonly diagnosed in society today and with more advanced medical studies and current knowledge of the disease and its' treatment, individuals diagnosed have been given a prolonged life (Adler & Page, 2008). Early detection, health and wellness and preventative health plays an important role in the oncology world. With the increased knowledge in early detection, five-year survival rates for those diagnosed with cancer has increased by upwards of 20%, supporting the need for education and advocacy within this area (Alder & Page, 2008).

Through the need's assessment, 62% of families indicated that they were provided with enough medical information from the hospital care team necessary to prepare for the possible

deficits related to treatment recovery however, a lack of competence was reported when participants were asked what those specific deficits were. Competence was measured by the patient's ability to correctly list at least 3 deficits related to the treatment (oncology treatment or BMT). Those who could not correctly list 3 deficits or responded something of this effect, "relapse plus a lot more," were considered not competent. This is concerning as there is distinct differences in all categories and it is important that OT's help provide patients and their families with accurate education to prepare as necessary to decrease occupational deprivation.

OT's Role at Brent's Place

With the stigma that exists regarding mental health, a gap currently exists surrounding the importance of mental health referrals and treatment among patients with a chronic disease (Adler & Page, 2008). General medical doctors may not refer to mental health services due to lack of training and knowledge in this area. Peer support groups were among the top requested services from cancer survivors that primary care physicians were unable to provide appropriate information for. OT's have the knowledge and ability to suggest and lead peer support groups within the community to meet the needs of this population (Adler & Page, 2008). The same concern was addressed in the collected results from the current needs assessment. In fact, when asked what family members were attending support groups, most of those indicated were caregivers.

Interventions

To address the needs identified by the past families of Brent's Place, I created multiple resources to be provided to families at check-out. Along with the booklet of resources, I created a check out process to increase the consistency of care provided to each family leaving Brent's Place. In order to logistically meet the indicated needs of the families, while also meeting

development goals of the staff members at Brent's Place, the following check out process was established.

Once a family has heard from their doctor that the patient will soon be discharged and released to return home, the family will schedule a time to meet with their family service staff member approximately one week prior to their departure. During this 15-20-minute meeting, families will complete their apartment cleaning check off as per protocol. Following the check, families will be given the opportunity to ask any last questions they have regarding the patient's treatment or the transition home. Given that the meeting is to occur within the family's last week at Brent's Place, this gives staff members the opportunity to reach out to the family's healthcare team or connect them to the resources needed for a successful transition.

Each family will be given the following resources and Brent's Place memorabilia which will serve as a physical reminder of the family's time in Aurora. Resource packets will include: a Venn diagram contrasting the late onset and long term effects of oncology treatment and bone marrow transplant (BMT) treatment, depending on the patient's disease treatment; a list of *Therapeutic Use of Activities* which combines principles from OT, physical therapy, and music therapy to use everyday activities to promote the development of milestones and preserve important fine motor, gross motor, and emotional regulation skills; a list of helpful tips to help maintain a clean-safe environment at home; ways to stay connected to Brent's Place, as many families expressed needs to continue participating in the established community but did not know how; instructions on how to reserve a hospitality suite, which acts as Brent's Place short-term living for past families returning to Aurora for check-up appointments as many families stated that this was reassuring to know that support was there if needed; how to sign up for a Brent's Place mentor to further that relationship with another family who has already been

through a similar situation; tips on ways to deal with stress specifically related to oncology/illness treatment and what to expect emotionally with the transition home; a list of national and local social and emotional supports available; a list of social media and online resources were also provided. The staff member(s) present at this process would be available to point out important information and answer any follow-up questions. During this scheduled time, other staff members would also have the opportunity to come say goodbye.

Lastly, the family will be given the opportunity to contribute to the Brent's Place Families mural with their thumbprint and name. A model of the mural can be seen in Figure 2.



Figure 2. Mural of past families at Brent's Place. When leaving to return home, each family will be given the opportunity to add their thumbprint to the tree with their name. A new tree will be printed on canvas each year and available for display at Brent's Place events. This opportunity also allows families the chance to leave their mark at Brent's Place, a place many indicated feeling a strong physical connection to.

Families will discuss with staff members when they plan to leave and will be given the option to have a send-off, which would include the opportunity to ring the noisemaker and have staff line the halls to cheer as the family left.

