A Guide to Occupational Therapy's Role in Hospice Care: Promoting Participation at the End-of-Life – Capstone Final Report

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Abstract

This capstone project aims to improve understanding, implementation, and advocacy regarding occupational therapy's (OT) scope of practice in hospice care through the development of targeted educational programs for entry-level OT students and practicing clinicians. Completed as part of Colorado State University's occupational therapy program, the project addresses critical barriers to OT's inclusion in end-of-life care—namely, limited education for OT professionals and insufficient interprofessional awareness of OT's distinct contribution as a member of the hospice team. Outcomes of the project include a guest lecture slide deck, an advocacy handbook, a curated resource list, and survey instruments, all aimed at reinforcing OTs value in promoting quality of life, comfort, and meaningful occupational participation at the end-of-life. These materials were trialed with 110 participants across academic and professional development settings. Data collected through pre- and post-surveys indicate significant increases in self-rated proficiency surrounding OT's role in end-of-life care, as well as improved confidence in advocating for OT services. Qualitative feedback further supports these findings and reflects insight into OT's contributions to hospice care. The project also established sustainable partnerships with mentors and professional organizations to promote long-term dissemination and impact. Anticipated outcomes include increased OT presence on hospice teams, enhanced client outcomes related to occupational engagement and wellbeing, and broader interprofessional and intraprofessional recognition of OT's value. This capstone provides an educational and advocacy model to support the integration of OT into end-of-life care.

Keywords: end-of-life, occupational therapy, hospice care, quality of life

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Thank you to my grandparents for sparking this passion to promote quality of life throughout the lifespan. This milestone belongs just as much to them as it does to me.

Finally, I am endlessly grateful to my family, friends, and partner for their constant support, encouragement, and love throughout this final chapter of my education. Thank you for being there every step of the way.

Introduction

The purpose of this capstone project is to improve understanding, implementation, and advocacy efforts related to occupational therapy's scope of practice in hospice care. The capstone project addresses this overarching goal through the development of educational programs that discuss occupational therapy's role in hospice care and are designed to be utilized in entry-level occupational therapy (OT) curriculum and professional development courses. The educational programs review OT practice in end-of-life (EoL) care and explore how OT services enhance quality of life, comfort, safety, and occupational participation in hospice care. The capstone is designed to uphold OT's distinct, significant value in EoL care.

This capstone project, in alignment with Accreditation Council for Occupational Therapy Education (ACOTE) capstone standards, fulfills graduation requirements for Colorado State University's (CSU) Clinical Doctorate in Occupational Therapy (OTD) program. The project aligns with CSU's capstone track of program development and three ACOTE areas of focus: education, advocacy, and program development and evaluation.

My interest in this topic stems from a strong commitment to promote quality of life through the end of life and a desire to pursue a career in EoL care. As a white individual from a middle-class socioeconomic background in a Western society, I recognize the privilege and experiences that shape my perspective. Prior to my completion of this capstone, I have had plentiful experience witnessing aging, death, and the dying process. My personal and professional history deepens my appreciation for the role of meaningful occupational engagement during the dying process and the importance of emphasizing quality of life throughout the lifespan. I believe OT is essential to exceptional care at the end of life for patients, as well as their loved ones and caregivers.

Literature Review

End-of-life trajectories vary widely from person to person, but a uniting feature across the dying process is decline—physical, cognitive, and/or emotional (Cohen-Mansfield, et al., 2017). Physical decline may appear as reduced activity tolerance, mobility changes, reduced appetite, shortness of breath, and increased pain (AOTA, 2023). Cognitive decline may emerge in difficulties with communication, sleep, or memory, reduced alertness, or increased confusion, agitation, and/or hallucinations (AOTA, 2023). Emotional decline may manifest similarly to depression, social withdrawal, or anxiety (Pizzi, 2015). Decline in functional status impedes occupational performance and participation in daily and meaningful activities. Beyond functional status, participation challenges commonly experienced at the end of life include the loss of social roles, reduced engagement in meaningful leisure activities, waning independence, fear for safety, limited grief coping strategies, and a lack of caregiver training and support (Eva & Morgan, 2018; Mueller et al., 2021; Pickens & Long, 2019; Sposato, 2016).

As an emerging practice area, there is a lack of recent, peer-reviewed evidence exploring occupational therapy's distinct role and value in EoL care. The application of OT practice in hospice care is widely different than OT practice in a rehabilitative or habilitative setting (AOTA, 2023). As a result, OT students and practitioners feel underprepared to adapt to the changing goals, declining functional statuses, and psychosocial needs present during the dying process (Chow et al., 2022; Martin & Herkt, 2018; Rose, 2016). Interprofessional hospice disciplines also have limited knowledge of OT's unique expertise and scope of practice as applicable at the end of life (Knect-Sabres et al., 2018). Additional barriers to OT's inclusion in the customary hospice team include the lack of a standardized outcome measure for OT in EoL care (Chow & Pickens, 2020) and current hospice benefit structures that delineate OT as an

auxiliary service that may be provided on an as needed, case-by-case basis (Centers for Medicare & Medicaid Services, 2024). These systemic factors inhibit OT service inclusion in hospice care, preventing patients and their families from reaping the benefits of OT intervention.

Driving Conceptual Model

The practice model selected to justify the relevance of occupation to the dying process is the Model for Occupation-based Palliative Care, developed by Yeh and McColl (2018). The model is depicted in Appendix A. The model, created following a scoping review of OT-related palliative care literature, justifies OT's role in spite of terminal illness and functional decline. The scoping review yielded five central themes, each depicted in the model (Yeh & McColl, 2018). First, the model emphasizes valued occupation as central to OT practice. Second, it classifies valued occupations within the *doing-being-belonging-becoming* framework (Wilcock, 1998). *Doing* occupations are activities objectively witnessed, such as a self-care task or a leisure activity. *Being* occupations reinforce existence, humanity, spirituality, and identity. *Belonging* occupations connect a person to a group, provide a sense of acceptance, and allow for emotional expression. *Becoming* occupations promote autonomy and a sense of control over one's destiny (Yeh & McColl, 2018). Third, the model posits that balance among these four dimensions is at the heart of affirming life and preparing for death. Fourth, it explores how occupations change over the trajectory of a terminal illness or dying process from early to end stages, implying a necessary shift in the OT practitioner's approach. Finally, the model highlights the influence of a safe and supportive environment on effective service delivery (Yeh & McColl, 2018). The Model for Occupation-based Palliative Care outlines the relevance of occupational engagement for the EoL population in terms of wellbeing, quality of life, dignity, role affirmation, social participation, identity reinforcement, and legacy building (Yeh & McColl, 2018).

