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Occupational therapy in palliative and hospice care: a certificate program

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BOSTON UNIVERSITY
SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Doctoral Project

**OCCUPATIONAL THERAPY IN PALLIATIVE AND HOSPICE CARE:
A CERTIFICATE PROGRAM**

by

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Submitted in partial fulfillment of the
requirements for the degree of
Doctor of Occupational Therapy

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DEDICATION

I dedicate my doctoral project to my father, Harlen G. Alcorn. I miss our discussions on psychology, occupational therapy, and life and death. Your interest in the power of engaging in meaningful occupations has made me a better occupational therapist.

Love you.

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I want to thank:

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- Former clients living with a serious illness, your challenges and celebration of life have inspired me and influenced this project.

OCCUPATIONAL THERAPY IN PALLIATIVE AND HOSPICE CARE:

A CERTIFICATE PROGRAM

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ABSTRACT

As the population ages and individuals with serious illnesses continue to live longer, they are experiencing disruptions in habits and routines, roles, and rituals that provide meaning to their lives. Many individuals receiving palliative or hospice care and their family members are unable to maintain their quality of life (QOL) and well-being due to the negative impact of the serious illness. Individuals and their family caregivers experience difficulty in participating and engaging in activities of daily living (ADLs) (i.e., dressing, bathing, eating) and instrumental activities of daily living (IADLs) (i.e., making meals, working, finances). Individuals are unable to maintain their independence, return home due to environmental barriers, and receive support from family members due to a lack of training. Family caregivers are thrust into the role of caring for their loved ones without training. Currently, there is an increased need for more health professionals to work in palliative and hospice care. Occupational therapy is one profession that can fill this gap; however, there is a lack of education for occupational therapy practitioners (OTPs) at both the entry and post-professional levels.

Occupational Therapy in Palliative and Hospice Care: A Certificate Program contains key components of related professional certification programs in palliative care. Program

content aligns with palliative care principles and specific evidence-based occupational knowledge so OTPs will become integral interprofessional palliative care team members. It aims to demonstrate occupational therapy's value in this setting and prepare OTPs to work successfully. Modules provide the foundational information needed to facilitate the use of the principles of palliative care, understand the clients, collaborate with members of the interprofessional team, and provide meaningful occupational interventions during this transition. This program addresses the gap and need for occupational engagement, health promotion, and occupational justice for these individuals and their family members at the end-of-life (EOL).

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LIST OF ABBREVIATIONS

ADL	Activities of daily living
AOTA	American Occupational Therapy Association
CEU	Continuing Education units
EOL	End-of-life
IADL.....	Instrumental activities of daily living
OT.....	Occupational therapy
OTP.....	Occupational therapy practitioner
QOL	Quality of life

GLOSSARY

End-of-life (EOL) is the umbrella term for palliative and hospice care.

Hospice care is for individuals with a life expectancy of six months or less. The focus is comfort care with no curative treatment. The goal is the same as palliative care: to improve the individual and family's quality of life.

Individual/Client/Patient are used interchangeably. They all mean an individual with a serious illness who is receiving palliative or hospice care.

Palliative care is specialized care for an individual living with a serious disease. It may be provided for many years and focuses on relieving the symptoms and stress of the illness. The goal is to improve the individual and family's quality of life.

CHAPTER ONE – Introduction

In my experience as an occupational therapist working in both skilled nursing, acute, and inpatient rehabilitation environments, I have observed a significant lack of understanding and training among therapists in caring for seriously ill patients whose rehabilitative potential is suboptimal. Typical rehabilitative therapy focuses on progressive treatment strategies emphasizing regaining independence in self-care and mobility. This standard therapeutic approach does not consider the physical, mental, or emotional limitations confronting individuals with life-threatening illnesses. Often, the rigors of traditional rehabilitation directly negatively affect the patient's quality of life and well-being.

Smith, et al. (2020) report that 74% of patients with a chronic disease preferred to receive palliative/hospice care at home in their final months of life. However, only 40% achieved their goal of dying at home. This was partly due to the patient and families feeling poorly equipped to manage symptoms and cope with declining function in mobilities and activities of daily living (ADLs). Consequently, this increases the burden of care on family members, resulting in the individual's return to institutionalized care. The authors found that *The Short Stay Family Training Program*, designed to educate and train patients and their families as a dyad, increases success by removing critical barriers to discharge for patients in the advanced stages of disease and facilitates their goal of discharging home.

Padgett et al. (2018) report that rehabilitation clinicians are unfamiliar with complex symptom management, are lacking in creating appropriate rehabilitative goals,

and are unable to address the functional deterioration in the rehabilitation process among advanced cancer patients. They recommend providing therapists with the knowledge needed to enhance care for these individuals and their families, including clarifying the goals of care, understanding methods of symptom management and appropriate treatment approaches, and a deeper consideration of the scope of palliative care.

Occupational therapy educational institutions are not providing adequate training for students to work with individuals receiving palliative or hospice care at entry-level positions. Continued education courses for palliative care need to specifically address the needs of occupational therapy practitioners (OTPs) in working or wanting to work with such individuals (Talbot-Coulombe & Guay, 2020).

Consequences to Individuals and Family Members

This problem of lack of occupational therapy for palliative/hospice clients and family members is the disruption in habits and routines, roles, and rituals that provide meaning to their lives. Clients and family members not receiving therapy are unable to maintain their quality of life (QOL) and well-being due to the negative impact in all areas with participation and engagement in all ADLs (i.e., dressing, bathing, eating) and instrumental activities of daily living (IADLs) (i.e., making meals, working, finances). Individuals cannot maintain their independence, return home due to environmental barriers, and support from family members due to lack of training (Nissmark & Fänge, 2020). In the hospital setting, patients do not receive therapy due to confusion over definitions of palliative care, hospice, and comfort care and whether the patient should have occupational therapy. The scope of the issues spreads into inpatient rehabilitation

and skilled nursing facilities not taking patients due to payment concerns, therapists not knowing how to bill for services appropriately, or a client being discharged from therapy because they have a poor prognosis for rehabilitation (Padgett et al., 2018; Wilson & Boright, 2017).

Potential Causes Contributing to the Problem

Key factors contributing to the problem include:

- I. The population and medical field lack knowledge about palliative, hospice, and comfort care definitions.
 - a. Inconsistency in definitions leads to confusion and recommendations for referrals to occupational therapy in facilities and community settings.
- II. Are documenting medical necessity and receiving insurance reimbursement.
 - a. OTPs are unclear in documenting the medical necessity for a person in decline.
 - b. Insurance companies are inconsistent with reimbursement for therapy that is for maintaining or slowing the decline of conditions.
- III. Lack of education and training for OTPs working with individuals receiving palliative or hospice care.
 - a. OTPs are unprepared to work with patients receiving palliative or hospice care as it is not a part of the profession's education standards.
- IV. Culture of fear of dying and avoidance of discussing end-of-life (EOL).
 - a. Fear of dying is a difficult discussion with medical teams and family members, leading to ambiguity with care and the value of occupational

therapy.

- V. Family members and caregivers lack training to care for their loved ones at home.
 - a. Family members are unprepared for the burden of care and typically do not receive training to care for their loved ones.

Addressing the Problem

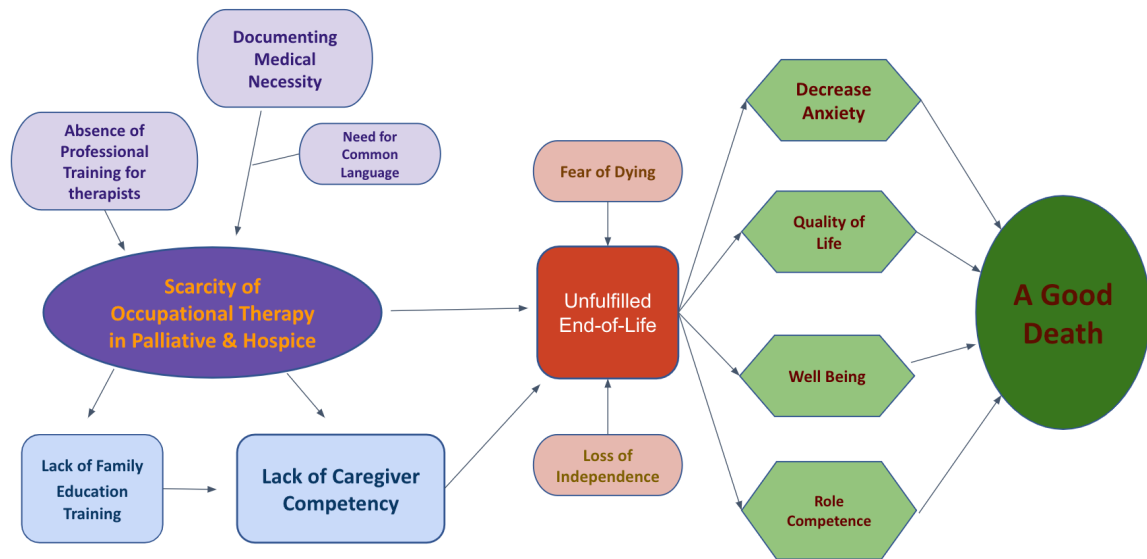
Core elements to addressing this problem include:

- I. Establish consistent definitions for palliative care, hospice, and comfort care in relation to occupational therapy.
 - a. Establish consistent definitions for palliative, hospice, and comfort care through a literature review and possible qualitative research.
- II. Create curriculum content for entry-level occupational therapy programs and continuing education for experienced therapists.
 - a. Research on continuing education formats, palliative care programs, and university course content to create new curricula for entry-level and post-professional OTPs.
- III. Policy changes at the national level for inclusion of occupational therapy as a member of the palliative hospice and hospice interprofessional team.
 - a. Advocacy at the national level for occupational therapy.
- IV. Create a group intervention for family caregivers to build confidence and competence in caring for their loved ones.
 - a. Research current interventions for family caregivers and develop a group intervention to meet the needs of family caregivers.

CHAPTER TWO – Theoretical and Evidence Base to Support the Proposed Project

Multiple factors drive the scarcity of occupational therapy in palliative care and hospice. Family members do not receive adequate training to care for their loved ones at home during their ultimate decline. This lack of training leads to incompetent caregiving and isolation of the caregiver. There is also an absence of professional training for occupational therapy students and experienced therapists. Insurance/stakeholder reimbursement is complex with documenting medical necessity and lacking a common language. The individual receiving palliative care or hospice is grieving the loss of independence with the occupations that provide meaning to their life. This may increase the fear of dying, making this life transition terrifying for the individual and making the situation stressful.

Training occupational therapists to intervene both with the individual and the family can change the trajectory of feelings of an unfulfilled life, confusion, stress, anxiety, incompetency, and ambiguity to a good death. Occupational therapy intervention can improve quality of life and well-being, increase caregiving competence, and decrease anxiety for the individual and family involved during this transition. See Figure 2.1 for the visual explanatory model of the problem.

Figure 2.1*Visual Explanatory Model of the Problem*

A literature review was conducted to address the multifaceted challenges of occupational therapy's involvement in palliative and hospice care. This review will be discussed in two sections: the first focuses on the caregiver, and the second on professional training in occupational therapy.

Needs of the Individual

The needs of the individual receiving palliative or hospice care were not a part of the research questions, as this paper focuses on caregiver confidence and competency and the lack of occupational therapy in these two settings. This section will briefly define those needs for reference. The Oregon Death with Dignity (2024) report for the last 26 years has listed the top four reasons for individuals to seek out assistance with death as not being able to engage in meaningful occupations, losing independence, loss of dignity, and being too much of a burden on family caregivers. Maersk et al. (2019) interviewed

22 participants with advanced cancer on the meaning of self. The article reports that individuals defined themselves through their occupations. As their health declined, they felt that they were losing their quality of life (QOL) and self-worth. Buwana et al. (2023) found the importance of meaningful occupation with adults with advanced cancer. Engaging in meaningful activities towards the end-of-life improved quality of life and well-being. The significance to individuals receiving palliative or hospice care is to remain engaged in occupations until death and not to be a burden on their families.

Needs of the Caregiver

Questions to guide the effects of caregiving, the preparedness of caregivers, and standardized training include: Is there evidence of caregiver confidence, knowledge, and competency while caring for a person receiving palliative care or hospice care? Is there evidence of the effects of caring for a person receiving palliative or hospice care, and is there evidence of standardized family education and training for palliative care and Hospice care? These questions were researched using the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and the American Psychological Association's PsycINFO databases. To ensure the most critical articles were located, key search words included palliative care, end-of-life, terminal care, life-limiting conditions, life-limiting illness, hospice care, standardized caregiving, family/families caregivers, informal caregivers, training, education interventions, programs, strategies, psychosocial effects, depression, anxiety, and occupational therapy. Inclusion criteria publications written in English, published within 2013–2023, adults/older adults, and were located in the community or home-based. After the initial search, the 75 articles were further reduced

by reading the abstracts, research questions, and conclusions. After the initial search, articles were decreased further by reading the abstracts, research questions, and findings. 19 articles met the inclusion criteria.

In the United States it is estimated that there are 1.2 million family or informal caregivers of terminally ill patients in the United States. This figure is expected to grow as the population ages (Starr et al., 2023). While most individuals with an incurable disease want to be cared for and die at home, this creates a more significant burden on family caregivers (Nissmark & Fänge, 2020).

Caregiving is time-consuming, with the average time of caregiving duties being 6.6 hours per day (Duimering et al., 2020). Towards the end-of-life, this time increases to an average of 8.3 hours per day and up to 66 hours per week during the patient's last year of life (Berry et al., 2017). In the development of the Weitzner's Caregiver Quality of Life Index-Cancer (CQOLC) survey of 197 caregivers of individuals with cancer assisting with activities of daily living (ADLs), instrumental activities of daily living (IADLs), and medical tasks, they reported a significantly QOL for the caregiver (Duimering et al., 2020). More than 50% of family caregivers reported needing to leave their jobs or reduce their work hours to provide care, causing a negative financial impact (Starr et al., 2023; Berry et al., 2017). For the caregiver, occupational balance becomes skewed, with roles, habits, and routines changing to fit the needs of the individual (Nissmark & Fänge, 2020).

Caregiving has been recognized as a significant health concern due to its adverse impacts on the mental and physical health of the caregiver. Psychological well-being,

spiritual distress, and marital relationships can be strained during this time (Grant et al., 2013). Nissmark & Fänge (2020), in their qualitative research, uncovered themes from caregivers of feelings of losing control, setting one's own needs aside, feeling invisible, being required or forced to take on new roles yet having to leave their own valued occupations, feeling lonely, and constantly stressed. Losing roles equals a loss of identity, and new roles can create feelings of insecurity and inadequacy. These themes can lead to caregivers having depression and anxiety. In a study of 176 Black caregivers and 546 White caregivers ages 18+ from the Midwestern and the Northeastern US, 32.1% reported moderate to severe anxiety symptoms compared to 2.7% in the general population, and 32.0% reported moderate to severe depression compared to 8% in the general population (Starr et al., 2022). When a patient's functional status declines, thus requiring increased assistance and increasing the burden of care, there is a direct correlation with increased severity of depression symptoms. Assisting with medical tasks, living with the patient, and taking time off from work also increased caregivers' distress levels (Duimering et al., 2020).

Continuing in the cycle of negative impacts, there is also a high prevalence of insomnia symptoms for hospice caregivers. In a recent study of 57 hospice family caregivers, 49.1% reported insomnia symptoms compared to 10–25% of adults in the US. Insomnia symptoms increase anxiety, depression, and caregiver burden while decreasing QOL. On a self-rated health survey that predicts morbidity and mortality, 53% of the participants reported that their health suffered due to caregiving. Insomnia may be acute during caregiving, but the risk for poor sleep continues up to 10 years after the caregiving

role ends (Starr, 2023). In another study conducted by Washington, Parker Oliver et al. (2018), one-third of hospice family caregiver participants experienced clinical-level sleep problems and anxiety. Sleep problems put the individual at a higher risk for cardiovascular disease, kidney disease, and impaired immune function. Participants were at increased risk for higher levels of anxiety and reported poorer overall health. They also reported increased fatigue, cognitive impairment, and negative mood. These symptoms could also negatively impact the individual's effectiveness in their caregiving role. A limitation of this study is that it did not distinguish between insomnia, sleep apnea, or other sleep disorders.