It was important that the staff be able to use this procedure for all families and situations leaving Brent's Place. For example, adults and children would both enjoy contributing their thumbprint to the mural. Including the entire family also gives grieving families the opportunity to leave something behind in memory of their deceased child. When families who lose their loved one leave Brent's Place, they will also be given optional resources on grief which were updated and organized for easy access for all staff members to distribute as needed. These resources include definitions and explanations of grief and its' varying stages, how to help surviving siblings grieve, how to help fathers, mothers, and grandparents grieve, and how to cope with the holidays, etc.

It was also indicated that families benefited from continued staff support once they left Brent's Place. Therefore, it was decided that a follow-up letter would be sent to each family one month after their departure. The letter would act as a reminder that Brent's Place was thinking about them and that staff were there for them if they ever wanted to talk or provide an update on the patient's health.

Student Leadership

This site required extensive self-initiation skills to effectively run, maintain, and trial a new program. Staff members were extremely busy with their own work schedule and therefore, did not have extra time to guide any temporary team member such as myself as a capstone student, or other interns. Through this experience, I had to be my own leader in how I wanted to approach this project, what goals I wanted to accomplish, and how to present the information in a way that best fit the needs of the families. I feel as though my communication skills have improved in this process with the need to communicate to others the importance of OT as well as the significance of the program developed.

With use of my leadership skills, I was also able to complete a couple of smaller side projects that promoted the use of occupational therapy principles. For example, one item identified in the results from my need's assessment indicated the need for more caregiver support. Currently, there is only one program aimed to specifically address caregiver needs at Brent's Place. To trial the need for caregiver support, an intern and I created a "Respite Care Night." We provided childcare to patients and their siblings while their caregivers were given the opportunity to rest, clean, or make phone calls without interruption.

Staff Development

The staff members at Brent's Place were engaged and willing to support this initiative to implement the use of a check out process because it aligned with one of the team's development goals. The team considered it an added bonus to have OT principles supporting the transition and showed interest in understanding the meaning behind the resources. For example, one of the staff members began pointing out OT skills related to fine motor control and core stability during interactions with the children living at Brent's Place.

The staff also developed in their understanding of the importance of follow-up care after a family returns home. Brent's Place is well equipped with community/donor support, so they have the necessary resources available to offer help to families in their transition home. It has been noted by past families and the staff themselves, that some families are never heard from again, and the support offered at Brent's Place goes dramatically from all to nothing. This is overwhelming to families and could lead to increased feelings of depression, anxiety, and stress, further supporting the significance of OT's involvement in the transition home.

Outcomes

To ensure quality improvement of the check-out program that I created, it has been established that staff members will use the materials and process on a trial basis for at least one quarter. At biweekly meetings with the family services team, the staff can discuss how the program is working to meet their needs and the needs of the families. This way, small changes to the program can be made as needed. Prior to my departure, I completed an outcome measure for the staff to gauge their understanding of the program, how to use it, and the importance of OT at Brent's Place. This let me know what changes I needed to make or suggest, to improve the program before leaving and what education I needed to provide for increased understanding. I also created a second outcome measure for the staff to utilize to measure the families understanding of the materials as well as how the resources specifically met their needs. I will not be present to implement the program and myself reach out to families and make the necessary changes. The questions to be included in each survey can be found in Figure 3 and Figure 4 below.

On a scale of 1-10, (1=not at all, 10=very) please rate the following statements regarding the implementation of the new check-out process

1 ----- 10
Not at all **Very**

1. How satisfied are you with the new check-out process?
2. How confident are you that the check-out process will be successful?
3. How confident do you feel implementing the process after MacKenzie leaves?
4. How accurately does the process fit with current development goals?
5. How confident do you feel that you have the skills necessary to make any changes to the program after MacKenzie leaves?
6. How confident do you feel in your understanding of how the check-out process aligns with OT principles?
7. How confident do you feel in your ability to explain the role that OT plays at Brent's Place to others?

Figure 3. Outcome measure for staff. This outcome was used to measure the usefulness of the check-out process' ability to meet development goals of the Brent's Place staff and families. The measure is also meant to analyze the understanding of carryover and understanding of OT at Brent's Place.

On a scale of 1-10, (1=not at all, 10=very) please rate the following statements regarding the implementation of the new check-out process

1	10

Not at all	Very
<ol style="list-style-type: none"> 1. How helpful were the provided resources in increasing your understanding of the national organizations available for support? 2. How helpful were the provided resources in increasing your understanding of the local organizations available for support? 3. How helpful were the provided resources in increasing your understanding of what to expect when returning home after treatment? 4. How helpful were the provided resources in increasing your understanding of how to decrease your stress related to recovery? 5. How helpful were the provided resources in increasing your understanding of the difference between the late-onset and long-term effects of treatment? 6. How helpful the provide resources were in decreasing your stress related to maintaining a clean-safe environment for your family? 7. How likely it is that you will use the resources provided? 8. Did the provided resources address your needs identified in the past survey? 9. Were the provided resources were easy to understand? 10. Were the provided resources were easy to access? 11. How important you think these topics are for recovery? 	