Capstone Plan and Process

In analysis of the literature review and needs assessment, a major barrier to occupational therapy's representation within hospice care is a gap in end-of-life education for occupational therapy students and practitioners (Mueller et al., 2021). This deterrent is directly correlated to the limited awareness of other EoL health and social care professionals regarding the distinct role of OT practitioners (Knect-Sabres et al., 2018). In response to the obstacle of limited understanding both within and outside of the OT field, this capstone project enhances multidisciplinary comprehension of OT's role in hospice care and promotes advocacy efforts regarding OT's value as a member of the hospice team. This capstone project aims to amplify understanding and advocacy through educational programs that underscore OT's role in promoting quality of life and participation at the end of life.

To achieve the goal of the project, seven individualized learning objectives were utilized. The objectives were time-specific and provided an outline for daily activities that denoted steady, successful progress toward the completion of the capstone experience and project goal. Please refer to appendix B to examine the objectives of the project. A logic model reflecting the project process and implementation is depicted in Appendix C.

Project Implementation

A detailed overview of activities taken to meet the project objectives can be found in Appendix B. The seven learning objectives are listed on the left side of the table within the appendix. On the right side of the table are the activities associated with each objective. External site and personnel responsibilities are not explicitly listed in the table. The first of these include the application to present at the AOTA Conference, which was submitted in June of 2024. The student was primarily responsible for completing this application with additional support

provided by capstone faculty mentor Laura Swink through three virtual meetings lasting approximately 30 minutes each. Following the acceptance of the application, the student was responsible for travel, food, and lodging costs associated with attending the conference. Colorado State University provided reimbursement for the conference registration, totaling $325.00. Outside of conference-related expenses, the student was also responsible for paying registration fees for the International End-of-Life Doula training, totaling $790.00. All costs associated with relocating to and living in Seattle, Washington, for the entirely of the capstone experience, as well as gas expenses related to home health visit traveling, were covered in entirety by the student.

Outside of financial resources, all members of the capstone team contributed generous amounts of their time and attention to the capstone. Capstone site mentors committed two hours per month to virtual meetings, time associated with reviewing and responding to emails, approximately three hours toward reviewing and revising the Memorandum of Understanding (MOU) and evaluating performance, and approximately forty hours each toward in-person shadowing experiences. The capstone faculty mentor contributed several hours to the Institutional Review Board (IRB) application process through virtual meetings and in-person courses. The faculty mentor was also available throughout the capstone experience for consultation via email for feedback on program development and data collection and review. The capstone coordinator also committed time toward reviewing and revising the MOU.

Project Evaluation and Results

To determine the effectiveness of the developed programs in meeting the capstone project's goal, data collection occurred at both program trials in a self-report pre-survey and post-survey format. The surveys administered at the program trials are included in Appendix D.

Data collection included both quantitative Likert-Scale data and qualitative narrative response data. Tables depicting quantitative data extraction from the university guest lecture and the AOTA conference can be found in Appendix E. As shown in the tables, the higher the Likert Scale score, the more proficient the audience considers themselves to be. Following both program trial sessions, attendees significantly improved their self-rated proficiency across all three key objectives, as shown in Appendix E. Qualitative data demonstrated similar findings that support the effectiveness of the educational programs: “In acute care, it’s easy for us to discharge OT orders because someone is going home on hospice. I don’t want to be the standard. I think there’s a lot of room for intervention acutely and preparing the family for going home.” Another participant reported “being able to advocate for the OT role in EoL care other than just environmental modification and adaptive equipment” following the session. Finally, an OT educator stated that they would “love to educate our students more on the role of OT in EOL care and how we can use these strategies.” Qualitative and quantitative data suggest that the student was successful in improving understanding, practice implementation, and advocacy efforts related to occupational therapy’s scope of practice in hospice care.

Outside of the overarching success of the project, the student evaluated objective-based progress through a day-by-day activity calendar established prior to the start of the project and edited as needed throughout to promote consistent effort toward goals. Biweekly meetings with capstone site mentors further reinforced perpetual progress and accountability as the student was responsible for reporting updates on program development. Lastly, the student completed weekly reflective journal entries to focus on personal growth, track transformational takeaways, and improve learning through enhanced critical thinking skills. Reflective practice through journal entries supported the prioritization of the purpose of the project throughout the experience.

Discussion and Impact

Occupational therapy practice in end-of-life care is distinct in comparison to other therapeutic settings. As opposed to a rehabilitative or habilitative approach, the goal of OT in EoL care is to promote quality of life and maintain occupational participation as desired by the patient (American Occupational Therapy Association, 2023). OT can also promote secondary outcomes of safety, comfort, and dignity (Chow et al., 2022). Occupation and the way that a person chooses to spend their remaining time and energy takes on a special significance at the end-of-life (Yeh & McColl, 2018). OT practitioners provide patients with opportunities to participate in activities that provide meaning (Chow et al., 2023). OT practitioners adapt and modify activities and environments, reduce risk while promoting patient autonomy, provide caregivers and patients with practical skills and support, prolong independence, support participation in activities that provide a sense of meaning and purpose, create opportunities for legacy building, and prescribe specialized equipment to maintain functional participation (American Occupational Therapy Association, 2023; Chow et al., 2023). Occupational therapy practitioners deliver holistic and individualized care to enable patients to achieve their desired outcomes and enhance participation in their daily lives in spite of terminal illness.

The capstone project resulted in immediate quantifiable impacts in the understanding and practice beliefs of current occupational therapy practitioners and entry-level students. Direct outcomes of the project include the improved proficiency of OT practitioners and entry-level students regarding the role of occupation at the end of life, awareness of OT practice in hospice care (assessment, intervention, and outcomes), and how to advocate for OT's value and scope in EoL care, as measured by a survey. These outcomes were reinforced by the content and delivery of the project itself, including five deliverables made readily available to capstone site mentors and all trial participants. The first deliverable is a slide deck presentation for a guest lecture or

conference presentation regarding the role of OT in hospice care. The second is an advocacy handbook designed for interprofessional and intraprofessional education on OT's scope within EoL care and the beneficence of OT as a member of the hospice team. The advocacy handbook is depicted in Appendix F. The third is a list of resources for individuals interested in learning more about OT in EoL care, shown in Appendix G. Finally, deliverables four and five are the survey materials (Appendix D) and the data tables generated from survey responses (Appendix E).