A higher burden of care increases the caregiver's mortality risk. Caregivers are asked to do complex tasks with assumed knowledge, yet there is no formal assessment of skills (Grant et al., 2013). Not only are there negative impacts on a caregiver's mental and physical health, but further consequences of not supporting the caregiver in their role can negatively impact the patient's effectiveness and quality of care (Washington, Demiris, et al., 2018). Not being prepared for the caregiving role is associated with fear, anxiety, stress, and feelings of insufficiency and uncertainty specific to the caregiver role (Williams, 2018; Kulkarni et al., 2014). Caregivers need the confidence to prevent physical and psychological injury to the caregiver and care recipient (DiZazzo-Miller et al., 2020). There is a need to provide evidence-based caregiver support interventions that strengthen the confidence and improve the well-being and QOL of the caregiver to improve the quality of care of the patient (Kulkarni et al., 2014; Starr et al., 2022; Grant et al., 2013). Caregivers need strategies to maintain their valued roles and occupations

(Nissmark & Fänge, 2020).

Connolly & Milligan (2014), in their qualitative, interpretative phenomenological approach, isolated these themes from eight caregivers of terminally ill patients at home. Caregivers want to know what the right thing is to do, want knowledge and practical skills, be able to manage symptoms and administer medications, and need practical and emotional support. These themes are also supported by the palliative health care professional's perspective on the needs of family caregivers. In Angelo et al. (2013) qualitative study, caregivers want to know how to care for themselves physically, emotionally, and spiritually, learn practical skills, and know what to expect and plan for as the family member's health declines. Education, training, mentorship, and support must be tailored to the caregiver's circumstances. This will ensure they can provide confident and effective care throughout the required period (Hendrix et al., 2015).

Caregiver Interventions

There has been research into interventions to meet the needs of caregivers providing care to palliative care and hospice patients. Interventions include psychoeducation, problem-solving, the provision of a guide booklet, and ADL training. Holm et al., 2015 and Holm et al., 2016, utilized an interdisciplinary approach to increase caregivers' preparedness, support their well-being, and decrease the negative consequences associated with caregiving. The intervention group demonstrated significantly increased preparedness for caregiving in the short and long term. Competence for caregiving also significantly improved in the short term, but there were effects on caregiver burden, health, anxiety, or depression. Another interdisciplinary

approach had four educational sessions organized by physical, psychological, social, and spiritual domains, plus the patient was discussed at interdisciplinary care meetings. Significant improvements were found in social QOL, psychological distress, and caregiver burden (Sun et al., 2015). Of note, an occupational therapist was not a part of the interdisciplinary team for both interventions (Borneman et al., 2015). The third psycho-educational intervention focused on the preparedness and competence of the caregiver while supporting a dying relative. In a three-arm randomized control trial comparing one or two home visits with a nurse, it was found that two visits significantly improved participants' levels of preparedness and competence, yet it did not decrease psychological distress (Hudson et al., 2013). A pilot study from social work provided three problem-solving intervention sessions to 23 hospice caregivers. After the sessions, caregivers reported higher overall QOL, lower anxiety levels, and improved problem-solving scores (Gregory & Gellis, 2020). The only intervention focused on activities of daily living (ADLs) for caregivers provided a single two-hour group session with an initial increase in caregiver confidence. However, at the three-month follow-up, caregiver confidence was not maintained (DiZazzo-Miller et al., 2020).

There are some limitations to these interventions regarding caregivers. None of the studies are holistic and address all the caregivers' needs with education and training. Only one study is from occupational therapy; however, it was not specific to palliative care or hospice.

Lack of Occupational Therapy

The second portion of the literature review focused on the reasons for occupational therapy's lack of involvement in palliative and hospice care. Questions addressed were: Is there evidence of information on palliative and hospice care in the Occupational Therapy Practice Framework (OTPF)? Is there evidence from the governing body of occupational therapy education regarding palliative and hospice care education? Is there evidence of entry-level or advanced education for occupational therapists in palliative and hospice care? Is there evidence of continuing education for occupational therapists in palliative and hospice care? Is there evidence that insurance companies will reimburse occupational therapy in palliative and hospice care, and do occupational therapists know how to document it for reimbursement appropriately? Is there evidence that healthcare professionals understand the role of occupational therapy in palliative and hospice care? These questions were researched using the Cumulative Index to Nursing and Allied Health Literature (CINAHL) database. To ensure the most critical articles were located, key search words included palliative care, end-of-life, terminal care, life-limiting conditions, life-limiting illness, hospice care, adult, older adult, occupational therapy, occupational therapist, education, and training. Inclusion criteria publications written in English, published within 2013–2023, adults/older adults, and were located in the community or home-based. After the initial search, the 40 articles were further reduced by reading the abstracts, research questions, and conclusions, with 11 articles meeting the inclusion criteria.

Limited Awareness of Occupational Therapy's Role in Palliative and Hospice Care

Other factors contributing to the underutilization of occupational therapists working in palliative care and hospice are other healthcare professionals' lack of understanding and knowledge of the role of occupational therapy in working with this population. There is limited awareness of OT's role in end-of-life (EOL), and stakeholder education is needed to utilize occupational therapy in this setting. Unfortunately, due to limited evidence of occupational therapy's effectiveness in EOL, this limits patients' access to these services. Agencies need additional training and resources to expand their understanding of occupational therapy's positive impacts on patients' lives in hospice settings (Mueller et al., 2021).

Chow et al. (2023) extracted three themes from semi-structured interviews with twenty decision-makers and twenty-one occupational therapists in EOL care. The main obstacle to using occupational therapy in EOL is that decision-makers such as physicians and directors do not understand occupational therapy's role. A more significant challenge is that the healthcare system fails to offer holistic care to terminally ill individuals. Lastly, there are cost constraints due to Medicare's hospice payment system, with some directors feeling restrained by the hospice per diem reimbursement. Occupational therapy's role in palliative care continues to be misunderstood by the interprofessional team, which is why occupational therapists are not essential to palliative care (Chow et al., 2023; Yeh & McColl, 2019). Knecht-Sabres et al. (2019) survey of 104 professionals, including physicians, registered nurses, social workers, physical therapists, occupational therapists, and other professionals working in hospice care from 31 states, found that occupational

therapy continues to be underappreciated and underrepresented in this setting.

Medical Necessity and Billing

Only one article was found written for physical therapists during research on documenting medical necessity for reimbursement of palliative care. Wilson & Boright (2017) discuss the 2014 decision of *Jimmo vs. Sebelius* that the Center for Medicare & Medicaid Services (CMS) “improvement standard” is not a requirement to receive medically necessary physical therapy. However, documentation must establish that skilled services are medically necessary even if the patient is not expected to improve. Of note, this decision does not pertain to other insurance companies.

Lack of Education for Occupational Therapy Practitioners

In terms of education from the governing bodies of occupational therapy, the American Occupational Therapy Association (AOTA) and the Accreditation Council for Occupational Therapy Education (ACOTE), the Occupational Therapy Practice Framework and the Education Standards and Interpretive Guide do not comment on either palliative or hospice care (American Occupational Therapy Association, 2020; ACOTE Standards and Interpretive Guide, 2018). The AOTA does have a position statement for occupational therapy’s role in EOL care; it will be discussed in Chapter Three. Several articles call for the profession to properly educate students and occupational therapy practitioners (OTPs) to work in palliative and hospice care to meet this population's needs (Ashworth, 2014; Hammill et al., 2014; Knecht-Sabres et al., 2019; Talbot-Coulombe & Guay, 2020; Yeh & McColl, 2019; Chow & Pickens, 2020; Chow et al., 2023; Eva & Morgan, 2018). Hammill et al. (2014) recommend that further

education is required at the undergraduate level and for clinicians working in this area. Although the education level has changed to the graduate level, there is still a lack of curricula for this setting. “Lack of clear knowledge base makes it difficult for clinicians to determine not only the scope of their practice but also the educational training and clinical skills required to work in this area” (Hammill et al., 2014, p. 583). Talbot-Coulombe and Guay’s (2020) scoping review confirms the need for education,

Introductory-level knowledge of Palliative and end-of-life care should be offered to all students, advanced training should allow occupational therapists to master the philosophy of this type of care, deepen the understanding of topics such as being confronted with death, and empower them to advocate for their unique contribution. (p. 609)

Without advanced training to develop competence, occupational therapists may not be prepared to attend to the intricacies of occupations at the end-of-life. This might be part of the reason occupational therapy is mainly ignored in palliative care (Badger et al., 2016). Knecht-Sabres et al. (2019) also recommend developing clinical practice guidelines and advanced specialization for occupational therapists to work in hospice care. One therapist in another study reported that working in palliative care and hospice,

takes experience and skills new students don’t have; I think it’s a very hard field for a new graduate . . . I don’t think I had the life skills and experience to work with patients and . . .the comfort level that I do now (Davis et al., 2013, p. 17). Talbot-Coulombe and Guay (2020) also report that occupational therapists lack training in the unique role of occupational therapy in palliative care and EOL.

Even if a therapist is not working in this setting, the majority of occupational therapists, at some point, will work with an individual who is dying.

Current Education Options

For continuing education, a search was completed on Google with the search words continuing education for occupational therapists in palliative and hospice care, resulting in eighteen websites. Of the eighteen websites, only five had continuing education courses on palliative and hospice care. Within those five continuing education courses, there was a total of 10 courses offered. Instructors for the ten courses included seven physical therapists, one nurse, and two occupational therapists. Only one course was on the distinct role of occupational therapy in hospice and palliative care (Home CEU, n.d.). Of note, the AOTA and National for Board in Certification Occupational Therapy Navigator sites did not have any continuing education courses for palliative and hospice care at the time of this research (AOTA Store, 2022; NBCOT, 2024).

Conclusion

Due to OTPs' lack of education and training in palliative and hospice care, many feel unprepared to work with this population. They are unable to help individuals and their family members. OTPs also cannot advocate for occupational therapy services for individuals and their families who need a holistic approach during this significant life transition. This leaves these individuals and their families in crisis with potentially poor outcomes during a time when they need to be the most supported. With specific EOL occupational therapy intervention, the opportunity for improved quality of life, well-being, competence, and decreased anxiety is possible..

CHAPTER 3 – Overview of Current Approaches and Methods

As stated in the previous chapter, occupational therapy has an ambiguous role in palliative and hospice care due to confusion about involvement, a lack of understanding from other professionals and stakeholders in occupational therapy's role, and a lack of education at entry-level and post-professional levels. This chapter discusses evidence for occupational therapy education in palliative and hospice care within the United Kingdom, Ireland, Australia, Canada, Sweden, and the United States. Exploring other professions' education in palliative and hospice care for physicians, nurses, social workers, and chaplains. Research questions guided this investigation: What evidence exists for occupational therapy education in palliative care in the US, Sweden, Canada, Australia, the UK, and Ireland? What evidence exists for occupational therapy interventions in palliative and hospice care? What evidence exists for palliative and hospice care education in other health professions, such as physicians, nurses, chaplains, and social workers? Databases used were the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PsycINFO, with search words of Occupational therapy AND (training or education or development or learning) AND (hospice care or palliative care or terminal care or end-of-life care). Inclusion criteria date range 2005–2024, in English, and for all results for occupational therapy educational programs in palliative care, 68 articles were located. Duplicates from Chapter Two were removed, the abstract was read, and the articles were reduced to 14 that met the inclusion criteria. Research on Google for professional education programs in the United States yielded 10 programs. Of note is that the search for occupational therapy education in Sweden yielded no results. Searches

were also conducted on Google for national and international occupational therapy education programs in palliative and hospice care, yielding one interprofessional program and one palliative care competency framework.

International Occupational Therapy in Palliative Care

Four international research articles from Australia, New Zealand, Canada, and Europe discuss occupational therapists working in the end-of-life (EOL) setting. Eva and Morgan (2018) conducted a cross-sectional survey of European occupational therapists. 237 valid responses were received from 21 countries, with the highest concentration of occupational therapists working in the United Kingdom (120), Ireland (38), the Netherlands (15), and Sweden (12). Of those surveyed, 72% in the UK, 52% in Australia, and 24% in European countries reported working full-time in the EOL setting. (Eva & Morgan, 2018; Martin & Herkt, 2018). Talbot-Coulombe et al.'s (2022) online survey of 67 Québec occupational therapists working in palliative and EOL care provides insights into the practice process and reasons for occupational therapy referral. Interventions focused on comfort and safety in meaningful occupations that included mobility, transfers, hygiene, adapting activities, modifying the environment, preserving clients' autonomy for as long as possible, and supporting caregivers. Hammill et al. (2017) focused on the workforce profile of Australian occupational therapists and the need to increase the number of occupational therapists working in the EOL setting due to the aging population and individuals living longer with serious illnesses.

United Kingdom

The United Kingdom has demonstrated a commitment to caring for individuals at the EOL. The Duke Global Health Institute reports that out of 81 countries, the United Kingdom ranked number one as the best place to die. Criteria for assessing end-of-life care include managing pain, having a safe environment, being treated in a kind manner, and providing treatments to improve quality of life—not just attempting to extend life (Finkelstein, 2022; Banks, 2022).

This commitment to care is demonstrated in developing *The Route to Success in the End of Life Care-Achieving Quality for Occupational Therapy*. This resource aims to provide occupational therapy practitioners with practical information to work in a variety of settings and to promote quality end-of-life care. Written by and for all occupational therapy stakeholders, it defines occupational therapy's role during the six steps in end-of-life care. Case studies, resources, and core skills are discussed in depth to provide guidance for occupational therapy practitioners and educate other healthcare professionals on the role of occupational therapy in end-of-life care (College of Occupational Therapists, 2011). The Royal College of Occupational Therapists is also a part of the National Palliative and End of Life Care Partnership. It is considered to have experience and responsibility for EOL care. Because of this involvement, the Royal College of Occupational Therapists participated in the *Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021–2026*. This framework provides six ambitions that include seeing each person as an individual, fair access to care, amplifying comfort and well-being, coordinated care, all professions being prepared

to care for the individual, and the recognition that community members should be ready to support one another during the living and dying process (Ambitions, 2021).

Education in the United Kingdom allows occupational therapist practitioners to take the European Certificate in Essential Palliative Care (ECEPC). Created in 2001, the ECEPC is a nine-week course that includes topics on what palliative care is and who it is for, symptom management in palliative care, patients with emergency conditions, care in the last 48 hours of life, breaking bad news to patients and families, bereavement and support, and common ethical issues (ECEPC, 2024). South East Technological University also offers a *Certificate in Palliative Care for Health Professionals* with courses that include holistic palliative care within a multi-professional context; symptom management; professional, legal, and ethical issues; communication; self-care practices; contemporary bereavement practice; and identifying the learners' individualized learning needs relevant to their discipline. (Postgraduate Certificate, 2024).

Ireland

Ireland is the second-ranked country on the list of the best places to die (Finkelstein, 2022; Banks, 2022). The Palliative Care Competence Framework was created for healthcare professionals involved in palliative care to standardize undergraduate and postgraduate education in Europe. Approved by the Association of Occupational Therapy Ireland (AOTI) for discipline-specific competencies on domains of competence for palliative care: principles of palliative care, communication, optimizing comfort and quality of life, care planning and collaborative practice, loss, grief, and bereavement, and professional and ethical practice in the context of palliative care.

Levels of knowledge and expertise for the Competence Framework Model were adapted from the Australian Model for Nursing in Cancer Control as ALL, SOME, and FEW.

This equates to level 1 — Palliative Care Approach, level 2 — General Palliative Care, and level 3 – specialist palliative care” (Ryan et al., 2014). Table 3.1 provides an example of these levels of expertise.

