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Rudessa Bedonie

Hannah Gianan

Riley Thomas

Kennedy Tooke

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Identifying the Role of Occupational Therapy in the Pediatric Palliative Care Team for Pediatric Cancer Patients

Rudessa Bedonie, OTS, Hannah Gianan, OTS, Riley Thomas, OTS & Kennedy Tooke, OTS

Department of Occupational Therapy, University of North Dakota, Grand Forks, North Dakota, United States

Please direct correspondence to Rudessa Bedonie at rudessa.bedonie@ndus.edu

Hannah Gianan at jossette.gianan@ndus.edu

Riley Thomas at riley.p.thomas@ndus.edu

Kennedy Tooke at kennedy.tooke@ndus.edu

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Rudessa Bedonie, Hannah Gianan, Riley Thomas, & Kennedy Tooke, 2022

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Focus Question

What is the role of occupational therapy in providing effective intervention during palliative care for pediatric cancer patients and their families during the transition to the end of life?

Clinical Scenario

Occupational therapy plays an essential role in the healthcare team, serving clients by using a holistic methodology to maximize the quality of life. This practice aims to assist individuals in improving independence in tasks that they need to do and promoting participation in desired activities based on their personal interests (American Occupational Therapy Association [AOTA], n.d.). Occupational therapists work alongside physicians, nurses, psychiatrists, and caregivers to come up with individualized, client-centered care plans with the goal of increasing occupational performance. Pediatric occupational therapy has been traditionally thought to exist within early interventions, sensory processing, and the school system. However, pediatric palliative care (PPC) has become a niche subspecialty in the healthcare industry, allowing occupational therapists to assume a critical role in this healthcare setting. The aim of this domain of care is to maximize the quality of end-of-life care for children diagnosed with life-threatening health conditions (Radbrunch et al., 2020).

According to the International Children Palliative Care Network, approximately 500,000 children in the United States are diagnosed with life-threatening illnesses every year, however, less than one percent of these children received palliative care (International Children Palliative Care Network [ICPCN], 2013). This subspecialty in palliative care is centered in, “improving the quality of life, maintaining the dignity, and ameliorating the suffering of seriously ill or dying children in ways that are appropriate to their upbringing, culture, and community,” (Himmelstein et al., 2004, p. 1752). This is done while also taking into account the medical, psychosocial, spiritual, and economic needs of a child and their family while preparing for the end of life. Currently, there are not many occupational therapists employed in palliative care services, making it crucial to advocate for occupational therapy services to enhance occupational participation related to self-care, leisure, and productivity during this period of time (Keesing & Rosenwax, 2011). An estimated one out of every 285 children will be diagnosed with a form of cancer before their 20th birthday (American Childhood Cancer Organization [ACCO], 2021), making PPC an important piece of pediatric oncology. Occupational therapy may not only be important in the health promotion and end-of-life preparation of a child with cancer but also in the occupational participation of their family members during this time. This profession brings a unique view regarding quality of life and well-being to the interdisciplinary team, bringing awareness to the need for occupational therapy services in the PPC setting.

This CAT will be conducted through the lens of the model of human occupation. This model is important to occupational therapy for it focuses on an individual’s volition, habituation, and performance capacity. Volition describes a person’s interests, values, and personal causation which drives their participation in their meaningful occupations (O’Brien, 2017). Having a terminal illness may change one’s perception of what is most meaningful to them, which in turn can alter their motivation to participate in varying occupations. Habituation refers to the organization of everyday activities that evolve into a person’s routines shaped by their habits and



roles (O'Brien, 2017). Terminal illness is a stage of change that often includes diminished participation in self-care, leisure, and productivity occupations, potentially impacting a person's routines, habits, and roles (Costa & Orthero, 2012). A person's occupational identity and competency make up their overall performance capacity. The ability to perform meaningful occupations often diminishes quickly when people are transitioning to the end of life, leading to a change in their sense of identity and self-efficacy. Lastly, the contexts in which a person performs their desired occupations are analyzed to get a better understanding of what supports and barriers to occupational engagement exist. These contexts included social, physical, cultural, economic, and political environments which contribute to a person's overall occupational performance (Ramafikeng, 2011). In palliative care, benefits of a supportive social and physical environment have been reported as longer life expectancy in the client, along with increased satisfaction in the end-of-life care services reported by family members (Costa & Orthero, 2012; Eva & Morgan, 2018; Marston et al., 2015; Pickens et al., 2010; Wallis et al., 2021).

