

HOW THE UTILIZATION OF OCCUPATIONAL THERAPY IN
END-OF-LIFE CARE IS DETERMINED

A DISSERTATION

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS

FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

IN THE GRADUATE SCHOOL OF THE

TEXAS WOMAN'S UNIVERSITY

SCHOOL OF OCCUPATIONAL THERAPY

COLLEGE OF HEALTH SCIENCES

BY

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DECEMBER 2020

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DEDICATION

To my Father God,

Thank you for whispering in my ear, “I will help you” and revealing your faithfulness.

To the joys of my life, my husband, Ed, and daughters, Trinity and Petra Chow

Thank you for your love, support, and sacrifice. This degree is as much yours as mine.

To my steadfast and loving parents, Kanji and Jane Kishi

Thank you for always being there for me.

ACKNOWLEDGEMENTS

“Mentorship guides movement of the novice from the periphery to the center of a community” (Noonan et al., 2007, p. 252). My deepest thanks to Dr. Noralyn Pickens for mentoring me over the last six years, helping me move towards the center of the hospice and palliative care occupational therapy community. Thank you for sharing your wisdom and modeling how to create, initiate, collaborate, and make opportunities. I cannot fully express my gratitude for your mentorship through every step of this process.

I thank my PhD committee, Dr. Tina Fletcher, my “foster mentor,” Dr. Patricia Bowyer, and Dr. Mary Thompson, for your insightful feedback and steadfast presence along this scenic route of the dissertation process. Thank you also to Dr. Gayle Hersch, Dr. Elaine Jackson, and Dr. Cynthia Evetts, for being highly influential in my PhD training, and to Dr. M. Heather McKay and Dr. Carol Rice, my external auditors and dear colleagues, for your ongoing support.

Thank you to the California Foundation for Occupational Therapy, the Bonita Kraft research fund, and the Virginia Chandler Dykes Scholarship for financially supporting this research of occupational therapy in end-of-life care.

Thank you to the people who helped me recruit and the 41 participants who shared their passion for end-of-life care with me.

Finally, thank you to my supervisor, Mr. Eric Lipton, for supporting my ongoing studies, and to Ms. Judy Lew for covering me at work through two advanced degrees, two maternity leaves, and life over the last 17 years.

ABSTRACT

JANICE KISHI CHOW

HOW THE UTILIZATION OF OCCUPATIONAL THERAPY IN END-OF-LIFE CARE IS DETERMINED

DECEMBER 2020

Aging with chronic illness and dying of a terminal disease are complicated and arduous processes. Occupational participation at the end of life may offer means to cope, co-exist with dying, and live with purpose and quality of life. Occupational therapists have the expertise to maximize occupational participation in critical end-of-life tasks. However, occupational therapy remains under-utilized in end-of-life services. This grounded theory study, based on the model of human occupation, investigated how the utilization of occupational therapy in end-of-life care is determined, from the perspectives of 21 occupational therapists and 20 decision makers. The model developed suggests utilization is contingent upon the decision maker's awareness of occupational therapy's role in end-of-life care and influenced by place of care demands and the decision maker's ability to adjust focus of the occupational therapy referral to accommodate the patient's goals and dying process. Although decision makers' awareness and place of care did not consistently support occupational therapy utilization, occupational therapists were found to facilitate occupational adaptation in their patients through patient-centered care, attention to environmental supports, and focus on participation rather than performance. Utilization also varied by place. In community-based hospices, utilization was contingent

upon the decision maker's understanding of occupational therapy's value and the Medicare Hospice Benefit. In non-traditional end-of-life care settings, occupational therapists had to autonomously identify and advocate for end-of-life care services. At a Veterans Affairs inpatient hospice setting, the occupational therapist needed to define occupational therapy's scope of practice to avoid over-utilization. Among the places of this study, occupational therapy was most utilized at community-based, continuum-of-care settings, due to occupational therapy's alignment with a common workplace mission to keep patients at home until the end of life and these settings being larger organizations to pool resources for occupational therapy services. There is a lack of decision makers' awareness of occupational therapy to support the occupational needs of people with life-limiting illness. Further research, occupational therapy educational reforms, and advocacy are warranted to increase greater occupational therapy utilization and to support meaningful occupational participation at the end of life.

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CHAPTER I

INTRODUCTION

Sixty percent of the U.S. population lives with a chronic, incurable disease, attributing to \$3.5 trillion in annual health care costs and resulting in the leading causes of disability and death (Centers for Disease Control and Prevention [CDC], 2019).

Although societal advances have contributed to longer life expectancy, more people are living longer with chronic illnesses, suffering consequent functional loss, experiencing increasing difficulty meeting daily demands, and dying of more complicated disease processes (CDC, 2019; National Health Council, 2014; Peoples et al., 2017; Wan et al., 2016). End-of-life care providers will need innovative methods to meet the growing demands of people living with life-limiting illness.

The use of occupational therapy at the end of life is a developing area of hospice and palliative care research (Hammill et al., 2014). *Occupation* is any daily life activity that has purpose, meaning, and perceived utility (American Occupational Therapy Association [AOTA], 2020). Occupational participation helps people with terminal illness adapt to end-of-life transitions (von Post & Wagman, 2019). Continued occupational participation helps people with life-threatening illness adapt to end-of-life transitions with experiences of normalcy, restoration, health, well-being, and maintenance of self-identity (Sviden et al., 2010).

Occupational therapists have a valuable role in end-of-life care. Through consideration and modification of environmental, contextual, and personal factors, occupational therapists have the expertise to address occupation-based needs and enable hospice patients to maximize occupational participation in critical end-of-life tasks, live with purpose, and experience quality of life at the end of life (AOTA, 2016; Hammill et al., 2014; von Post & Wagman, 2019). Occupational therapy services are covered under the Medicare Hospice Benefit for symptom control or to maintain activities of daily living and basic function skills (Centers for Medicare and Medicaid Services [CMS], 2018). Occupational therapists are recognized as a supportive member of the hospice team (National Hospice and Palliative Care Organization [NHPCO], 2018).

Statement of Problem

Despite occupational therapy's valuable role, occupational therapy services remain under-utilized in hospice care (Knecht-Sabres et al., 2018). Occupational therapy service provision is contingent upon the team's referral, often limited to maintenance of daily activities and functional skills and commonly used for equipment issue and discharge planning from the hospital to the community (CMS, 2018; Keesing & Rosenwax, 2011; Mills & Payne, 2015). Palliative rehabilitation offers occupational therapy a primary and established interdisciplinary role focused on improving function in patients with advanced disease. However, hospice patients do not fit a traditional rehabilitation model due to poor rehabilitative potential and typically do not receive occupational therapy for occupation-based needs as they decline (Ashworth, 2014; Barawid et al., 2015; Schleinich et al., 2008). There remains under-utilization of

occupational therapy to address broader occupational needs and support engagement in meaningful, self-defining activities and end-of-life tasks (Ashworth, 2014; Keesing & Rosenwax, 2011).

Researchers investigating under-utilization of hospice occupational therapy services cite major barriers as lack of funding, insufficient insurance reimbursement, misunderstanding of occupational therapy's role by health care professionals, and limited evidence of the effectiveness of occupational therapy at the end of life (Eva & Morgan, 2018; Halkett et al., 2010; Keesing & Rosenwax, 2013; Knecht-Sabres et al., 2018). However, there is a paucity of literature that elucidates the perspectives of hospice care decision makers who determine service utilization and hospice occupational therapists who seek to provide occupation-based interventions. Hospice decision makers create an environment that demands occupational therapists successfully interface and negotiate with to advocate for occupational therapy services. Research on how hospice decision makers determine services and how occupational therapists respond may lead to strategies that increase support of occupational therapy in end-of-life care. A grounded theory study was conducted to investigate the experiences of these two groups, decision makers and occupational therapists, and their influence on each other, in order to provide deeper understanding of the barriers and facilitators of hospice occupational therapy utilization in end-of-life care and to develop a theory to strategize appropriate increased service use.

Statement of Purpose

The purpose of this study was to describe utilization of occupational therapy services from the perspectives of hospice care decision makers and hospice occupational therapists and to develop a theory of hospice occupational therapy utilization.

Research Questions

The central research question is, “How is the utilization of hospice occupational therapy services determined?” Subsidiary questions are as follows:

- What are the demands and expectations of hospice care decision-making?
- How do hospice care decision makers determine which services to offer?
- How do hospice care decision makers view hospice occupational therapy?
- How does interaction of hospice care decision makers with occupational therapists influence what hospice services are provided?
- How does the interaction of hospice occupational therapists with the hospice institutional context affect the occupational therapist’s (a) sense of efficacy (volition); (b) role perception (habituation); and (c) skill acquisition/competence (performance) to provide hospice occupational therapy services?
- What are the barriers and facilitators of hospice occupational therapy utilization?

Research Aims

The research aims included the following.

Research Aim 1: Describe how hospice care decision makers determine hospice occupational therapy utilization. A grounded theory approach by interview was used to address the following research questions:

- What are the demands and expectations of hospice care decision making?
- How do hospice care decision makers determine which services to offer?
- How do hospice care decision makers view hospice occupational therapy?
- How does interaction of hospice care decision makers with occupational therapists influence what hospice services are provided?
- What are the barriers and facilitators of hospice occupational therapy utilization?

Research Aim 2: Describe how the interaction of hospice decision makers and occupational therapists influence hospice occupational therapy utilization. A grounded theory approach by interview was used to address the following research questions:

- How does interaction of hospice care decision makers with occupational therapists influence what hospice services are provided?
- How does the interaction of hospice occupational therapists with the hospice institutional context affect the occupational therapist's (a) sense of efficacy (volition); (b) role perception (habituation); and (c) skill acquisition/competence (performance) to provide hospice occupational therapy services?

- What are the barriers and facilitators of hospice occupational therapy utilization?

Research Aim 3: Develop a theory on how hospice occupational therapy utilization is determined. A grounded theory approach to data analysis was conducted to address the research question:

- How is the utilization of hospice occupational therapy services determined?

Assumptions

This researcher based this study on the following assumptions:

- End-of-life care providers seek to alleviate a patient's pain and suffering at the end of life (Gutiérrez-Sánchez et al., 2020).
- The environmental impact exerts demands and constraints, which influence feelings about self, motives, actions, roles, and habits (Fisher et al., 2017).
- Humans are intrinsically motivated to master one's environment and achieve competence (Florey, 1969).
- Occupational adaptation is the negotiation of three elements
 - Environmental impact
 - Construction of an occupational identity
 - Establishment of occupational competence to meet one's occupational identity (de las Heras de Pablo et al., 2017).

Operational Definitions

The following terms are important concepts used in this study and are presented in alphabetical order:

Comfort care: medical care provided at the end of life to prevent and relieve suffering and improve quality of life (National Institute on Aging [NIA], 2018a). Care may address physical comfort, mental and emotional needs, spiritual issues, and practical tasks needed to be carried out at the end of life (NIA, 2018a).

Community-based practice: “provision of skilled therapy services within a client’s own home or community...” (Medical Dictionary for the Health Professions and Nursing, 2012, “community-based practice” entry).

Continuum of care: “in medicine, describes the delivery of health care over a period of time. In patients with a disease, this covers all phases of illness from diagnosis to the end of life” (National Cancer Institute, n.d., “continuum of care” entry).

Decision maker: “a person who makes important decisions” (Oxford University Press, 2020, “decision maker” entry); professionals who determine or affect allocation and utilization of health care services.

Decision making: “the cognitive process of choosing between two or more alternatives, ranging from the relatively clear...to the complex” (American Psychological Association [APA], n.d.-a, “decision making” entry).

End-of-life: a period of limited prognosis and irreversible decline prior to death; life expectancy of 6 months or less (based on hospice admission criteria; Hui et al., 2014).

End-of-life care: the support and medical care provided within the days, weeks, and/or months before death (NIA, 2018c).

Environment: “the particular physical, social, occupational, economic, political, and cultural components of one’s contexts that impact upon motivation, organization, and performance of occupation” (Fisher et al., 2017, p. 93).

Environmental impact: “the actual influence (in the form of opportunity, resources, demand, or constraint) that the physical and social aspects of the environment have on a particular individual” (Fisher et al., 2017, p. 105).

Habituation: patterns of behavior structured by habits, routines, and roles (Lee & Kielhofner, 2017a).

Hospice: non-curative, comfort care and psychosocial support for people living with a terminal illness and have a live expectancy of 6 months or less (CMS, 2018).

Influencers: a sub-group of decision-maker professionals; interdisciplinary team members who recommend (or not) an occupational therapy referral to a decision maker.

Occupation: a daily life activity that has purpose, meaning, and perceived utility (AOTA, 2020).

Occupational adaptation: the ability to sustain occupational competence to meet one’s occupational identity over time (Bowyer, 2019).

Occupational competence: “...the degree to which one sustains a successful pattern of occupational participation that reflects one’s occupational identity” (de las Heras de Pablo et al., 2017, p. 117).