Anticipated impacts of the project can be intuitively deduced from the immediate outcomes of the capstone. First, advocacy efforts promoting OT's presence in hospice care will rise as more stakeholders understand the role of OT in end-of-life care and become equipped with resources to defend the continuation of services during the dying process. Second, there will be an increased presence of OT practitioners practicing EoL care across a variety of settings as the interprofessional hospice team becomes increasingly aware of the distinct value of OT services. Within these settings, improved outcomes of occupational participation, functional maintenance, and quality of life will coincide with the presence of OT services. Finally, sustainability initiatives will continue to support the momentum of the capstone project's mission. In prolonged partnership with the capstone site, capstone mentors, content mentors, and the AOTA Palliative Care Community of Practice, the deliverables of the capstone project will continue to equip OT students and practitioners with knowledge regarding OT's role in EoL care. Further, interprofessional disciplines do not have adequate understanding of occupational therapy's scope of practice or purpose at the end of life. I will partner with team members to promote increased presence at interprofessional conferences and advocacy meetings with physicians, nurses, case managers, social workers, and other members of the care team to promote understanding, increased referrals, interprofessional advocacy.

Conclusion

The purpose of this capstone project was to develop educational programs on occupational therapy's role in hospice care to be utilized in entry-level occupational therapy curriculum and professional development courses to advocate occupational therapy's value in hospice care. The capstone was developed in response to barriers preventing occupational therapy's inclusion on the hospice team, namely the limited preparedness of occupational therapy practitioners and students to adapt to the ever-changing therapeutic goals in end-of-life care and interprofessional disciplines' lack of understanding about occupational therapy practitioners' unique expertise and scope of practice in relation to end-of-life care. The educational programs discuss occupational therapy practice in end-of-life care and explore how occupational therapy services can enhance wellbeing and participation in hospice care. The programs were trialed to 110 participants during the capstone experience where survey data was collected to determine the effectiveness of the programs in meeting the goal of the project. Data indicates that the programs significantly enhanced understanding, supported practice application, and furthered advocacy efforts related to occupational therapy's scope of practice in hospice care. The capstone project and deliverables will continue to result in measurable improvements in understanding, greater representation of occupational therapy practitioners in end-of-life practice, and long-term initiatives to promote occupational therapy's value within hospice settings.

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Appendix A: Model for Occupation-based Palliative Care

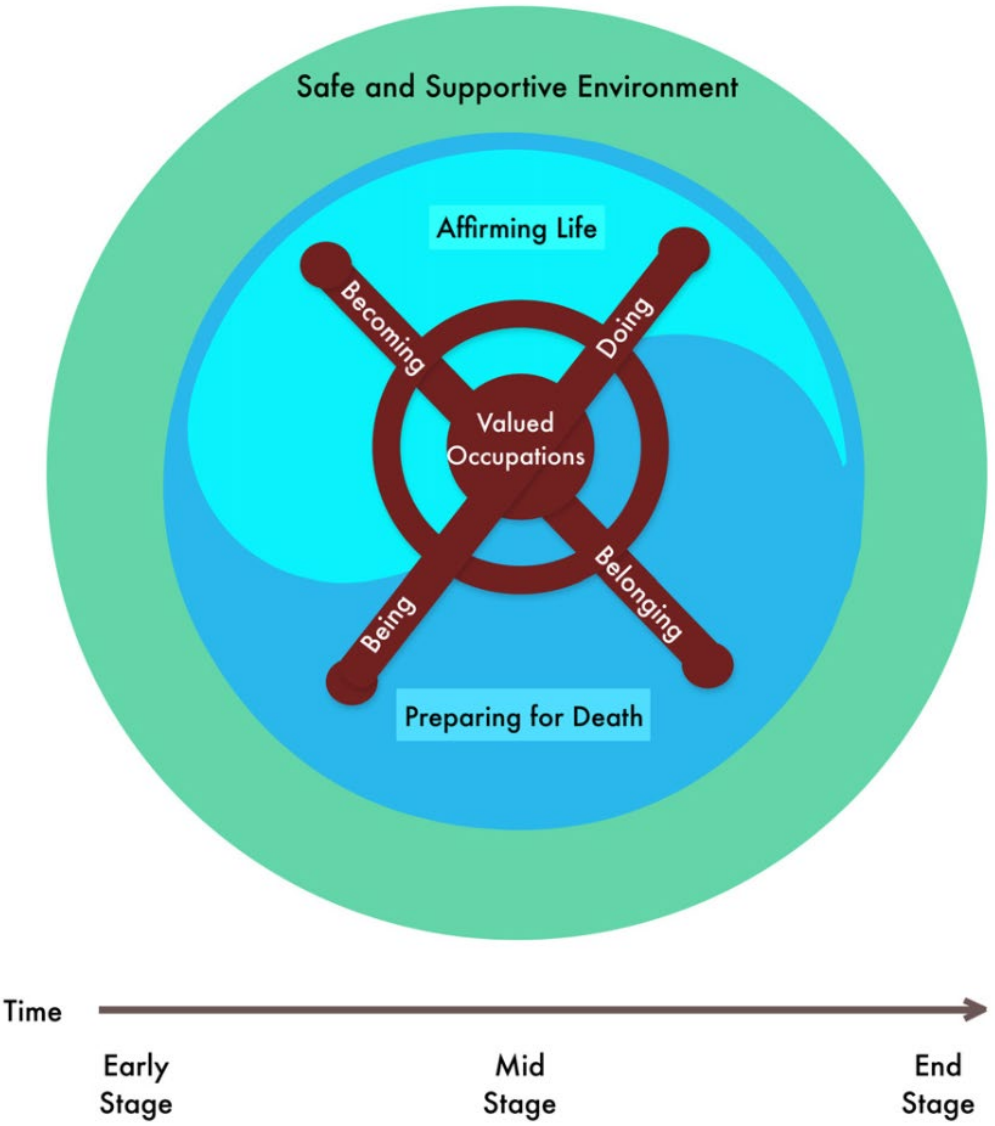


Figure 1. A model for occupation-based palliative care.

