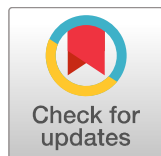


OT Forum



Occupational Therapy's Opportunity to Impact Care at the End of Life

Macey Genzlinger & Mackenzie L. Feldhacker

University of South Dakota

To cite this article: Genzlinger, M., & Feldhacker, M. L. (2023). Occupational therapy's opportunity to impact care at the end of life. *Student Journal of Occupational Therapy*, 4(1), 24-28.

<https://doi.org/10.46409/001.PYGH3803>

Conflict of interest statement: The authors declare no competing interests.



This article is licensed under the [Creative Commons Attribution, Non-Commercial license](#) (CC-BY-NC 4.0). You are free to copy and distribute the work under the following terms: You must give appropriate credit and include a link to the original work. This cover page or a standard citation including the DOI link will meet this term. You must also include the link to the CC-BY-NC license. You may not use the material for commercial purposes.

Abstract

Navigating and managing the end of life can be difficult. The focus of occupational therapy in care at the end of life is to aid the patient and caregiver through these challenges by facilitating improved safety, comfort, and quality of life through the participation in meaningful occupations. Despite the ways that occupational therapy benefits these patients, occupational therapy involvement in care at the end of life is misunderstood, under-researched, and underutilized. There is a general lack of awareness regarding this topic and a stigma that occupational therapy focuses only on rehabilitation and therefore does not belong in care at the end of life. To combat these issues, there needs to be additional education and training for all healthcare professionals, including occupational therapy practitioners, about occupational therapy's role in care at the end of life. Occupational therapy professionals in this area of practice must strive to educate others and advocate for their role to improve the understanding of this practice area and thus positively impact more patients and families.

Keywords: occupation, occupational therapy, end of life, quality of life

End of Life

Dying affects patients physically, cognitively, socially, emotionally, and spiritually. There is typically physical or cognitive decline at the end of life, and patients can be left socially isolated as a result (American Occupational Therapy Association [AOTA], 2017; von Post & Wagman, 2019). There are also various emotions coming from the patient regarding the dying process, and religion or spirituality is a common avenue to turn to during this time (Martin & Herkt, 2018; Mills & Payne, 2015). Due to decline, isolation, and emotions, there is a decreased ability to engage in meaningful occupations at the end of life which results in occupational role loss and occupational deprivation. Since occupational engagement provides meaning to life, a loss of participation in occupations leads to a decreased quality of life (Hammill et al., 2014; Hammill et al., 2019).

Occupations, and thus occupational therapy, are relevant at end-of-life, as people do not stop living once they are diagnosed or once they begin palliative or hospice care. People at the end of their lives can still participate in many of their typical occupations such as activities of daily living, rest and sleep, leisure, and social participation occupations; however, these individuals may also participate in occupations unique to this life stage. Life review, legacy building, bucket list items, and accepting decline and death are primary examples of meaningful occupations that are unique to end of life (AOTA, 2015; Essential Yeh & McColl, 2019; Hammill et al., 2019). This combination of typical and new occupations demonstrates the dichotomy of dying as these people attempt to affirm their life by engaging in occupations while preparing for death and finding closure (Essential Yeh & McColl, 2019; Hammill et al., 2019). Occupational therapy can play a key role in fostering engagement in both pre-existing and new occupations at the end of one's life.

Care at the End-of-Life

Care at the end-of-life is characterized by care services typically received while in hospice or palliative care. A person is eligible for hospice care if they have a life-limiting diagnosis and a doctor determines they have less than six months to live

(National Institutes of Health [NIH], 2021). Hospice care provides non-curative measures to improve quality of life for patients and caregivers (NIH, 2021). Palliative care can provide curative and non-curative measures that can be received during any stage of the condition with a focus still to improve quality of life (NIH, 2021). The National Hospice and Palliative Care Organization (2021) reported that 1.61 million people utilized hospice services in the United States in 2019, a 3.9% increase from the previous year. This number is expected to continue rising due to the aging of the population and more people living with chronic diseases (Chow & Pickens, 2020), making it vital that healthcare professionals merge to this area of practice.