Using the model of human occupation to highlight the importance of occupational therapy services within the PPC setting has brought to light the unique role of this profession in the care team. The primary focus of occupational therapy in this setting is to address areas of change in a client's life and work collaboratively with the rest of the interprofessional team to maintain the client's identity and quality of end of life. This critically appraised topic will address the gaps in PPC services and the importance of holistic, occupation-focused, and client-centered care through the lens of the model of human occupation.

Purpose Statement

As seen in the reviewed evidence base, there is a need for specialized professionals in the PPC setting. The current research outlines the importance of PPC in increasing the quality of end-of-life care, however, neglects to address where occupational therapy fits into the healthcare team. The purpose of this critically appraised topic is to explore the role and efficacy of occupational therapy as a part of the palliative care team for pediatric cancer patients and their families during the transition to the end of life.

Data Collection Procedures

The focus of this project was to identify the role of occupational therapy as a part of the PPC team and explore the efficacy of occupation-based intervention for children and their families. While a literature base on PPC exists, there is limited research connecting occupational therapy to this healthcare setting. In order to find the most relevant literature, the following phrases were used to search PubMed, CINAHL, EBSCOhost, and the UND SMHS library. The phrases used were ("pediatric" or child*" AND "palliative care"), ("palliative care" AND "occupational therapy"), ("palliative care" OR "end of life care" AND "best practices" AND "treatment" AND "parent" Or "caregiver"), ("pediatric palliative care" AND "cancer" NOT "systematic review"), and ("Palliative" AND "Palliative Care" OR "Children" AND "Pediatric" OR "Occupational Therapy" AND "Occupation").

After the initial research, there were 52 articles obtained. While developing the focus question, six articles were chosen to synthesize the literature for the critically appraised topic. These articles were closely reviewed for their level of evidence and were all determined to be



Level N/A due to their qualitative design; three cross-sectional surveys (Eva & Morgan, 2018; Jasemi et al, 2008; Wallis et al., 2021), two semi-structured interviews (Keesing & Rosenwax, 2011; Marston et al., 2015), one grounded theory (Papadatou et al., 2021), and one ethnography (Pickens et al., 2010). Additionally, some articles were obtained for background and statistical information to gain a better understanding of the topic. All articles reviewed were related to the experiences of individuals through palliative care from various viewpoints including patient, parent, and interdisciplinary team members' perspectives. Thirty-seven of the articles were excluded from the study after closer analysis of the types of study done and narrowing of the focus question to look at PPC in relation to childhood cancer. Systematic reviews were excluded from this CAT, while articles that did not have aspects relating to holistic care, decision making, or family involvement were also excluded. Of the 15 articles included, each article contained at least one aspect to support the need for occupational services in PPC or the efficacy of occupation-based interventions. All articles reviewed were published in English. Articles with specific background and statistical data were also used to supplement the findings in the articles reviewed.

Literature Synthesis

The purpose of this CAT is to explore and define the role of occupational therapy in the pediatric palliative care team in providing effective intervention for pediatric cancer patients and their families during the transition to the end of life.

Using a Holistic Care Approach

The first theme that was established from the review of the evidence base was the need for occupational therapy and holistic care approaches in pediatric palliative care. A holistic care approach refers to providing health care for clients that is based on an understanding of multiple dimensions, including physical, psychological, emotional, and spiritual concepts (Jasemi et al., 2017). The purpose of this article was to define holistic care using a hybrid model to demonstrate comprehensive care and improve the patient's condition. Occupational therapy's core philosophy is focused solely on the use of occupation to promote independence, health, and wellbeing for all populations (Keesing & Rosenwax, 2011). Through a holistic care approach, occupational therapy evaluates the client through a lens that focuses on volition, habituation, and performance capacity, which are the key aspects of the model of human occupation (O'Brien, 2017). These aspects identify the client's motivation, routines, the experience of their performance, and environments.