(Yeh & McColl, 2019)

Appendix B: Activity Overview

Objective	Activities
1. I will obtain clinical experience from my capstone site mentors throughout the first four weeks (~32 hours per week) and as needed throughout the capstone experience to inform my needs assessment and program development.	I obtained approximately 120 hours of in-person observation of an occupational therapist working in hospice care, approximately 40 hours per site mentor. I observed assessment, intervention, outcomes, and discharge in end-of-life care.
	I took detailed notes during observations and during debriefs with the therapist following each session. I asked many questions to support my learning and clinical decision-making.
2. By February 8, 2025, I will complete my end-of-life doula training to inform psychosocial and spiritual intervention strategies to support dying clients and their circle of care.	I completed a 40-hour end-of-life doula virtual training program through the INELDA. I completed all preparatory, live, and post-session coursework to apply my learning. I engaged fully in class discussions to support learning and skill building. This opportunity was funded with my personal finances.
3. By February 21, 2025, I will conduct a literature review and needs assessment and analyze their findings to determine common themes and content for the educational programs.	I conducted a needs assessment through semi-structured interviews with my capstone site mentors and additional content experts/key informants to determine the desired outcome of the project.
	I conducted a literature review of peer-reviewed evidence and grey literature (previous capstone projects) using a search strategy informed by the findings of my needs assessment (emphasis on education, advocacy, and scope of practice efficacy). I utilized and was limited by CSU's access to research databases, no additional pieces of evidence were purchased.
	I compiled findings of the needs assessment and literature review to determine common themes and content for the program. I organized articles from the literature review into various topic areas for ease of access for myself in completing the capstone project and for my capstone mentors in future referral to the evidence.
4. By April 1, 2025, I will develop an educational program on occupational therapy practice in hospice care that can be	Utilizing the information and common themes obtained from the needs assessment, literature review, end-of-life doula coursework, and observation hours, I constructed two educational programs: a one-hour professional

delivered to occupational therapy students and practitioners.	development course and a two-hour guest lecture on OT practice at the end of life. Throughout the development process, the programs underwent several revisions during which I, my site mentors, and key informants reviewed and revised the programs for optimal effectiveness.
	I developed a pre- and post-survey available through a virtual format for session participants to self-rate their proficiency related to understanding, applying, and advocating for OT's role in end-of-life care. This survey was designed to test the effectiveness of the capstone project in meeting the overall goal of improving understanding regarding OT's distinct value.
5. By April 6, 2025, I will trial my program at a professional conference and an entry-level occupational therapy educational institution and receive measurable data through a self-reported pre- and post-survey to determine the effectiveness of the programs.	I trialed the two-hour guest lecture course at a Francis Marion University on February 27 to a classroom of 11 first-year occupational therapy students. Data collection through a pre- and post-survey occurred virtually and in a self-report format (11 responses).
	In June of 2024, I applied to disseminate my project at the 2025 national AOTA conference. I was accepted and trialed the one-hour professional development course at the American Occupational Therapy Association's annual Inspire conference in Philadelphia, Pennsylvania to an audience of 99 participants. Travel, lodging, and food was covered by the student when Colorado State University was reimbursed by CSU. Data collection through a pre- and post-survey occurred virtually and in a self-report format (71 responses).
	I analyzed quantitative and qualitative data on the effectiveness of the program trials and constructed tables for simplicity of data review. Effectiveness was deemed as the self-reported proficiency scores for the three objectives of the course.
6. By April 18, 2025, I will grow in my confidence collaborating with dying individuals as measured by a reflective weekly journal entry throughout the capstone experience.	I completed weekly journal entries following these targeted prompts: (1) This week I learned…, (2) This week I felt …, (3) Next week I will …. The journal supported reflective practice, accountability toward consistent progress on the capstone, and enhanced learning and problem-solving.
7. By April 18, 2025, I will advocate occupational therapy's	I collaborated with my capstone site mentors, content experts, and my peers to determine the most effective

role in hospice care to promote the longevity of occupational therapy's inclusion in hospice services at my capstone site.	method to engage in advocacy work as a student. Due to my limited opportunity to engage with Compassus leadership throughout the merger, I instead opted to create an advocacy handbook that is designed: (1) as a toolkit for OT practitioners, (2) as a method to defend the cost-effectiveness and job security of OTs to employers, and (3) as a document to educate interprofessional disciplines about OT's role in end-of-life care. Please see Appendix F for the advocacy handbook. I also developed a list of additional resources for further exploration (Appendix G). All slide decks for presentations were transitioned to blank and professional slide decks.

Appendix C: Logic Model

Appendix D: Survey Materials

Assessment Method: Retrospective Pre/Post Survey

Session title: A Guide to Occupational Therapy's Role in Hospice Care: Promoting Participation at the End-of-Life

Objective 1

Recognize the importance of an occupation-based dying process.

Before the activity

____ Not at all Proficient ____ Slightly Proficient ____ Moderately Proficient ____Very Proficient

After the activity

____ Not at all Proficient ____ Slightly Proficient ____ Moderately Proficient ____Very Proficient

Objective 2

Identify and feel confident in applying strategies to maximize participation for individuals at the end-of-life.

Before the activity

____ Not at all Proficient ____ Slightly Proficient ____ Moderately Proficient ____Very Proficient

After the activity

____ Not at all Proficient ____ Slightly Proficient ____ Moderately Proficient ____Very Proficient

Objective 3

Recognize and advocate for occupational therapy's distinct purpose in hospice care.

Before the activity

____ Not at all Proficient ____ Slightly Proficient ____ Moderately Proficient ____Very Proficient

After the activity

____ Not at all Proficient ____ Slightly Proficient ____ Moderately Proficient ____Very Proficient

Assessment Method: Commitment to Change Post-Survey

Session title: A Guide to Occupational Therapy's Role in Hospice Care: Promoting Participation at the End-of-Life

I am a(n):

____ Occupational Therapist

____ Occupational Therapy Assistant

____ Student

____ Other

Please describe your current practice setting or desired future practice setting if you are a student:

_____

_____

Information from this session will be incorporated into my occupational therapy practice.

____ Strongly Disagree ____ Disagree ____ Neutral ____ Agree ____ Strongly Agree

Changes in my practice that I am going to make:

1. _____

   _____

2. _____

   _____

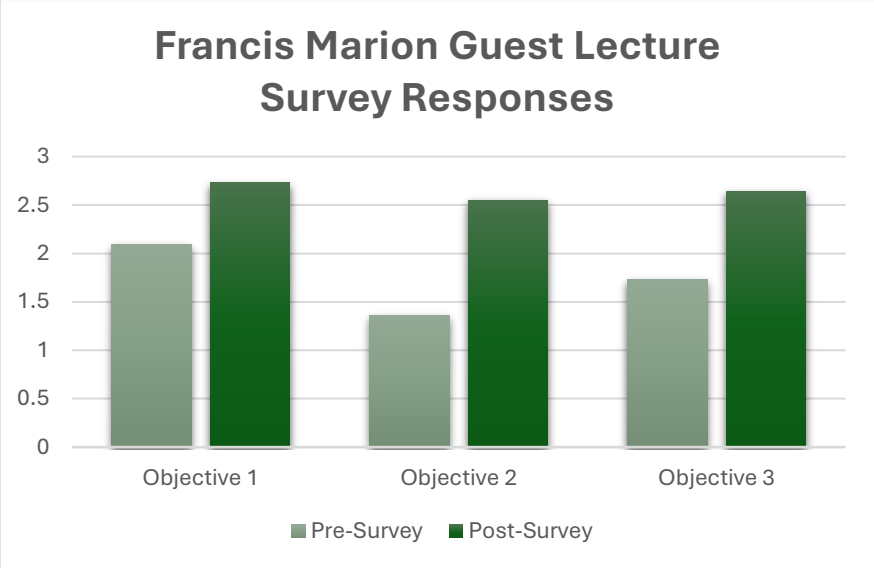
If no changes, why not?

