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Occupational Therapy in Palliative Care: Incorporating Meaningful Occupations and Education Programs for Occupational Therapists

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Occupational Therapy in Palliative Care: Incorporating Meaningful Occupations and Education Programs for Occupational Therapists

Focus Question

How can we improve quality of life for adults 21 years of age or older in the palliative care setting by identifying the role of the occupational therapist, implementing specialized education for the OT in this setting, and engaging clients in meaningful occupations?

Case Scenario

Care that is specifically designed for those with a terminal illness is known as palliative care. The main goal of palliative care is to give clients comfort and lessen symptoms, improving quality of life (Center to Advance Palliative Care, 2014). According to the Center to Advance Palliative Care (2014), approximately six million adults could benefit from palliative care. Of this number, a majority are 21 years or older, which is why we chose this as our population. The need for palliative care has continued to expand as the population gets older and the rate of diseases increases (World Health Organization, 2020).

The Center for Disease Control and Prevention (CDC) defines the quality of life (QOL) as a “broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life” (Center for Disease Control and Prevention, 2018, “What is quality of life” section). Due to the need for improving the quality of life for palliative care patients, occupational therapy (OT) has the potential to work with individuals to create meaningful occupations within their environment. Based on the literature reviewed for this CAT, the potential has not yet been achieved since little has been studied and defined about an OT’s role within the palliative care setting. The American Occupational Therapy Association (2020) defines occupational therapy as “the therapeutic use of everyday life occupations with [the client] for the purpose of enhancing or enabling [their] participation” (p. 1).

For the sake of this CAT, we reviewed aspects of end-of-life care including implementing education programs for occupational therapists and incorporating meaningful occupations for clients. We will be defining occupations as “activities that bring meaning and purpose to a person's life,” including the things “a person needs, wants and is expected to do” (AOTA, 2020, p. 7). We will further define the occupation of leisure as the “nonobligatory [activities] that [are] intrinsically motivated and engaged in during discretionary time” (Parham & Fazio, 1997, p. 250, as cited in AOTA, 2020).

Although the role of an occupational therapist is often overlooked, hospice care has created a more solidified expectation of OT’s. An occupational therapist's main goal is to preserve independence for their clients, regardless of restrictions, rather than rehabilitate them (Russell & Bahle-Lampe, 2016). Rather than looking specifically at activities of daily living (ADLs) and instrumental activities of daily living (IADLs), the best way to support the occupational demands of an individual with a terminal illness is to “broaden [the] view of end-of-life occupations” (Chow & Pickens, 2020, p. 8). In a phenomenological study by Badger et al. (2016), it was concluded that occupational therapy services increased safety rather than engaged clients in meaningful occupations.

From an OT’s perspective, end-of-life care can be an emotionally draining setting to work in, making it extremely difficult for a first-time occupational therapist. A lot of training in this setting type is done on the job through interaction with coworkers and clients, and various



workshops. This type of training is extremely time consuming, but could be avoided if therapists were provided the correct education for end-of-life care (Davis et al., 2012).

An important part of this type of care is addressing every aspect of the transactional relationship, including the person, the environment, and the occupation (Law et al., 1996). Baptiste (2017), and Law et al. (1996) explained that the Person-Environment-Occupation model focuses on finding and understanding the best fit between the person, environment, and occupation. Occupational performance is reached when all three of these align (Law et al., 1996). When looking through the Person-Environment-Occupation (PEO) lens within palliative care, it's important to align the occupation for optimal fit within the environment and person (Law et al., 1996).