Figure 4. Outcome measure for families. This outcome is to be used to measure the usefulness and understanding of the materials provided to Brent's Place families at check-out.

I also completed a GOAL Attainment Scale to measure how successful I was in completing the goals of my project and time at Brent's Place. Below, Figure 5 lists the goals that I established during the beginning stages of my DCE.

	-2 Much Less Than Expected	-1 Less Than Expected	0 Most Likely Outcome	+1 More Than Expected	+2 Much More Than Expected
Goal 1	I will present results of needs assessment regarding suggestions for Brent's Place exit ceremonies.	I will research/brainstorm exit ceremonies and suggest appropriate programs based off results of needs assessment.	I will plan/set-up an exit ceremony to implement with all families leaving Brent's Place for all situations, including satisfaction survey development to monitor success.	I will run 1 exit ceremony for a family leaving Brent's Place including presentation of "What to Expect When Going Home" packet and distribute satisfaction survey.	I will run 2+ exit ceremonies for families leaving Brent's Place with presentation of "What to Expect When Going Home" packet and take results from satisfaction surveys to suggest appropriate changes.
Goal 2	I will present results of needs assessment regarding suggestions for helpful resources to provide families exiting Brent's Place.	I will research/brainstorm appropriate resources to suggest providing to families leaving Brent's Place to ease the transition home based off results of needs assessment.	I will create a "What to Expect When Going Home" packet to provide with families moving out of Brent's Place to ease the transition home with useful local resources as indicated by results of needs assessment. Included will be a satisfaction survey to measure success of program.	I will present the materials to Family Services team at Program Huddle to train staff how to use packet and implement use at family check out.	I will take results from the satisfaction survey to make appropriate edits to improve success of program.
Goal 3	I will share paper with team members to discuss importance of occupations in activities at Brent's Place.	I will brainstorm/research activities to incorporate into current programs at Brent's Place and present to Family Service team at Program Huddle.	I will incorporate occupations into current programs at Brent's Place and make master list of suggested activities for Brent's Place staff members to utilize.	I will run 1 arts and crafts night with occupation-based activity.	I will run 2+ arts and crafts or science nights with occupation-based activity.

Goal 4	I will discuss use of therapeutic activities in collaboration with PT and AT to promote discussion among staff members to include rehabilitation as part of team.	I will create "Use of Therapeutic Activities list to provide to families to utilize during stay at Brent's Place to reduce occupational deprivation.	I will create a "Therapeutic Use of Activities" list in collaboration with PT and AT to provide to families to utilize during stay to reduce occupational deprivation.	I will present list to 1+ family at check in with Family Services Staff member to demonstrate appropriate use.	I will create and send out need's assessment to current Brent's Place families to measure need for onsite therapy clinic and provide appropriate suggestions.
---------------	---	--	--	--	---

Figure 5. GOAL attainment scale. This scale measured my progress on the goals specific to my developed DCE program and time at Brent's Place.

I was able to meet all my established goals. I was not able to implement the program myself but was able to present the materials and complete a mock check-out to train staff members on my vision for using the materials with an occupational therapy perspective. As per my goal, I was able to create a resource packet for families to take home as part of the check-out process. The outcome measures described above were used to gauge the success of the programs and resources. I was able to surpass my goal of integrating occupational therapy principles into activities and programs at Brent's Place by leading two craft nights integrating fine motor and sensory principles. I further created a Pinterest account where I have stored crafts, science activities, sensory activities, and gross motor activities or ideas to use during programs. Lastly, I was able to complete the *Therapeutic Use of Activities* list and have printed and bound copies distributed in every apartment. In addition, I collaborated with the music therapist to create a therapy room with sensory areas for the families to help decrease stress and anxiety.

Meeting Society's Need

The societal need that I am addressing is the need to improve follow-up care for patients diagnosed with cancer and the lack of OT involvement in the current treatment plan. When undergoing treatment, patients are forced to isolate themselves to decrease the risk of exposure to germs while immune-compromised, increasing occupational deprivation (Connelly, 2015). In addition, research supports the growing population of those diagnosed with cancer (NRC, 2003), further supporting the need for more occupational therapy involvement in follow-up care. The need for rehabilitation is critical for this population.