Table 3.1

Example for each Knowledge Level, Domain of Competence 5: Loss, Grief, and Bereavement

Domain of Competence 5 Loss, Grief, and Bereavement	
All Level 1 – Generalist	<ul style="list-style-type: none"> • Have knowledge of theories of loss and grief • Know when to refer to other palliative care professionals • Demonstrate understanding of the different stages of grief and loss
SOME Level 2 – Intermediate	<ul style="list-style-type: none"> • Awareness of disenfranchised grief in the individual their families and carers • Apply appropriate methods of addressing this grief
FEW Level 3 – Core role as a palliative care provider	<ul style="list-style-type: none"> • Demonstrate advanced knowledge of the grieving process • Support individuals with a serious illness and their families throughout the disease trajectory • Proactively respond to complex grief reactions • Mentor and educate colleagues • Supporting them to recognize and reflect on their own loss responses • Encourage self-care

Another program from Ireland is Project ECHO (Extension for Community Healthcare Outcomes). This program is a 4-month videoconferencing technology to support and train primary care occupational and physical therapists remotely every two weeks. The ECHO curriculum is based on the domains of Competence from the Palliative

Care Framework and provides teaching and case-based discussions facilitated by palliative care specialists. The curriculum includes palliative rehabilitation; palliative care needs assessment, communication — breaking bad news/managing difficult conversations, pain, effects of pharmacology on function, breathlessness, palliative edema, fatigue, anxiety, depression, stress, and neurological symptoms. Increased knowledge and confidence were found during the analysis of pre- and post-program questionnaires, with 85% of participants recommending the program to their colleagues (Usher et al., 2021). From one learner's perspective:

We are meeting these palliative care clients quite a lot now on our caseloads and it's one area I don't have a lot of experience in but now in primary care a lot of people are choosing to be at home for end-of-life care so I feel it is very relevant and I feel a lot of the lectures were very beneficial. (Usher et al., 2021, p. 1147)

Canada

The Canadian Association of Occupational Therapy (CAOT) Position Statement (2017) on end-of-life care provides recommendations to promote the development of research and quality occupational therapy service standards and engage in continuing professional education. As a member of the Quality End-of-Life Care Coalition of Canada (QELCCC), the CAOT continues to advocate for initiatives related to EOL care in Canada. For professional education, recommendations for curriculum include spirituality and issues related to EOL care. There is also a call for increased access to professional development in EOL care for occupational therapists.

Australia

Occupational Therapy Australia's position statement on palliative care establishes a “commitment to helping people actively engaged in life until they die” (Position Paper, 2015; p. 3). Besides defining the role of occupational therapy in palliative care, it calls for the profession to be an integral member of the palliative care team. Recommendations are made to incorporate advanced palliative care training and a palliative approach into undergraduate and postgraduate curriculums. To facilitate this, access to support and education for implementing an evidence-based palliative care approach is needed, and more research is needed on the benefit of occupational therapy in this setting (Position Paper, 2015). The Occupational Therapy Registration Board South Australia (OTSBA) has developed an advanced scope of practice framework for occupational therapy practitioners (OTPs) and palliative care. The document provides the benefits of having advanced practice roles, the scope of practice, practice pillars for advanced and extended scope, and the implementation of advanced scope for OTPs (Advanced Scope of Practice, 2015).

United States

The American Occupational Therapy Association's (2023) position statement clearly defines the need for further education for occupational therapists to work in the EOL setting successfully. Under the education and training heading, occupational therapists require knowledge of dying trajectories of diagnoses, understanding of loss of function due to physical changes through the dying process, psychosocial needs, occupational preferences, goals, cultural humility, grief responses, and self-care practice

to be able to support clients and fellow professionals. In the early stages, typical rehabilitation is appropriate; however, as an individual continues to decline, there is a transition to palliative rehabilitation, environmental modifications, use of assistive technology, compensatory strategies, and caregiver training.

In the United States, there are several programs for palliative care and hospice training; the majority of the programs are for physicians, physician assistants, nurse practitioners, and nurses. These include certificates, master's and doctor of philosophy degrees (University of Colorado, 2024; Creighton University, 2024; Penn State, n.d.; University of Maryland, n.d.; Palliative Care Certification and Accreditation, 2024). Both social workers and chaplains' professional organizations offer specialty credentials in palliative and hospice care. Once meeting the qualifications and receive approval for their application, social workers may use the credentials of a Certified Hospice & Palliative Care Social Worker (CHP-SW) (Certified Hospice & Palliative Care Social Worker, n.d.). Chaplains can apply for the Palliative Care and Hospice Advanced Certification (PCHAC), which has prerequisites and additional competencies to complete (Palliative Care and Hospice Advanced Certification (PCHAC), 2024).

The Center to Advance Palliative Care, the Shiley Haynes Institute for Palliative Care, and the Coleman Medicine Training Program provide continuing education units. However, these organizations do not have continuing education units (CEUs) approved by the American Occupational Therapy Association (AOTA). Once the CEU certificates are received, an individual therapist must request approval from the AOTA (Professional Development in Communication and Support Care, 2022; CAPC Clinical Training, n.d.;

Shiley Haynes Institute for Palliative Care, n.d.).

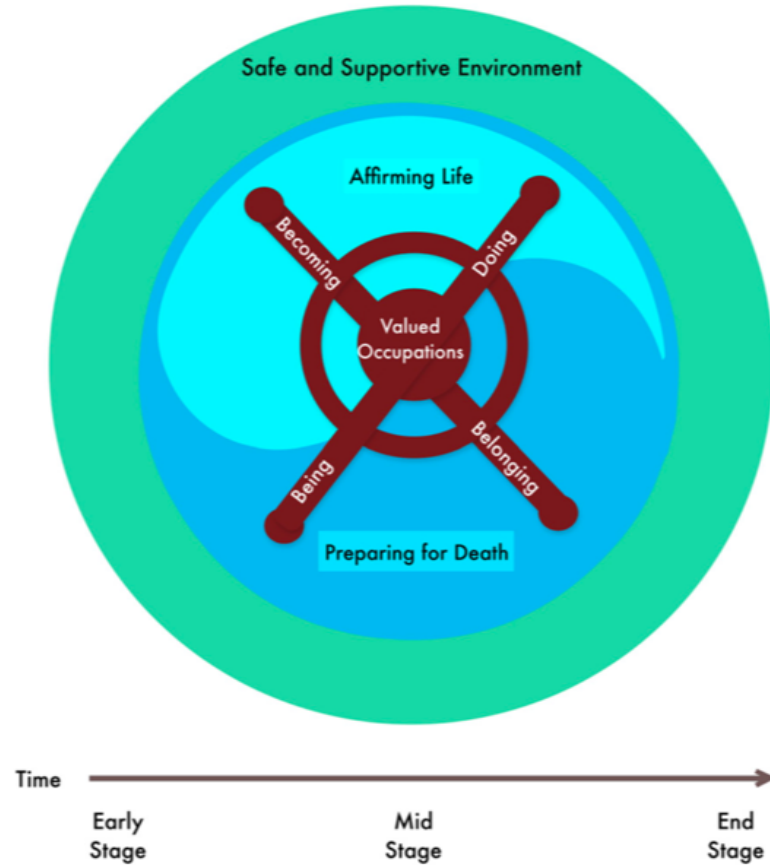
Of the above-listed educational opportunities, the University of Colorado, Anschutz Medical Campus, is the only program that lists therapists as potential participants in either a certificate or a Master of Science in palliative care with an allied health professional track. Sample content includes core palliative care concepts and principles, communication skills, psycho-social-spiritual care for patients and caregivers, pain assessment and management, and ethical concerns (University of Colorado, 2024).

Occupation-Based Model and Utilization in Palliative Care

To guide occupational therapists in working in palliative and hospice care and develop educational curricula to meet the needs of the setting, Yeh and McColl (2019) developed a model for occupational-based palliative care via a scoping literature review. The resulting themes are based on Ann Wilcock's Doing, Being, Becoming, and Belonging. Themes include the meaning of occupations even at EOL, the trajectory of a serious will change engagement in occupations, balance continued living while preparing for death, meaningful occupations can be classified into Wilcock's model of occupation, and the environment must be safe and supportive for successful palliative care (Yeh & McColl, 2019). Figure 3.1 provides a visual model of occupational therapy in palliative care.

Figure 3.1

Yeh & McColl's (2019) Model for Occupation-Based Palliative Care



Note: Valued occupations are placed on a ship's steering wheel while surrounded by the interaction of affirming life while preparing for death. The environment encases occupations and this life transition, providing safety and support.

EOL interventions are emphasized to prevent loss of identity and roles.

Occupation is used to explore the meaning of living and dying while balancing reality with future plans. Table 3.2 lists examples of occupations using Yeh and McColl's model.

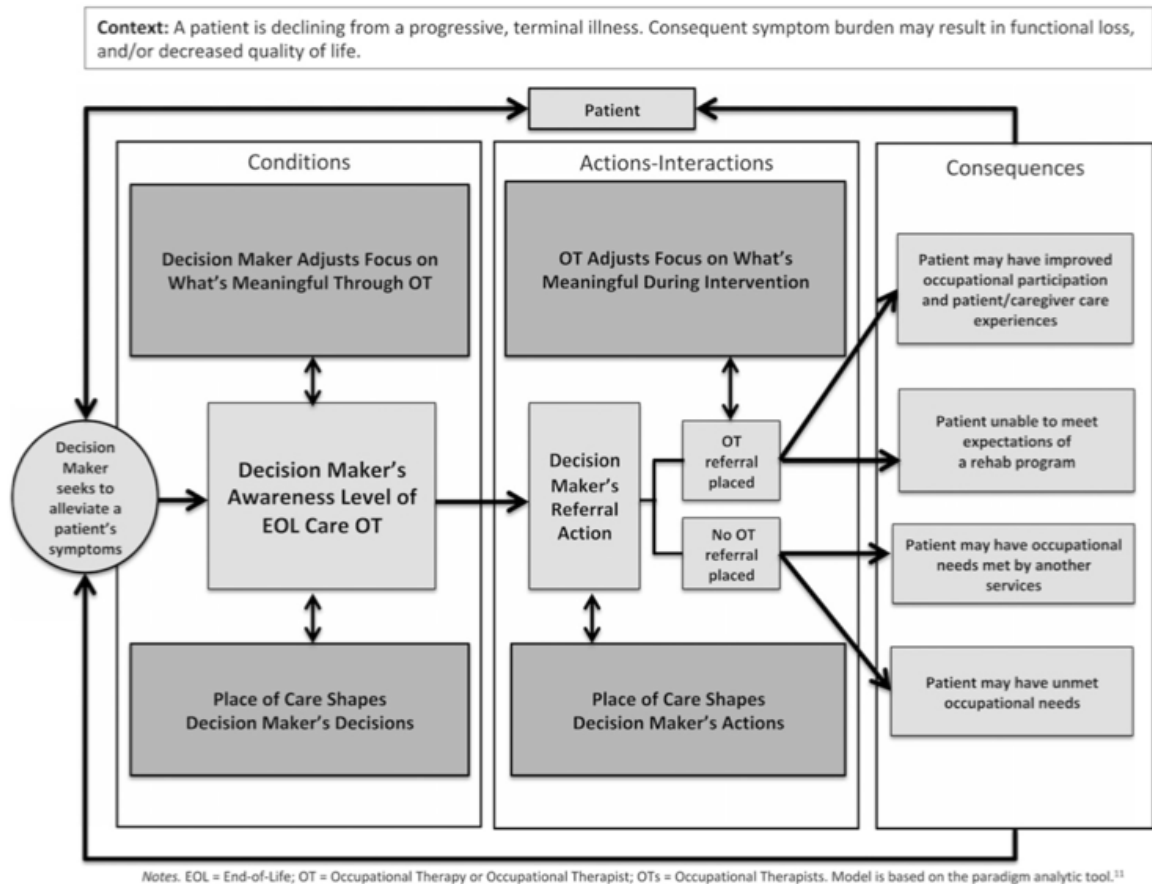
Table 3.2*Examples of EOL interventions*

EOL Interventions for Occupation	
Doing	Activities of daily living (ADLs), social participation, engagement in leisure, modifying occupation, and using assistive devices to maintain autonomy.
Being	Reflection of life events by journaling, connecting with people, and use of coping strategies during this transition.
Belonging	Focus on relationships, expressing all emotions, and creation of legacy projects.
Becoming	Symptom management including energy conservation, coping strategies, mindfulness practice and pain. Finding peace with an incurable illness, affirming life and preparing for death, and seeking closure.

Chow et al. (2023) developed the Model of Occupational Therapy Utilization in EOL care to further the use of occupational therapy at EOL due to the under-utilization of occupational therapy in this area. Depending on the decision maker's awareness level of occupational therapy means the difference in client's having access to the profession's services. Part of the challenge with access is the undefined role in the setting and occupational therapy's focus on rehabilitation and potentially discharging a client early from care. See Figure 3.2 for themes and flow of decision-making. Both models from Yeh and McColl (2019) and Chow et al. (2023) enhance the potential of OTPs working in palliative and hospice care settings.

Figure 3.2

Chow et al. (2023) Model of Occupational Therapy Utilization in End-of-Life Care



Education Curriculum

Several articles have established that there is a need for extensive education in palliative care. The lack of entry-level and post-professional training and the development of practice guidelines for advanced specialization are needed (Ashworth, 2014; Knecht-Sabres et al., 2019; Tavemark et al., 2019). Talbot-Coulombe and Guay's (2020) scoping review provides recommendations for curricula inclusion. The review included 27 articles from Australia—11, Canada—6, the United Kingdom—4, the United

States—5, and Spain—1. The authors' reasoning for completing this scoping review is to define what areas OTPs need competence:

Introductory-level knowledge of Palliative and end-of-life care should be offered to all students, advanced training should allow occupational therapists to master the philosophy of this type of care, deepen the understanding of topics such as being confronted with death, and empower them to advocate for their unique contribution. (p. 609)

Topics for inclusion are the role of the occupational therapist, the need for a practice model, defining the scope of intervention, knowledge of medical factors, symptom management, engagement in occupations with the awareness of functional deterioration, documentation, ethical and cultural considerations, grief and bereavement skills, philosophy of palliative care, knowledge of team member roles, understanding of the psychology surrounding death, and clinician self-care strategies.

Educational Strategies for this curriculum include graduate-level interprofessional courses, role play, observation, clinical case studies, advanced specialization courses, clinical practice guidelines, workshops, and self-reflection on death. Potential undergraduate education strategies include palliative care in the curriculum, student fieldwork placement in the setting, narrative and dialogic reflexivity, and self-reflection on one's own experiences, values, and beliefs about death (Talbot-Coulombe & Guay, 2020).

Conclusion

There is a need for occupational therapy education in palliative care. Opportunities to positively impact individuals receiving palliative care and their family members have been missed. As an integral palliative care team member, OTPs can improve the quality of life and well-being at the individual's EOL.

To demonstrate the value of occupational therapy practitioners working in palliative care, the World Health Organization Policy Brief on Integrating Rehabilitation into Palliative Care Services highlights five case studies from various European countries to demonstrate the integration of rehabilitation into palliative care. An example from the Netherlands is occupational therapists as part of the multidisciplinary team for chronic obstructive pulmonary disease (COPD). Because of the multidisciplinary palliative team, the organization is able to see more clients and provide services earlier in the illness. Another example is from the Cancer Center in Denmark. Again, occupational therapy is a part of the team that provides a 12-week educational program that includes symptom management, sleep, rest and relaxation, nutrition, and emotional and psychological concerns. The last example is from St Christopher's Hospice, London, United Kingdom, where occupational and physical therapy have been a part of the time multidisciplinary team from early on. It is now called the Rehabilitation and Wellbeing team and has developed a living-well-at-home team. Because of the rehabilitation team, the program can provide more services, and clients can self-refer. (World Health Organization, 2023). For programs like these in the United States, occupational therapy practitioners need education and training in the area of palliative and hospice care. The educational level of

becoming an occupational therapist requires a master's or doctoral degree, and the Accreditation Council for Occupational Therapy Education (ACOTE) does not include this setting in the education standards; a post-professional certification is needed to address the lack of education, demonstrate, and define the role of occupational therapy, and validate occupational therapy's value in this setting.