Occupational identity: a concept of self, based on roles, relationships, values, goals, and desires (de las Heras de Pablo et al., 2017).

Occupational participation: engagement in work, play, and activities of daily living, ranging from participating in specific occupational roles to having a subjective sense of commitment and satisfaction of an occupation (de las Heras de Pablo et al., 2017).

Occupational therapist: practitioners who “are responsible for all aspects of occupational therapy service delivery process” (AOTA, 2020, p. 1).

Occupational therapy: “the therapeutic use of everyday life occupations with persons, groups, or populations...for the purpose of enhancing or enabling participation” (AOTA, 2020, p. 1).

Occupational therapy practitioners: refers to both occupational therapists and occupational therapy assistants. Occupational therapists and occupational therapy assistants “use their knowledge of the transactional relationship among the client, the client’s engagement in valuable occupations, and the context to design occupation-based intervention plans” (AOTA, 2020, p. 1).

Occupational therapy assistant: practitioner who “deliver[s] occupational therapy services under the supervision of and in partnership with an occupational therapist” (AOTA, 2020, p. 1).

Palliative care: non-curative, comfort care and psychosocial support for people living with a terminal illness, provided at any stage of the disease process and may be in conjunction with curative treatments (NIA, 2018b).

Palliative rehabilitation: an interdisciplinary team approach that provides rehabilitation to people with chronic and terminal illness to improve mobility, activities of daily living, endurance, pain relief, and quality of life (Barawid et al., 2015).

Patient: “a person receiving health care from a licensed health professional” (APA, n.d.-b, “patient” entry).

Performance: “discrete acts, or units of doing, that are performed” (de las Heras de Pablo et al., 2017, p. 107).

Personal causation: the sense of capacity and self-efficacy to engage in an occupation (Lee & Kielhofner, 2017b).

Primary hospice team: the main hospice care team, typically consisting of a physician, nurse, social worker, and chaplain (National Consensus Project, 2013).

Provider: “a professional...that provides health care services to patients” (APA, n.d.-c, “provider” entry).

Role: “incorporation of a socially and/or personally defined status and a related cluster of attitudes and actions” (Lee & Kielhofner, 2017a, p. 67).

Self-efficacy: “thoughts and feelings concerning perceived effectiveness in using personal abilities to achieve desired outcomes in life” (Lee & Kielhofner, 2017b, p. 54).

Task: “any goal-oriented activity undertaken by an individual or a group” (APA, n.d.-d, “task” entry); “identifies what a person is trying to do in his or her coping, the specific effort that he or she is making to achieve what is required or desired” (Corr et al., 2019, p. 143). People may engage in specific tasks regarding physical, psychological, social, and/or spiritual areas to cope with dying (Corr et al., 2019).

Terminally ill: a state of incurable illness with a limited life expectancy (Hui et al., 2014). In review of the literature, limited life expectancy may range from days to 24 months (Hui et al., 2014).

Utilization: “to make use of: turn to practical use or account” (Merriam-Webster, n.d., “utilization” entry).

Volition: one’s thoughts and feelings about occupation, consisting of values, interests, and personal causation (Lee & Kielhofner, 2017b).

Researcher’s Stance

In 1995, I became an occupational therapist with a simple desire to help people through difficulty. “Evidence-base practice” was not fully embedded in our profession, and “best practices” was still the hallmark of competent, compassionate care. Although I took continuing education courses, I relied more heavily on “best practices.” In 2003, I took a position at the Palo Alto Veterans Affairs (VA) Hospice and Palliative Care Center not fully knowing what I could offer as an occupational therapist but drawn to a place where I could possibly “help.” I realized rehabilitative occupational therapy is not widely effective against terminal, functional decline, yet adapting occupations to enable participation, even momentarily, may bring meaning at the end of life. I returned to school, seeking to advance my practice, and quickly learned that there was lack of research to support evidence-based occupational therapy in end-of-life care.

My research stance encapsulates my years of well-intended “best practice,” recalibrated through a lens of occupation-based theory and steeped in the need for research of occupational therapy in end-of-life care. I selected an occupation-based

theory that enables me to describe what I have already seen and practically frame research to investigate occupational participation at the end of life. Within the model of human occupation (MOHO; Taylor, 2017), volition gives voice to how people view themselves and what they find as meaningful as they negotiate their functional abilities (performance) to meet valued roles expectations (habituation) within their environment, whether it is the context of dying or the context of providing occupational therapy in end-of-life care. This MOHO-based, grounded theory study is an integration of a desire to help people going through difficulty, occupation-based theory, and research rigor to yield evidence.

Effects of the Coronavirus Pandemic

Ten months into this 12-month study, the coronavirus disease (COVID-19) pandemic erupted in the United States. Global distress surmounted with high mortality rates, mandated shelter-in-place in selected regions, and the uncertainty of how to effectively treat the critically ill and protect oneself against the virus. During the initial weeks, participant recruitment waned. The researcher speculated health care providers and administrators did not respond to study invitations as they were drawn to more urgent matters at the workplace and at home. One enrolled decision maker participant with administrative duties had to reschedule his second interview multiple times due to conflicts with workplace demands.

As less emergent health care services shut down to limit viral exposure, recruitment increased. Some participants found themselves with extra time, working from home via video conferencing, or having their services called off. The researcher also had

less personal commitments outside the home, enabling her to transcribe, analyze data, and schedule the second interview faster. Fifty-four percent of the participants ($n = 22$) were recruited and interviewed within the last 2 months of the study. Although there was “down-time,” participants often verbalized compounded stress and noted “before-and-after-COVID-19” protocols in providing end-of-life care services.

CHAPTER II

BACKGROUND AND SIGNIFICANCE

A review of the literature in four parts presents the research on the utilization of hospice occupational therapy. To articulate the value of hospice occupational therapy, the first part centers on palliative care literature and establishes how dying trajectories shape the human need to engage in end-of-life tasks as a means of coping with the dying process. These end-of-life tasks translate to end-of-life occupations in occupational therapy literature. The second part offers the evidence for occupational therapy in end-of-life care, presenting the literature on the therapeutic value occupational engagement at the end of life as well as the role and effectiveness of occupational therapy in end-of-life care. To establish the disparity between the therapeutic value and the actual utilization of hospice occupational therapy, the third part summarizes the current research on hospice occupational therapy under-utilization. Lastly, the MOHO (Taylor, 2017) is introduced as a theoretical framework to investigate the experiences of hospice occupational therapist and hospice care decision makers and understand the process of hospice occupational therapy utilization.

Part I: How Dying Trajectories Shape End-of-Life Tasks

Dying trajectories define a disease pattern and provide caregivers guidelines to anticipate disease-specific needs (Lunney et al., 2003). Within palliative care research, Lunney et al. (2003) identified dying trajectories for people with cancer, organ failure, and frailty. Changes in late-stage disease treatments and better management of co-

morbidities in the last 20 years have resulted in people living longer and greater understanding of these trajectories (Morgan et al., 2019). Building off the work of Lunney et al. (2003), Morgan et al. (2019) looked specifically at patients' last 120 days of life and scores from the Australia-Modified Karnofsky Performance Status scale throughout this period to establish a trajectory for cancer, organ failure, and cardiovascular disease patterns and another trajectory to describe dementia and neurological conditions. Subsequent studies indicate dying trajectories shape end-of-life care needs (Houben et al., 2015; Kendall et al., 2015; Lloyd et al., 2016; Morgan et al., 2019; Reinke et al., 2008). These end-of-life care needs are *tasks* people engage in to adapt to dying (Corr et al., 2019).

Cancer

Patients with cancer often remain highly functional until the last 6 months of life, experience physical symptoms and psychosocial distress throughout the disease process, and rapidly decline in the last months to weeks of life (Lunney et al., 2003; Murray et al., 2007). Morgan et al. (2019) noted that cancer patients within the last 120 days typically have a higher level of function than patients with neurological conditions and dementia, but have a steeper decline in the last 14–22 days of life. Patients often maintain hope alongside a fear of dying and hold a strong illness narrative, marked by time of diagnosis, treatment, discharge from treatment, disease progression, and entrance into the terminal stage (Kendall et al., 2015; Murray et al., 2007). Depending on cancer type and/or effects of anticancer therapies, patients may experience symptom burden and functional loss (Padgett et al., 2018). Common end-of-life tasks include pain management, maximizing

function to maintain roles and autonomy, preparing family for their deaths, putting affairs into order, leaving a legacy, and dying at home (Khan et al., 2014). These end-of-life tasks underscore the need for early palliative care referral to provide holistic support throughout the entire illness trajectory (Hoerger et al., 2019; Montagnini et al., 2020).

Organ Failure

The organ failure trajectory includes diagnoses such as lung diseases and heart failure (Lunney et al., 2003). Patients decline over a 6 to 24-month period with fluctuation of exacerbations and slight recovery, significant decline in the last 3 months, and death caused by a sudden, acute event, leaving the bereaved shocked and unprepared (Lunney et al., 2003). Morgan et al. (2019) identified the period of sharp functional decline within the last 14 days before death, similar to cancer patients. Patients struggle to pinpoint the start of the disease or string a narrative between exacerbations and recovery periods (Kendall et al., 2015). They avoid speaking about death, preferring to focus on maintaining function (Reinke et al, 2008). Physicians see exacerbations as transitions in the disease process, while patients do not see exacerbations as decline and wait until the physician tells them they are dying (Houben et al., 2015). With difficulty prognosticating and the desire to maintain a patient's hope, physicians frequently defer end-of-life discussions even in the last year of life (Houben et al., 2015). Patients may benefit from a palliative care referral early in the disease process to maximize function, initiate end-of-life conversations, provide psychosocial support, and prepare patients, families, and caregivers for death (Lowey et al., 2013).

Frailty

Patients who do not have organ failure or cancer often develop dementia or frailty of multiple body systems (Lunney et al, 2003). This dying trajectory is less predictable with 6 to 8 years of gradual cognitive decline, weakness, weight loss, and/or slowed activity (Lunney et al., 2003). Behavioral and psychological changes may include fear, paranoia, confusion, and/or physically and verbally aggressive behavior, while physical decline may include refusal or inability to eat, ceasing to talk, immobility, falls, incontinence, inability to recognize caregiver, and wandering (Hovland & Mallette, 2020). Death is often preceded by substantial decline or an acute event (Cardona-Morell et al., 2017).

Differing from cancer patients, frailty patients have difficulty providing an illness narrative, as transitions are vague (Kendall et al., 2015). Patients may become overwhelmed by inability to functionally adapt to disease progression and report greater fears of losing self-identity and being institutionalized than fear of death itself (Lloyd et al., 2016). Given a prolonged trajectory, health care providers frequently neglect to consult palliative care (Cardona-Morell et al., 2017; Kendall et al., 2015). Morgan et al. (2019) found that patients with dementia are typically at a lower functional status 120 days prior to death compared to cancer and organ frailty patients; however, they have a slower rate of decline overall. Patients and caregivers need support sooner and for a longer period of time (Morgan et al., 2019) to help adapt self-defining roles to match functional levels (Lloyd et al., 2016), establish long-term care networks, and initiate

advanced care planning to enable patients control over their dying process (Cardona-Morell et al., 2017).

Although dying is unique to the individual, researchers and clinicians can utilize dying trajectories of cancer, organ failure, and frailty as a framework to understand how illness shapes patients' end-of-life needs and enable them to adapt during the dying process. With such knowledge, health care providers can integrate evidence-based and patient-centered interventions to support participation in end-of-life tasks, be alert to deviations from typical patterns, and facilitate quality of life. Increased hospice resources are needed to help patients modify daily routines to changing functional levels, connect with palliative care and community-based services early in the dying trajectory, engage in end-of-life discussions and advance care planning, put affairs into order, and prepare themselves, family, and caregivers for death (Cardona-Morell et al., 2017; Houben et al., 2015; Lloyd et al., 2016).

Review of palliative care literature points to the valuable role of occupation and occupational therapy in end-of-life care. Palliative care research has found dying trajectories shape end-of-life needs (Kendall et al., 2015; Lloyd et al., 2016). These needs direct engagement in end-of-life tasks to adapt and cope with the dying process (Corr et al., 2019; Kendall et al., 2015; Lloyd et al., 2016). *Tasks* may be compared to *occupations*—"everyday activities that people do...to occupy time and bring meaning and purpose to life" (AOTA, 2020, p. 7) in occupational therapy literature. Palliative care research urges health care to increase support of hospice patients' engagement in end-of-

life tasks (Cardona-Morell et al., 2017; Houben et al., 2015; Lloyd et al., 2016), inferring the therapeutic value of occupation and the role of occupational therapy.