When looking at the person aspect of the PEO model, the person in palliative care experiences a significant disruption or disengagement in occupation as their usual roles and activities shift to end-of-life concerns (Kessing & Rosenwax, 2011; Law et al., 1996). As the client declines, the physical environment can inhibit their participation in meaningful occupations; environmental changes can help support individuals in their autonomy and performance (Cooper & Kite, 2015, as cited in Chow & Pickens, 2020). When the environment is supportive, the client is most likely to engage in occupations that will further an optimal fit (Law et al., 1996). As for occupation, individuals in palliative care have reported disruptions in daily routine, valued occupations, and social isolation (Kessing & Rosenwax, 2011). With occupational deprivation as the primary concern, it is essential for OT's to solidify their role within palliative care to further enhance end of life happiness. This will enhance occupational performance with the fit between person, environment, and occupation being met as seen through the PEO lens (Law et al., 1996).

Purpose Statement

Based on the literature reviewed for this critically appraised topic (CAT), end-of-life care has become a more popular setting, and healthcare workers are beginning to see the need for occupational therapists. Due to the undefined role of an OT in this setting, it is difficult for the client to be provided with the best care that increases their quality of life near death, as well as inadequate training for how to address intervention. The issue found within palliative care is that clients are not provided the opportunity to engage in the meaningful activities that bring them joy. The purpose of this critically appraised topic was to answer the question: How can we improve quality of life for adults 21 years of age or older in the palliative care setting by identifying the role of the occupational therapist, implementing specialized education for the OT in this setting, and engaging clients in meaningful occupations?

Methodology

Databases of scholarly literature were searched to answer the clinical question raised for our critically appraised topic: "How can we improve quality of life for adults 21 years of age or older in the palliative care setting by identifying the role of the occupational therapist, implementing specialized education for the OT in this setting, and engaging clients in meaningful occupations?" When first considering the setting of palliative care, we noticed the lack of focus on meaningful activities within the environment. Our goal was to understand how this decrease in meaningful occupations is related to the absence of defined roles for an occupational therapist in palliative care. Other topics covered within our research included education programs, personal experiences of patients and therapists, the importance of



meaningful occupation, and relation to quality of life. After looking at occupational therapists' perspectives on lack of education, we were curious if implementing a program for the palliative care setting would increase the use of meaningful occupations in therapy, thus improving client quality of life.

We decided to use the Person-Environment-Occupation (PEO) Model to guide our research. Articles used were found on multiple databases including Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase, PubMed, the American Journal of Occupational Therapy (AJOT), and the Advanced Premier Search. All of these databases provided valid and reliable scholarly articles about our topic of adults in palliative care and the role of occupational therapy. The terms used to search these databases can be found in Table 1.

Table 1
Key Terms Searched

Palliative Care	End of Life Care	Hospice	Comfort Care
ADLs	Leisure	Happiness	Depression
Occupational Therapy	Intervention	Quality of Life	Occupation
Adults	Elderly	Environment	Studies

The information from our articles was recent with most taking place within the last 15 years. It was found that there was not enough literature to have a smaller time period. All of the articles were about palliative care or some other end-of-life setting, as this was our topic of interest. We ensured articles included information about occupational therapy within this setting. Articles were included if they referenced leisure activities or meaningful occupations within palliative care as well. The information gathered from these articles will create a baseline of what is known about occupational therapy within palliative care, and facilitate further development of research.

Study Parameters

A limitation found during our literature search was the lack of recent studies pertaining to occupational therapy in the palliative care setting. Another limitation was the lack of universal language for 'palliative-care'. For example, other vocabulary such as 'end-of-life care', hospice, and alternative terms. Exclusion criteria included any population that was under the age of 21, otherwise known as pediatrics. If the article required a paid subscription to access it, then it was excluded from our search. Lastly, any articles not in the English language were not used. Inclusion criteria consisted of the perspectives of adults in palliative care and occupation, occupational therapy, and the role expectations or viewpoints of occupational therapists within the setting of palliative care. This information helped us further contribute evidence to support the implementation of an education program, defining the role for occupational therapists within palliative care, and using meaningful occupation as intervention.