CHAPTER FOUR – Description of the Proposed Program

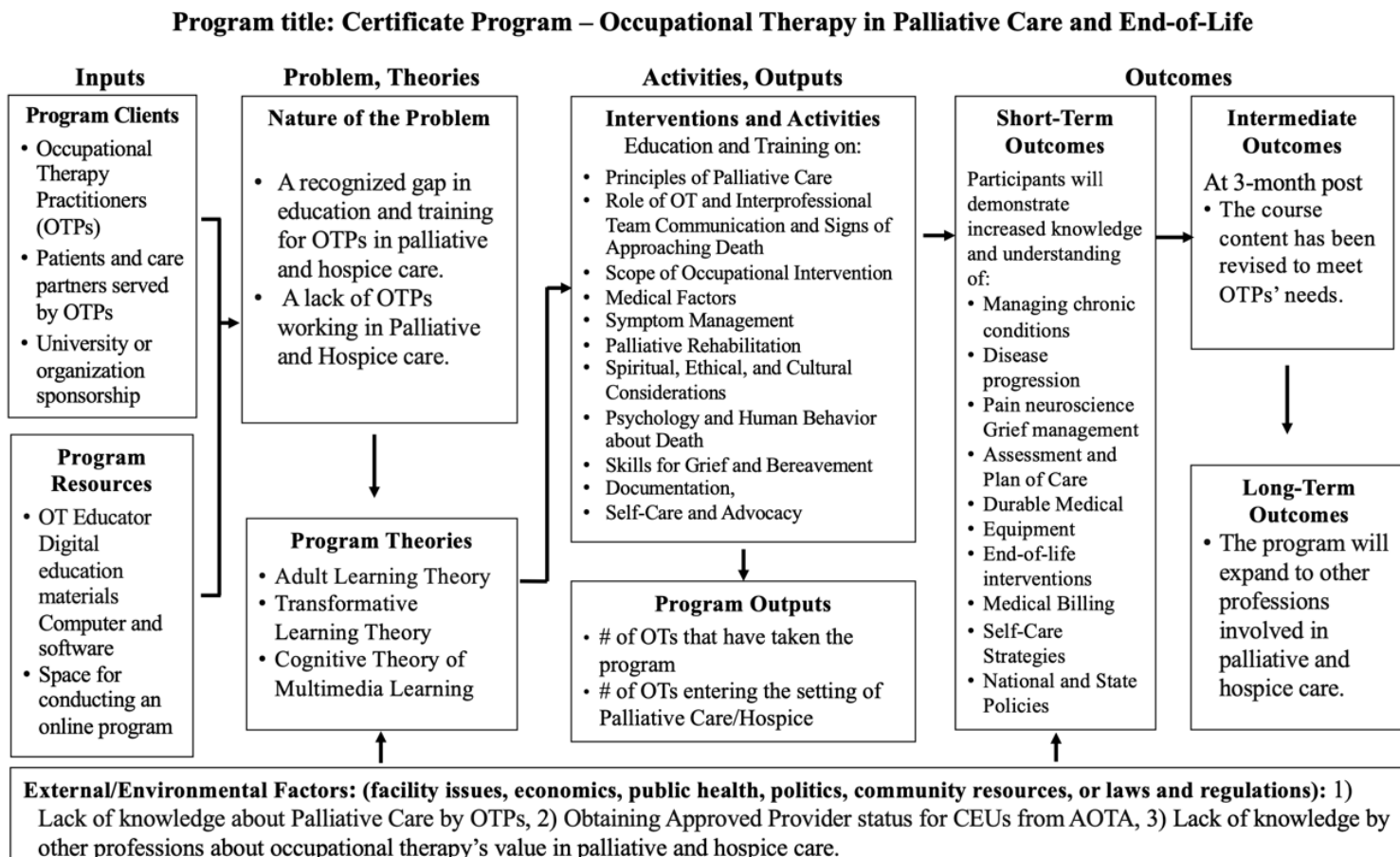
The author's innovative program is an educational certificate in palliative and hospice care for occupational therapy practitioners (OTP). This prepares OTPs to work in palliative and hospice care settings as integral interprofessional team members and provide meaningful occupational intervention to improve individuals and their family members' quality of life. This online synchronous certificate program will require individual study preparation of 4–5 hours per week and a 60-minute once-a-week online class. Participants will have required online content to read before weekly discussions, study guides, journal entries, module quizzes, and a comprehensive exam administered pre and post-program. Readings, case scenarios, and other content will be current, evidence-based information for each weekly topic. The content comprises 12 learning modules with 1. Introduction and Principles of Palliative Care, 2. Role of Occupational Therapy and Interprofessional Team Members and Their Roles, 3. Communication – Empathetic and Active Listening, and Signs of Approaching Death, 4. Scope of Occupational Intervention, 5. Medical Factors, 6. Symptom Management, 7. Palliative Rehabilitation and Engagement versus Performance 8. Spiritual, Ethical, and Cultural Considerations, 9. Psychology and Human Behavior about Death, 10. Counseling Skills for Grief and Bereavement, 11. Documentation, and 12. Self-Care and Advocacy.

The certificate program's learners are post-professional OTPs interested in or working in palliative and hospice care. These individuals may be recent graduates or experienced therapists of diverse backgrounds, education, and work experience. Recruitment will be through marketing at conferences, brochures, emails, journal advertisements, one-to-one meetings, social media use, and podcasts.

Logic Model

Figure 4.1

Logic Model of the Proposed Program Occupational Therapy in Palliative and Hospice Care: A Certificate Program



Program Features and Approaches

To provide a comparative program to other professional certificate programs, overarching content will be created to give OTPs the same level of education. The creation and implementation of this program and its alumni will demonstrate occupational therapy's value to other professions and the need to have OTPs as integral members of the palliative interprofessional team. Current core team members include physicians, nurses, social workers, and chaplains. The overarching content of similar programs consists of the principles of palliative care, management of chronic conditions and disease trajectories, symptom management including pain, communication, role identity and interprofessional team member roles, spirituality, ethics, psychological concerns, grief and bereavement, signs of approaching death, and advocacy (University of Colorado, 2024; Creighton University, 2024; Penn State, n.d.; University of Maryland, n.d.; Palliative Care Certification and Accreditation, 2024; Certified Hospice & Palliative Care Social Worker, n.d.; Ryan et al., 2014). Content specific to occupational therapy has been distilled from frameworks from the United Kingdom, Ireland, and Australia. This provides the established international focus. (Postgraduate Certificate, 2024; Ryan et al., 2014; Advanced Scope of Practice, 2015). Articles from the last ten years have also informed the development of this program (Talbot-Coulombe & Guay, 2020; Yeh & McColl, 2019; Ashworth, 2014; Hammill & Cook, 2014; Hammill et al., 2019; Hammill et al., 2017; Davis et al., 2013; Chow & Pickens, 2020; Chow et al., 2023; Eva & Morgan, 2018; Knecht-Sabres et al., 2019).

Outcomes

Outcomes for the certificate program include:

Short-term: By the end of the course training, occupational therapists will be able to demonstrate knowledge competency by passing a comprehensive exam based on education and training based on the content from the 12 modules.

Intermediate: The course content will be revised three months post-program to meet OTPs' needs.

Long-term: Five years after the certificate program's beginning, the number of occupational therapists employed in palliative and hospice care settings will increase by surveying the former course participants' employment. Expand the program to other professions involved in palliative and End-of-Life care. This would include physical therapists and speech-language pathologists. Establish OTPs as integral interprofessional team members, and national policies and institutions recognize their value in these areas.

Potential Barriers and Challenges

New initiatives and programs that face potential barriers and challenges during development and implementation are listed with potential solutions in Table 4.1.

Table 4.1*Barriers/Challenges to the Program with Potential Solutions*

Barriers and Challenges	Potential Cause or Effect	Solutions
Unable to obtain sufficient start-up costs for content development, administration, and marketing.	This could possibly delay the start of the program, or the program may not come into existence.	<ol style="list-style-type: none"> 1. Consider a smaller format such as each module being a separate individual workshop. 2. Expand search for funding opportunities.
Unable to find a sponsor to house the program through a university or continuing education site (Professional education, n.d.).	Possibly the university or continuing education site may not see the cost benefit of sponsoring the program.	<ol style="list-style-type: none"> 1. House the program independently through a learning management system (Learning management systems, 2024).
Not qualifying as an American Occupational Therapy Association (AOTA) Approved Provider for professional development units (Approved Provider, 2024).	This may deter OTPs from taking the program as it would denote a program of poor quality and not worth the time or cost to take the course.	<ol style="list-style-type: none"> 1. Ensure content is relevant, occupation and evidence based. (Talbot-Coulombe and Guay, 2020)
Lack of participants	Potential participants could lack buy-in, deem the cost of the program may be too expensive, and have time restraints due to working full-time.	<ol style="list-style-type: none"> 1. Marketing campaign on multiple platforms. See Chapter 7 Dissemination Plan for further information. 2. Be cognizant of the cost of the program and the amount of CEUs offered. 3. Realistic amount of time needed for studying set for 4–5 hours per module.

Certificate Program Modules and Content

The Occupational Therapy in Palliative and Hospice Care: A Certificate Program contains key components of related professional certification programs in palliative care and specific occupational knowledge. Its purpose is to demonstrate occupational therapy's value in this setting and prepare OTPs to work successfully in it. Modules provide the foundational information needed to facilitate the use of the principles of palliative care, understand the needs of the individuals and their family members, work with members of the interprofessional team, and provide meaningful occupational interventions during this life transition. Table 4.2 provides the content and justification of each module.

Table 4.2*Example of modules and potential content*

Module	Content	Justification
<ul style="list-style-type: none"> • Introduction • Principles of Palliative Care 	<ul style="list-style-type: none"> • Welcoming environment for learning and support. • Principles of palliative care in the context of occupational therapy. 	<p>Create a safe and supportive learning environment.</p> <p>Principles of palliative care are the foundations of care.</p> <p>(Udermann, 2019; Ryan et al., 2014)</p>
<ul style="list-style-type: none"> • Role of Occupational Therapy • Interprofessional Team Members and their Roles 	<ul style="list-style-type: none"> • Value of occupational therapy during transition and end-of-life • Roles of the interprofessional team including physicians, nurses, social work, chaplains, and allied health professionals. 	<p>Unique role of occupational therapy during end-of-life.</p> <p>Knowledge of team members scope of practice strengthens client-centered care.</p> <p>(American Occupational Therapy Association, 2023; CAOT Position Statement, 2017; McLaney et al, 2022)</p>
<ul style="list-style-type: none"> • Communication – Empathic and Active Listening • Signs of Approaching Death 	<ul style="list-style-type: none"> • Key terminology and concepts • Physical and cognitive changes of approaching death 	<p>The most reported frustration of individuals and family members is the lack of communication and “Just being heard”.</p> <p>Individuals and family members want to understand the process of dying.</p> <p>(Talbot-Coulombe and Guay, 2020; Davis et al., 2013; Hammill et al., 2014; Bauer and Figl, 2008; O’Bryan, 2022; Kortes-Miller, 2018).</p>
<ul style="list-style-type: none"> • Scope of Occupational Intervention 	<ul style="list-style-type: none"> • Caregiver training • Activities of daily living (ADLs) and instrumental activities of daily living (IADLs) • Equipment recommendations • End-of-life occupations 	<p>Interventions to maintain autonomy.</p> <p>Flexibility in adjusting to sudden declines.</p> <p>Specific end-of-life interventions.</p> <p>(Buddelmeyer, 2023; American Occupational Therapy</p>

		Association, 2023; CAOT Position Statement, 2017)
<ul style="list-style-type: none"> • Medical Factors 	<ul style="list-style-type: none"> • Top 10 hospice diagnoses and their effect on occupation • Medical procedures/medication and their effect on occupation 	<p>Progressive diseases symptoms. Potential medical procedures related to diagnoses and symptom management. (Hammill et al., 2014 & 2017; NHPCO, 2023 Atchison & Powers Dirette, 2023)</p>
<ul style="list-style-type: none"> • Symptom Management 	<ul style="list-style-type: none"> • Breathlessness • Pain • Fatigue • Depression and Anxiety 	<p>Non pharmaceutical management strategies for the most common symptoms. (Buddelmeyer, 2023; Yeh & McColl, 2019; Louw et al., 2019)</p>
<ul style="list-style-type: none"> • Palliative Rehabilitation • Engagement versus Rehabilitation 	<ul style="list-style-type: none"> • Traditional rehabilitation in early intervention • Meaning of palliative rehabilitation • Importance of the transition from participating to engagement toward end-of-life. 	<p>The importance of maintaining independence Transition from performance to engagement in meaningful activities. (Hammill et al., 2019)</p>
<ul style="list-style-type: none"> • Spiritual • Ethical and Cultural Considerations 	<ul style="list-style-type: none"> • Exploration of death in different religions and cultures. • Ethics of dying including medical assistance in dying, role of occupational therapy. 	<p>Therapists need to be aware of different religions and cultures at the end-of-life to provide client-centered care. Knowledge of ethical issues unique to end-of-life. (Hammill et al., 2014; Akdeniz, et al., 2021)</p>
<ul style="list-style-type: none"> • Psychology and Human Behavior in Relation to death 	<ul style="list-style-type: none"> • Death anxiety • Psychological death • Societal death • Active versus passive coping 	<p>Specific behavior surrounding end-of-life with positive and maladaptive coping behaviors. (Lazzara, 2020)</p>
<ul style="list-style-type: none"> • Counseling Skills for Grief and Bereavement 	<ul style="list-style-type: none"> • Techniques to address grief and bereavement 	<p>Grieving process both for the individual and family members</p>

	<ul style="list-style-type: none"> • Client – loss of autonomy • Caregiver – loss of roles 	with loss/change of occupations and loss of a loved one. (Hammill et al., 2014; Hone, 2017)
<ul style="list-style-type: none"> • Documentation 	<ul style="list-style-type: none"> • Potential assessments • Language use in documentation • Billing codes 	Appropriate documentation is important for reimbursement and to demonstrate need. (American Occupational Therapy Association, 2023; Wilson & Boright, 2017)
<ul style="list-style-type: none"> • Self-care strategies • Advocacy 	<ul style="list-style-type: none"> • Community of support • Strategies for self-care • Resources • Strategies for advocacy for client and family members • Strategies for advocacy with organizations • Strategies for advocacy with national policy 	In this setting there is a high level of burnout. The role of occupational therapy is not understood on multiple levels and advocacy is needed to disseminate our value. (Treggalles & Lowrie, 2018; Kirsh, 2015; Talbot-Coulombe & Guay, 2020; Hammill & Cook, 2014)

Learning Theories

These three learning theories have informed the design, presentation, delivery, and course content of this certificate program as it has been developed.

Cognitive Theory of Multimedia Learning (CTML) by Richard E. Mayer

The primary construct for CTML is how we process information through a dual-channel process of visual and auditory information. Humans have a hard limit on how much information can be processed simultaneously. The role of the educator is to provide high-quality material, guiding students through the appropriate cognitive process of selecting, organizing, and integrating information. It is also essential for the educator to provide timely feedback that will foster the generative process, boost self-efficacy, and

decrease anxiety in the learning environment (Davis & Norman, 2016; Mayer, 2024).

Kolb's Experiential Learning Theory by David A. Kolb

Knowledge creation is a transformational process that occurs during active learning activities. A learner is not a blank slate but an individual with past experiences influenced by the environment. Learning requires active experimentation, concrete experience, reflective observation, and abstract conceptualization (Kitchie & Arnaud, 2020).

Self-Directed Learning Theory by Malcolm S. Knowles

A learner-centered experience is created when the appropriate materials are provided to the learners. This theory fosters and promotes the responsibility of learning on the learner. Learners are responsible for planning, implementing, and evaluating their learning needs (Charokar & Dulloo, 2022).

Refer to Appendices A–D for the learner profile, learner bill of rights, teaching plan, and learning tool for module three.

Conclusion

The Occupational Therapy in Palliative and Hospice Care: A Certificate Program is based on evidence-based content to provide current and pertinent education to its participants. This program will provide OTPs who want to work in this setting with a solid foundation of knowledge to participate as integral members of the interprofessional team successfully and provide client/family-centered care. This program distills content from other health professions and fills the gap for occupational therapy education in this area. The timing is right for this new program; not only will OTPs benefit, but their

clients/family members, palliative and hospice organizations, and our healthcare system will also feel the positive impacts of occupational therapy.

CHAPTER FIVE – Program Evaluation Research Plan

Program Scenario and Stakeholders

The program, an educational certificate in palliative care and hospice for occupational therapy practitioners (OTPs), prepares occupational therapists to work in palliative care/hospice settings. Modules of learning cover foundational knowledge needed to work in this setting: 1. Introduction and Principles of Palliative Care, 2. Role of Occupational Therapy and Interprofessional Team Members and Their Roles, 3. Communication – Empathetic and Active Listening, and Signs of Approaching Death, 4. Scope of Occupational Intervention, 5. Medical Factors, 6. Symptom Management, 7. Palliative Rehabilitation and Engagement versus Performance 8. Spiritual, Ethical and Cultural Considerations, 9. Psychology and Human Behavior about Death, 10. Counseling Skills for Grief and Bereavement, 11. Documentation, and 12. Self-Care and Advocacy.