Part II: The Evidence for Occupational Therapy in End-of-Life Care

The Therapeutic Value of Occupational Participation

Review of occupational therapy literature indicates occupational participation is essential at the end of life. Using semi-structured interviews and/or participant observation, five qualitative studies of people living with a life-threatening illness found occupational engagement helps develop a sense of normalcy, restoration, and pleasure (Jacques & Hasselkus, 2004; Lyons, et al., 2002; Park Lala & Kinsella, 2011; Sviden et al., 2010; Vrkljan & Miller-Polgar, 2001). When provided means to reengage in valued occupations, participants reported a renewed sense of health, efficacy, and meaning (Lyons et al., 2002). Conversely, when people with terminal illness became disengaged from valued occupations, they experienced loss of control, self-identity (Vrkljan & Miller-Polgar, 2001), decreased meaningful engagement, and dependence on others (Hammill et al., 2019).

Occupations specific to end-of-life have also been identified. Jacques and Hasselkus (2004) found in an ethnographic study of a residential hospice setting, people at the end stages of life prioritized time to activities “that mattered.” Mundane tasks became extraordinary events in the context of dying. Participants focused on preparing for death by putting affairs into order, making amends, saying “goodbye,” pondering the meaning of life, and waiting to die. In a phenomenological study of eight people with a terminal illness, Park Lala and Kinsella (2011) similarly noted an emphasis on spending

time with others, having closure, and pondering existentialism. In a grounded theory study of 38 women, Hunter (2008) identified legacy building as a means to transcend self after death by passing on belongings or instilling one's values.

Continued occupational participation has been found to help people with life-threatening illness adapt to end-of-life transitions (Sviden et al., 2010). In a qualitative study of 47 people living with cancer, involvement in daily activities, regardless of declining functional performance, provided experiences of competence, well-being, and maintenance of self-identity (Sviden et al., 2010). Findings from a focus group of 23 people at a day hospice, suggested occupational participation in day program activities provided participants means to develop new interests, foster learning, and make a contribution to one's community (Lyons et al., 2002). Sustained occupational participation is essential at the end of life to enable hospice patients to adapt and be resilient during the arduous dying process. Effective therapeutic intervention to support occupation-based needs is thus critical in end-of-life care (AOTA, 2016).

Role of Occupational Therapy in End-of-Life Care

Occupational therapists have the expertise to address occupation-based needs and enable patients to maximize occupational participation in critical end-of-life tasks, live with purpose, and experience quality of life at the end of life (Hammill et al., 2014; Kasven-Gonzalez et al., 2010; Sviden et al., 2010). Occupational therapists facilitate occupational participation through discernment of a patient's goals, contextual demands, and personal factors (Eva & Morgan, 2018; Mills & Payne, 2015). As a result of the occupational therapist modifying the environment and helping patients adjust internal

expectations, patients achieve a better fit with valued occupations and experience competency, even with disability (Lyons et al., 2002; Yeh & McColl, 2019). Clinicians also reframe practice to affirm life through maximizing occupational performance while preparing patients for death with coping strategies to sustain loss (Eva & Morgan, 2018; Hammill et al., 2014; Yeh & McColl, 2019). Occupational therapy interventions to promote occupational performance include activities of daily living retraining (Panchmatia & Urch, 2014), adaptive equipment issue, environmental modifications (Keesing & Rosenwax, 2011), caregiver training (Kasven-Gonzalez et al., 2010), stress (Miller & Hopkinson, 2008) and fatigue management (Littlechild, 2016), leisure activities (Norris, 1999), creative arts (la Cour et al., 2007), life review (Sakaguchi & Okamura, 2015), and legacy making (Hunter, 2008). Integrating these elements, occupational therapists help patients achieve goals and participate in valued occupations at the end of life.

Effectiveness of Occupational Therapy in End-of-Life Care

Regardless of descriptive evidence or theoretical premise depicting occupational therapy's practice domain, finite health care resources and accountability to best practices mandate evidence-based interventions (AOTA, 2020). A limited number of outcome studies support the effectiveness of occupational therapy to increase occupational participation at the end of life. Among six studies with small sample sizes, occupational therapy increased engagement in self-care tasks (Kasven-Gonzalez et al., 2010; Lee et al., 2005; Norris, 1999; Panchmatia & Urch, 2014); fatigue management (Littlechild, 2016); and life review (Sakaguchi & Okamura, 2015). In a retrospective study of 327

participants, occupational therapy improved stress management (Miller & Hopkinson, 2008). Functional performance outcomes were briefly sustained and eclipsed by quality of life outcomes of experiencing a sense of control (Kasven-Gonzalez et al., 2010; Panchmatia & Urch, 2014), self-efficacy, well-being (Sakaguchi & Okamura, 2015), and satisfaction (Norris, 1999). These small studies provide emerging evidence of the effectiveness of occupational therapy in end-of-life care but suggest the need for further research.

Part III: The Under-Utilization of Occupational Therapy in End-of-Life Care

Despite supportive evidence on the therapeutic use of occupational participation and the effectiveness of occupational therapy during the end of life, occupational therapy remains under-valued and under-utilized in end-of-life care. In a survey of 100 U.S. hospice care professionals, only 68% of respondents found occupational therapy a vital profession within the hospice care team (Knecht-Sabres et al., 2018). Within this same study, only 38% of respondents reported having an occupational therapist on their hospice care team, of which 46.2% reported rarely working with the occupational therapist (Knecht-Sabres et al., 2018).

There is limited research on the under-utilization of hospice occupational therapy. A small number of qualitative or mixed method studies have been conducted with occupational therapists, other health professionals, and/or family members/caregivers (Eva & Morgan, 2018; Halkett et al., 2010; Hammill et al., 2017; Kealey & McIntyre, 2005; Keesing & Rosenwax, 2011; Knecht-Sabres et al., 2018). The majority of these studies have been carried out in Australia (Halkett et al., 2010; Hammill et al., 2017;

Keesing & Rosenwax, 2011) with the remaining studies from Europe (Eva & Morgan, 2018; Kealey & McIntyre, 2005) and the US (Knecht-Sabres et al., 2018). Although study locations have varied, there are common findings. Frequently cited external barriers are lack service funding, insufficient reimbursement, misunderstanding of occupational therapy's role, limited team presence or employment opportunities, and insufficient research on the use of occupation-based interventions (Eva & Morgan, 2018; Halkett et al., 2010; Keesing & Rosenwax, 2011; Knecht-Sabres et al., 2018). Intrinsic barriers include fear occupational therapy promotion may lead to increased demand beyond clinicians' resources (Eva & Morgan, 2018) and feeling inadequately trained in end-of-life care (Eva & Morgan, 2018; Halkett et al., 2010).

Distinction between external and intrinsic barriers underscores the dynamic interaction of the occupational therapist negotiating with the health care environment. There is currently no research investigating how occupational therapists engage with the health care environment to overcome barriers and advocate for occupational therapy services in end-of-life care. Given hospice care decision makers are foremost in determination of hospice occupational therapy services, an in-depth study of the experiences of hospice care decision makers and hospice occupational therapists may elucidate barriers and facilitators of service utilization.

Part IV: A Theoretical Framework for a Study on Hospice Occupational Therapy Under-Utilization

The MOHO depicts occupation as the integration of three components, volition, habituation, and performance capacity, within an environmental context (Taylor, 2017).

Volition describes how one views occupation, as influenced by a person's values, interests, and sense of competence to engage in the occupation (Lee & Kielhofner, 2017b). Gravitating toward valued occupations, one develops consistent actions or habits (Lee & Kielhofner, 2017a). These habits coalesce into routines and roles. Roles define social identity and address social expectations (Lee & Kielhofner, 2017a). Performance capacity encompasses the physical, mental, and cognitive abilities needed to do role-required tasks (Tham et al., 2017). The MOHO proposes physical, social, cultural, and temporal contexts provide expectations of occupational engagement and shape occupational behavior (Fisher et al., 2017). Successful occupational engagement, or occupational adaptation, is contingent upon one's occupational competence to satisfactorily integrate volition, habituation, and performance components to sustain one's sense of occupational identity over time while negotiating the impact of the environment (Bowyer, 2019).

The MOHO is an appropriate theoretical model to investigate the negotiation of the hospice occupational therapist with hospice care decision makers. The occupational therapist, as worker, needs to have a sense of capacity and self-efficacy (volition) to fulfill the role of a hospice occupational therapist (habituation) with competent clinical skills (performance) while meeting the complex needs of end-of-life care. Occupational adaptation is the successful management of volition, habituation, and performance components to sustain the identity of a hospice occupational therapist while negotiating the demands and expectations of not only the hospice patients and their families but also the expectations of hospice decision makers who determine occupational utilization.

Within the literature, the MOHO has not been applied to the dynamic relationship between hospice occupational therapists and hospice care decision makers. However, the MOHO has been readily used to predict work-related occupational participation within the work environment and to achieve positive vocational outcomes under challenging circumstances (Lee & Kielhofner, 2010). In a MOHO-based intervention program for people with AIDS, addressing volition, habituation, performance capacity, community, and workplace environments, 66.7% of participants who completed the program achieved employment, returned to school, or began a volunteer/internship (Kielhofner et al., 2004). In another MOHO-based, 4-week program for domestic violence survivors, participants were able to successfully develop life skills essential for employment (Helfrich & Rivera, 2006). Lastly, in a MOHO-based vocational program for people with serious mental illness, participants showed significant improvements in volition, vocational habits, and work-related skills (Turner & Lydon, 2008). Although these participant groups greatly differ from this study's participants, the MOHO will foreseeably serve as a strong theoretical framework to understand the complexity of hospice occupational therapists coordinating intrinsic components of volition, habituation, and performance to effectively work with hospice care decision makers and advocate for occupational therapy services in end-of-life care.

Summary

Aging with chronic illness and dying of a terminal disease are complicated and arduous processes. Occupational engagement at the end-of-life may offer means to cope and co-exist with dying to live with purpose and quality of life. Occupational therapists

have the expertise to maximize occupational participation in critical end-of-life tasks. However, occupational therapy remains under-utilized in end-of-life services. Researchers have identified general barriers to service utilization. Further research is needed to understand more in-depth the perspectives of hospice occupational therapists and hospice care decision makers. A grounded theory study using the MOHO will capture the experiences of hospice occupational therapists and hospice care decision makers with consideration of the multiple components of occupational participation, to describe and better understand utilization of occupational therapy services in end-of-life care.

CHAPTER III

METHODOLOGY

The aim of this study was to conduct a systematic analysis of perspectives of hospice care decision makers and hospice occupational therapists to explain the utilization of hospice occupational therapy in end-of-life care. The focus was on gaining in-depth participant descriptions through an interview process to identify themes and build a theoretical framework from the data. Expected outcomes were that the defined theoretical framework would elucidate how hospice occupational therapy utilization is determined.

Research Design

This study used a grounded theory research design. Grounded theory is a qualitative methodology that seeks to construct a theory from the data to explain the investigated phenomenon (Corbin & Strauss, 2015). A grounded theory approach was well suited for this study to not only describe the perspectives of end-of-life care decision makers of occupational therapy utilization and the occupational therapists who provide end-of-life care but also develop a theory of hospice occupational therapy utilization. The researcher conducted this study according to the methods approved by the Institutional Review Board at Texas Woman's University.

Participants

The inclusion criteria were English-speaking hospice care professionals who have at least 1 year of experience in hospice care services and who affect utilization of

occupational therapy in end-of-life care. There were two groups of participants—hospice care occupational therapists and decision makers, with a sub-group of decision-maker professionals called “influencers.” Occupational therapists were licensed occupational therapy practitioners who treated a minimum of six patients at the end of life within the last 18 months. Decision makers were professionals who determine service funding and/or place referrals for occupational therapy services. Influencers were interdisciplinary team members who recommend (or not) an occupational therapy referral to a decision maker. As the study progressed, the researcher found many professionals providing end-of-life care do not formally work in hospice care. The researcher thus reworded the criteria to include “end-of-life care professionals” rather than “hospice care professionals.” An exclusion criterion was the inability to complete the interview process (as described in the Data Collection section). To investigate barriers and facilitators of service utilization, participants were purposefully sought from a mix of organizations that did or did not provide occupational therapy services.

Participant Recruitment

The researcher used purposive sampling to recruit participants. To access palliative care decision makers, the researcher contacted two major national hospice and palliative care organizations—the National Hospice and Palliative Care Organization (NHPCO) and the American Academy of Hospice and Palliative Medicine (AAHPM). The NHPCO only collaborates with researchers affiliated with NHPCO studies and declined to circulate study information; however, the AAHPM emailed a study flyer to their membership upon approving the researcher’s application. To access occupational

therapists, the researcher utilized the AOTA social media site (CommunOT), networked at the annual conference, and emailed presenters on end-of-life care issues listed in the annual conference program. Drawing upon the researcher's contacts through working at the Palo Alto Veterans Affairs Health Care System (PAVAHCS), the researcher accessed VA occupational therapists through two national VA email groups. The PAVAHCS hospice medical director facilitated email introductions with PAVAHCS Hospice and Palliative Care Fellowship alumni on the researcher's behalf. The researcher integrated snowball sampling and initiated cold calls to local hospices and providers on the National Hospice Locator website. A social worker PAVAHCS fellowship alumnus and a Texas Woman's University social work professor also posted a study flyer on a national social workers listserv. With participant nomenclature shifting from "hospice" to "end-of-life care professionals," the researcher also recruited from non-hospice settings such as acute care, oncology rehabilitation, home health, and adult day health care. See Table 1 for details on recruitment outcomes.