As described by Pickens et al., the holistic approach takes into consideration the whole person by recognizing both body and mind while understanding all factors that may affect their quality of life and well-being. Disruptions to occupational participation seen during the end-of-life can impact a person's roles, habits, and routines, which in turn may distort their sense of identity and self-confidence. The role of occupational therapy is to provide unique care services for the PPC population using specific interventions to improve quality of life, independence, autonomy, function, and dignity until the end of life (Pickens et al., 2010). Pickens et al. (2010) aimed to understand the nature of the occupational experiences of five family caregivers and 25 non-family caregivers of dying patients. The focus of palliative care is to maximize the quality of



life while providing support and comfort to both clients and their families in their last days. The evidence base provides insight into the importance of utilizing occupational therapy services in a client's care plan to assist in filling the gaps in services that other healthcare staff cannot address.

Occupational therapists obtain the skills to examine changes caused by illness or disease that limit occupational engagement in patients. Palliative care allows occupational therapy's philosophy to be utilized in the setting and implemented into the daily experiences of clients dying within the palliative phase (Keesing & Rosenwax, 2011). Keesing and Rosenwax (2011) aimed to gain insight into the experiences and occupational needs of 12 primary caregivers of palliative care clients along with 18 occupational therapists. Making decisions during the palliative phase is not an easy transition for the client and family or caregivers. Many clients prefer to be transferred home, and because of this, occupational therapy serves as a valuable team member in this setting. Occupational therapy evaluates the home before the approval of discharge to ensure proper care can be given and address any potential risks or barriers that may be encountered within the home care setting (Marston et al., 2015). Occupational therapy can also educate clients with information about what to expect during their end-of-life care in terms of independence and well-being. Occupational therapists are able to, "provide the means for a good death" (Pickens et al., 2010, p. 237), alongside the support of their family members and caregivers. From an occupational therapy perspective, independence and well-being may manifest in many ways. For pediatric palliative care clients, this will most likely take the form of the occupational therapist providing intervention that incorporates play and leisure activities for the child. The goal here would be to bring joy and fun into the child's life within the restrictions of their disease. Occupational therapy can also help to prepare the child and their families for their death by employing therapeutic use of self and providing space for families to discuss this time in their lives. Topics such as expected health status progression and the needs of each family member can be discussed during this time. The role of occupational therapy in pediatric palliative care is to address the needs of the client beyond what is necessary to treat them medically. By addressing their needs as a person, rather than just a patient, occupational therapists can foster an environment that gives the dying person a sense of normalcy and contentment in this period of their life. All in all, occupational therapy is essential for recipients of PPC and their families; it views palliative care in a holistic and multi-faceted manner, therefore allowing for the maximization of quality of end of life.

Joint Decision-Making

The next theme that emerged from the literature was that there were incidences of difficulties with joint decision-making between physicians, patients, and their families. It was indicated that there was a need for a more efficient and equal decision-making process when determining the PPC setting, the course of treatment, and who would be a part of the care team. A successful decision-making process involves collaborative and professional communication that facilitates education in all factors of diagnosis. Decision-making is a crucial component of PPC due to the length of the process and determines how the patient will be cared for. Factors that can impact the decision-making process can include how well the setting will accommodate their needs, the caregiver's competency, and professional confidence in the plan of care



(Papadatou et al., 2021). Papadatou et al. (2021) used a semi-structured interview to look at factors affecting the decision of end-of-life care and the death of 36 bereaved parents of 22 children who died at home or in a hospital. These factors can impact the decision of whether to receive care at home or at a hospital as the setting for end-of-life care. In the decision-making process, parents are best supported when information is presented clearly, and they are given opportunities to enhance their competency to care for their child at home (Papadatou et al., 2021). Providing end-of-life care is not an easy task and weighs heavily on the health of the caregiver. This may lead to burnout and therefore impact the clarity of decision-making for their loved one. The preference for care setting is typically at home, but the family often chooses hospice care so that the patient has professional support and their needs are met (Pickens et al., 2010). The decision-making process allows occupational therapy to play a supporting role in discharge planning from a hospital setting to a home-based PPC setting. Occupational therapy can provide education and support during the transition to accommodate the needs of the patient and family. In Eva and Morgan (2018), the aim was to determine the scope of occupational therapy services in palliative care by gaining insight from 237 occupational therapists and they found that occupational therapy had a key role in facilitating discharge planning to manage self-care through education, equipment prescription, and symptom management for patients and caregivers. Although the role of occupational therapy in the decision-making process is not clearly defined, utilizing a client-centered approach can be beneficial to the patient and their families, for it verifies that their input is being respected and heard. Occupational therapy puts the patient at the center of the decision-making process, where the patient and their family are listened to, advocated for, and provided with choice (Marston et al., 2015). The decision-making process has many factors to consider before concluding how and where PPC will be carried out. Overall, the role of occupational therapy is valuable in decision-making during the PPC process due to the holistic and client-centered approach that aims to increase the quality of end-of-life.