The certificate program initially would serve the OTPs taking the course. Further beneficiaries would be the companies that hire the OTPs. The individuals receiving occupational therapy through palliative and hospice care are the ultimate beneficiaries of the certificate program.

The certificate program will be delivered online via a learning management system such as Canvas or Blackboard. Active program delivery providers would include an occupational therapist educator, expert speakers on specific topics such as the grieving process, an information technology consultant for placing digital content for the course and technology issues, and administrative services such as registration. Intended users of

the program evaluation include future OTPs interested in the course, American Occupational Therapy Association Approved Provider designation, the university or organization hosting the program, organizations that provide palliative and hospice care, members of the interprofessional team, clients and their family members, and national policymakers.

Research Practice Scenario

Jennifer is a 31-year-old occupational therapist who has been working at a skilled nursing facility for five years since she graduated from a master's in occupational therapy program. She enjoys working with older adults on both the short-term and long-term floors. Early in her five years, she worked with some patients who were receiving palliative care but did not quite understand why they were going through rehabilitation when they had a life-threatening illness. As Jennifer matured as an occupational therapist, her understanding of palliative care grew. However, she felt that she did not have the knowledge base to provide interventions to her patients that would prepare them for transitioning home and facilitate continued independence and control during their decline in health. Jennifer was wondering why occupational therapy was not involved with patients when they transitioned to hospice.

Jennifer meets with some of her former classmates every three months for a journal club. At the most recent meeting, Jennifer shared her frustration with needing to feel more competent working with patients receiving palliative care and hospice. One classmate mentioned seeing an advertisement in the recent OT Practice about the 12-week, live online certificate/continuing education program (CEU) program in palliative

care and hospice for occupational therapists and encouraged Jennifer to check out the program. When Jennifer returned home, she located her OT Practice and found the advertisement. After reading the course content, which consisted of different modules, including the principles of palliative care, pain neuroscience, and managing grief, she reviewed the positive quotes from previous participants. Jennifer enrolled in the certificate program to gain the knowledge she felt she was missing. She was excited to think about her patients who would benefit from the education.

Ultimately, Jennifer completed the certificate program. Before the program started, Jennifer took a survey asking about her confidence, knowledge base, and hopes for what she wanted to learn. After each module, a quiz is taken to demonstrate competency in the content. At the end of the program, Jennifer took a comprehensive exam and completed a survey asking the same questions as the pre-course survey. Taking the course increased Jennifer's confidence when working with patients receiving palliative care, and she was also able to advocate for occupational therapy services for the patients receiving hospice care at her facility.

Vision and Implications for Occupational Therapy

The vision of this program is to increase the number of OTPs working in palliative care and hospice by providing quality, current, evidence-based education. Define occupational therapy's role in this setting and demonstrate our distinct value on the interprofessional team. The implications of this certificate program for occupational therapy are multi-focused. For OTPs, provide confidence that your knowledge is equivalent to that of other professionals working in these settings. With this education,

OTPs will be able to demonstrate their value as integral team members to palliative and hospice organizations by providing clients and family members with support and holistic and meaningful occupations toward the end-of-life. Ultimately, the inclusion of occupational therapy in policies to improve the lives of individuals living with serious illnesses.

Key Stakeholders

Key stakeholders include the author, teaching staff, and administrative staff, who provide direct contact with the certificate program participants. Other stakeholders will be an educational institution or university hosting the program. Community stakeholders include the American Occupational Therapy Association (AOTA) for approving CEUs and policymakers who can impact occupational therapy's involvement in palliative care and hospice.

Stakeholder Engagement

For the success of the certificate program and the gathering of appropriate data, stakeholders will be involved through a utilization-focused evaluation process (Giancola, 2021). The needs of the stakeholders are to be met through their involvement from the beginning of the program through the end. Meetings will be held virtually: a meeting at the program's start, another at the halfway mark, and a final meeting after the program. Stakeholders or their representatives will be provided with information outlining the recognized gap in occupational therapy's involvement in palliative and hospice care, the logic model, and a summary of the planned content for each module. All stakeholders would be invited to solicit their needs, input, and recommendations at the first and last

meeting. The middle session would focus on the occupational therapy educator, guest speakers, IT consultant, and administrative staff for input on any improvements needed for the program's second half. At the end of each meeting, a summary of information and recommendations will be verbalized to gain consensus with all present stakeholders. If communication is needed outside of a meeting, an email will be sent to all stakeholders for feedback.

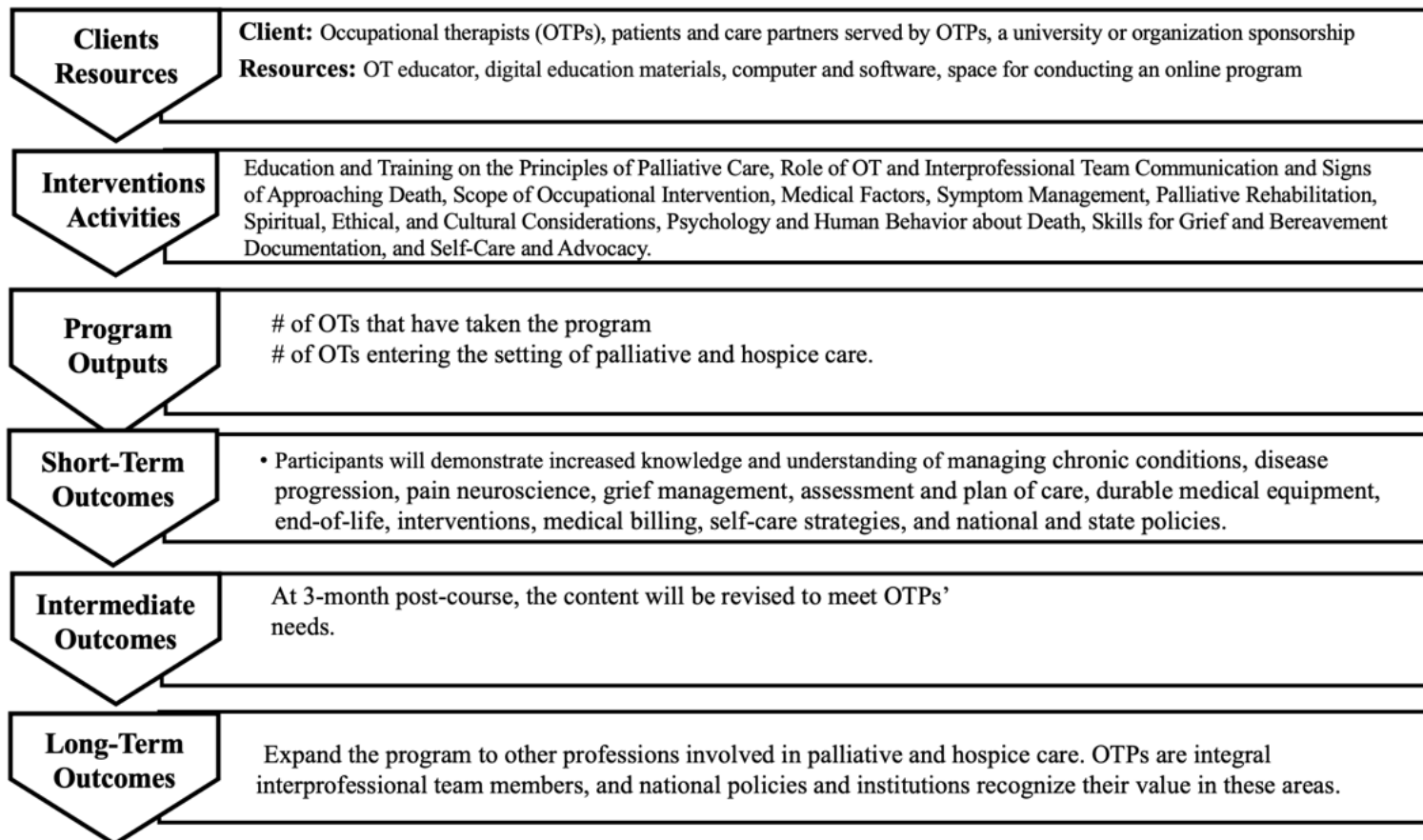
Communicating Evaluation Results

Communication with all stakeholders will be timely in maintaining relationships and interest in the certificate program. Secure and encrypted emails will be used to communicate evaluation results for individuals providing the program, such as the OT educator, guest speakers, IT consultant, and administrative assistant. Online scheduled meetings will be another opportunity to provide evaluation results. A more formal presentation of evaluation results will be provided to the university or organization hosting the certificate program, the American Occupational Therapy Association, and palliative and hospice experts. A two-page executive summary with graphics will be sent via email or mail to these individuals. A full executive summary will be provided if a more in-depth report is requested. Another audience interested in evaluation results is potential future participants. An infographic will be distributed via email-to-email lists and advertisements in a magazine such as OT Practice (Giancola, 2021).

Simplified Logic Model

Figure 5.1

Simplified Logic Model



Preliminary Exploration and Confirmatory Process

Background information and supporting documentation would be provided before the first virtual meeting with the identified key stakeholders. This background information includes the simplified logic model, a summary of the research demonstrating the need for this certificate program, sample teaching plans, sample competency exam questions, the fact sheet or executive summary, the budget, and how this program would align with current legislation, Senate Bill 1845—Expanding Access to Palliative Care Act and Senate Bill 4260—Palliative Care and Hospice Education and Training Act (S. 1845 – 118th Congress, 2023–2024; S. 4260 – 117th Congress, 2021–2022).

Program Evaluation Research Questions by Stakeholder Group

Table 5.1 provides potential formative and summative questions from each stakeholder group.

Table 5.1

Stakeholder Program Evaluation Research Questions

Stakeholder or Stakeholder Group	Types of Program Evaluation Research Questions
Researcher (this author)	<p><i>Formative:</i></p> <ul style="list-style-type: none"> ○ Was the program content and online delivery sufficient for the participating OTPs? ○ Are the OTPs using the skills that were taught during the modules? <p><i>Summative:</i></p> <ul style="list-style-type: none"> ○ Will the program participants report increased perceived confidence and competence in using the skills they have gained? ○ Are the OTPs that have completed the program being hired to work in palliative and hospice care?

<p>Persons actively involved in program delivery</p> <p>OT Educator Guest speakers IT consultant Administrative assistant</p>	<p><i>Formative:</i></p> <ul style="list-style-type: none"> ○ Was the information presented relevant? ○ Was the information presented too easy or too complicated? ○ Was teaching delivered at an optimal pace for learning? ○ Was the instruction sufficient for the participants to begin using it with clients? ○ Was the program duration adequate, or should it be shorter or longer? ○ Were some aspects of the program more versus less useful or effective? ○ Is there anything that should be changed to improve program content or delivery? ○ What other key issues or problems faced by participants were not addressed in the program? <p><i>Summative:</i></p> <ul style="list-style-type: none"> ○ Did participants gain needed knowledge consistent with program goals? ○ Did participants gain needed skills consistent with program goals? ○ Did participants gain perceived confidence in their ability to work with individuals and their care partners in palliative care and hospice? ○ Did participants gain perceived competence with regard to working with individuals receiving palliative care and hospice?
<p>Facility, educational institution or organization administration or management (Such as a university or organization that provides CEUs)</p>	<p><i>Formative:</i></p> <ul style="list-style-type: none"> ○ Does the content of the program match organizational goals? ○ Does the course content align with faculty needs and the requirements of working in a palliative care and hospice setting? ○ Is the online course delivery format suitable for post-graduate students? ○ Were program participants sufficiently prepared to apply the learning content in their clinical practice or future practice? ○ Were any problems or issues reported? ○ Did external factors impede execution of the research methodology? <p><i>Summative:</i></p> <ul style="list-style-type: none"> ○ Will the research data show that the course content led to desired change in participants knowledge? ○ Can the research data be used to demonstrate improved knowledge in the course content? ○ Do participants report long-term working in palliative and hospice care?

	<ul style="list-style-type: none"> ○ Is delivery of the program more costly than other means of delivery? ○ What were the rates of program withdrawal?
AOTA Policymakers Experts in the field of Palliative Care and Hospice	<p><i>Formative:</i></p> <ul style="list-style-type: none"> ○ Do participants report increased understanding of the distinctive role of occupational therapy in working in palliative care and hospice settings? ○ Are participants confident that they will be able to advocate for the role of occupational therapy as a change agent in palliative care and hospice? ○ Are the long-term goals of the project realistic and achievable? ○ Will the project increase awareness of developments in the field? <p><i>Summative:</i></p> <ul style="list-style-type: none"> ○ Can the research data be used to demonstrate desired change in recipients of OT intervention as the result of the project? ○ Will the research data demonstrate the importance of the role of OT for providing services relevant to the project? ○ In light of the health care system in...is the program justified based on study findings? ○ Will findings demonstrate that the course content matches the knowledge needed to close the clinical gap the project is addressing?

Research Design

This certificate program is in development and will be administered as a pilot study. In a non-experimental/single-group design with pre- and post-data collection, the participants' conditions for the program experience will not be manipulated. Comparing one cohort to another will allow additional data for further research.

Overview of Summative and Formative Approaches

Formative approaches will be post-program surveys using open-ended questions. Surveys would be completed online and posted with the module content. Summative approaches will be Likert-style questions on a survey administered before the program and following program completion.

Participants, Selection, and Recruitment

The certificate program is open to any postgraduate OTP registering for the course. There will not be a selection process for participants. Recruitment will utilize social media advertising, AOTA OT Practice, emailing postgraduate occupational therapists through educational program alum communication, and rehabilitation companies. The number of participants for a cohort will be determined by the minimum needed to cover the program financially.

Location, Setting, and Time Frame

The certificate program will be provided virtually via Microsoft Teams or Zoom. Sessions will be provided in the evening and at a convenient time convenient for participants from multiple time zones. The coursework will take 12 weeks, with two additional months to take the competency exam. Initially, the course will be offered once during the first year and then expanded to two or three courses per year.

Methods Section***Intervention, Delivery, Activities, and Flow***

The certificate program consists of 12 learning modules with the subjects of 1. Introduction and Principles of Palliative Care, 2. Role of Occupational Therapy and Interprofessional Team Members and Their Roles, 3. Communication – Empathetic and Active Listening, and Signs of Approaching Death, 4. Scope of Occupational Intervention, 5. Medical Factors, 6. Symptom Management, 7. Palliative Rehabilitation and Engagement versus Performance 8. Spiritual, Ethical, and Cultural Considerations, 9. Psychology and Human Behavior about Death, 10. Counseling Skills for Grief and

Bereavement, 11. Documentation, and 12. Self-Care and Advocacy.

Participants will have required online content to read before weekly lectures/discussions, journal entries, module quizzes, and a comprehensive exam administered pre- and post-program. Content for reading will be current, evidence-based information and resources about the weekly topic.

Dependent Variables and Outcome Measurements

Dependent variables will be connected with changes in participants' confidence and knowledge. Participants' self-perceptions of confidence would be measured with a 10-point rating scale pre- and post-program. Knowledge acquisition will be calculated using the pre- and post-program comprehensive exam scores.

Data Collection and Storage Protocols

Data would be stored on a password-protected laptop or a protected server. Only appropriately trained individuals involved in the data collection would have access to the information. Co-coding would also minimize input errors, and participants would be engaged to survey the initial summary for member checking (Busetto et al., 2020).

Controls and Ethical Considerations

Appropriate training for all individuals involved in the research through the Institutional Review Board (IRB). Coding individual identifiers such as names, birthdates, and other demographics would be removed from data collection. Data will be stored on a password-protected device, with only the lead evaluator/researcher having access to identifying material. Encrypted emails would be used to protect data (Kaiser, 2009). Informed consent for the certificate program participants would be a part of the

registration process (Giancola, 2021).

Data Analysis

Quantitative Statistical Testing

As this will be the first launch of the certificate program, the focus will be on descriptive statistics to compile data from Likert scale questions on pre- and post-program surveys. The data from module quizzes and the comprehensive exam would also provide important information on the validity of exam questions. Microsoft Qualtrics would be used as the data collected can be exported into an Excel spreadsheet for analysis.