Table 1*Recruitment Sources*

Recruitment Source	No. of Contacts	No. of Participants
National Hospice and Palliative Care Organization	0	0
American Academy of Hospice and Palliative Medicine	4	4
American Occupational Therapy Association	15	6
Veterans Affairs Health Care System – Occupational Therapists	20	8
Palo Alto Veterans Affairs Palliative Care Fellowship	11	6
Snowballing	48	17
Cold Calls	34	0
Total	132	41

Corbin and Strauss (2015) assert, “the basis of sampling is concepts, not persons” (p. 146). However, the researcher needed to project a sample size for the Institutional Review Board application and to request grant funding for participant rewards. Creswell (2014) recommends 20 to 30 people for a grounded theory study. Given two groups and one subgroup, the researcher projected a sample size of 60, with 20 occupational therapists, but anticipated size fluctuation depending on theme saturation or need for more clarifying evidence (Corbin & Strauss, 2015).

Data Collection

The researcher provided potential participants information and answered questions about the study via email. If the potential participant agreed to participate, the researcher obtained consent and scheduled interview times. The researcher logged participants on an Excel sheet by name, phone number, and email and then assigned a pseudonym based on the first letter of the participant group and identification number based on sequence in enrollment. For example, the first occupational therapy participant was OT1 Oakley. The first decision maker participant was D1 Drake, and the first influencer was I1 Irene. Based on the participant's availability, preference, and/or geographical location, interviews were conducted face-to-face in a quiet, private location, or remotely via phone or video conference call.

The researcher engaged each participant in two interviews. The first consisted of a semi-structured interview aligned with the research questions and inclusive of MOHO elements (volition, habituation, and performance components and environmental contexts). With regards to volition, the researcher was influenced by interview questions from the occupational circumstantial assessment and interview rating scale (Forsyth et al., 2006) and survey questions from Knecht-Sabres et al. (2018). To assess question distribution balance, the researcher constructed a matrix, organized by question type, MOHO elements, and grounded theory analysis categories. Question types consisted of background/demographic information, behavior (what a person does), opinion, feeling (emotional response), and knowledge (factual information) questions (Patton, 2015). Grounded theory analysis categories included context, conditions, actions-interactions,

and consequence (Corbin & Strauss, 2015). (These categories are further explained under Data Analysis; see Appendices A and B for interview question matrices.) The researcher intentionally distributed questions across categories to address the research questions. Prior to data collection, the researcher piloted questions with a fellow PhD candidate, evaluating the clarity, sequence order, and effectiveness in prompting responses that address research questions.

After transcription and initial data analysis, the researcher conducted a second interview for member checking and asked any clarifying questions that arose from data analysis (Corbin & Strauss, 2015). The researcher sought to complete the second interview 3 to 7 days after the first interview to allow the participant to reflect on responses but “not lose connection” with the topic (Seidman, 2014, p. 24). However, the researcher was unable to meet the proposed window between the first and second interview as she underestimated the time required to transcribe, prepare for member checking, accommodate participants’ scheduling constraints, or account for the effect of COVID-19 on workplace demands. The average days between the first and second interview was 16.20 days with a range of 6 to 52 days. The average time of the first interview was 44:48 minutes, with a range of 25:07 to 67:08 minutes. The average time of the second interview was 19.18 minutes, with a range of 6:46 to 55:13 minutes. See Table 2 for details on interview times for each participant group.

Table 2*Average Interview Times*

Participant Group	Average Time in Minutes Interview #1	Range in Minutes Interview #1	Average Time in Minutes Interview #2	Range in Minutes Interview #2
Occupational Therapist	49:34	31:38–67:08	20:30	8:02–55:13
Decision Makers	40:23	25:07–64:00	19:47	8:30–37:14
Influencers	38:01	25:34–51:35	12:43	6:46–25:06
Total	44:48	25:07–67:08	19:18	6:46–55:13

The researcher audio-recorded each interview and took notes. Upon completion of the second interview, the researcher thanked participants and provided them with a \$20 Amazon e-gift card, paid with a grant from the California Foundation for Occupational Therapy. The researcher then transcribed interviews verbatim using an automated transcription service (Nvivo Transcription™) and edited transcripts for accuracy using transcription software (Express Scribe 2™) and a foot pedal. By transcribing her own interviews, the researcher reviewed and reflected on the data more thoroughly and initiated the analysis process sooner than if she hired a transcriber. To ensure participant confidentiality, the researcher removed personally identifying information from data and stored audio-files and electronic documentation on a secured laptop and hard drive. The researcher used OneNote to organize field notes, journals, transcripts, and auditor reports and NVivo 12™ for coding.

To increase rigor, the researcher took field notes to document thoughts and observations and diagram preliminary relationships between concepts as well as maintained a journal to serve as an audit trail and a source of reflexivity (Corbin & Strauss, 2015). The researcher engaged in constant comparison throughout data collection. To answer questions about concepts and relationships between concepts, the researcher conducted theoretical sampling, collecting additional data until saturation (Corbin & Strauss, 2015). With consent, the researcher also contacted key informants after data analysis to member check and obtain feedback on whether the developed theoretical model reflected their experiences with the central phenomenon.

Data Analysis

To address Research Aims 1, 2, and 3, the researcher conducted data analysis according to Corbin and Straus (2015). The researcher engaged in open coding, proceeding line-by-line through the transcript, organizing excerpts into codes, and grouping similar codes under categories. The researcher organized categories into themes. Basic-level categories, using details directly from the data, served as a foundation and grounded the theory in the data. Higher-level, abstracted categories provided theory structure. The researcher took memos to document in-depth thinking and analysis during the coding process.

To determine relationships between themes and construct a theory, the researcher engaged in axial coding. The researcher first determined the *context* of the data, looking at the “events, the set of circumstances, or conditions that make up part of any situation, the meanings given to these (a problem, goal, etc.), the action and interaction persons

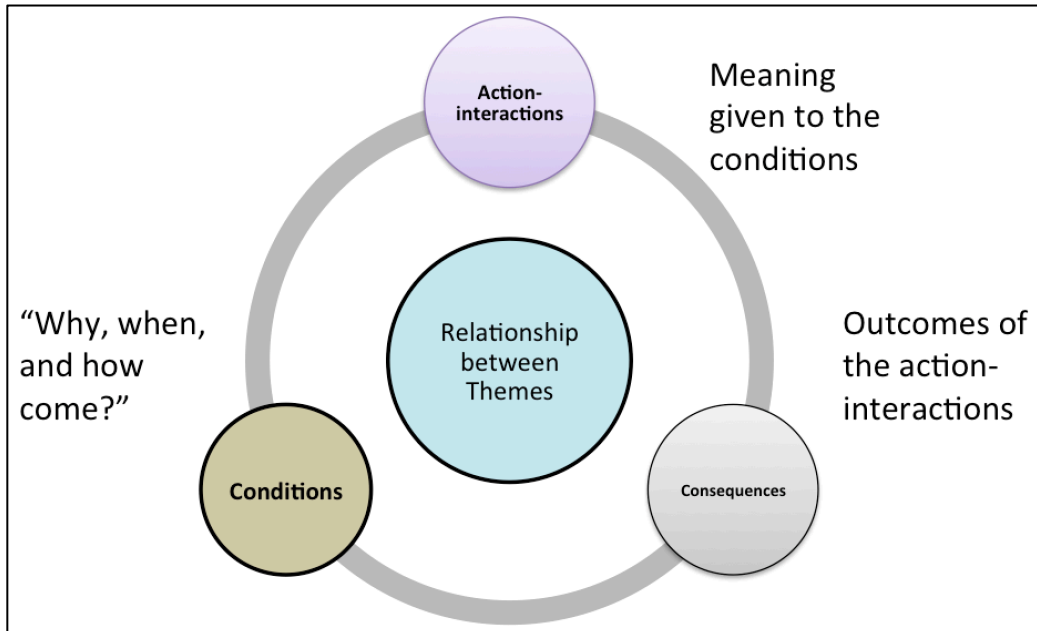
take to manage or achieve desired outcomes, and the actual consequences that result from their action” (Corbin & Strauss, 2015, p. 155). Setting the context helped the researcher understand the conditions in which the central phenomenon took place, possible reasons for a participant’s response to the phenomenon, and the consequences of these responses (Corbin & Strauss, 2015). Data on context included description of the participant’s workplace environment, workplace mission, clients, job role, and barriers and facilitators of occupational therapy utilization.

The researcher used Corbin and Strauss’ (2015) paradigm analytic tool (see Figure 1) to analyze links between the categories by looking at *conditions*, *actions-interactions*, and *consequences*. Conditions provided the reason for responses and answered questions about “why, when, and how come” (Corbin & Strauss, 2015, p. 157). Foreseen study conditions included the economic and social demands that shape service fund allocation, an occupational therapist’s impetus to advocate for end-of-life services, or the life experiences that prepared the clinician to work with dying clients. Actions-interactions addressed the meaning given to conditions and set of events (Corbin & Strauss, 2015) such as the value a decision maker places on occupational therapy services or the satisfaction participants derived from their role as a hospice care provider. Consequences were “anticipated or actual outcomes of action and interaction” (Corbin & Strauss, 2015, p. 158) such as allocation of funds for occupational therapy after increased awareness of the therapeutic benefits of occupation-based interventions in end-of-life care.

For deeper analysis, the researcher then created a conditional/consequential matrix, looking at the relationship between conditions, actions-interactions, and consequences as well as the variance across health care contexts (Corbin & Strauss, 2015). To increase rigor, the researcher maintained a journal, asked reflective questions about the data, engaged in constant comparison, and used NVivo 12™ for data analysis. The researcher's PhD mentor, not involved in data collection, provided peer-debriefing (Patton, 2015).

Figure 1

Paradigm Analytic Tool



Note. As interpreted from Corbin, J., & Strauss, A. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (4th ed.). SAGE.

Audit Trail

To establish trustworthiness, the researcher also enlisted two PhD colleagues, not involved in data collection, to evaluate the audit trail. The researcher and two PhD mentors developed an audit tool, “Auditor Guide for Trustworthiness” (Chow et al., 2019; see Appendix C), which overlays analysis areas of Corbin and Strauss (2015) over Halpern’s (1983) auditor framework. It prompts for feedback on whether the data supported the identified categories and themes, whether negative cases were accounted for, and if credibility was maintained. The auditors were asked to conduct two audits of three participants. For the first round of audits, the researcher randomly selected three participants, one from each participant group among the first 18 participants, which the researcher had completed coding at that time. For the second round of audits, the researcher purposively selected three participants, one from each participant group, among the latter 23 participants and based on thematic saturation.

To help the auditors efficiently proceed through the evaluation form, the researcher provided the following written materials: the study prospectus, Audit Trail Guidelines for Trustworthiness: Directions (directions with a “read-only” OneNote™ link to the researcher’s digital notebook), Audit Trail: Categories and File Types (table of contents of the digital notebook), and Audit Area Locator (list of data locations in the digital notebook). The researcher filled out an Audit Area Locator handout for each selected participant and also gave instructions on how to run a file search on OneNote™. See Appendices D, E, and F for instruction handouts and forms.

The auditors were directed to review all of the provided written materials and the data for each participant in the OneNote™ notebook. They were then asked to fill out one Auditor Guide for Trustworthiness form, considering all three participants together. The auditors were to mark an “X” on the scale to answer the prompt, giving their first inclination. The researcher reassured auditors not to worry if they were unable to answer a prompt but to make a note why they could not answer a question (e.g., “There was not enough data to answer this question”).

The auditors took approximately 2 to 4 weeks to complete the audit. After the first audit, both auditors emailed their completed Auditor Guide for Trustworthiness form and discussed their findings with the researcher on the phone. For the second audit, the researchers emailed their Auditor Guide for Trustworthiness forms and overall findings.

CHAPTER IV

RESULTS

Forty-one health care professionals across varied roles, areas of care, and geographical regions, participated in this study. Repeatedly, participants cited awareness of occupational therapy's role in end-of-life care as the key to understanding the value of occupational therapy and utilizing occupational therapy services. Secondly, a participant's awareness underscored how they adjust focus on what the patient finds important, while accommodating a patient's dying process and supporting meaningful occupational engagement. The workplace mission, available resources, and insurance reimbursement of place, or context of care, shaped a decision maker's decisions and actions. Upon integrating awareness, adjust focus, and place into a paradigm, the researcher noted a decision maker's awareness may drive the occupational therapy referral process, but a decision maker and occupational therapist's ability to adjust focus and their place of care may influence what types of occupational therapy services patients receive and the patients' treatment outcomes. Looking deeper into the consequences of awareness, adjust focus, and place across the range of participants' place(s), the researcher observed that if place aligns with awareness, occupational therapists and decision makers often potentiated occupational therapy services for their patients. In particular, these data demonstrate a community-based, continuum-of-care model highly leverages occupational therapy services in end-of-life care in comparison to other health

care contexts. Together, awareness, place, and adjust focus formed a grounded theory model on the utilization of occupational therapy in end-of-life care.