Family Involvement in PPC

The third theme that surfaced was the aspect of familial and caregiver involvement in the PPC process. This theme was brought up in discussions about addressing the family's needs through the end-of-life care process, the occupational therapist's role in familial occupational participation, and how occupational therapy can assist in the lived experiences of families going through the PPC process. According to Pickens et al. (2010), a theme that was apparent was providing a sense of normalcy without overshadowing the needs and decisions of the caregivers. Many families and caregivers feel a sense of uncertainty when discussing the decisions regarding their children's occupational needs through the PPC process. This uncertainty often leads to skepticism by the caregiver about the overall occupational health and well-being of their children. Additionally, Papadatou et al. (2021) discussed that the decisions regarding the location of care are an essential factor when determining the end-of-life care for a family's child, which in turn can impact the overall family dynamic. These decisions often impact both personal and interpersonal decisions, and it is important that these families have support when it comes to decisions about their children's care. Occupational therapy can play a supporting role in the decision-making process regarding PPC and family involvement by being transparent and honest about what the expectations are for familial and caregiver competency. Regarding an



occupational therapist's role in decision-making during the PPC process, it is vital to provide the best care while upholding the profession's ethical standards. Additionally, Pickens et al. (2010) discussed the various perceptions of how occupational therapy is essential for providing a holistic approach to PPC. Promoting and reflecting on these concepts will allow occupational therapists to address the needs of families and caregivers during the PPC process.

Discharge Planning

Discharge planning is commonly found within the PPC process and allows for a more defined role for occupational therapy as they assist with transitioning to end-of-life care. According to Marston et al. (2015), it was found that the themes of shared roles in discharge planning are essential for palliative care and the perceived benefits of the modification for discharge to the natural home environment directly fall into the scope of practice for occupational therapy. With occupational therapy not having a defined role in palliative care, it is crucial to understand that discharge planning to home is directly related to end-of-life care. Being able to adapt and cope with unexpected events, along with taking responsibility for understanding the familial and caregiver involvement, will allow for a more defined role for occupational therapy support and resources for PPC. Understanding occupational therapy's professional and personal functions allow for a more effective discharge plan, which will increase the collaboration of occupational therapy in PPC and end-of-life care.

Summary

A review of the literature showed that most articles relating to PPC identified that a patient's diagnosis was predominantly managed by the primary physician and the patient. The evidence showed that the gap in the literature focused on the role of specialized services, like occupational therapy, in PPC during the transition to the end of life, however, did not explicitly discuss what the role of occupational therapy was. In our research, four main themes emerged relating to the role of occupational therapy: (1) a lack of the utilization of a holistic care approach, (2) difficulties with joint decision-making, (3) an insufficient family involvement in the PPC process, and (4) the modifications of discharge planning. It was determined that these gaps are all within the scope of practice for occupational therapy, making it essential for their role in the PPC team to be defined and recognized.

Clinical Bottom Line

The purpose of this critically appraised topic is to evaluate and identify the role of occupational therapy in the pediatric palliative care (PPC) team for children with cancer during the transition to the end of life. While occupational therapy is a part of many healthcare teams, there is little evidence to outline the specific roles of this practice in relation to PPC. Therefore, it is important to not only identify what elements of PPC fall within the scope of occupational therapy practice but also to identify what occupation-based interventions are most pertinent in this practice setting. The evidence base outlined many gaps in the PPC process, including the lack of holistic care, difficulty addressing the multifaceted processes of joint decision-making, and limited familial involvement in PPC (Eva & Morgan, 2018; Keesing & Rosenwax, 2011; Papadatou, 2021; Pickens et al., 2010; Wallis et al., 2021).