Qualitative Coding

The open-ended questions on the pre-and post-program surveys will be analyzed using qualitative coding. Options for analysis and extracting themes include NVivo, Codeit, or KnowledgeHound (Portugal, n.d.). Semi-structured group interviews with the educators during the midpoint and end of the course would be used to revise course content. Speech-to-text would generate transcripts of these group interviews using Microsoft Word or transcription software.

Anticipated Strengths and Limitations

Program Fidelity and Rigor

For intervention fidelity, consistency with course content and instructors would be important across cohort studies after the initial launch period. Observing participant engagement during discussions and monitoring time spent viewing course content online would facilitate fidelity. The checklist Standards for Reporting Qualitative Research

(SRQR) will be used to ensure transparency (O'Brien, 2014). Reflexivity will be used weekly to maintain appropriate relationships between the researcher and participants (Olmos-Vega, 2022). Member checking will provide accurate data collection and analysis for the semi-structured group interviews with the educators.

Threats to Internal Validity and Potential Sources of Bias

Potential threats to internal validity include participant performance on quizzes and the comprehensive exam. External threats include natural disasters or world events that interrupt the program or an individual's participation in the certificate program. Timing of the year may also impact internal validity, such as participation close to holidays or during the summer months when many people take vacations. The Rosenthal or Pygmalion Effect has the potential for bias. The collected data will be skewed if the instructor has low or high expectations of the participants or provides unequal attention to them (Perera, 2024).

Limitations and Strengths

A potential limitation of the evaluation would be a small sample size due to minimal enrollment for statistical measurement. To compensate for a small sample size, the program could be offered several times yearly to boost the sample size. It is also possible for research and participant bias. To counteract this possibility, coding for themes from the open-ended survey questions would be analyzed by two OTPs not affiliated with the certificate program. For participant bias, in the survey instructions, ask for honest responses so as not to skew the data. Another possible limitation is the validity of module quizzes and the competency exam, which needs to assess the intended

knowledge. To account for this, palliative and hospice care experts will be recruited to vet all quiz and competency exam questions and their validity.

Conclusion

The embedded evaluation has been designed to provide data to demonstrate the value of this program for key stakeholders. Through the selection, engagement, and consistent communication with key stakeholders to the research design for accurate data, this certificate program's continual improvement and success rely on the support of all key stakeholders and their expert knowledge.

CHAPTER SIX – Dissemination Plan

Proposed Program

The program is an educational certificate in palliative care and hospice for occupational therapy practitioners (OTPs). It prepares OTPs to work in palliative care/hospice settings. With the increase in the aging population and the need for more health professionals working in the setting, this program addresses the gap and need for occupational engagement, health promotion, and occupational justice at the end of life. The program aligns with palliative care principles and specific occupational knowledge so that OTPs will become integral interprofessional palliative care team members. With live discussions, this online program consists of ten learning modules with the subjects 1. Introduction and Principles of Palliative Care, 2. Role of Occupational Therapy and Interprofessional Team Members and Their Roles, 3. Communication – Empathetic and Active Listening, and Signs of Approaching Death, 4. Scope of Occupational Intervention, 5. Medical Factors, 6. Symptom Management, 7. Palliative Rehabilitation and Engagement versus Performance 8. Spiritual, Ethical, and Cultural Considerations, 9. Psychology and Human Behavior about Death, 10. Counseling Skills for Grief and Bereavement, 11. Documentation, and 12. Self-Care and Advocacy.

Dissemination Goals

The long-term goals for this certificate program are to demonstrate occupational therapy's distinct value for clients and their family members in end-of-life care and to have OTPs as integral members of the interprofessional team. The second long-term goal is to create national policy change by including occupational therapy as a needed

profession in expanding palliative care providers. Short-term goals include recruiting OTPs and having the first cohort complete the program. Another short-term goal is to revise and refine the program with input from the first cohort and other involved stakeholders.

Target Audiences

The primary audience for the certificate program is OTPs. After completing the program, OTPs will have the education and knowledge to work confidently in the end-of-life setting, be productive and supportive team members, and support clients and their family members during this life transition. The secondary audience consists of several populations. The OTP's newly gained skills will mainly benefit clients and family members. Other professionals on the palliative care team will benefit from knowing the curriculum and role of occupational therapy in this setting. It is also essential for palliative care and hospice organizations and key decision-makers to be aware of this educational opportunity and to know how hiring an OTP will benefit their organization and clients. Nationally, policymakers need to be aware of this program and occupational therapy's value to end-of-life (EOL) care.

Key Messages

Key messages for the primary audience explain how the certificate program will benefit their career and desire to work in the end-of-life setting. Specifically, it provides cost information, the number of continuing education units (CEUs), the program's content, how it compares to other professional programs, and how to advocate for involvement in palliative care. Key messages for the secondary audience, specifically

clients and their family members, are how working with OTPs trained and education in end-of-life care will benefit themselves or a family member. For organizations, disseminating how occupational therapy benefits the team can specifically optimize the quality of life, facilitate client autonomy and comfort, and holistically address symptoms. The potential cost benefit of offering occupational therapy and decreased hospital stays would be of importance to this particular audience population. For policymakers, the key message would be to demonstrate the value of occupational therapy in this setting and support this profession to benefit their constituents.

Sources/Messengers

Primary audience messengers will include this author and, potentially, Janice Kishi Chow, PhD, DOT, OTR/L. Chow is an occupational therapist at the Veterans Affairs Palo Alto Health Care System and author/researcher of several articles relating to occupational therapy and end-of-life care. This author will also be a secondary audience messenger. With more exposure to this secondary audience, specifically decision-makers in the hospice setting, another secondary audience messenger will be recruited to become a spokesperson for the program and support occupational therapy in end-of-life care.

Dissemination Activities, Tools/Techniques, Timing, and Responsibilities

Primary Audience Activities

Written Information.

This author will initially develop all written information. As the program grows, incorporating entry-level students completing capstones will become part of the written process.

- This author will create the design and content of a brochure for use at conferences and in mailings. It will be completed after funding has been secured and sponsorship of the program has been determined.
- During the content creation process, a peer-reviewed journal article such as the American Journal of Occupational Therapy will be written. It will detail the reason and need for the post-professional course and include module content.
- After two cohorts have completed the program, a second peer-reviewed journal article will be written to disseminate the program outcomes.

Electronic Media.

- During the program's development and implementation, the author will participate in podcasts such as Boston University's First Monday.
- During the program's development and implementation, the author will provide universities with free prerecorded lectures to generate interest in entry-level students.
- A dedicated YouTube channel to facilitate and support OTPs in the setting.

Person-to-Person Contact.

The author will conduct initial person-to-person contact until other spokespersons are identified.

- During the development phase, the author will present a poster at the American Occupational Therapy Association *Inspire* conference and

Colorado conferences.

- Live lectures on occupational therapy in end-of-life will be offered to occupational therapy programs during the development and implementation phases of the program.
- To trial content during the development phase, workshops on single topics will be offered to refine the content.

Secondary Audience Activities

Written Information.

This author will initially develop all written information. As the program grows, incorporating entry-level students completing capstones will become part of the written process.

- This author will create the design and content of a brochure for use at in-person marketing events such as conferences, in-person meetings, and other gatherings such as churches, senior centers, organizations of individuals with serious illness, and mailings. It will be completed after funding has been secured and sponsorship of the program has been determined.
- During the content creation process, a peer-reviewed journal article will be written. It will detail the reason and need for the post-professional course and include module content.
- After two cohorts have completed the program, a second peer-reviewed journal article will be written to disseminate the program outcomes.

Electronic Media.

The author will conduct initial electronic media dissemination until an individual can be hired for administrative tasks. A student assistant may also complete this.

- Social media content on Facebook and Instagram disseminating education on the value of occupational therapy at the end-of-life. This will be completed during both the development and dissemination phases.

Person-to-Person Contact.

The author will conduct initial person-to-person contact until other spokespersons are identified.

- Non-occupational therapy conferences will be attended to educate the value of occupational therapy in end-of-life care through potential poster presentations and presentations. This will be completed during both the development and dissemination phases.
- Meetings will be conducted with decision-makers with local chapters of organizations such as the Alzheimer's Association and the American Cancer Society. This will be completed during both the development and dissemination phases.

Budget

Tables 6.1 and 6.2 provide information on budgeted items for primary and secondary audiences. Budgets have been created for the first two years of the certificate program.

Table 6.1*Budgeted Items for Dissemination to Primary Audience*

Budgeted Item	Year 1	Year 2	Justification
Marketing	\$2,600.00	\$2,600.00	OT Magazine ½ page ad in 12 issues
	\$5,000.00	\$0	AOTA Webinar – sponsor and content (2024 AOTA Media Planner, 2024)
	\$0	\$0	Email from provided lists as AOTA (Approved Provider, 2024)
	\$0	\$0	Posting on Facebook and Instagram
	\$460.00	\$460.00	Printed Brochures/Postcards \$.46 x 1,000
	\$340.00	\$340.00	Mailing – Postage \$.67 x 500
Conferences	\$480.00	\$480.00	Estimate AOTA Conference Fees
Travel	\$750.00	\$750.00	Flight
	\$700.00	\$700.00	Hotel
	\$350.00	\$350.00	Meals
			Estimate of travel to 2025 and 2026 AOTA conference in Philadelphia PA and in Anaheim, CA
Total	\$10,680.00	\$5,680.00	

Table 6.2

Budgeted Items for Dissemination to Secondary Audiences and Budgeted Totals for both Primary and Secondary Audiences

Budgeted Item	Year1	Year 2	Justification
Marketing	\$1,500.00 \$250.00 \$0 \$460.00 \$340.00	\$1,500.00 \$250.00 \$0 \$460.00 \$340.00	Conference Exhibitor Booth Marketing Collateral – Brochure in attendee’s registration packet Posting on Facebook and Instagram Printed Brochures/Postcards \$.46 x 1,000 Mailing – Postage \$.67 x 500
Conferences	\$450.00	\$450.00	Estimate Rocky Mountain Health & Hospice Conference (2024 Rocky Mountain, 2024)
Travel	\$110.00 \$300.00 \$200.00	\$110.00 \$300.00 \$200.00	Milage Round Trip Hotel Meals Estimate of travel for 2025 and 2026 to the Mountain health & Hospice Conference
Total	\$3,610.00	\$3,610.00	
Total for Both Primary and Secondary Audiences	\$14,290.00	\$9,290.00	

Evaluation

The dissemination plan will be evaluated by maintaining detailed records. For the primary audience of OTPs, this will include recording the type of dissemination activity or tools used, the number of responses and inquiries to the certificate program, and the number of OTPs who register and take the course. For the secondary audience, the number of conferences, meetings, workshops, and responses generated will be analyzed and communicated to important stakeholders such as policymakers and decision-makers at organizations. A more significant outcome would include occupational therapy in policies about palliative care and education needed for health care professionals.

Conclusion

This dissemination plan has been developed to be realistic of the budget items needed for the first two years of the certificate program. Disseminating the value of occupational therapy in end-of-life care will benefit OTPs, the clients and family members they serve, palliative and hospice organizations, and the larger healthcare system.

CHAPTER SEVEN – Funding Plan

Project Description

The program, an educational certificate in palliative care and hospice for occupational therapy practitioners (OTPs) prepares occupational therapists to work in palliative care/hospice settings. With the increase in the aging population and the need for more health professionals working in the setting, this program addresses the gap and need for occupational engagement, health promotion, and occupational justice at the end-of-life. The program aligns with palliative care principles and specific occupational knowledge so that occupational therapists can become integral interprofessional palliative care team members. With live discussions, this online program consists of 12 learning modules with the subjects of 1. Introduction and Principles of Palliative Care, 2. Role of Occupational Therapy and Interprofessional Team Members and Their Roles, 3. Communication – Empathetic and Active Listening, Signs of Approaching Death, 4. Scope of Occupational Intervention, 5. Medical Factors, 6. Symptom Management, 7. Palliative Rehabilitation and Engagement versus Performance 8. Spiritual, Ethical, and Cultural Issues, 9. Psychology and Human Behavior in Relation to Death, 10. Counseling Skills for Grief and Bereavement, 11. Documentation, and 12. Self-Care and Advocacy.

Available Local Resources

Potential local resources include developing this program for Colorado State University's (CSU) occupational therapy department or their online courses. With this option, infrastructure would provide administration assistance, information technology (IT) support, a learning management system, and some marketing. Other local resources

include Pathways Hospice and Covell Care for expert consulting.

Needed Resources: Budget

Table 7.1

Two-Year Budget Plan

Budgeted Item	Year One	Year Two	Justification
Course Development	\$6,000.00	\$1,200.00	Year 1:12 Modules x10 hrs per module x \$50.00 an hour Year 2: Revisions
Educator Salary and Benefits	\$6,000.00	\$6,000.00	Costs for one course a year at 10 hours a week for 12 weeks at \$50 an hour. Benefits would be covered under standard teaching responsibilities.
Guest Speaker Fees	\$400.00	\$400.00	Honorarium for guest speaking live or from recorded video. (\$100.00 per individual)
Marketing, Conferences, and Travel	\$14,290.00	9,290.00	Estimate for conferences fees, travel, flight, meals, hotel, advertising, brochure, and mailings.
AOTA – Approved Provider, Professional Development (AOTA CEUs)	\$950.00	\$450.00	1 st year includes provider application, professional activity application, annual fees and annual report fees. 2 nd ear includes annual fee and annua report fee. (Approved Provider, 2024)
Conferences	\$480.00	\$480.00	Estimate AOTA Conference Fees
Administration and IT	\$0	\$0	In kind from CSU infrastructure
Learning Management System – Canvas	\$0	\$0	In kind from CSU infrastructure
Computer	\$0	\$0	Have use of a CSU laptop with web camera or facilitator will donate use of personal laptop with web camera.
Office Space	\$0	\$0	Have use of office at CSU or will donate personal office space.
Course Materials	\$0	\$0	All course materials may be printed by the participants
Total	\$28,120.00	17,820.00	

Potential Funding Sources

The occupational therapy department budget could possibly cover the funding for this project as part of online programming. However, the CSU occupational therapy department has yet to expand into online post-professional courses. Other potential funding sources include foundation grants and angel capital.

Funding Opportunities

Table 7.2

Potential Funding Sources

Funding Type	Funding Source and Description	Implementation or Dissemination
Foundation	<ul style="list-style-type: none"> • Anschutz Family Foundation • Grants for human services and older adults/aging • Award range from \$5,000 to \$10,000 (2023 Grant Breakdown, 2024) 	Implementation
Foundation	<ul style="list-style-type: none"> • Gary and Mary West Foundation • Grants for seed grant funding for advancing palliative care education and research • Award range from \$5, 000 to \$210,000 (High-Impact Grantmaking, 2024) 	Implementation and Dissemination
Angel Capital	<ul style="list-style-type: none"> • CSU occupational therapy alumna • Award potential unknown 	Implementation and Dissemination

Conclusion

The potential impact of this certificate program benefits not only the occupational therapists participating in it but also their future clients and family members. A greater impact is that these occupational therapists become integral interdisciplinary team

members providing occupational, holistic, quality care during the last part of an individual's life span.

CHAPTER EIGHT – Conclusion

As the population ages and individuals with serious illnesses continue to live longer, they are experiencing disruptions in engaging in their habits and routines, roles, and rituals that provide meaning to their lives. Many individuals receiving palliative or hospice care and their family members are unable to maintain their quality of life (QOL) and well-being due to the negative impact of the serious illness. Individuals and their family caregivers experience difficulty in participating and engaging in activities of daily living (ADLs) (i.e., dressing, bathing, eating) and instrumental activities of daily living (IADLs) (i.e., making meals, working, finances). Individuals report being unable to engage in activities that make life enjoyable, losing their autonomy and dignity, and being a burden on family and caregivers. Family caregivers are thrust into caring for their loved ones without training. (Oregon Death with Dignity, 2024; Nissmark & Fänge, 2020, Grant et al., 2013). Caregiving is time-consuming, with the average time of caregiving duties being 6.6 hours per day (Duimering et al., 2020). Towards the end-of-life, this time increases to an average of 8.3 hours per day and up to 66 hours per week during the patient's last year of life (Berry et al., 2017). Caregiving is not without risks to the caregiver. Insomnia may be acute during caregiving, but the risk for poor sleep continues up to 10 years after the caregiving role ends (Starr, 2023). Sleep problems put the individual at a higher risk for cardiovascular disease, kidney disease, and impaired immune function. Not only are there negative impacts on a caregiver's mental and physical health, but further consequences of not supporting the caregiver in their role can negatively impact the patient's effectiveness and quality of care (Washington et al.,

2018). Not being prepared for the caregiving role is associated with fear, anxiety, stress, and feelings of insufficiency and uncertainty specific to the caregiver role (Williams, 2018; Kulkarni et al., 2014). Caregivers need the confidence to prevent physical and psychological injury to the caregiver and care recipient (DiZazzo-Miller et al., 2020). According to Angelo et al. (2013), caregivers want to know how to care for themselves physically, emotionally, and spiritually, learn practical skills, and know what to expect and plan for as the family member's health declines. Education, training, mentorship, and support must be tailored to the caregiver's circumstances. This will ensure they can provide confident and effective care throughout the required period (Hendrix et al., 2015).