Participants

One consented occupational therapist dropped out due to scheduling constraints prior to engaging in any interviews. The final sample size was 41, with 21 occupational therapists, 15 decision makers and five influencers. See Table 3 for participant group information. Participants were primarily from the United States, amongst 16 states, while two occupational therapists were from Western Canada and two decision makers were from Eastern Africa. For confidentiality, participants are listed by regional locations as defined by the U.S. Census Bureau (n.d.). See Table 4 for the U.S. states represented by participant group. See Tables 5 to 7 for more participant details.

Table 3

Participant Group Information

Participant Group	<i>n</i>	% Female	Age Range	Age Mean	Age Median
Total	41	75.61	28–74	48.95	50.5
Occupational Therapists	21	90.48	28–64	42.76	37
Decision Makers	15	46.66	39–66	53.4	52
Influencers	5	100.00	42–74	62.4	66

Table 4

U.S. States Represented by Participant Group

Occupational Therapists	Decision Makers and Influencers
California	California
Connecticut	Hawaii
Illinois	Indiana
Kentucky	Massachusetts
Massachusetts	North Carolina
Nevada	Oklahoma
New York	Oregon
North Carolina	Rhode Island
Pennsylvania	Texas
Texas	
Utah	

Table 5*Occupational Therapist Participants*

Participant Pseudonym	Age	Gender	Years in EOL Care	Years of Practice	Practice Area	Population for EOL Care	Regional Location	Setting	Interview Context
Oakley	62	D	20	40	OPT therapy in the home	Older adults	West	Suburban	Phone
Olympia	52	F	23	25	HHH, A	Adults	Northeast	Suburban	Phone
Odette	28	F	1 yr., 8 mo.	1 yr., 8 mo.	HH	Older adults	West	Suburban	Phone
Ophelia	64	F	8	42	HHH	Older adults	West	Suburban, Rural	In-person
Oona	36	F	15	17	PHC	Adults	Western Canada	Suburban, Urban	Video
Octavia	60	F	18	32	INPT Mental Health	Adults	Northeast	Suburban	Phone
Orianna	36	F	1 yr., 2 mo.	8	PHC	Adults	Western Canada	Suburban, Rural	Phone
Oreta	37	F	11	11	VA HBPC	Older adults	South	Suburban	Phone
Owen	37	M	6	8	VA HBPC	Older adults	South	Rural	Video
Ocean	36	F	5	11	VA CLC, OPT	Older adults	Northeast	Urban	Phone
Onassis	32	F	4	7	HHH	Older adults	Northeast	Suburban	Phone
Odonna	36	F	3	10	VA HBPC	Older adults	West	Suburban	Phone

Participant Pseudonym	Age	Gender	Years in EOL Care	Years of Practice	Practice Area	Population for EOL Care	Regional Location	Setting	Interview Context
Oliveta	44	F	10	17	VA HBPC	Older adults	West	Urban, Suburban	Phone
Obed	32	M	9	9	VA HBPC, A	Older adults	South	Rural, Urban	Phone
Osaka	38	F	12	14	SNF	Older adults	Northeast	Suburban	Video
Orchid	34	F	10	10	Onc. Rehab	Adults	Midwest	Urban	Phone
Obassi	32	F	3	5	Acute Care	Adults	South	Urban	Video-
Odessa	53	F	7	30	ADHMC, C	Frail older adults	South	Urban, Suburban, Rural	Phone
Omyra ^a	59	F	7	35	VA HBPC	Older adults	West	Suburban, Urban	Phone
Orinda ^b	30	F	2	7	SNF, OPT	Older adults	South	Suburban	Video
Opal	60	F	15	19	VA Acute Care	Older adults	West	Suburban	Phone

Notes. A = Academia; ADHMC = Adult Day Health Medical Center = ADHMC; C = Community; CLC = Community Living Center (Extended Care); D = Declined to answer; EOL = End-of-Life; F = Female; HBPC = Home-based Primary Care; HH= Home hospice; HHH = Home health and hospice; INPT = Inpatient; M = Male; Onc. = Oncology; OPT = Outpatient; PHC = Palliative Home Care; SNF = Skilled Nursing Facility; VA = Veterans Affairs. ^aOmyra worked at the same location as participant Dennis. ^bOrinda worked at the same location as participant Irita.

Table 6*Decision Maker Participants*

Participant Pseudonym	Age	Gender	Years in EOL care	Years of Practice	Practice Area	Population	Regional Location	Setting	Interview Context
Drake	63	M	39	39	MD, Family Practice, Community-based	All ages (Family Practice)	South	Rural	Phone
Deanna	39	F	10	13	MD, CBH	Older adults	West	Suburban	Phone
David	66	M	25	32	MD, VA Hospital administrator	Older adults	West	Suburban	In-Person
Daniel	59	M	11	21	MD, HMD, CBH, Primary Care	Older adults	West	Suburban	In-Person
Davina	D	F	30	45	MD, HMD, CBH	Adults	Northeast	Suburban	Phone
Dean	61	M	12	34	MD, Family Practice, Community-based, HMD	All ages (Family Practice)	South	Rural	Phone
Declan	50	M	12	12	MD, CMO, CBHPC	Adults	South	National organization	Phone
Dennis ^a	47	M	5	12	NP, VA HBPC	Older adults	West	Suburban	Phone
Danielle	57	F	25	40	Clinical Care Director, outpatient hospice	Older adults	West	Suburban	Phone
Donatello	53	M	14.5	29	MD, CMO, CBHPC	Older adults	South	Suburban Rural Urban	Phone

Participant Pseudonym	Age	Gender	Years in EOL care	Years of Practice	Practice Area	Population	Regional Location	Setting	Interview Context
Donna	51	F	9	20	MD, HH, PCMD, Assistant HMD	Adults	West	Suburban Rural Urban	Phone
Dominique	45	F	13	21	MD, consult attending, inpatient palliative care	Adults	Northeast	Urban	Phone
Deborah	48	F	15	22	MD, HMD, CBH	Adults	South	Suburban Urban Rural	Phone
Dylan	58	M	10	15	Clinical assistant, inpatient & CBHPC	Adults	Eastern Africa	Rural	Video
Dailyn	51	M	9	25	Nurse, palliative care coordinator, inpatient & CBHPC	Adults, Children	Eastern Africa	Rural	Video

Notes. CBH = Community-based Hospice; CBHPC = Community-based Hospice and Palliative Care; CMO = Chief Medical Officer; D = Declined to Answer; EOL = End-of-Life; F = Female; HBPC = Home-based Primary Care; HH = Home Hospice; HMD = Hospice Medical Director; M = Male; MD = Medical Doctor; NP = Nurse Practitioner; Palliative Care Medical Director = PCMD; VA = Veterans Affairs. ^aDennis worked at the same location as participant Omyra.

Table 7*Influencer Participants*

Participant Pseudonym	Age	Gender	Years in EOL care	Years of Practice	Practice Area	Population	Regional Location	Setting	Interview Context
Irene	74	F	15	46	SW, HH	Adults	West	Suburban, Urban	In-person
Ilena	66	F	2	37	RN, inpatient hospice	Adults	West	Suburban	Phone
Irita ^a	42	F	13	20	OT, Former Dir. of Rehab-SNF; Dir. of Outpatient Clinic	Older adults	South	Urban	Phone
Imogene	72	F	10	35	SW, HH	Adults	South	Urban	Phone
Ida	58	F	3	30	COTA, HHH	Adults, Children	Midwest	Urban	Phone

Notes. COTA = Certified Occupational Therapy Assistant; Dir. = Director; EOL = End-of-life; F = Female; HH = Home health; HHH = Home health & hospice; OT = Occupational Therapist; RN = Registered Nurse; SNF = Skilled Nursing Facility; SW = Social Worker.

^aIrita worked at the same location as participant Orinda.

Researcher-Participant Relationship

The researcher drew upon professional colleagues and networks for participant recruitment. Consequently, the researcher knew some participants prior to the study and took care to not recruit participants she currently or had worked with in the past 5 years. Of the 41 participants, six completed their palliative care fellowship training at the researcher's worksite over 5 years prior to the study and had not collaborated with the researcher since they left their fellowship training. At the time of the study, three participants worked at the researcher's facility in different departments and areas of care. One participant intermittently served on the same interdisciplinary team as the researcher but had worked more so with other occupational therapists in end-of-life care.

Awareness, Adjusting Focus, and Place

The overarching theme was awareness. The two secondary themes were adjust focus and place. Given the iterative process of open coding, the researcher continued to group and regroup categories even after the themes had emerged. See Tables 8 and 9 for excerpts depicting the evolution of the categories over a 3-week span. Upon category solidification, participants' in vivo quotations were used to ground the categories in the data.

Table 8*Open Coding Excerpt 1*

Awareness	Place	Adjusting Focus
Barriers of OT Utilization	Community-based Practice	Adaptation-accommodation
Dissatisfaction	Context Non-conducive to EOL Care	Advocating for patients and EOL OT
Facilitators of OT Utilization	Continuum	Comfort & QOL
IDT Market hospice services	Decision Maker Role	Documentation-communication
OT influence on IDT	Hospice Competing for Business	EOL care in a non-EOL healthcare setting
Participant has realization	IDT Collaboration	Functional abilities assessment
Satisfaction	Larger company vs. smaller company	Goal-setting
Self-efficacy	Medicare-insurance shapes care	Integration of dying context
Suggestions for Advancement	Mission	Medical Model-Rehab vs. Wellness
View of OT	OT and workplace mission align	Participants shaped by life experience
	Outcome measures	Patient-centered care
	Patient and Family Role	Promotes coping
	Service value	QOL vs. Quantity of life
	Unique hospice services offered by volunteers	Safety
	VA provides a little bit extra	Supports occupational Engagement

Notes. EOL = End-of-life; IDT = Interdisciplinary Team; OT = Occupational Therapy; QOL = quality of life; VA = Veterans Affairs.

Table 9*Open Coding Excerpt 2*

Awareness	Place	Adjusting Focus
Barriers to OT utilization	Continuum	Contrast Against Medical Model
Facilitators of OT utilization	Expectations	Integration of dying context
Satisfaction and Self-efficacy	Insurance Influence	Participants Shaped by life experiences
View and Influence OT	Larger vs. smaller company	Supports Occupational Engagement
	Mission	

Note. OT = Occupational Therapy

The researcher noted that the categories corresponded with environmental context levels as described by the MOHO (Taylor, 2017) with the person interfaced with the intermediate, local, and global environmental contexts. For this study, the personal context was the occupational therapist. The intermediate context was the interface between the occupational therapist and the decision makers, patients, families, team, and/or treatment facility. The local context was the greater views of the health care system the occupational therapist and decision maker works in. The researcher did not identify a global context within the scope of this study. As an example, for awareness, “Wow, it makes a difference in this person's life,” reflected the personal experience of the occupational therapist at the personal level. “Physicians don’t understand about occupational therapy,” described aspects of how the team views occupational therapy on an intermediate level. The attitude, “Rehab is to get better. Hospice is to die,” reflected thinking regarding health care provision on the local level within the participants’ health

care system. See Table 10 for the final themes and categories with exemplar quotations at the corresponding level of environmental influence.

Table 10

Open Coding—Final Themes and Categories at Environmental Level of Influence

Environmental Level of Influence	Awareness (Central Theme)	Adjusting Focus	Place
Person	“Wow, it makes a difference in this person's life.”	“I’ve had both my sister and my mom pass away within 6 months of each other.”	“It’s to provide...the best service to people at the end of life.”
Intermediate	“Physicians don't understand about occupational therapy.”	“How can we...improve and keep as good a quality of life as possible?”	“We have the ability to borrow from the home health discipline service line.”
Local	“Rehab is to get better; hospice is to die.”	“The system really only supports clinical interventions that are focused on fighting disease.”	“The services that we offer in terms of the team and everything is mandated by Medicare.”

Note. OT = Occupational Therapy

Awareness: “How Can There Be Utilization Without Awareness, Right?”

When asked, “What are the barriers to the utilization of occupational therapy in end-of-life care?” Dennis, a nurse practitioner and decision maker, replied, “I mean, probably a fundamental one is people don’t even know what OT is and what it does, what it can do. I mean, how can there be utilization without awareness, right?” As the central theme, the awareness level undergirded facilitators and barriers of occupational therapy

utilization on multiple environmental levels. At the local level, the attitude, “Rehab is to get better; hospice is to die,” conveys the pervasive thought that occupational therapy is for curative purposes only and is not reimbursable under the Medicare Hospice Benefit. At the intermediate level, “Physicians don’t understand about occupational therapy,” reflected how the perceived definition of occupational therapy’s role in end-of-life care continues to lack distinction and value. Within the personal context, “Wow, it makes a difference in this person’s life,” described how awareness intrinsically fueled the occupational therapist’s level of satisfaction in providing end-of-life care and the confidence to arbitrate lack of environmental supports.