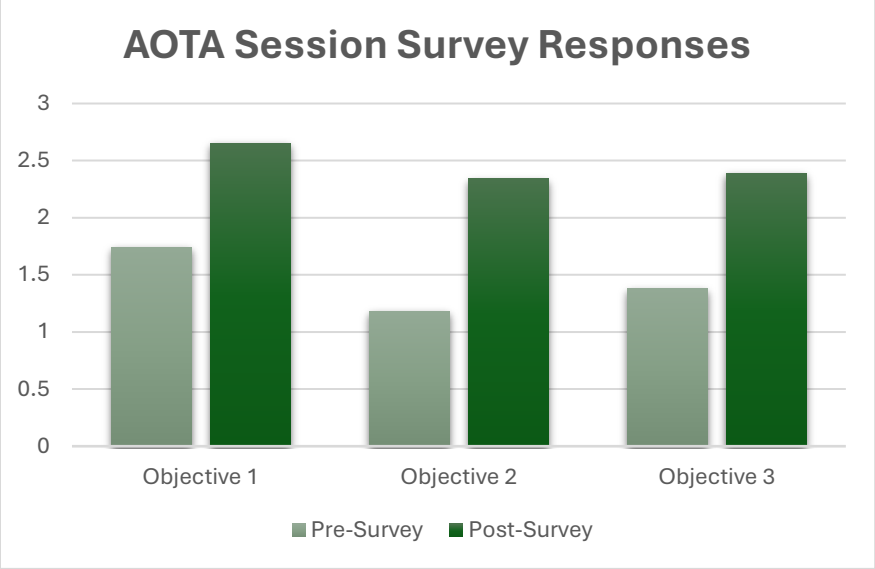
_____

_____

Appendix E: Quantitative Data Tables

Survey Objectives	
Objective 1	Recognize the importance of an occupation-based dying process.
Objective 2	Identify and feel confident in applying strategies to maximize participation for individuals at the end-of-life.
Objective 3	Recognize and advocate for occupational therapy's distinct purpose in hospice care.





Legend:

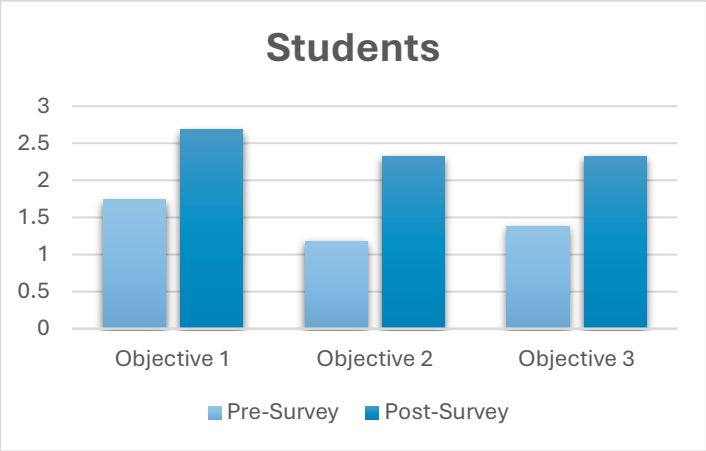
0 = "not at all proficient"

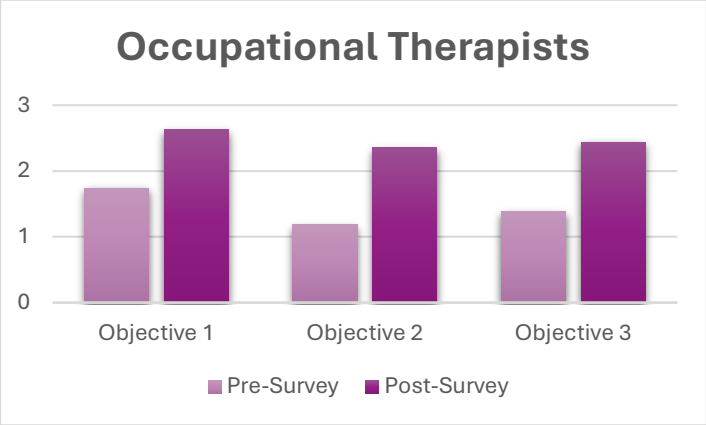
1 = "slightly proficient"

2 = "moderately proficient"

3 = "very proficient"

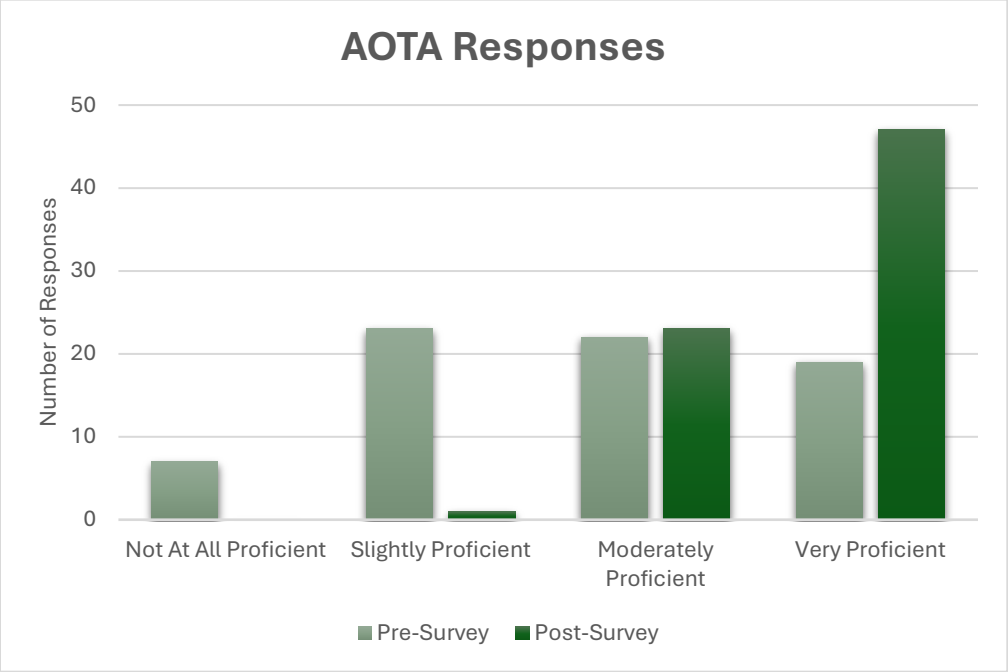
Audience Demographics	
Francis Marion - Students	11
AOTA - Students	22
AOTA - Occupational Therapists	43
AOTA - Occupational Therapy Assistants	6