There is an urgent and increased need for more health professionals to work in palliative and hospice care. Occupational therapy is one profession that can fill this gap; however, there is a critical lack of education for occupational therapy practitioners (OTPs) at both the entry and post-professional levels. This lack of education is not just a matter of professional development but a pressing need to meet the needs of the population. Several articles call for the profession to properly educate students and OTPs to work in palliative and hospice care to meet this population's needs (Ashworth, 2014; Hammill et al., 2014; Knecht-Sabres, 2019; Talbot-Coulombe & Guay, 2020; Yeh & McColl, 2019; Chow & Pickens, 2020; Chow et al., 2023; Eva & Morgan, 2018).

Other factors contributing to the underutilization of occupational therapists working in palliative care and hospice are other healthcare professionals' lack of understanding and knowledge of the role of occupational therapy in working with this

population. There is limited awareness of OT's role in end-of-life (EOL), and stakeholder education is needed to utilize occupational therapy in this setting. Unfortunately, due to limited evidence of occupational therapy's effectiveness in EOL, this limits patients' access to these services. Agencies need additional training and resources to expand their understanding of occupational therapy's positive impacts on patients' lives in hospice settings (Mueller et al., 2013; Chow et al., 2023).

Due to OTPs' lack of education and training in palliative and hospice care, many feel unprepared to work with this population. They are unable to help individuals and their family members. OTPs cannot advocate for occupational therapy services for individuals and their families who need a holistic approach during this significant life transition (Hammill et al., 2014). This leaves these individuals and their families in crisis with potentially poor outcomes during a time when they need to be the most supported. With specific EOL occupational therapy intervention, the opportunity for improved quality of life, well-being, competence, and decreased anxiety is possible (Ashworth, 2014; Hammill et al., 2014; Knecht-Sabres, 2019; Talbot-Coulombe & Guay, 2020; Yeh & McColl, 2019; Chow & Pickens, 2020; Chow et al., 2023; Eva & Morgan, 2018).

To address the gap in caregiver support and the lack of education for OTPs, this author has developed the Occupational Therapy in Palliative and Hospice Care: A Certificate Program. This program is not just a solution but a significant step towards improving the quality of life for individuals and their families at the end-of-life. It contains key components of related professional certification programs in palliative care. After completing the course, OTPs will have an equivalent knowledge base to other professionals in this setting. Program

content is aligned with palliative care principles and specific evidence-based occupational knowledge so OTPs will become integral interprofessional palliative care team members. It aims to demonstrate occupational therapy's value in this setting and prepare OTPs to work successfully. Modules provide the foundational information needed to facilitate the use of the principles of palliative care, understand the clients, collaborate with members of the interprofessional team, and provide meaningful occupational interventions during this transition. This program addresses the gap and needs for occupational engagement, health promotion, and occupational justice for these individuals and their family members at the end-of-life.

APPENDIX A – Learner Profile**Occupational Therapy in Palliative & Hospice Care: A Certificate Program
Learner Profile**

Student Name:
Pronoun Preferences:

Please use this Learner Profile to reflect on your learning styles, successes and challenges in previous learning experiences, and guidance needs during your doctorate. Your information is confidential and will only be used by your instructor to facilitate your learning experience.

After reviewing the syllabus, please answer these questions. Responses need to be written in complete sentences.

Tell me about Yourself

What is your previous education and work experience?

What has motivated you to take this program?

What type of setting do you hope to work in, and with what population?

Learning Style, Study Techniques, and Learning Environment

Please describe your learning style used for learning or reviewing new content. (visual, auditory, kinesthetic, reading/writing)

What techniques and materials do you use outside class to master new information?

When learning new material, what questions do you ask yourself to process the information?

What type of environment is conducive to studying? (quiet, background music, white noise, alone, with others, at home, at the library, coffee house, etc.)

Occupational Therapy in Palliative & Hospice Care: A Certificate Program

Describe the learning community that you would like to create for this course.

How do you prefer receiving feedback? (immediately after a practical or presentation, need time to process before feedback, verbally, written, in private, in a group, etc.)

How have you handled stress in past learning and life experiences? Do you have resources and tools to help you during stressful times?

Knowledge

From the syllabus content, describe any previous experience or knowledge of the topics.

From the syllabus content, describe any topics entirely new to you.

Goals

Please write a short-term learning goal for each module.

Module 1: Introduction & Principles of Palliative Care

Module 2: role of Occupational Therapy & Interprofessional Team Members and their Roles

Module 3: Communication – Empathic and Active Listening & Signs of Approaching Death

Module 4: Scope of Occupational Intervention

Module 5: Medical Factors

Module 6: Symptom Management

Module 7: Palliative Rehabilitation & Engagement versus Performance

Module 8: Spirituality & Ethical and Cultural Issues

Occupational Therapy in Palliative & Hospice Care: A Certificate Program

Module 9: Psychology and Human Behavior in Relation to Death

Module 10: Counseling Skills for Grief and Bereavement

Module 11: Documentation

Module 12: Self-Care & Advocacy

Please write two course-long learning goals.

Goal 1:

Goal 2:

What do you need from Me?

What two questions do you have for your instructor about supporting you during your palliative and hospice care learning experience?

Would you like to share anything else about yourself that would help your instructor in your learning journey?

APPENDIX B – Learner Bill of Rights**Occupational Therapy in Palliative & Hospice Care
Learner Bill of Rights**

During this program, you have a right to:

Content

- Current, valid, accurate, and evidence-based content
- Course content that has logical and efficient navigation
- Quality learning materials that are clean and readable

Environment

- An environment based on adult learning principles that meet your individual needs
- A safe environment to explore new concepts and expand your perspective
- An environment of critical thinking

Communication

- Clear and sufficient instructions on accessing the course materials, live discussions, course and module objectives
- Awareness of challenging/triggering subjects
- Timely feedback from your instructor(s)
- Responses from instructor(s) by stated times and availability

Support

- A Community of professional learners who are respectful, supportive, and prepared
- Cognizant of your working schedule and preparation time
- Live discussions that are stimulating and support content
- Technology issue support

Beyond this program

- Tools to facilitate advocacy for occupational therapy in palliative and hospice care, your clients/families, and interprofessional team
- Knowledge that has prepared you for a career in palliative hospice care
- A lifelong community of like-minded colleagues

The Learner Bill of Rights has been developed for the online Occupational Therapy in Palliative & Hospice Care certificate program for occupational therapists. The program's educators consist of the lead instructor and potential guest lecturers. The certificate program's learners are post-professional occupational therapists interested in or working in palliative and hospice care. These individuals may be recent graduates or experienced occupational therapists of diverse backgrounds, education, and work experience. The Learner Bill of Rights will be part of the program's syllabus and distributed to stakeholders, including guest lecturers, program administration, IT support, and members of the sponsoring institution. It could also be used in whole or in part in promotion/advertising materials.

Learner Rights included in the program are framed with quality content, a safe learning environment, clear communication, support, and knowledge beyond this course. The decision to include these principles was influenced by another student bill of rights from the Online Post-professional Doctor in Occupational Therapy (OTD) Student Orientation Handbook – Boston University, the Occupational Therapy Department at Colorado State University, Quality Matters Bill of Rights for Online Learners, and personal experience from teaching entry-level doctorate occupational therapy students with their requests for their learning environment (Online Post-professional, 2022; Bilsky, 2022; The Quality Matters, n.d.). Another influence is the AOTA 2020 Occupational Therapy Code of Ethics. The principles of beneficence, nonmaleficence, autonomy, justice, veracity, and fidelity are expected from both the instructor(s) and learners involved in the program (AOTA, 2020).

References

- AOTA 2020 Occupational Therapy Code of Ethics. (2020). *American Journal of Occupational Therapy*, 74(3). 7413410005p1–7413410005p13. doi: <https://doi.org/10.5014/ajot.2020.74S3006>
- Bilsky, C. (2022). OTD Program Handbook. Colorado State University Occupational Therapy Department.
- The Quality Matters Bill of Rights for Online Learners (n.d.). Quality Matters. Retrieved April 22, 2024, from <https://www.qualitymatters.org/qa-resources/resource-center/articles-resources/bill-of-rights-for-online-learners>
- Online Post-professional Doctor in Occupational Therapy (OTD) Student Orientation Handbook. (2022). *Boston University College of Health & Rehabilitation Sciences: Sargent College*.

APPENDIX C – Teaching Plan

Teaching Plan Table					
Module 3 Communication – Empathic & Active Listening					
Overall learning goal: Learners will be able to utilize active listening skills while describing all potential signs of approaching death in preparation of working with clients and family members receiving palliative or hospice care.					
Specific learning objective	Learning activity(ies) and supporting learning theory(ies)	Method of teaching	Time allotted (in minutes)	Resources (e.g., instructional materials)	Method of evaluation
1. After completing the readings, (A) learners will (B) demonstrate their comprehension by (C) completing (D) 100% of the study guide and uploading it by 11:59 pm the evening prior to class. Cognitive (knowledge and application) and Psychomotor (set and adaptation) (Bastable & Rabbia, 2020).	Activity: Readings and a study guide will be provided for each module. For this module reading and study guide focus is active listening and signs of approaching death. Self-Directed Learning Theory: Learner-centered by providing the appropriate resources for learning. Fosters and promotes the responsibility of learning on the learner. (Charokar & Dulloo 2022)	Self-Instruction	Self-paced prior to online class	Assigned readings Study Guide with key terminology to be defined and questions to facilitate preparation for the online class discussion and role-play for active listening and signs of approaching death.	Individual written feedback will be provided to each learner on their uploaded study guide.
2. (A) Learners will (B) synthesize the concepts of active listening skills during discussion with other learners	Activity: Seminar style directed by the instructor to facilitate synthesis of active listening skills concepts through the discussion of the signs of approaching death.	Seminar	20 minutes	Guiding questions to facilitate processing active listening	Observation on learner involvement during seminar with providing one insight or response.

<p>by providing (D) one insight or response (C) during the 20-minute seminar.</p> <p>Cognitive (synthesis)</p> <p>(Bastable & Rabbia, 2020).</p>	<p>Information Processing, Cognitive Theory. Emphasizes the thinking process and how information is stored and retrieved.</p> <p>(Braungart et al.,2020)</p>				
<p>3. (A) Learners will (B) apply all active listening skills concepts in two role-playing scenarios as therapist and client (C) during discussing signs of approaching death.</p> <p>Cognitive (application and synthesis) and Affective (responding and valuing)</p> <p>(Bastable & Rabbia, 2020).</p>	<p>Activity: Break out into pairs to complete role-play between therapist and client, utilizing active listening skills while educating signs of approaching death.</p> <p>Large group debrief to synthesize the role-play experience.</p> <p>Kolb's Experiential Learning Theory is a process where knowledge is created during experiential learning activities. It requires active experimentation, concrete experience, reflective observation, and abstract conceptualization.</p> <p>(Mcleod, 2024)</p>	<p>Role-Play</p> <p>Group Discussion</p>	<p>15 minutes</p> <p>15 minutes</p>	<p>Each pair will be given two written scenarios of a therapist and client interaction regarding a discussion over signs of approaching death.</p> <p>Guiding questions to synthesize the role-play experience.</p>	<p>Check in with each pair of learners to observe active participation during role-playing.</p>

This teaching plan is for module 3 of the Occupational Therapy in Palliative and Hospice Care certificate program.

Davis et al. (2013) qualitatively inquired about listening behaviors with occupational therapists experienced in palliative and hospice care. In their research, it was reported that individuals with a terminal illness do not feel adequately listened to, nor do occupational therapists feel prepared with the skill of active listening. Recommendations for occupational therapists wanting to work in this setting are to gain active listening skills to meet the needs of this population. This teaching plan will facilitate my teaching efforts by providing learners with curated and pertinent materials and learning experiences to meet the program's learning goals. This will include readings, discussion, and opportunities to practice active listening skills practice with feedback. Learners will gain an important and needed skill to help their clients feel less isolated and supported while helping ease pain, process feelings, and create an environment to explore life and death safely (Davis et al., 2013).

References

- Bastable, S. B., & Rabbia, J. (2020). Behavioral objectives and teaching plans. In S. B. Bastable, M. M. Braungart, P. R. Gramet, K. Jacobs, & D. L. Sopczyk (Eds.), *Health professional as educator: Principles of teaching and learning* (2nd ed., 467–505). Jones & Bartlett Learning.
- Braungart, M. M., Braungart, R. G., & Gramet, P. R. (2020). Applying learning theories to healthcare practice. In S.B. Bastable, M. M. Braungart, P. R. Gramet, K. Jacobs, & D. L. Sopczyk (Eds.), *Health professional as educator: Principles of teaching and learning* (2nd ed., 75–126). Jones & Bartlett Learning.
- Charokar, K., & Dulloo, P. (2022). Self-directed Learning Theory to Practice: A footstep towards the path of being a life-long learner. *Journal of advances in medical education & professionalism*, *10*(3), 135–144.
<https://doi.org/10.30476/JAMP.2022.94833.1609>
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APPENDIX D – Learner Tool

Study Guide for Module 3 Communication – Empathic & Active Listening and Signs of Approaching Death

Due Date: Night before Live discussion at 11:59 pm MST.

Introduction:

Section 1 introduces communication skills, specifically empathic and active listening. Research has found that individuals with terminal illnesses do not feel adequately listened to, and occupational therapists do not feel prepared with the skill of active listening (Davis et al., 2013). Effective communication is important while working with individuals with serious illnesses. It is a key element for individuals and their families to feel heard and supported and alleviate stress (Bernacki et al., 2014).

Section 2 discusses the signs of approaching death. Many individuals with a serious illness and their family members want to be prepared for the dying process. There is concern that discussing death and dying may cause undue stress. However, research has demonstrated that conversations about the dying process do not cause undue stress and can be helpful to individuals with a serious illness and their families (Emanuel et al., 2004).

Module Objectives:

After completing the readings on communication—empathic and active listening—, the learner will be able to explain 100% of the key terminology and concepts in the study guide to prepare for discussions with future clients and family members receiving palliative or hospice care.

After completing the readings on signs of approaching death, the learner will be able to explain 100% of the key terminology and concepts in the study guide to prepare for discussions with future clients and family members receiving palliative or hospice care.

After completing the key terminology in the study guide, the learner will be able to synthesize the concepts of communication and signs of approaching death when writing responses to the four guiding questions in preparation for working with individuals and family members receiving palliative or hospice care.

Section 1: Readings for Communication – Empathic & Active Listening

Read sections from Table 1 through Benefits of Active Listening in:

Bauer, C. & Figl, K. (2008). *"Active listening" in written online communication – A case study in a course on "soft skills for computer scientists"* [Session T1A]. 38th ASEE/IEEE Frontiers in Education Conference, Saratoga Springs, NY, United States.

Read Chapters 5 & 6, Listening and Core Interviewing Skills:

Miller, W. R. & Rollnick, S (2013). *Motivation interviewing: Helping people change* (3rd Ed.). The Guilford Press.

Read through the article and watch the two videos, How to Actively Listen to Others by Scott Pierce and Empathy by Brené Brown.

O'Bryan, A. (8th, February 2022). How to practice active listening: Examples & techniques. PositivePsychology.com. Retrieved April 18, 2024, from <https://positivepsychology.com/active-listening-techniques/#worksheets>

Key Terminology for Communication – Empathic & Active Listening

From Bauer & Figl

In your own words, please define:

1. Active Listening
2. Passive Listening
3. Inattentive Listening
4. Pretend Listening
5. Conversational Listening
6. Argumentative Listening
7. Informational Listening

Provide examples of these active listening concepts from Table 2.