With these things in mind, along with the results of my need's assessment, I created a *What to Expect When Going Home* resource packet for families moving out of Brent's Place. Although this is a small group of those in the community affected by cancer, it will act as a good starting point for OT's involvement. I included the partnering hospital of Brent's Place to offer collaboration efforts to provide a more holistic and comprehensive level of care for all members of the family. Included in my packet of resources is the discharge checklist provided to patients when getting ready to be discharged from the hospital. This will increase the ease of access to all support resources available to families. My hope is that in working with the hospital, they will be reminded of the importance of follow-up care and increase their efforts in supporting families who are discharged.

Overall Learning and Leadership

Overall, I feel that my professionalism has improved because of the multiple forms of communication I was required to use while at Brent's Place. I had to initiate all projects, set my own goals, and reach out to Brent's Place staff members and partners in order to effectively justify the use of my program. In all forms of communication, I tend to be wordy. This

experience taught me the importance of being concise and to the point to be respectful of each other's busy schedules. I also improved in my ability to effectively explain what OT is when communicating with families and staff members who do not have an understanding of OT. Below are some specific examples of how I was able to improve my communication skills through interactions while at Brent's Place.

Most of my interactions with families took place when they came into the office to ask questions or with those who attended events and meal nights. One of the caregivers living at Brent's Place is an active advocate for their child and has a lot of information and experience with support networks and the national organizations available to families. I used them as a resource to compile a list of supports available to other families dealing with their child's chronic condition to include in my program's resource packet.

Professionally, I was also able to provide education to staff members and other professionals working at Brent's Place through an in-service, leading team meetings/discussions, and reaching out to partners for advice and collaboration. I was also able to advocate for the role of OT in general and specifically at Brent's Place in these same efforts by creating a program with integrated OT principles.

In all my interactions I was sure to be polite and respectful of not only the other person's profession but also their time and knowledge. Professional communication for me includes good eye contact, open body language, and appropriate facial expressions. Even though I was not able to personally relate to the family's situation living at Brent's Place, I was able to practice my use of empathy to form relationships and emotionally support them to practice my therapeutic use of self. I acknowledge that these skills will be useful in my future career as an OT.

In order to be successful at this placement, I had to self-initiate my learning which encouraged the development of my leadership skills. Through these efforts I gained leadership skills in setting realistic goals, collaborating with other professionals, working as a member of a team, communicating effectively, and advocating and educating others on my role as an OT in the team. This placement has helped me gain confidence in my abilities as an OT and although not performing direct OT services, the skills I listed above will indirectly serve in my success as a practitioner.

References

- Adler, N. E., & Page, A. E. (2008). *Cancer care for the whole patient: Meeting psychosocial health needs*. Washington, DC: National Academies Press.
doi:<https://doi.org/10.17226/11993>
- American Cancer Society. (2018). Key Statistics for Childhood Cancers. Retrieved from <https://www.cancer.org/cancer/cancer-in-children/key-statistics.html>
- Baker, J. N., Levine, D. R., Hinds, P. S., Weaver, M. S., Cunningham, M. J., Johnson, L., Angheliescu, D., Mandrell, B., Gibson, D. V., Jones, B., Wolfe, J., Feudtner, C., Friebert, S., Carter, B., ... Kane, J. R. (2015). Research priorities in pediatric palliative care. *The Journal of Pediatrics*, *167*(2), 467-70.e3.
- Bonnel, W.E., & Smith, K.V. (2018). *Proposal writing for clinical nursing and DNP projects*. New York, NY: Springer Publishing Company.
- Brent's Place. (2019). Retrieved January 22, 2019, from <https://www.brentsplace.org>.
- Castaneda, R., Olson, L., & Radley, L. (2013). *Occupational therapy's role in community mental health*. aota.org, Bethesda, MD.
- Cole, M., & Tufano, R. (2008). *Applied theories in occupational therapy: A practical approach*. Thorofare, NJ: SLACK Incorporated.
- Connelly, C. (2015). Pediatric oncology clients undergoing stem cell transplant: The impact on occupational performance. *OT Practice*, *20*(9), 7-12.
- Garre, M.L., Gandus, S., Cesanna, B., Haupt, R., De Bernardi, B., Comelli, A., Stella, G., Vitali, M.L., Picco, P., et al. (1994). Health status of long-term survivors after cancer in childhood: Results of an uniinstitutional study in Italy. *American Journal of Pediatric Hematologic Oncology*, *16*(2), 143-52.