“Rehab Is to Get Better; Hospice Is to Die”

A major barrier to occupational therapy utilization in end-of-life care was a pervasive attitude at the local level that occupational therapy is for curative and rehabilitative purposes only. As Irita, a previous director of rehabilitation at a skilled nursing facility, explained,

It’s actually they often just, they often make a blanket connection, “Rehab is to get better. Hospice is to die.” So, it’s just the way of the world, and so, we just have to work to try to change that, to try to change that mind set.

The juxtaposition between the medical model and the end-of-life care further precluded understanding of occupational therapy’s role in end-of-life care. As Osaka, an occupational therapist at a skilled nursing facility, noted,

And so sometimes I feel like the medical professional team might not even think that occupational therapy has a role in end-of-life care. I mean, I’ve been in

situations where I've seen, you know, physicians just say like there is absolutely no reason for therapy and that mindset of the medical model being curative and rehabilitative. It's not congruent to what the end-of-life client needs.

Because occupational therapy was often considered curative or rehabilitative, providers did not think occupational therapy was covered under the Medicare Hospice Benefit and refrained from referring hospice patients. Daniel, a community-based hospice medical director, felt this is one of the major barriers to occupational therapy utilization.

So as far as I know, just like physical therapy, it's sort of viewed as more curative. And so it's not a covered service. So, if we provide it or not, it's not... we're not being reimbursed for that extra service even though it makes sense that it would be beneficial.

Dean, a hospice medical director and family practice physician, also explained, "The hospice rules and regs basically prevents any kind of therapy...hospice forbids any therapy by standards." He added that the patient has "accepted the fact they are going to die within 6 months and they've agreed to palliative care..." Although Dean acknowledged rehabilitation services, such as speech therapy, may be covered for a one-time dysphagia assessment and training session for comfort, Dean would typically discharge a patient from hospice if he or the patient felt that rehabilitation would be beneficial, "Here is what the patient wants...Based on what they want, they really need to come off service, get a certain therapy, whatever it is."

The misconception that occupational therapy was not covered under the Medicare Hospice Benefit appeared to have created a shortfall in addressing private sector hospice

health care needs. Oliveta, an occupational therapist working with VA Home-Based Primary Care, observed that private sector hospice care looks to the VA to cover this gap for occupational therapy and physical therapy:

I actually just came across this today right before you called, but I was trying to get the end, wrapped up where the VA here was going to order home health OT [occupational therapy] and PT [physical therapy], but the person's on hospice with [hospice agency name], and they won't let OT and PT come on because it's not going to be reimbursed as long as hospice's in there. So I was calling them to see, "Are you guys going to graduate him from hospice, or should we order, go ahead and order this OT/PT anticipating the graduation from hospice? Or should we just wait?" And it turns out, the person probably is going to pass away so they're not going to order the OT and PT. So I just double check to make sure there wasn't anything else they needed.

There was lack of awareness of how occupational therapy can add quality of life and was covered under the Medicare Hospice Benefit. Olympia, a community-based hospice occupational therapist who successfully received reimbursement for her services, explained,

What I put in every note that gets reimbursed is quality of life. So it doesn't matter what you are doing. If it contributes to that person's quality of life, then it's covered by the hospice benefit. It does not have to be ADLs [activities of daily living] or mobility or safety awareness...it's anything that contributes to quality of life. Again this is education. People are not aware of it. Even the people

making the referrals and the agencies, think that the things that they bill for rehab patients have to be the same for hospice patients or they will not get covered. I will tell you that that is not true. Every single one of my visits has been paid for.

Utilization of occupational therapy services at the end of life was highly influenced by the provider's awareness of occupational therapy's role and what services were reimbursable under the Medicare Hospice Benefit. The attitude that "occupational therapy is curative" impeded providers from seeing how occupational therapy may improve quality of life at the end of life and making occupational therapy services available to terminally ill people. As Irita suggested, we have to "try to change that mindset."

"Physicians Don't Understand About Occupational Therapy"

At the intermediate levels, occupational therapists had an opportunity to interact with decision makers, patients, and families and advocate for occupational therapy services. Participants' own or their observations of other's level of awareness of occupational therapy highly varied from a "not understanding about occupational therapy" to seeing occupational therapists as helping patients develop a meaningful "new normal" at the end of life. There remained an inconsistent view of occupational therapists and the value they offer in end-of-life care.

Decision makers noted that providers, patients, and/or families sometimes did not know what occupational therapy was and, consequently, did not ask for or see a need for an occupational therapy consultation. Donatello, a chief medical officer of a community-based hospice and palliative care organization, explained,

Physicians don't understand about occupational therapy. Unless you are a rehab doctor, they don't...about the value. So, it's a matter of having that experience of opportunity to, to see outcomes when that, those therapies can be applied, how that changes [a] family's outlook on patients.

Dominique, a palliative care consult attending at a major metropolitan hospital, noted families and patients are aware of physical therapy but not occupational therapy.

I do know that I think it's very beneficial service and that families and patients ask for it all the time. Well, they ask for PT all the time. They don't think about OT as much...they sometimes do. I don't think they know the difference.

When asked why her team had chosen not to have an occupational therapist on her team, Deanna, a community-based hospice physician, replied, "I think because it is not understood how it can be of service."

A common perception of occupational therapy's role was to restore functional movement in the upper body. Drake, a family practice physician, described occupational therapists as "professionals who evaluate patients'...capacity to perform, work basically, or tasks, mainly the upper extremity...that helps them compensate for losses and recover from different deficits..." Orinda, an occupational therapist who worked at a skilled nursing facility, reported, "I know a lot of times when people on our team think of OTs, a lot of them think, 'Oh, it's upper body. It's ADLs [activities of daily living].' You know, splinting." Osaka commented, "I often hear this horrifying statement, 'OT upper body. PT lower body.' I hear that a lot."

With the perception of restoring movement, occupational therapists were thought to provide just exercise. According to Odette, a community-based hospice occupational therapist,

First impression that anyone thinks who may not be familiar with occupational therapy, is exercises, and so, a lot of the time whenever a case manager would put in their small blurb about wanting me to see them, it would be solely for plain exercises.

Oliveta recalled with some dismay,

When I first graduated school, I'll never forget, I had a doctor at a hospital, it was like an inpatient setting, we overheard him making fun of OTs to the other doctors, of how we just like walk around with a TherabandTM and that's all we do...

Decision maker participants sometimes blurred occupational therapy together with physical therapy and interchangeably referred the two services. Irene, a community-based hospice social worker described her consultation process, referring occupational therapy and physical therapy as one entity:

Well, I've had a couple of people with atypical Parkinson's disease who I thought would benefit from OT/PT because of their, you know, because of their disease progression and knowing that, I mean knowing what we know now, that exercise and movement can be very helpful to quality of life and safety, and that those are the patients I have sort of punted for.

Danielle, a community-based hospice clinical care director, interchangeably refers occupational therapy or physical therapy for fall risk management, depending on which is first available:

Quite honestly...we work with a contracted provider...whichever service [OT or PT] is available, but, occupational therapy I think for fall risk tends to be the preferred. But we'll go, you know, with whatever we can get.

For Dominique, it was not clear if there was a distinct occupational therapy service at her hospital. She shared, "I think it's merged with physical therapy, because I don't ever see the word 'occupational therapy.' We always call it – I think they're merged in one, in one group."

Some decision makers distinguished occupational therapy from physical therapy as helping patients restore function with daily living, and accommodating functional loss. Declan, the chief medical officer for a large hospice and palliative care organization, described the difference between occupational therapy and physical therapy:

Physical therapy, I guess, on the other hand, is rehabilitation post-injury, surgery- more the entire body, to get back to perhaps a higher functional level of ambulation, walking, running, engagement at that level. OT may be more geared towards the intimacy of day-to-day living...and maybe much more specific with respect to a, you know, utilization of our hands...

Daniel similarly differentiated between occupational therapy and physical therapy as Declan:

So physical therapists will cause... or help the patient gain strength, conditioning, and the physical ability to do things. Occupational therapist is more about how to do things. How do you do things more efficiently and more safely, more effectively? How to make their living better or easier.

Donna, a community-based palliative care director and assistant hospice medical director, explained how occupational therapists help patients build a “new normal” in the context of decline while describing how her team transitions care between home health to hospice:

Maybe because we do home health also, so where the focus, you know, I think for a lot of us, like you’re saying, think of it more rehabilitative, but for me, hospice is...not recovering the same function lost like after a surgery or acute event like a stroke. But this, a new normal, and how do we help maximize function and how people live the best they can to really impact quality.

Further distinguishing occupational therapy from physical therapy, some participants deeply connected occupational therapists not only with functional restoration and accommodation but means to experience connection with others and improved quality of life. Davina, a community-based hospice medical director, reflected how there was little rehabilitation could offer her patients with amyotrophic lateral sclerosis (ALS), yet her occupational therapist colleague developed an interdisciplinary feeding group that fostered community among the patients and their families:

And we were sharing some patients that had Lou Gehrig’s disease, and it became very, very apparent that the little we could do was very little... [Occupational

therapist colleague] really was the one that took the lead...And so we would have lunches with the families, have the families all come in, because families trying to feed an ALS patient alone sometimes, it's very, very difficult. But when we brought them in as a group and other families were all in there together, it turned into parties, and they saw what other people were doing, and actually helped speech therapists with swallowing and seeing different foods.

Dennis provided additional examples of how enabling basic occupations support quality of life:

I believe that OT is definitely improved quality of life for patients. I think it has reduced the incidence of, of skin breakdown and discomfort from being inappropriately positioned or in the wrong kind of bed. I think it's definitely helped patients to be able to get up out of bed and up to into the wheelchair and to be ambulating as long as possible and, you know, to be able to get outside and enjoy the sunshine.

Donatello shared how occupational therapists identify opportunities for quality of life with patients who have otherwise plateaued in rehabilitation:

[Rehabilitation clinicians] say, "Plateau—there's no longer any improvement of the functional level." That is after being involved with a patient... If we bring [the patient] in, [the occupational therapists] always find an opportunity of therapeutic action, therapy that would improve quality, 'cuz, quality, there's a perception of how you do vs. why you are doing it...Maybe we just have a breed of OT around here that they can see the value.

Participants' view of occupational therapy ranged from limited understanding of occupational therapy's role to seeing occupational therapists as enabling people experience quality of life in the context of declining and dying. There was a predominant view of occupational therapists being synonymous with physical therapy. Yet, some participants did distinguish occupational therapy as helping declining patients engage in daily tasks and thus improving quality of life.

The predominant view of occupational therapy as being synonymous with physical therapy may have posed a significant barrier to occupational therapy utilization in end-of-life care. As David, a hospital administrator, explained,

For many conditions, patients go to maybe their primary care doctor and say, "I really want to see a dermatologist."...I don't know how often people go ...and say, "I really need to see an occupational therapist." My sense is they don't very often when they frankly ought to. And so you're dependent on a clinician usually a non-OT person translating whatever they're talking about into say, "Oh, what I think you need is this," and then making a referral.

A providers' level of awareness affected what value they saw in occupational therapy, whether they placed a referral, and for what type of service.

"Wow, It Makes Such a Difference"

Given the limited awareness and support of occupational therapy in end-of-life care in the intermediate and local environments, the researcher looked at the personal context and asked occupational therapist participants what gave them satisfaction and confidence to do their work. Participants found satisfaction in helping people realize their

abilities and meet their goals in the context of dying. They often drew confidence from their work experience and positive feedback. However, they seemed most inspired by their patients' and families' feedback, realizing they had made a difference.

In the state of decline, terminally ill people may feel abandoned and left to die. As Osaka explained, "I think that a lot of times when people write off the dying as kind of voiceless, like, you know, the end is eminent, there really isn't anything we can do, just keep them comfortable." Many participants cited satisfaction in identifying what is important to the patients, helping them tap into their remaining abilities, meet their goals, and experience joy in the process. Ocean, an inpatient hospice occupational therapist, shared,

The most satisfaction is to bring a smile but whatever that worth, um, despite the outcome...Despite the fact that they know they don't have much left... But just to see that smile even though, I don't even know how to say it right....Well, let's say I teach someone or issue a power wheelchair and you see that smile...I did this communication device with my ALS patient who died a few days, a week ago. Just to see that smile, being able to communicate or do something, it just means everything to me.

For Oliveta, her source of pride was,

Helping the patients meet their goals, whether it's to die at home or to be able to get out of bed and spend some time outside. I had one veteran on hospice who,... I got him a custom wheelchair so he could spend an hour or two a day outside watching the birds before he died.

Olympia had repeatedly seen how she had helped patients experience joy at the end of life:

I guess taking probably the most difficult time in a family or somebody's life and bringing some joy to that...and I've heard so many times from especially families is, "I can't believe...I never thought we could still experience joy at this point."