Types of Articles Reviewed

As a cohesive group, we had a total of 37 articles and 16 were selected for additional review. From the 16 articles, eight were level NA (Badger et al., 2016; Chow & Pickens, 2020; Davis et al., 2012; Kessing & Rosenwax, 2011; Mueller et al., 2021; Russell & Bahle-Lampe, 2016; Talbot-Coulombe & Guay, 2020; Tavemark et al., 2019), One article was level IV (Knecht-Sabres et al., 2019). Four established groups associated with occupational therapy and other health care disciplines were used to define complex terms and gather more supporting evidence (AOTA, 2020; Center for Disease Control and Prevention, 2018; Center to Advance Palliative Care, n.d; Center to Advance Palliative Care, 2014; WHO, 2020). Two educational resources were referenced to support the use of theories within the occupational therapy profession (Baptise, 2017; Law et al, 1996).

Table 2
Types of Studies Used for Critically Appraised Topic

Study Design	Number of Articles Used	Citations
Critical History Analysis	1	(Russel & Bahle-lqa,pe, 2016)
Grounded Theory	1	(Kessing & Rosenwax, 2011)
Mixed Methods	1	(Knecht-Sabres et al., 2019)
Phenomenological Research	2	(Badger et al., 2016; Davis et al., 2012)
Qualitative Descriptive Study	1	(Tavemark et al., 2019)
Retrospective Study	1	(Muller et al., 2021)
Scoping Review	2	(Chow & Pickens, 2020; Talbot-Coulombe & Guay, 2020)
Level of Evidence		
IV	1	(Knecht-Sabres et al., 2019)
NA	8	(Badger et al., 2016; Chow & Pickens, 2020; Davis et al., 2012; Kessing & Rosenwax, 2011; Mueller et al., 2021; Russell & Bahle-Lampe, 2016; Talbot-Coulombe & Guay, 2020; Tavemark et al., 2019)

Synthesis

Theoretical Base

The main goal of this critically appraised topic (CAT) was to determine an occupational therapist's role in palliative care to improve the interventions used to increase quality of life for adults' ability to engage in meaningful occupations. The CAT was looked at through the theoretical model of Person-Environment-Occupation (PEO) (Law et al., 1996). Doing so allowed us to look at every aspect of the person, environment, and occupation to provide a holistic, occupation-based approach (Law et al., 1996). The literature provided evidence indicating occupational therapists had limited opportunities to focus on the dying individual's meaningful occupations due to a lack of time and resources. Lack of resources and time has caused OTs to have difficulty addressing leisure activities and other meaningful occupations (Kessing & Rosenwax, 2011). Managing all aspects of PEO would provide an optimal fit for the client's needs even towards the end of life (Law et al., 1996).

Impact of Occupation in Palliative Care

Occupational therapy in palliative care addresses the changes in a person and environment to optimize their engagement in occupations (Mueller et al., 2021). Researchers found in a retrospective study and critical historical analysis study that engaging in meaningful occupations is important for those in palliative care, a majority of which prioritize socialization, purpose, and reflecting on life (Mueller et al., 2021; Russell & Bahle-Lampe, 2016). Occupation in end-of-life care has other positive impacts on those who are able to engage. Learning how to manage stress, symptoms, and coping improves a client's mental health and can increase their ability to engage in occupations (Mueller et al., 2021).

Role of an Occupational Therapist in Palliative Care

As in most healthcare settings, palliative care consists of an interdisciplinary team. End-of-life care focuses on viewing the process of death as a positive experience and accepting it as part of life (Russell & Bahle-Lampe, 2016). The overall goal in palliative care is an increased quality of life, and the occupational therapist assists in that by focusing on physical, social, psychological, and spiritual needs of the patient and their family (Knecht-Sabres et al., 2019). An OT does this by providing hope through therapeutic use of self and implementing meaningful occupations into a client's routine (Mueller et al., 2021). Other techniques often used in end-of-life care are energy conservation, transitions between activities, and education to others on safety, transfers, and operation of healthcare devices (Russell & Bahle-Lampe, 2016). What makes an occupational therapists' role unique is how they alter their interventions to align with the patient's interests and needs (Tavemark et al., 2019).