The healthcare standards of PPC often follow those of adult palliative care services in the sense that the diagnosis is primarily managed by the physicians, nurses, and the patient. It is important to note that PPC is unique for pediatric clients in three main ways: life-threatening illness is not “normal” or expected for most children, medical decisions are ultimately made by the parents/caregivers, and PPC should involve healthcare professionals that address childhood occupations, like play. The interprofessional team is crucial in managing the symptoms of cancer and its associated treatments, discharge, and post-hospital planning, as well as facilitating education on all factors for decision-making. In a number of cases, occupational therapy was identified as a part of the healthcare team that was critical in the decision-making process due to the holistic approach to care and incorporation of the family in the PPC process (Eva & Morgan, 2018; Marston et al., 2015; Papadatou, 2021; Pickens et al., 2010). Decisions on the care setting, place of death, disease progression considerations, and post-death planning are multi-faceted determinations that occupational therapy may be a part of. Depending on the given PPC setting, occupational therapy may take on the role of symptom management, family education, and overall occupational participation.

Occupational therapy plays an important role within the multidisciplinary approach in PPC in the means of using a holistic care approach. Both occupational therapy and PPC share the philosophy of focusing on the importance of understanding multiple components of the client when administering care. The holistic approach involves taking into consideration a person’s physical, mental, spiritual, and social components that can be impacted due to changes from illness or disease. The services provided by occupational therapists can improve the care experienced by clients during the end-of-life stages. Although making the decision to progress into palliative care can be very difficult for both the client and their family, the transition can be made easier with the use of occupational therapy services. With future research, occupational therapy has an opportunity to create predominant roles in the area of end-of-life care by individualized therapy, centered around meaningful occupations to allow the client to maintain independence and well-being until the end of life.

The decision-making process is an important aspect of providing PPC that involves the caregiver, patient, and a team of professionals. Quality end-of-life care can either happen at home or in a hospital, and the decision relies on the needs of the patient and the ability of the setting to accommodate those needs. It is also dependent on the competencies of the caregivers and the interprofessional team to implement the care plan. Providing PPC is a challenging task that can affect the health and well-being of the caregiver which is another factor that plays a role in the decision-making. Because many people are involved in the decision-making process, the role of occupational therapy is not clearly defined but occupational therapists can provide support during discharge planning from a hospital-based setting to home-based PPC. Occupational therapy can provide management of self-care through education and symptom management. Occupational therapy uses a client-centered approach which is beneficial to the decision-making process because the patient and family are provided with a choice and are not overshadowed. Future research can provide evidence to support a clearly defined role of occupational therapy in the decision-making process for PPC to provide quality end-of-life.

When occupational therapists provide PPC, it is essential to understand familial and caregiver involvement by addressing the family's needs throughout the process. Occupational



therapists can advocate for the family's occupational participation and be able to adopt a defined role on how occupational therapy might support the lived experiences of the caregiver and/or family members. The PPC process is complex and difficult for all parties involved. Being able to incorporate the familial perspective on how occupational therapists and other healthcare professionals can support the family's needs may aid in providing better quality care. Promoting normalcy without overshadowing the needs of the family and allowing for decision-making from the caregiver may provide a more definitive role for occupational therapists in the PPC process. In addition, it is essential to gain perceptions from caregivers to increase familial involvement in the PPC process to provide the best quality of life care and well-being while preparing for end-of-life care.

Conclusion

All in all, occupational therapy plays an important role in the PPC process because occupational therapists are trained to provide holistic care approaches which impact joint decision-making and take into consideration the involvement of a client's family. A number of qualitative studies were conducted on healthcare teams, bereaved parents of children who received PPC, and palliative caregivers which indicated that occupational therapy intervention was beneficial in the transition to the end of life (Eva & Morgan, 2018; Keesing & Rosenwax, 2011; Marston et al., 2015; Papadatou, 2021; Pickens et al., 2010; Wallis et al., 2021). The concerns addressed in these studies stipulate a gap in the current PPC practices, with open-ended solutions to the problems. The answer or the solution to many of these gaps have the potential to fall into the skills and competencies of an occupational therapist, making it essential for the role of occupational therapy in PPC to be defined. Due to a lack of evidence outlining the role of occupational therapy in the PPC process, it is recommended that further research into the type of care fall within the scope of practice for occupational therapy.



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