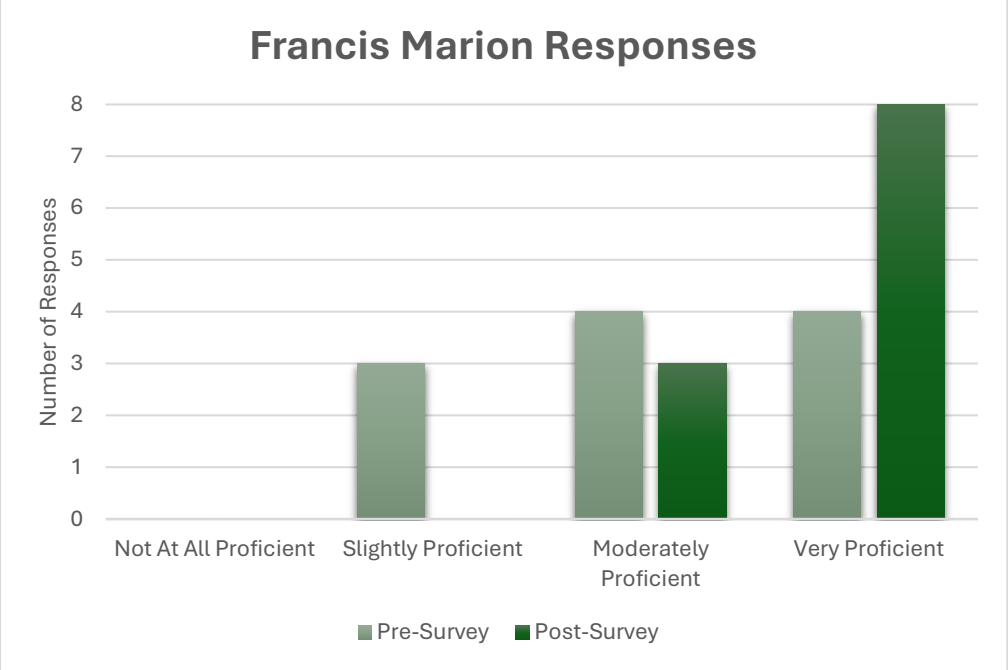




Objective 1

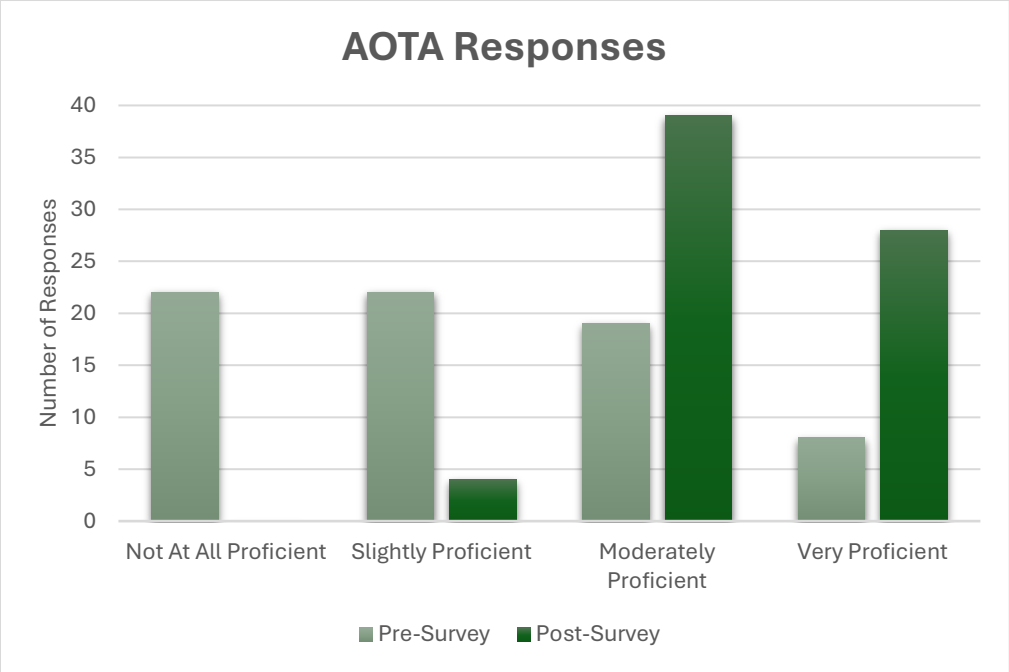
"Recognize the importance of an occupation-based dying process."