Usually, an occupational therapist's knowledge of their role in end-of-life care is lacking. In a mixed method study conducted by Knecht-Sabres et al. (2019), it was found that there were five different aspects of palliative care where an OT was underutilized. These included "lack of reimbursement, timing of referral, knowledge of the role of OT, refusal of services by family members, and lack of OT presence in this setting" (Knecht-Sabres et al., 2019, p. 386). It is thought that a consistent presence of occupational therapy in hospice and palliative care for clients would provide the opportunity for clients to reach their end-of-life goals no matter what their life expectancy may be (Knecht-Sabres et al., 2019).



Occupational Therapy Education Programs

The Need for Occupational Therapist Training

From literature reviewed for this CAT, it was concluded that occupational therapy is already very misunderstood by those who are unfamiliar with it, but when a therapist is unqualified for the setting they are in it can create a greater misunderstanding of the profession. Hospice clients have expressed that they would like to have occupations incorporated more in their care, as this is often overlooked (Chow & Pickens, 2020). Occupational therapy education already gives students the tools and strategies needed to help individuals in palliative care since it teaches the holistic approach of how the person fits within the environment and their occupational needs. Specifically, addressing the occupational needs of clients in end-of-life care is something that occupational therapists excel in (Chow & Pickens, 2020).

Despite this knowledge, occupational therapists have expressed that they feel a lack of training in how to integrate into the palliative care setting (Connor et al., 2002; Dawson & Barker, 1995, as cited in Talbot-Coulombe & Guay, 2020). Various topics are missing within the curriculum, such as “philosophy of palliative care, grief, bereavement, loss, and achieving a good death” (Talbot-Coulombe & Guay, 2020, p. 617). In order to gain this, knowledge such as self-reflection, exposing students to the harsh realities of end-of-life care, and providing a safe learning environment should be implemented (Talbot-Coulombe & Guay, 2020).

Benefits of Education Programs

Incorporating an education program designed specifically for OT’s and students going into palliative care could do a lot to prepare them for the setting and learning how to embody the role of an occupational therapist in that interdisciplinary team. Currently, ADLs and IADLs are considered the main occupations in end-of-life care. Implementing an education program would teach students to explore a client’s role and their interests beyond the ADLs and IADLs (Chow & Pickens, 2020). This could be done by using strategies such as “guest speakers, guidelines for clinical case studies, exposure to dying clients, self-reflection, and role play” (Talbot-Coulombe & Guay, 2020, p. 616). Education programs prioritizing occupational therapists in palliative care would allow an expansion of the influence of occupation and engagement during the last stages of life no matter what abilities the client may or may not have (Chow & Pickens, 2020). By including information on occupational therapy in palliative care education programs we would be able to help OT’s clarify their role within the setting and learn how to advocate for their unique role on the interprofessional team (Talbot-Coulombe & Guay, 2020).

Summary

There were 37 articles initially reviewed and 16 were chosen to review further. The topics of the articles chosen included occupational therapy’s role in palliative care, lack of education on the role of OT in the setting, and importance of incorporating meaningful occupations with patients. The main points found between the articles included:

- Palliative care can be a difficult setting for an occupational therapist to work in. There is often a lack of education and support for OT’s, and the work is emotionally draining (Davis et al., 2012).
- A barrier to client success is often when a persons’ environment inhibits their performance in their occupations. Adapting the environment can increase a clients’ participation in occupations (Cooper & Kite, 2015, as cited in Chow & Pickens, 2020).