Underutilization and Knowledge Gaps

Although occupational therapy could offer many benefits to care at the end of life, it is minimally utilized. Mueller et al. (2021) found from the National Home and Hospice Care Survey in 2007 that 87.3% of participants required assistance with activities of daily living, but only 9.9% received the help they needed. Additionally, only 10.6% of all the participants received any occupational therapy at all (Mueller et al., 2021). There is likely an underutilization of occupational therapy services in care at the end of life because knowledge gaps exist regarding the role occupational therapy should play in this setting (Knecht-Sabres et al., 2019). Occupational therapy is traditionally known to promote functional independence. Because this is not a focus for patients at the end of life, the goal switches from occupational performance to occupational participation (AOTA, 2017; Chow & Pickens, 2020). Many healthcare professionals are not aware of this switch. Occupational therapy involvement in care at the end of life is also under-researched, and many healthcare professionals, including occupational therapy practitioners, do not ever receive training on what occupational therapy in this setting should entail. These knowledge gaps may leave occupational therapists unprepared to participate in end-of-life work, leading to fewer practitioners working in this practice area (Knecht-Sabres et al., 2019). Unpreparedness to advocate could result in fewer or late referrals from other

healthcare professionals due to a lack of understanding of when and why a client should be referred to occupational therapy (Knecht-Sabres et al., 2019; Martin & Herkt, 2018). Difficulty understanding the breadth of knowledge needed to appropriately advocate for occupational therapy's role may even lead to a lack of reimbursement for services (Knecht-Sabres et al., 2019). Because the occupational therapy role is unclear, this could lead to a lack of occupational focus overall (Chow & Pickens, 2020; Knecht-Sabres et al., 2019; Martin & Herkt, 2018). Unfortunately, the additive effect of this may further lead to decreased patient quality of life, which is why it is imperative occupational therapy practitioners become more involved in advocacy and education regarding this area of practice (Hammill et al., 2014).

Occupational Therapy at the End of Life

Though hospice and palliative care are generally well-understood in the healthcare industry, occupational therapy involvement in care at the end of life is commonly misunderstood. In the literature and in practice, occupational therapy is typically described as a profession that facilitates increased functional independence in everyday occupations (Hammill et al., 2014; Knecht-Sabres et al., 2019; Mueller et al., 2021). While this can be true at end of life, it is not the focus. The focus of occupational therapy in care at the end of one's life is to improve quality of life for patients and caregivers, ensure patient comfort, and facilitate occupational participation (AOTA, 2017; Chow & Pickens, 2020). Occupational therapy practitioners can approach this in a multitude of ways. For the patient, they could recommend environmental modifications and adaptive equipment, teach appropriate seating and positioning, educate on energy conservation and sleep hygiene techniques, and assist in creating a legacy project (AOTA, 2015; AOTA, 2017). Legacy work is a project or activity that is completed to pass on the patient's legacy. This can take a variety of forms, such as making a scrapbook, writing letters to family, donating to a charity, or planning one's funeral (Javaherian et al., 2016).

Occupational therapy practitioners have the capability to assist caregivers while the patient is alive but can also facilitate grieving and bereavement after the patient passes. While the patient is still receiving care, caregiver training and education is crucial to ensure maximum quality of life for both the patient and the caregiver (Chow & Pickens, 2020). For example, an occupational therapy professional could train a caregiver on how to help the patient complete bed mobility and transfers using proper body mechanics. This will make the task easier for both patient and caregiver, facilitating occupational participation for the patient and preventing caregiver injury. Caregivers may have many questions and need assistance processing the situation, so the occupational therapy practitioner could educate on the disease process and help to manage realistic expectations. After the patient passes, caregivers may find themselves struggling with their grief. In this case, the occupational therapy practitioner could encourage participation in meaningful occupations to help the bereaved find healthy ways to express their emotions as well as offer resources for support (AOTA, 2015; AOTA, 2017; Essential Yeh & McColl, 2019).

Implications for Occupational Therapy

Occupational therapy practitioners should be educated on occupational therapy's role in care at the end of life. It has been found that occupational therapy clinicians are not sufficiently prepared to work in this practice area, so there should be increased education on this topic in the academic setting before entering the field (Essential Yeh & McColl, 2019; Hammill et al., 2014; Pizzi, 2014; Talbot-Coulombe & Guay, 2020). In addition, occupational therapy practitioners who work or are involved with care at the end of life must advocate for their role as well as educate the interdisciplinary team, including physicians, that they are vital and valuable members of the team. Increased education and training for occupational therapy professionals and the interdisciplinary team could increase awareness, lead to less role confusion, and create more beneficial interdisciplinary communication possibly leading to increased referrals (Hammill et

al., 2014; Knecht-Sabres et al., 2019; Martin & Herkt, 2018; Mills & Payne, 2015). Additionally, there is currently a lack of research in this practice area due to the difficulty of studying this patient population (Chow & Pickens, 2020; von Post & Wagman, 2019). Therefore, there is a need for more research about the end of life as well as the effectiveness of occupational therapy with these patients and their caregivers. If more rigorous research existed and appropriate occupational therapy outcome measures were established, this would guide occupational therapy practitioners in their practice as well as demonstrate the benefit of occupational therapy services (Chow & Pickens, 2020; Martin & Herkt, 2018; Mills & Payne, 2015).