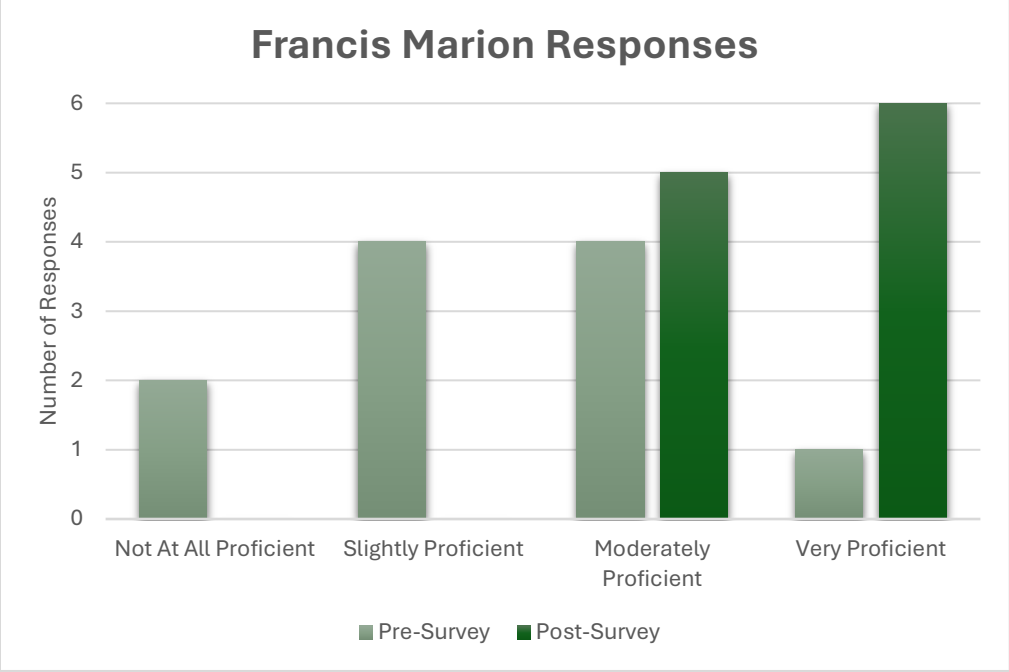




Objective 2

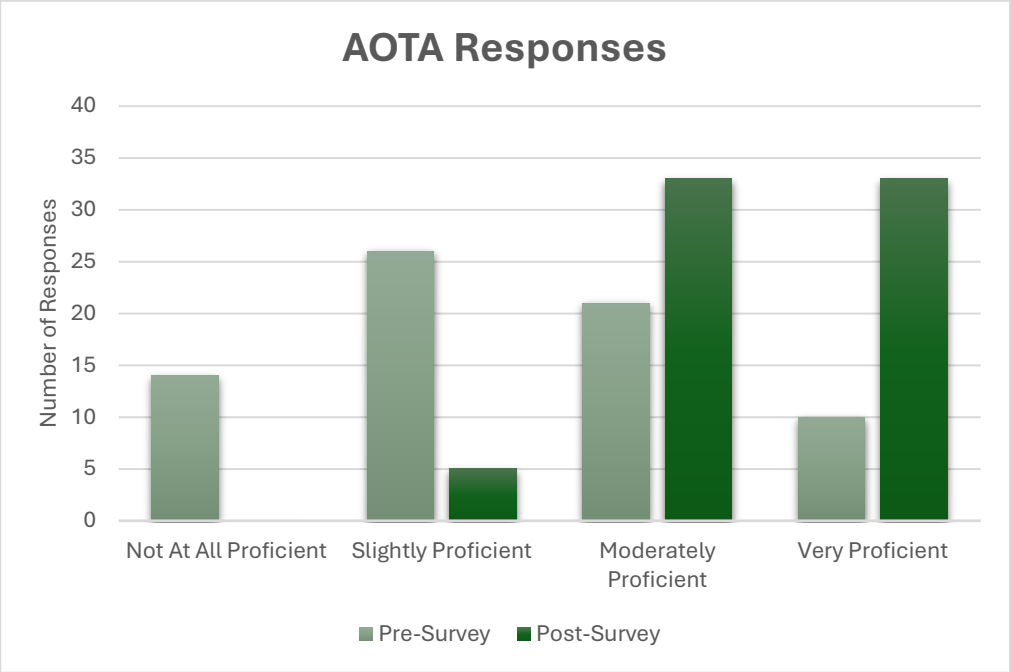
"Identify and feel confident in applying strategies to maximize participation for individuals at the end-of-life."

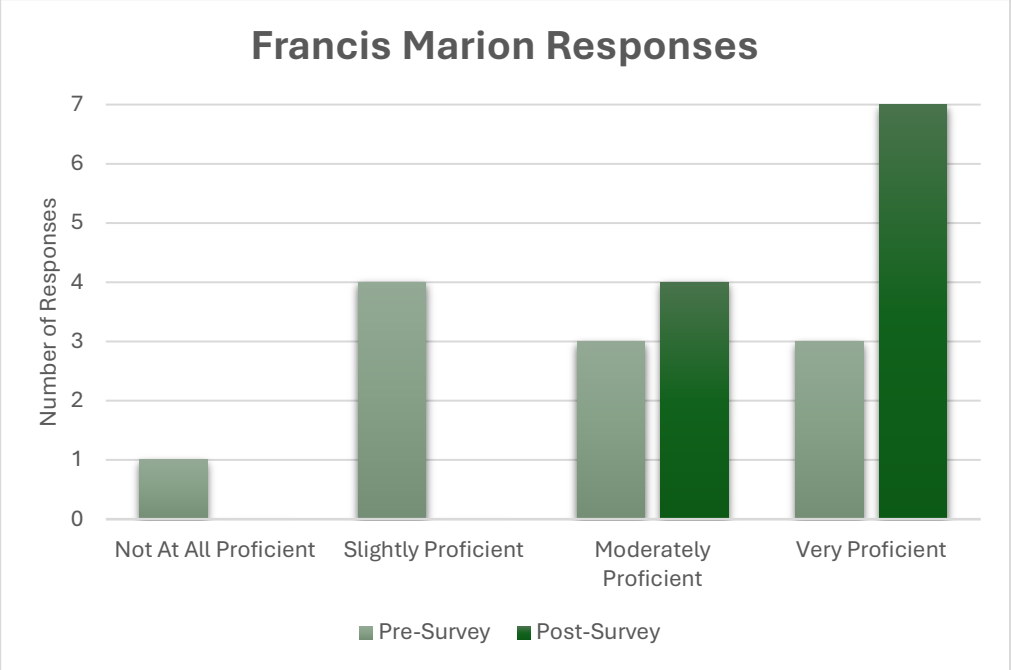




Objective 3

"Recognize and advocate for occupational therapy's distinct purpose in hospice care."





Appendix F: Deliverable – Advocacy Handbook

Occupational Therapy in End-of-Life Care

A Handbook for End-of-Life Care Professionals

This publication is designed as a practical resource guide to enable occupational therapists working across a variety of settings to implement high-quality end-of-life care. This handbook is also designed to increase awareness of other end-of-life health and social care professionals regarding the unique role of occupational therapists.[1] The role of occupational therapy is clearly detailed within this document to enable practitioners to feel confident in articulating and advocating for the value of occupational therapy in end-of-life care.

Table of Contents

What is Occupational Therapy?

Occupational therapy (OT) is a crucial aspect of end-of-life care. OT helps patients maintain comfort, safety, and dignity in the final stages of life.[2] The primary role of OT is to deliver holistic and person-centered care through the adaptation and modification of activities and environments, enabling patients to achieve their desired outcomes and enhance participation in their daily lives despite their terminal illness.[3] By focusing on the patient's ability to participate in activities of everyday life, occupational therapists (OTs) contribute to improving the quality of life of patients and their circle of care.[4]

Outcomes of OT at the End-of-Life[2]

- Safety
  - For the dying person and caregivers
- Comfort
- Quality of Life
- Appropriate Adaptive Equipment Use

Patient Outcomes

"Occupational therapy practitioners provide skilled interventions to improve quality of life by facilitating engagement in daily life occupations throughout the entire life course, including at the end of life."
— American Occupational Therapy Association, 2020, p. 1

Occupational therapy consistently improves patient outcomes in end-of-life care. "Occupation" refers to an activity that people participate in regularly that provides their lives with meaning and purpose, including self-care, work, leisure, and social participation.[3] At the end of life, "occupation" takes on special significance as everyday activities serve the dual purpose of validating life and preparing for death.[5] OT practitioners provide patients with opportunities to participate in activities that bring meaning to the end-of-life, therefore making an essential contribution to high-quality patient care and satisfaction.[6]

Cost-Effectiveness of Occupational Therapy Services

OT intervention generates significant cost-savings by reducing hospital visits, preventing complications, reducing the need for more intensive care, and optimizing the use of hospice resources.