1. Paraphrasing
2. Verbalizing Emotions
3. Asking
4. Summarizing
5. Clarifying
6. Encouraging
7. Balancing

From Miller & Rollnick

In your own words, please define or explain:

Chapter 5

1. Thomas Gordon's Roadblocks and the effect on active listening.
2. Nonverbal Listening
3. Reflective Listening

Chapter 6 – OARS

1. Open Questions
2. Affirming
3. Reflecting
4. Summarizing

From O'Bryan

In your own words, please define or explain:

1. Listening for Total Meaning
2. Response to Feelings
3. Note all cues
4. Unconditional Positive Regard

Section 2: Readings for Signs of Approaching Death

Signs of Approaching Death (2024). *Hospice Foundations of America, Inc.*
Retrieved April 12, 2024, from <https://hospicefoundation.org/Hospice-Care/Signs-of-Approaching-Death>

Shega, J. (25th, September 2023). End-of-life timeline: Clinical signs by stage.
Vitas Healthcare. Retrieved April 12, 2024, from
<https://www.vitas.com/for-healthcare-professionals/making-the-rounds/2020/march/signs-of-active-dying>

Key Terminology for Signs of Approaching Death

It is important to note that this information provides a general overview of the symptoms of dying. Other factors, such as a person's diagnosis and medications, can influence the process.

From the two readings, in your own words, list and explain the signs of approaching death as you would to your client and their family members.

Response:

Guiding Questions

1. How will you prepare to have a conversation with a client who is asking about signs of approaching death? What active listening principles will you utilize?
2. Research has shown that individuals with serious illnesses do not feel supported and heard during their life experiences. How will you communicate with your client if you have a differing opinion on a situation?
3. During a discussion with a client and their partner, they express different opinions on wanting to know the signs of approaching death. How will you support each of them to alleviate stress and conflict?
4. After this module, how do you plan to continue working on your empathic and active listening skills?

References

- Bernacki, R. E., & Block, S. D. (2014). Communication about serious illness care goals: A review and synthesis of best practices. *JAMA Internal Medicine*, 174(12). doi:10.1001/jamainternalmed.2014.5271
- Davis, J., Asuncion, M., Rabello, J., Silangcruz, C., & van Dyk, E. (2013). A qualitative review of occupational therapists' listening behaviors and experiences when caring for patients in palliative or hospice care. *American Occupational Therapy Foundation* 33(1), pp. 12–20. doi: 10.3928/15394492-20121012-01
- Emanuel, E., Fairclough, D. L., Wolfe, P., & Emanuel, L. L. (2004). Talking with terminally ill patients and their caregivers about death, dying, and bereavement. *ARCJ Intern Med* 164.

Teaching tool, audience, format, and delivery

The teaching tool I have developed is the study guide for one of the learning modules for my OTD project, Occupational Therapy in Palliative and Hospice Care: A Certificate Program. The certificate program's learners are post-professional occupational therapists. The study guide contains the module introduction, selected readings, key terminology, and reflective questions. The study guide is a pre-training on communication—empathic and activity listening—and signs of approaching death (Kaye, 2020). The study guide will be accessed from a learning management system such as Canvas or Blackboard. It is a Microsoft Word document that the learners complete and upload the night before the online class for feedback.

Knowledge of your learners

The certificate program's learners are post-professional occupational therapists interested in or working in palliative and hospice care. These individuals may be recent graduates or experienced occupational therapists of diverse backgrounds, education, and work experience. This population's internal motivation and readiness would be high as they voluntarily take this certificate program to grow their knowledge of palliative and hospice care. Health literacy level and literacy may vary as learners' education ranges from a bachelor's to a doctorate in occupational therapy. The average health literacy level and literacy level for an individual with a four-year degree is considered intermediate, meaning the individual has the skills necessary to perform moderately challenging literacy activities (National Center for Education Statistics, 2003; Baer et al., 2006)

Learning theory

The completion of the study guide is considered self-instruction and was informed by the Self-directed Learning Theory; the theory is learner-centered by providing the appropriate resources for learning and fosters and promotes the responsibility of learning on the learner (Charokar & Dulloo, 2022).

Teaching tool helps learners meet learning objectives

The study guide provides an active learning experience on the two topics. Both are essential concepts and tools for working in palliative and hospice settings.

(C) After completing the readings on communication – empathic and active listening, (A) the learner will be able to (B) explain (D)100% of the key terminology and concepts on the study guide to prepare for discussions with future clients and family members receiving palliative or hospice care.

(C) After completing the readings on signs of approaching death, (A) the learner will be able to (B) explain (D)100% of the key terminology and concepts in the study guide to prepare for discussions with future clients and family members receiving palliative or hospice care.

(C) After completing the key terminology in the study guide, (A) the learner will be able to (B) synthesize the concepts of communication and signs of approaching death when writing responses to the (D) four guiding questions in preparation for working with individuals and family members receiving palliative or hospice care.

Teaching Method

The study guide was developed using the Cognitive Theory of Multimedia Learning (CTML) principles. Dedicated readings have been provided with cues to focus on specific sections to reduce cognitive load. Information has been segmented with key terms and concepts highlighted to manage the intrinsic load. Generative processing is facilitated by having the learners summarize or explain the new material (Mayer, 2024).

References

- Baer, J., Cook A. L., & Baldi, S. (2006). *The Literacy of America's College Students*. American Institutes for Research. Retrieved April 19, 2024, from <https://www.air.org/sites/default/files/The-Literacy-of-Americas-College-Students-Jan-2006.pdf>
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- National Center for Education Statistics (2003). *Health Literacy*. Retrieved April 21, 2024, from https://nces.ed.gov/naal/health_results.asp

APPENDIX E – Executive Summary

Description of the Program

The program is an education certificate in palliative care and hospice for occupational therapy practitioners (OTPs). It prepares OTPs to work in palliative care/hospice settings. With the increase in the aging population and the need for more health professionals working in the setting, this program addresses the gap and need for occupational engagement, health promotion, and occupational justice at the end-of-life. The program aligns with palliative care principles and specific occupational knowledge so that OTPs will become integral interprofessional palliative care/hospice team members.

Brief Explanation of Palliative and Hospice Care

Both palliative and hospice care are client-centered specialized care for individuals living with a serious illness. Medicare defines palliative care as “patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering” during the disease progression (Federal Register, 2023. p. 51164). The goal of hospice care is “to help terminally ill individuals continue life with minimal disruption to normal activities while remaining primarily in the home environment.” (Federal Register, 2023. p. 51164).

Risk for Individuals and Families

This problem of lack of occupational therapy for palliative/hospice clients and family members is the disruption in habits and routines, roles, and rituals that provide meaning to their lives. Clients and family members not receiving therapy are unable to

maintain their quality of life (QOL) and well-being due to the negative impact in all areas with participation and engagement in all activities of daily living (ADLs) (i.e., dressing, bathing, eating) and instrumental activities of daily living (IADLs) (i.e., making meals, working, finances). Individuals are unable to maintain their independence, return home due to environmental barriers, and support from family members due to lack of training (Nissmark & Fänge, 2020). In the hospital setting, patients do not receive therapy due to confusion over definitions of palliative care, hospice, and comfort care and whether the patient should have occupational therapy. The scope of the issues spreads into inpatient rehabilitation and skilled nursing facilities not taking patients due to concerns over payment, therapists not knowing how to bill for services appropriately, or a client being discharged from therapy because they have a poor prognosis for rehabilitation (Padgett et al., 2018).

Occupational therapy educational institutions are not providing adequate training for students to work with palliative/hospice clients in entry-level positions. Continuing education courses for education on palliative care do not specifically address the needs of OTPs in working with palliative/hospice clients (CAOT Position Statement, 2017; Yeh & McColl, 2019; Chow & Pickens, 2020; Eva & Morgan, 2018; Talbot-Coulombe & Guay, 2020; Hammill et al., 2014).

The Need for Occupational Therapy

OTPs use everyday occupations to support individuals throughout their lifespans; they are uniquely trained to facilitate engagement with meaningful occupations and improve QOL and well-being (AOTA, 2020). Through collaboration with the client and

family members, OTPs are able to provide individualized and holistic interventions to support this life transition (AOTA, 2023).

Why this Program is Needed

The American Occupational Therapy Association (2023) position statement clearly defines the need for further education for occupational therapists to work in the EOL setting successfully. Under the education and training heading, occupational therapists require knowledge of dying trajectories of diagnoses, understanding of loss of function due to physical changes through the dying process, psychosocial needs, occupational preferences, goals, cultural humility, grief responses, and self-care practice to be able to support clients and fellow professionals. However, in terms of education from the governing bodies of occupational therapy, the American Occupational Therapy Association (AOTA) and the Accreditation Council for Occupational Therapy Education (ACOTE), the Occupational Therapy Practice Framework (OTPF) and the Education Standards and Interpretive Guide do not comment on either palliative care or hospice (American Occupational Therapy Association, 2020; ACOTE Standards and Interpretive Guide, 2018). Several articles also call for the profession to properly educate and train students and post-professional occupational therapists to work in palliative and hospice care to meet this population's needs (Yeh & McColl, 2019; Chow & Pickens, 2020; Eva & Morgan, 2018; Talbot-Coulombe & Guay, 2020; Hammill et al., 2014).

Justification of program

Due to OTPs' lack of education and training in palliative care and hospice, many feel unprepared to work with this population. A certificate program is needed to provide

the needed education. They also feel incapable of advocating for occupational therapy services for individuals and their families who need a holistic approach during this significant life transition. This leaves these individuals and their families in crisis with potentially poor outcomes during a time when they need to be the most supported. With specific end-of-life occupational therapy interventions, the opportunity for improved QOL, well-being, competence, and decreased anxiety is possible (Yeh & McColl, 2019; Chow & Pickens, 2020; Eva & Morgan, 2018; Talbot-Coulombe & Guay, 2020; Hammill et al., 2014).

Objectives

The main goals of this program are to educate occupational therapists on palliative care and hospice and increase the number of occupational therapists working in these settings. By the end of the course training, occupational therapists will be able to demonstrate knowledge competency by passing a comprehensive exam based on education content and training listed below in the program details. Five years after the certificate program's beginning, the number of occupational therapists employed in palliative and hospice settings will increase by surveying the former course participants' employment. Expand the program to other professions involved in palliative and hospice care. This would include physical therapists and speech-language pathologists. Establish OTPs as integral interprofessional team members, and national policies and institutions recognize their value in these areas.

Program Details

The certificate program has been developed for learners who are post-professional OTPs interested in or working in palliative and hospice care. These individuals may be recent graduates or experienced therapists of diverse backgrounds, education, and work experience. This online synchronous certificate program will require 4–5 hours of individual study preparation and a 60-minute online live discussion once a week. Evidenced-based readings, case studies, and study guides will facilitate the live discussions.

This online program consists of 12 evidence-based learning modules with the subjects of 1. Introduction and Principles of Palliative Care, 2. Role of Occupational Therapy and Interprofessional Team Members and Their Roles, 3. Communication – Empathetic and Active Listening, Signs of Approaching Death, 4. Scope of Occupational Intervention, 5. Medical Factors, 6. Symptom management, 7. Palliative Rehabilitation and Engagement versus Performance 8. Spiritual, Ethical, and Cultural Considerations, 9. Psychology and Human Behavior in Relation to Death, 10. Counseling Skills for Grief and Bereavement, 11. Documentation, and 12. Self-Care and Advocacy.

Budget

A two-year budget has been crafted to fully fund the certificate program's development, implementation, and dissemination. Needed resources include course development, educator salary, guest speaker fees, dissemination, American Occupational Therapy Association Approved Provider fees for professional development units, and administration/information technology support. The author will donate the use of a laptop

computer and office space as needed. Course materials will be housed on a learning management system, and participants can download all materials. The total estimated cost for the certificate program is \$45,940.00. Potential funding sources have been located through foundations and angel capital (2023 Grant Breakdown, 2024; High-Impact Grantmaking, 2024; Approved Provider, 2024).

Dissemination Plan

The certificate program will be disseminated to two audiences. The first audience is potential OTPs interested in taking the course. The second audience consists of several populations that include potential recipients of occupational therapy in palliative and hospice care, interprofessional team members, palliative care and hospice organizations, and key decision-makers to be aware of this educational opportunity and how hiring an OTP will benefit their organization and clients. Nationally, policymakers need to be aware of this program, and the value occupational therapy brings to end-of-life care. Dissemination activities and tools for both audiences will comprise written information, electronic media, and person-to-person contact. Tools will include brochures, advertisements, email mailings, peer-reviewed journal articles, podcast participation, and prerecorded lectures. Activities include poster presentations, conference attendance, live lectures, and single-topic workshops.

Conclusion

The potential impact of this certificate program benefits not only the OTPs participating in it but also their future clients and family members. A more significant impact is that these OTPs become integral interdisciplinary team members providing

occupational, holistic, quality care during the last part of an individual's life span. The culmination of the certificate program is to solidify occupational therapy's distinct value in palliative and hospice care.

APPENDIX F – Fact Sheet



Occupational Therapy in Palliative
and Hospice Care: A Certificate
Program
Kara L Alcorn-Borodach, MOT, OTR/L
OTD Candidate

The Problem

- Increase of individuals living longer with a serious illness.
- Need for health professionals to work in palliative and hospice care.
- Lack of education in palliative and hospice care for occupational therapy practitioners (OTPs).
- Unclear role of occupational therapy in palliative and hospice care.
- OTPs are not considered integral members of the interprofessional team.



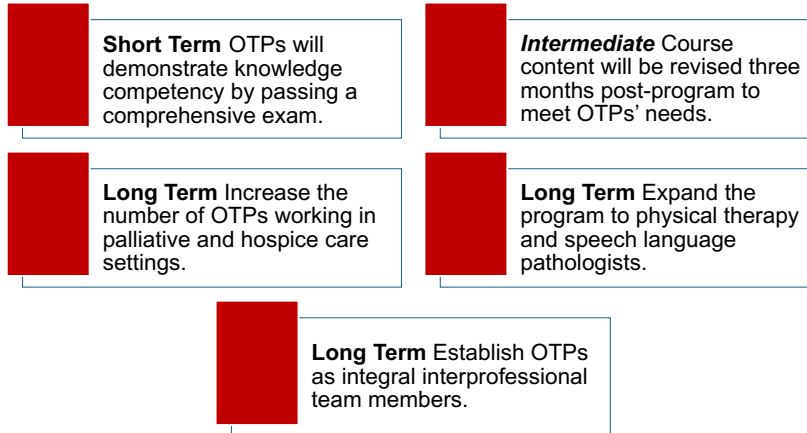
<https://attentivequalitycare.com/pages/long-term-care-management>

(Knecht-Sabres et al. 2019; Chow et al., 2023; Talbot-Coulombe & Guay, 2020)

The Solution

- An educational certificate program in palliative care and hospice for OTPs.
- Addresses the gap and needs for occupational engagement, health promotion, and occupational justice at the end of life.
- The program aligns with palliative care principles and specific occupational knowledge.
- They comprise readings, case studies, study guides, live discussions, and a competency exam.
- Contains 12 modules:
 - History and Principles of Palliative Care and Hospice
 - Role of Occupational Therapy and Interprofessional Team Members
 - Communication and active listening, Signs of Approaching Death
 - Scope of occupational intervention
 - Medical factors, Managing Chronic conditions, and Disease Trajectories
 - Symptom management
 - Palliative Rehabilitation and Engagement
 - Spirituality and Ethical/Cultural Issues
 - Psychology and Human Behavior about Death
 - Counseling Skills for Grief and Bereavement
 - Assessment, Documentation, and Billing
 - Self-Care Strategies and Advocacy

Program Outcomes



Implications for Occupational Therapy

- **OTPs** - confidence that your knowledge is equivalent to other professionals working in these settings.
- **Clients and family members** - are supported by holistic, meaningful occupations at the end of life.
- **Palliative and hospice organization** - the addition of a qualified member to improve the quality of life of your clients and their family members.
- **National policy** - the inclusion of occupational therapy in policies to improve the lives of individuals living with serious illnesses.



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