- Hassani, A. M., Hasani, M., & Amini, M. (2016). The comparison of participation in school-aged cerebral palsy children and normal peers: A preliminary study. *Iranian Journal of Pediatrics*, 26(3). doi:10.5812/ijp.5303
- Manav, G., & Ocakci, A. (2016). Play model for "evaluation of self-concept of children with cancer". *Iranian Journal of Nursing and Midwifery Research*, 21(2), 124. doi:10.4103/1735-9066.178227
- McLeod, S. (2018). *Maslow's hierarchy of needs*. Retrieved January 25, 2019, from <https://www.simplypsychology.org/maslow.html>.
- Mohammadi, A., Hassani Mehraban, A., Ansari Damavandi, S., Alizadeh Zarei, M., & Amini, M. (2017). Participation in daily life activities among children with cancer. *Middle East Journal of Cancer*, 8(4), 213-222. Retrieved from <http://mej.c.sums.ac.ir/index.php/mejc/article/view/572/326>
- Morey, C., Urbina, M., & Muenks, E. (2018). Development of a BMT survivorship program. *Biology of Blood and Marrow Transplantation*, 24(3). doi:10.1016/j.bbmt.2017.12.054
- National Research Council [NRC]. (2003). *Childhood cancer survivorship: Improving care and quality of life*. Washington, DC.: The National Academic Press. <https://doi.org/10.17226/10767>
- Nielsen, S. S., & Christensen, J. R. (2018). Occupational therapy for adults with overweight and obesity: Mapping interventions involving occupational therapists. *Occupational Therapy International*, 2018, 1-17. doi:10.1155/2018/7412686
- Oeffinger, K. C., Eshelman, D. A., Tomlinson, G. E., Buchanan, G. R., & Foster, B. M.

- (2000). Grading of late effects in young adult survivors of childhood cancer followed in an ambulatory adult setting. *Cancer*, 88(7), 1687-1695. doi:10.1002/(sici)1097-0142(20000401)88:73.3.co;2-d
- Palmadottir, G. (2010). The role of occupational participation and environment among Icelandic women with breast cancer: A qualitative study. *Scandinavian Journal of Occupational Therapy*, 17(4), 299-307. doi:10.3109/11038120903302874
- Silver, J.K., & Gilchrist, L.S. (2011). Cancer rehabilitation with a focus on evidence-based outpatient physical and occupational therapy interventions. *American Journal of Physical Medicine & Rehabilitation*, 90(suppl 1). Doi: 10.1097/phm.0b013e31820be4ae
- Socie, G. (2003). Nonmalignant late effects after allogeneic stem cell transplantation. *Blood*, 101(9), 3373-3385. doi:10.1182/blood-2002-07-2231
- Stevens, M., Mahler, H., & Parkes, S. (1998). The health status of adult survivors of cancer in childhood. *European Journal of Cancer*, 34(5), 694-698. doi:10.1016/s0959-8049(98)00012-4
- Stowell, M.S. (1987). Psychosocial role of the occupational therapist with pediatric bone marrow transplant patients. *Occupational Therapy in Mental Health*, 7(2), 39-50.
- Thorsteinsson, T., Helms, A. S., Adamsen, L., Andersen, L. B., Andersen, K. V., Christensen, K. B., . . . Larsen, H. B. (2013). Study protocol: Rehabilitation including social and physical activity and education in children and teenagers with cancer (RESPECT). *BMC Cancer*, 13(1). doi:10.1186/1471-2407-13-544
- Unruh, A. M., & Elvin, N. (2004). In the eye of the dragon: Women's experience of

- breast cancer and the occupation of dragon boat racing. *Canadian Journal of Occupational Therapy*, 71(3), 138-149. doi:10.1177/000841740407100304
- Unruh, A. M., Smith, N., & Scammell, C. (2000). The occupation of gardening in life-threatening illness: A qualitative pilot project. *Canadian Journal of Occupational Therapy*, 67(1), 70-77. doi:10.1177/000841740006700110
- Vonderweid, N., Beck, D., Caflisch, U., Feldges, A., Wyss, M., & Wagner, H. P. (1996). Standardized assessment of late effects in long-term survivors of childhood cancer in Switzerland: Results of a Swiss pediatric oncology group. *International Journal of Pediatric Hematology/Oncology*, 3.
- Vrkljan, B., & Miller-Polgar, J. (2001). Meaning of occupational engagement in life-threatening illness: A qualitative pilot project. *Canadian Journal of Occupational Therapy*, 68(4), 237-246. doi:10.1177/000841740106800407