In the context difficulty and hardship, participants witnessed patients still experiencing pleasure and joy through occupational engagement.

When asked about their source of confidence to do their job, participants often reflected on their experience. For Omyra, a VA home-based and palliative care occupational therapist, "I just feel like the life experience...all the different experiences. I just feel like I have a really big tool bag, you know." Obassi, an occupational therapist in acute care, similarly drew from her life experiences to provide end-of-life care at her setting:

When I first started, what gave me confidence, well, two things, one would be my training, like I worked in home health as one of my fieldworks.... As far as confidence in being an end-of-life practitioner would be probably my, my personal experience with knowing what a good end-of-life and not good end-of-life experience could look like from the three experiences I had with my grandparents and end-of-life in hospice...Now I think it's just having more experience as an OT ...gives me confidence now.

In addition to finding satisfaction in their work and drawing confidence from their experiences, many participants felt empowered by the positive feedback from their

patients and families and realized what a difference they made. Onassis, a community-based occupational therapist, shared how a family member's feedback gave her confidence in her work:

I recently just lost a hospice patient, and I went to her funeral, and her husband gave me a card that said, "You know, not only did my wife like you, but she respected you." And, I feel like when you go above and beyond to make somebody be able to function however they want at this stage of their life, and you succeed, and you get the feedback from the caregivers and family and patients, I think that gives you the strength to know that, or gives me the strength to know that what I'm doing is making a difference, and that I would say, you know, four years in, I'm more confident than I was.

O'donna, a VA home-based primary care occupational therapist, explained her team got feedback through surveys, helping them understand the impact they made:

And we always get great feedback. And [the families] remember our names and what we did, and it always breaks my heart when we do have a patient that dies, and the family mentions us in the obituary, like we, you know, "Poppa couldn't live an extra year, if it wasn't like..." just reading those, and being, "Yeah, I did make a difference."

Ocean shared about the moment a patient connected with therapy and the lasting impact on her:

We see so many people do that, and you know, there's like no reaction sometimes, and then you have someone they do it and they're like, "Oh my God." And you're

like, “Wow, it makes a difference in this person's life.” You know, you can see that reaction.

Although many decision makers did not fully understand or recognize occupational therapy’s role in end-of-life care, occupational therapists found great satisfaction in helping patients engage in meaningful occupations. They drew confidence from their experiences and were highly inspired by patients and families’ encouraging words. Overall, they realized that how they enabled patients to connect to the world “makes a difference in this person’s life.” With such awareness, they were intrinsically motivated and empowered to advocate for occupational therapy services in end-of-life care as they negotiated the intermediate and local health care contexts.

In summary, the central theme, awareness, underlines various environmental levels of occupational therapy utilization. At the local level, “Rehab is to get better; hospice is to die,” attitude that occupational therapy was for curative purposes and ineligible for Medicare Hospice Benefits widely limited consideration and utilization of occupational therapy for end-of-life care. At the intermediate level, “Physicians don’t understand about occupational therapy,” providers were often unaware of occupational therapy’s distinct value, influencing whether they referred occupational therapy and for what services. At the personal level, “Wow, it makes a difference in this person’s life,” occupational therapists’ awareness of how occupational therapy made a difference, intrinsically motivated them to continue to advocate for patients despite limited external support among referring providers and their health care system.

Adjusting Focus: “Adjust, Focusing on What Is Most Meaningful to the Person”

The secondary theme, adjusting focus, describes how participants adjust interventions to meet the needs of people declining and dying. As Obed, a VA home-based primary care occupational therapist reflected,

I always say that for me, that my job is to help a person continue, and we certainly help people prepare for death and have a more satisfying death, but my job is still to help people with living. And I think that OT can bring people a more positive end-of-life experience. Adjust, focusing on what is most meaningful to the person.

Adjusting focus could be seen at three levels of environmental contexts as well.

The personal level, “I’ve had both my sister and my mom pass away within 6 months of each other,” captured the participants’ experiences that led and prepared them to work with terminally ill people. Momentarily sidestepping the intermediate level, the local level, “The system really only supports clinical interventions that are focused on fighting disease,” depicted the marginalization of people who are dying and their end-of-life care needs. Returning back to the intermediate level, participants shared how they adjusted focus of occupational therapy services to still accommodate the dying process and care for people whose needs may not otherwise be recognized within the health care system.

“I’ve Had Both My Sister and My Mom Pass Away Within 6 Months of Each Other”

At the personal level, multiple participants had experienced the death of a close family member, preparing them to work with people at the end of life. Odette, the youngest study participant, shared,

I've had both my sister and ...my mom pass away within 6 months of each other.

I think I'm just an old soul, and I can really relate to the wisdom my own patients give to me, you know. Life experiences allow you to be able to relate to them.

For Oona, her sisters' deaths and mother's work as a hospice chaplain were foundational to her professional development in end-of-life care:

I had a couple of sisters who passed away when I was younger. So I think that was probably early, early years, and my mom was a chaplain at the hospice. So I think death and dying is something that's always been something we've talked about as a family unit probably more so than the average person (laughs). So I think that definitely helped prepare things.

Orchid developed an interest in end-of-life care occupational therapy when her mother entered hospice after a 7-year battle with cancer:

And it was her, the hospice experience that really made an impression on me because I was, I was kind of using my OT...The nurse would come, the hospice nurse would come, and I'd say, "Hey, why don't we like why can't we move the hospital bed over here?"...Do I need a medication chart to ease my dad's anxiety about medication stuff? Or like having my mom participate in sponge bathing instead of the nurse doing it for her. These simple things where I was like, why isn't this more common?

Many participants sustained losses that sensitized them to the needs of the dying and prepared them to provide end-of-life care.

“The System Really Only Supports Clinical Interventions That Are Focused on Fighting Disease”

With such personal experiences, participants’ brought a unique and passionate perspective to the local context of their care setting. They saw the needs of the dying but felt health care focused too heavily on cure and failed to recognize the needs of people living in incurable states. As Declan explained, “The system really only supports clinical interventions that are focused on fighting disease...If I could do anything, I’d say, ‘Look, we’ve got to change how we think about care in that palliative and hospice are anything but about death.’”

Participant’s observed this lack of focus on end-of-life care in hospice care as well. Oakley recalled,

Many hospices that I used to contract, have become home health hospice companies and have merged with home health, and now they’re required to use their home health therapist instead of using us...this is not my standard home health patient, and they’re not thinking about the fragility of the patient compared to their standard home health patient...They’re treating it like a rehab patient, like home health.

Aware of the needs of people at the end of life, participants were attuned to how health care was not providing services that prepared and supported people through the dying process. Daniel noted, in addition to physical pain, he needed to attend to a patient’s suffering with functional loss:

But I know that people just don't function well, and so part of their suffering is they can't function, and part of their emotional well-being is the fact that I'm more of a burden because I cannot not function well. So those things are important.

Donatello explained in the context of functional loss, there is an opportunity to make a difference for people with only months to live by using occupational therapy:

Can you imagine in an ALS person, that no longer can speak, and for those basic things, but still has some strength? And just enable to get some guidance and... treatments or sessions, basically, even if he, for a few weeks...the quality achieved, so fulfilling to the patient and family...I mean, we have seen things that families and patients are so satisfied about what they are now able to achieve, even yes, the patient may not live, about three more months, but for that next month, that quality achieved [is] so meaningful...

As Obed pointed out, occupational therapists can make such an impact providing end-of-life care in non-end-of-life care settings:

We are seeing these patients in their last phase, in some context, you know, even if that might be an acute, it might be in rehab. It, it may not be the right fit, but we still may encounter these folks in different health care settings and just realizing that we don't have to be quick to dismiss or discharge or limit our role for them, even though they're a person who may be in that last phase.

Occupational therapists also recognized the opportunity to teach providers about the role of occupational therapy at the end of life in non-end-of-life settings. Orchid shared about her experiences at an oncology rehabilitation program:

When I'm educating providers, I make sure to reiterate that part, like we can also do family training...The OT part doesn't really change. It's people like providers' perceptions change that like all of a sudden they might not need any therapy because they'd like, "Oh, well, end-of-life, hospice...discharge." So like reinforcing and re-educate, you know, I just constantly like make it a point to say, "OT, we're here to provide services. And even if someone is at or near end-of-life, we can still do these things."

There was a lack of support at the local level within health care. Participants recognized the needs of people living with terminal illness but noted health care settings tended to focus on cure rather than on supporting people suffering from incurable states and functional loss. However, occupational therapists observed an opportunity to expand occupational therapy's role by seeing end-of-life needs in non-end-of-life settings and taking the opportunity to educate providers.

"How Can We...Improve and Keep As Good a Quality of Life As Possible?"

To close the gap between end-of-life care needs and a cure-focused health care environment, decision makers and occupational therapists adjusted focus, identifying what was meaningful to the patient to improve quality of life. Based on level of awareness, decision makers adjusted focus by how they referred occupational therapy services. Occupational therapists adjusted focus by assessing occupational needs, helping

the patient set goals, and modify occupational engagement within the context of decline and dying.

How Decision-Maker Participants Adjusted Focus. Depending on their level of awareness of occupational therapy's role in end-of-life care, decision makers adjusted focus in how they worded their consults and referred occupational therapy services for people at the end of life. At one extreme level of awareness, Irita described when decision makers did not adjust focus for end-of-life care and request occupational therapy for rehabilitation to negotiate placement needs:

But people go with the rehab side in those instances because one, prior level of function. The patient may have been functioning at home, and you like for them to get back to going home, but two, financially, you know, they have that Medicare benefit with those 100 days...So they often sign up for rehab when, as a therapist, you go and you're like, "Oh, my God, they're just blinking."...In that instance that you know that this patient is best served under hospice services for comfort and just end of life care versus trying to provide rehab services. Whereas rehab services, we have to go in every day.

Moving toward the middle range of awareness, Deanna noted that she had not been able to locate an occupational therapist for end-of-life care in her area, but her hospice contracted with physical therapists. Even still, she learned how to specifically word consult requests and screen for clinicians who understand end-of-life care, else the patient would be discharged for lack of rehabilitation potential:

Unless they've had experience with hospice and end-of-life patients, [the physical therapists] tend to still be in their restorative mind-set...and we will get like a totally different assessment...oh, it will just say, "This patient is bedbound." And they'll go like, "This patient is not able to participate at all." And then that's it...versus, you know, then we'll have to ask for a home hospice associated physical therapist to go out and just say, "Ok, well, actually more, you know, this is maybe the family's goal are to see if they can even just get into a chair and do some range of motion or, you know, what is the minimal they can do, 'cuz the family is hoping they just be able to get them up and about."

At a midpoint of awareness, Dennis knew how to utilize occupational therapy for specific services in end-of-life care. When asked how occupational therapy helped increase care outcomes, he replied,

It's things like pain scores. It's how comfortable the patient reports that they are or aren't after such OT interventions as providing an air mattress to someone who is bed bound...If patients say that they are, or caregivers, are reporting smoother transfers, easier to transfer patients and less discomfort during that process...how much easier it may be to deliver every day bedside care with other interventions offered by OT like something as simple as a hospital table and a bedside urinal or commode, so they don't have to walk all the way to the bathroom and fall, those kinds of things.

Further along the scale of awareness, Davina drew upon occupational therapists' creativity to promote comfort and quality of life at the end of life:

And OTs can be very, very creative. They're probably the most creative of all the therapists...[occupational therapy colleague] did some work in dream therapy with the OTs, and a lot of work and relaxation...It kind of went far away from getting somebody dressed in the morning. But it was all very creative and lifesaving for the patients.

Depending on the decision makers' awareness of occupational therapy's role in end-of-life care and how they adjusted focus of the occupational therapy referral, a patient would or would not receive occupational therapy that best met their occupational needs at the end of life.

How Occupational Therapist Participants Adjust Focus. The other component of adjust focus was how the occupational therapists accommodated the dying process to improve quality of life. One caveat was that not all colleagues of occupational therapists felt able or comfortable providing end-of-life care. However, occupational therapists freely shared how they adapted intervention to the dying process through assessing occupational needs, helping the patient set goals, and modifying the environment to support occupational engagement.

"I'm Willing to Do It." When asked what promotes occupational therapy in end-of-life care, Oreta, an occupational therapist working in VA home-based primary care replied, "I think the fact that I'm willing to do it." Many of the participants noted their colleagues felt uncomfortable or unable to work with terminally ill patients. Osaka shared,

The feedback has been like, “I never learned how to work with somebody that was dying.” Like a lot of it is like hands off. I think that people get a little nervous about hurting somebody or causing more pain or causing more anxiety.

Olympia commented, “The OTs that they have hired are not comfortable seeing ALS patients, so I’m seeing almost 100% ALS patients at this time.”

Other colleagues were reportedly unaware of occupational therapy’s scope of practice and would discharge hospice patients based on lack of rehabilitation potential.