The Medicare Hospice Benefit recognizes occupational therapy as a covered service; however, hospice cost constraints may limit the flexibility of available services.[7] To be covered by Medicare, hospice agencies are expected to furnish all covered services to the extent specified by an individual's plan of care.[8] OT falls under coverage category 40.1.8, which states "occupational therapy [...] services may be provided for purposes of symptom control or to enable the individual to maintain activities of daily living and basic functional skills" (Centers for Medicare & Medicaid Services, 2024, p. 33). This handbook asserts that OT is a vital component of high-quality end-of-life care and services should be made readily available to all patients. OT has proven to be a cost-effective service under current per diem hospice reimbursement systems:

1	**Occupational therapy reduces hospital admissions and emergency room visits[9,10]**
2	**Occupational therapy optimizes resource utilization, including personnel and medical equipment[11]**
3	**Occupational therapy prevents complications, such as pain and skin breakdown, and reduces the need for more intensive care[2]**
4	**Occupational therapy reduces the risk of falls and promotes patient and provider safety[12]**
5	**Occupational therapy improves patient satisfaction, supporting patient retention and acquisition[6,13]**

Occupational Therapy Assessment

Occupational therapy evaluation is multifaceted and holistic.[3] OT practitioners determine the patient's needs and wishes, functional status, medical and adaptive equipment needs, and any necessary environmental modifications.[2] The overarching mission of assessment is to determine the patients priorities and collaborate to construct a meaningful, personalized, and realistic treatment plan.[7]

Build Rapport
Develop a strong relationship with the dying person and their circle of care through collaboration, open communication, and active listening.

Observe the Patient
Analyze the dying person's functional potential, limitations, activity tolerance, and level of independence.

Observe the Caregivers
Assess the competency and capacity of caregivers in providing for the needs and the wishes of the dying person.

Assess the Environment
Analyze the effects of the physical and psychosocial environments on safety, function, social participation, and wellbeing.

Standardized Assessments Applicable to End-of-Life[14,15]

Braden Scale	Modified Barthel Index	Adult Sensory Profile
Biomechanical Tests (i.e. manual muscle testing, range of motion)	Pain Assessment in Advanced Dementia Scale (PAINAD)	Functional Assessment of Chronic Illness Therapy (FACIT)
Fall Risk Assessment (i.e. STEADI)	Brief Fatigue Inventory (BFI)	Modified Caregiver Strain Index (MCSI)
Needs at the End-of-Life Screening Tool (NEST)	Palliative Performance Scale version 2 (PPSv2)	Integrated Palliative Care Outcomes Scale (IPOS)

Please visit the National Palliative Care Research Center's website for additional standardized assessment tools covering various end-of-life domains.[15]

Intervention Toolkit

The primary objective of occupational therapy intervention is to **enhance participation** in everyday activities.[3] Participation enables individuals to maximize their quality of life and their independence despite the constraints of a terminal illness.[4,16] OT supports individuals to maintain their routines, to find meaning through activity engagement, to prioritize safety, to enhance their comfort, and to experience a "good" death.[2] OT practitioners take a flexible, creative, and compassionate approach to care, which anticipates and responds to the changing needs of patients and their caregivers.[6]

Promote engagement in necessary and desired occupations through adaptation, modification, and compensation[2,6,17]

Increase the accessibility and safety of the environment through adaptation and modification[2,18]

Reduce risk and promote autonomy through discussing safety concerns and providing alternatives for engagement in desired activities[5,19]

Provide caregivers with practical skills training and emotional support[20,21]

Maintain dignity through promoting independence in self-care activities[4,16]

Support continued participation in activities that provide a sense of meaning and purpose[22]

Create opportunities for legacy building and passing down meaningful traditions, values, or family history, as indicated by the patient[23,24]

Prescribe specialized equipment to assist with mobility, safety, or comfort, as well as the maintenance of functional participation in daily activities:[17,21]

Hospital bed	Low air loss mattress	Hoyer lift and slings
Bed rails	Trapeze bar	Fall mats
Slide board	Wheelchairs	Walkers
Cushions	Reachers	Bedside commode
Elevated toilet seat	Grab bars	Shower chair
Dressing aides	Cooking aides	Feeding aides

Intervention Toolkit (continued)

Education	• Common functional changes and symptoms to expect in the final stages of life, in addition to symptom management strategies[6,7] • Non-pharmacological pain management strategies[2,19] • Pre-medication prior to mobility or pain-provoking activities and routines[18] • Anxiety management (i.e. sensory considerations, guided mindfulness, or relaxation techniques)[2,5] • Fatigue management and energy conservation[2,21] • Positioning techniques for improved comfort and skin integrity[19,13] • Functional mobility training and the appropriate use of adaptive equipment[2,17] • Simplification of tasks and directions[25] • Transfer training and ergonomic safety[5,18] • Assistive technology to promote quality of life[2,4] • Restorative programs for range of motion[13] • Strategies to reduce caregiver burden[20,26]

Resources:

Link to additional resources for exploration:

Link to references page:

This handbook was developed by Ellie Hahn as a portion of the completion of her doctoral capstone project in Occupational Therapy at Colorado State University.

Suggested Citation: Hahn, E. (2025). *Occupational therapy in end-of-life care: A handbook for end-of-life care professionals* [Doctoral project, Colorado State University].

Appendix G: Deliverable – List of Resources

ADDITIONAL RESOURCES

Occupational Therapy in End-of-Life Care

Websites	☐ Website created by OT capstone student Emily VandeKieft with adovcacy materials for OT's role in end-of-life care: OTpall ☐ National Palliative Care Research Center
AOTA's Palliative Care Community of Practice	☐ Monthly meetings that promote networking and growth in this area of practice: Communities of Practice - AOTA's CommunOT
Barbara Karnes' End-of-Life Education Materials	☐ RN, hospice care innovator, and end-of-life educator whose materials provide essential information about the dying process: End of life education materials for families and professionals
YouTube Videos	☐ Interdisciplinary Palliative Care "Chalk Talks" ☐ TEDTalk - What really matters at the end of life | BJ Miller
Books	☐ Being Mortal - Atul Gawande ☐ Tuesdays with Morrie - Mitch Albom
Podcast Episodes	☐ Occupational Therapists are an — The Heart of Hospice Podcast — Apple Podcasts ☐ Hospice & Palliative Care in O–The OT Flourish Podcast – Apple Podcasts