- Occupational deprivation is an issue of concern for clients in palliative care. The goal is for them to remain as independent as possible, participate in their meaningful occupations, come to terms with their death and fulfill their purpose (Chow & Pickens, 2020; Kessing & Rosenwax, 2011; Russell & Bahle-Lampe, 2016).
- Occupational therapists' purpose in palliative care is often underrepresented. As a profession, there is a need for advocacy, demonstration, and research. Occupational therapists are a valuable part of the palliative care team and that needs to be represented and communicated (Kessing & Rosenwax, 2011; Talbot-Coulombe & Guay, 2020).
- Education programs about the importance of OT in palliative care and what can be done is important and valuable (Chow & Pickens, 2020; Talbot-Coulombe & Guay, 2020).

The goal of this critically appraised topic was to research the impact of occupational therapy-based services in the palliative care setting and how these would improve client's quality of life. Our research indicated that education programs for OTs about the importance and role of occupational therapists in palliative care is essential. These programs could help therapists advocate for the program and better the lives of clients.

Clinical Bottom Line

How can we improve quality of life for adults 21 years of age or older in the palliative care setting by identifying the role of the occupational therapist, implementing specialized education for the OT in this setting, and engaging clients in meaningful occupations?

There is a lot of literature that addresses the unknown of occupational therapy in the setting of palliative care. Not only are clients unsure of the goal for occupational therapy, but there is also confusion between healthcare professionals and what their expectations should be of an OT. To understand how the occupational therapy role can be further established, the PEO model was used to look at the person, environment, and occupation within the palliative care setting (Law et al., 1996). The possibility of implementing an education program created specifically for occupational therapists wanting to work in an end-of-life care setting was also explored. Current literature reviewed for this CAT showed that there is little preparation for OTs working in this setting and that many therapists felt as though first-year therapists would not be able to excel with the lack of preparation (Talbot-Coulombe & Guay, 2020).

The current models of occupation seem to be ill-fit for the palliative care setting. Since palliative care is not focused on long-term rehabilitation, therapists focusing on prolonged engagement in occupation is unrealistic (Holland & Tigges, 1981). Instead, short term models are the ones that should be utilized in end-of-life. This includes the ideas of being and becoming that Wilcock used to define occupation and promoting the idea of occupational roles even in hospice or palliative care settings (Russell & Bahle-Lampe, 2016). After reviewing the research, we found many aspects of intervention in a palliative care setting are lacking in OT education programs. Incorporating things such as exposure to death, self-reflection, and role play could increase the confidence in first year occupational therapists (Russell & Bahle-Lampe, 2016).

Another aspect of occupational therapy within palliative care that was explored for this critically appraised topic was the incorporation of meaningful activities in client interventions. Currently, a lot of practitioners focus on activities of daily living and disregard the wants and passions of the client. If occupational therapy interventions focused on engagement in meaningful activities, happiness and quality of life would increase in those who are in palliative care (Chow & Pickens, 2020).



Based on articles reviewed, the idea that occupational therapists' role within the palliative care setting has yet to be defined. This has created a negative impact on the care they are able to give their patients since it is unclear what is expected of them (Connor et al., 2002; Kessing and Rosenwax, 2011; Tavemark et al., 2019). Articles reviewed showed a need for clarity in occupational therapist training, even though this has not been specifically researched within the palliative care setting. Taking what we know from other settings of occupational therapy, we can apply that knowledge and see a need for creating an educational program designed specifically for occupational therapists working in end-of-life care. Although there is a lack of evidence of the effectiveness of this for OT services in the palliative care setting, all current findings are still relevant to palliative care specific training programs. If students were properly trained for providing interventions in this setting they would be more prepared and equipped with reliable resources which ultimately leads to delivering better care and an increase in patient quality of life. Based on the articles reviewed, if the role of an occupational therapist in end-of-life care was defined and OT's were better educated for this setting, patients would be allowed to engage in occupations that are meaningful to them, increasing their quality of life (Chow and Pickens, 2020; Connor et al., 2002; Kessing and Rosenwax, 2011; Tavemark et al., 2019).



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