Conclusion

The end of life brings many challenges, including the difficulty of participating in meaningful occupations. Occupational therapy sets itself apart from the interdisciplinary team with its unique focus on occupations which can lead to improved quality of life for the patient (Martin & Herkt, 2018). However, occupational therapy in the setting of care at the end of life is not utilized to its full potential which could be related to the knowledge gaps that exist surrounding this niche practice. The gaps in knowledge include the stigma that occupational therapy is not appropriate for care at the end of life, there is not enough education or training for healthcare professionals, and there is a lack of research on the topic. Thus, it is imperative that occupational therapy practitioners advocate for their role in this practice area. There should be additional research completed and increased education and training for the interdisciplinary team, including occupational therapy professionals, in both the academic and clinical settings to promote occupational therapy's involvement in care at the end of life.

References

- American Occupational Therapy Association. (2015). *The role of occupational therapy in palliative and hospice care*. https://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/PA/Facts/FactSheet_PalliativeCare.pdf
- American Occupational Therapy Association. (2017). The role of occupational therapy in end-of-life care. *American Journal of Occupational Therapy, 70*, 1–12. <http://dx.doi.org/10.5014/ajot.2017.706S2RA> [CCreview](#)
- Chow, J. K., & Pickens, N. D. (2020). Measuring the efficacy of occupational therapy in end-of-life care: A scoping review. *American Journal of Occupational Therapy, 74*(1), 7401205020p1–7401205020p14. <https://doi.org/10.5014/ajot.2020.033340>
- Essential Yeh, H.-H., & McColl, M. A. (2019). A model for occupation-based palliative care. *Occupational Therapy in Health Care, 1*-16. <https://doi.org/10.1080/07380577.2018.1544428>
- Hammill, K., Bye, R., & Cook, C. (2014). Occupational therapy for people living with a life-limiting illness: A thematic review. *British Journal of Occupational Therapy, 77*(11), 582–589. <https://doi.org/10.4276/030802214X14151078348594>
- Hammill, K., Bye, R., & Cook, C. (2019). Occupational engagement of people living with a life-limiting illness: Occupational therapists' perceptions. *Australian Occupational Therapy Journal, 1*-9. <https://doi.org/10.1111/1440-1630.12557>
- Javaherian, H., Lewis, K., Moss, L., & Hewitt, L. (2016). Legacy building: A pilot program for end-of-life clients. *OT Practice, 21*(3), 7–11. https://higherlogicdownload.s3-external-1.amazonaws.com/AOTA/84e73d98-5d62-cdcc-7653-67cd4d7956fd_file.pdf?AWSAccessKeyId=AKIAVRDO7IEREB57R7MT&Expires=1648447649&Signature=SchH7gxwl8b2yjVzaiEpAzKZ6fAI%3D
- Knecht-Sabres, L. J., Weppner, A., Powers, C., & Siesel, B. (2019). Do health-care professionals really understand the role of occupational therapy in hospice care? *American Journal of Hospice & Palliative Medicine, 36*(5), 379–386.

- <https://doi-org.usd.idm.oclc.org/10.1177/1049909118812858>
- Martin, E. & Herkt, J. (2018). The reality and potential of occupational therapy within hospice care. *New Zealand Journal of Occupational Therapy*, 65(2), 23–29. <https://search.informit.org/doi/abs/10.3316/informit.982583863899720>
- Mills, K., & Payne, A. (2015). Enabling occupation at the end of life: A literature review. *Palliative and Supportive Care*, 13(6), 1755–1769. <https://doi.org/10.1017/s1478951515000772>
- Mueller, E., Arthur, P., Ivy, M., Pryor, L., Armstead, A., & Li, C. Y. (2021). Addressing the gap: Occupational therapy in hospice care. *Occupational Therapy in Health Care*, 35(2), 125–137. <https://doi.org/10.1080/07380577.2021.1879410>
- National Hospice and Palliative Care Organization. (2021). *NHPCO Facts and Figures*. <https://www.nhpco.org/hospice-care-overview/hospice-facts-figures/>
- National Institutes of Health. (2021). What are palliative care and hospice care?. <https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care#palliative>
- Pizzi, M. (2014). Promoting health, wellness, and quality of life at the end of life: Hospice interdisciplinary perspectives on creating a good death. *Journal of Allied Health*, 43, 212-220. https://www.researchgate.net/publication/268987631_Promoting_health_wellness_and_quality_of_life_at_the_end_of_life_Hospice_interdisciplinary_perspectives_on_creating_a_good_death
- Talbot-Coulombe, C., & Guay, M. (2020). Occupational therapy training on palliative and end-of-life care: Scoping review. *British Journal of Occupational Therapy*, 83(10), 609-619. <https://doi.org/10.1177/0308022620926935>
- von Post, H., & Wagman, P. (2019). What is important to patients in palliative care? A scoping review of the patient's perspective. *Scandinavian Journal of Occupational Therapy*, 26(1), 1-8. <https://doi.org/10.1080/11038128.2017.1378715>