Ocean shared,

So what happened was that ALS patient was on a different unit, and he had a consult with another therapist. The therapist discharged him so, knowing that there's nothing to do...And when I got a phone call because he was transferred to a bed in my hospice unit...I said, “I can’t believe he been here for so many months and nobody did anything.” And that’s when the therapist said, “Oh, I didn’t realize.” And I said, “Of course you got to do something.”

Occupational therapists saw themselves as promoters of end-of-life care. In comparison to their colleagues, they were more comfortable being around people who are dying and knowledgeable in adjusting focus of occupational therapy services to accommodate functional decline. Just being, as Oreta said, “willing,” reflected a simple desire to advocate for occupational needs at the end of life.

“What’s Most Important to You?” Most occupational therapists felt able to meet the demands of end-of-life care. Starting with assessment, participants adapted the

assessment process to be sensitive to the patient's stage of life. Obed explained how he first targeted what is most important to the patient:

Yeah, and I think just for the practitioner to be able to recognize that for themselves and know that, know that their practice looks different, you know, that there's something different about what I'm doing when I'm encountering these situations. It's not, "Let me get you out of bed and let's get to this sink. And you know, what's most important to you?" Like that should, no matter what setting you work in, that should be your number one question you ask is, "What's most important? What do you want to work, you know, what you want to focus your energy on?" And that, that's more end-of-life you know, than, than anything.

Oakley shared how she evaluated a patient's functional status bearing in mind how to adapt rather than remediate function:

So my role is to determine what deficits are there are in the person's function...the person's bodily ability...their environment...and the tasks they're doing...and try to align those so that the person is doing the best they can. And sometimes that is physically doing the best they can. Sometimes it's cognitively...accommodating to decreased function, and sometimes it's emotionally, psychologically adapting to a different ability, or adapting to declining health, or adapting to caregiver distress, or it's helping the caregiver adjust to a change in what the person is able to do.

Oona shared how a clinician needs to be able to integrate both physical and psychosocial issues while helping people adapt to continuous change:

I think to work in palliative care and in this kind of a role you need to have skills in being able to assess a client well in terms of physical and psychosocial needs as well as environmental to be able to facilitate increased independence as much as possible. I think you need to have be able to feel comfortable having difficult discussions about psychosocial issues where you might say, “Hey, you know what. What’s going on? What are you struggling with right now and how do we try and address that?”...I think you need to be able to do activity analysis really well in order to help people adapt as things continuously change.

Occupational therapists adjusted focus by assessing patients, mindful of limited time, declining function, and both physical and psychosocial issues.

After assessing the patient’s needs, participants adjusted focus by helping patients set goals within the context of the dying process. Opal shared how goal setting is more so patient-driven by what is important in this phase of life:

I have a different kind of approaching when it comes to hospice, like what is meaningful for this time of your life. They may not care at all about getting dressed. They don’t care about getting out of bed. But they want to be able to face time with a relative or they want to be able to do something...Everything is client-based as far as what they want to do.

In addition to upholding the patient’s wishes, Olympia evolved goals as the patient declined and emphasized participation rather than performance:

A lot of times there’s a lot of heart-to-heart discussions...They had the goal, “I want to be able to feed myself,” and we get to a point where they’re not able to do

that. I will sit them down and say look, “We’re changing right now...you’re changing and you’re not going to be able to maintain that goal. What do you want it to look like right now? How much help you want to have?” Sometimes they wanted at least playing a role in it... I don’t have the goal say, “Min or mod assist.” I have it say, “Will modify to continue to enable engagement in order to maintain quality of life.”

Odette shared how she used her “OT-eye” to see an opportunity and suggest a goal:

The sad but really gratifying thing is that you are coming in and helping them do a first, and it’s crazy...but the very, very fresh experience that just comes to mind is a patient that I have right now – she has been bound for three years...three years!...So our first visit, she got up sitting at edge of bed partially, maybe 80% before we had to cut the visit short...So the second visit, she sat up edge of bed... her feet touched the floor in the first time in years, and she was so happy that she made me take a picture of her with her two sons. She sat up really nicely for a good 15–20 minutes... She wasn’t so much a candidate for manual transfers, but she was certainly a candidate for Hoyer lift...Looking into the environment and then the wheelchair they had in the home before. She was bedbound...the size was not suitable for her anymore. We got those addressed on that second visit with the OT-eye...I left the house, I told her, “We’re going to get you out of bed, even if it’s for 10 minutes, next week.” She told me walking out the door, “I love you”...because it’s just so meaningful to them when you take that time with them.

Irita shared how goals can still center on health to make the most of time:

And that's a big thing with the geriatric population. They're always like, "I'm ready to die"...And I'm like, "Okay, that's great. We're glad you got it all worked out... But there's no guarantee that you're gonna die tomorrow, so we've gotta make the most of what we have today. And how are you gonna spend your day? And maintaining being healthy along way, as healthy as you can... We don't want wounds on your feet, on your bottom, your heels..." And so those are all things that OTs work with. We work with positioning. We work with feeding... We also work [with] their activities department... We work with them in helping them in coming up with ideas of different things that can be done, to make the most of the time.

By helping patients identify meaningful and realistic goals with, as Odette said, an "OT-eye" over the continuum of decline, the participants skillfully demonstrate the difficult process of goal setting within the dying context to make the most of time and promote quality of life.

Third, participants adjusted focus through external supports such as environmental modification, equipment issue and training, and caregiver training/education. Ida, a certified occupational therapy assistant, recalled how an occupational therapist colleague she worked with, enabled a patient to return to college through environmental modifications:

[Occupational therapist colleague] had one that was a college student...he was in hospice, but he still wanted to go back to school and finish his semester because

he had to come home because he was really sick, but then he was doing a bit better, in remission, and he wanted to go back to college. [Occupational therapist colleague] was able to go back there and help make adaptations to the room, with his roommate, how things were set-up...And he was able to go back to school for a little while until...the cancer progressed, and he end up passing.

Oreta shared how her expertise in adaptive equipment supported her patients' particular needs:

Or, you know, or the UTI [urinary tract infection] thing. "This person is having a lot of UTIs...She is a hemi. OK, let's look into getting a bidet because obviously trying to get a one-handed... something long-handled...to wipe...that's not going to work for her. So we really need to look into maybe getting a bidet." So it's more education on the equipment that we can order, and none of our equipment is cookie cutter.

Onassis explained how she trained caregivers to help keep a patient in their home:

I guess when you, from a caregiver perspective, when you can make their lives, little bit easier by maybe recommending a piece of equipment that they didn't know about or giving them a different idea to set up the environment so that they can provide better care...I really enjoy working with the caregivers so that they feel empowered that they can provide this level of care, especially on the hospice side, you know, in the home, both home health and hospice. I feel I have a strong passion for keeping people in their home.

Participants saw the need to advocate for occupational needs at the end of life. At the intermediate level of adjust focus, decision makers adjusted focus based on their awareness of occupational therapy and how they worded their consults. Occupational therapists adjusted focus by zeroing in on what is meaningful to the patient during assessment and goal setting and drawing on their expertise to adapt the environment for optimal occupational engagement. There were varying levels of awareness in how to adjust focus among decision makers and occupational therapists, possibly affecting a patient's outcomes.

In summary, adjust focus began at the personal level, "I've had both my sister and my mom pass away within 6 months of each other," where participants' losses gave rise to a passionate vision to work in end-of-life care. With such a unique perspective, participants were highly aware of how the local level, "The system really only supports clinical interventions that are focused on fighting disease," failed to meet the needs of the dying. At the intermediate level, "How can we...improve and keep as good a quality of life as possible?" participants drew upon their awareness of occupational therapy to negotiate this gap in health care, support occupational engagement throughout a patient's functional decline, and, consequently, improve quality of life at the end of life.

Place: "It Is the First and Only Place Where I Feel Like I Am Fairly Limitless"

Under the central theme, awareness, and alongside the secondary theme, adjust focus, is place. Place described the context care was provided. At the personal level, "It's to provide...the best service to people at the end of life," captured the participant's guiding workplace mission. At the intermediate level, "We have the ability to borrow

from the home health discipline service line,” underscored how workplace size may affect how participants fulfill their workplace mission. At the local level, “The services that we offer in terms of the team and everything is mandated by Medicare,” spoke of how insurance regulation broadly shapes care based on the context of care. These three levels influenced awareness and occupational therapy utilization.

“It’s to Provide...the Best Service to People at the End of Life”

To understand how place shaped occupational therapists at the personal level, the researcher asked, “What is your workplace mission?” and/or “What mission guides your practice?” Most frequently, participants reported their organization desired to provide “the best service” at the end of life. However, definitions of “best” varied. For Oriana, her team sought to provide comprehensive care, addressing symptom management and psychosocial support with the patient’s desired environment:

And the palliative care team is more about I think, providing access to a safe and honorable death and supporting people to live their life with the best quality of life possible for as long as possible and then supporting them in their family to manage their symptoms, whether it’s in the home or in the community, so that they can die in the place of their choosing, whether that’s supported by family as long as possible or in a hospice setting, or in a hospital setting...

For Osaka, her workplace mission focused on dignity and safety, “I would say the mission of the facility for the people that live there are, you know, to maintain their dignity and their abilities to function in a safe environment.” For community-based occupational therapists, the mission often was to help patients live out their lives safely at

home such as Odessa's workplace mission was, "to help our elders in our community be able to remain living in their community and provide the best quality of life and health care through the end of their life."

Participants' workplace missions often guided their actions and role. All six of the VA Home-Based Primary Care occupational therapists verbalized a mission similar to Omyra, "to help our vets live their lives out safely, in their home." As such, occupational therapy was used to uphold function, safety and quality of life over a continuum of care. Omyra reported working with veterans over a number of years until they die. She linked her workplace mission to her role:

I think it goes back to the same thing that we have a very strong mission of having them stay safely at home...So as OTs, we play a role in the safety part, the fall prevention, the equipment, the caregiver's training for self care if needed...my setting is quality of life all the way through...continuing to end of life. So they may not get better, but we can certainly make...their lives better and the caregiver's life better.

At a personal level the workplace mission was influential, defining the participants' role and services at their workplace.

"We Have the Ability to Borrow From the Home Health Discipline Service Line"

While the workplace mission guided personal actions, the size of the workplace organization at the intermediate level affected funding for occupational therapy.

Participants from smaller hospices reported having very limited resources, while participants from larger organizations comparatively had more financial resources and

staff to draw upon. When asked how he determined what services to provide at his hospice agency, Daniel replied, “I think the bottom line is ...there’s definitely practical considerations of costs and what is reimbursed and what practically our smaller hospice can provide.” He also added, “I think because we’re a smaller hospice, we’re limited in who we can have on staff.” In comparison, a larger organization may have had more financial flexibility. Irita explained her larger company could absorb the cost of a therapist better than a smaller company:

We’re the same company versus those companies where, for example, say at [a home hospice agency name], and they want a therapist, then they’re needing to go and hire a therapist and pay a therapist their per diem, which their hourly contracted rate is \$65–\$75/hour, and then, that’s a large bill because they don’t have a lot of funds, where as we work together within the department, as the whole company.

Donna similarly shared how her home health and hospice organization afforded hospice occupational therapy:

The majority of our occupational therapy is on home health patients instead of hospice patients, and we have the ability to borrow from the home health discipline, service line. And so we can hire, we have the luxury, I guess, of being able to pull...occupational therapy support from, you know, we can have our occupational therapists see a specific hospice patient [without] needing to hire somebody full time.

Although workplace missions guided actions at the personal level, the size of the health care context at the intermediate level affected funding sources and, consequently, utilization of occupational therapy services.

“The Services That We Offer in Terms of the Team and Everything Is Mandated by Medicare”

At the local level, insurance guidelines more broadly influenced what health care services were offered. While it was not within the scope of this study to ascertain the policies and regulation of each participant’s insurance reimbursement system, participants within the private sector often cited Medicare (Center for Medicare and Medicaid Services [CMS]) guidelines setting standards of care and shaping available services. Participants within the public sector, the VA Health Care System offered an example of a more socialized, longitudinal system supportive of end-of-life care. Examples from both the private and public sectors illustrated how insurance affected end-of-life care services.

Private Sector. Medicare guidelines set standards of care. As Danielle, a clinical care director for outpatient hospice care, stated, “Medicare mandates...the services we provide...so we go over and above.” Declan explained, “CMS says, ‘You have to see a hospice patient to meet hospice certification standards, once every two weeks. That would be the 100 level. If you fulfilled that...you’re just meeting certification needs.’” He justified how exemplary his organization is by how it exceeds Medicare standards:

We focus on, not limiting our staffing models and such to what CMS guidelines recommend or mandate. We have staffing ratios that are anywhere from 5 to 10 times more staff per patient load than any one else in the country.

Medicare further shaped what services were offered. Deborah explained, “Physical and occupational therapy are both required...It means that you’re required to have them available, not that you are required to give them.” Yet, under the limited Medicare per diem payment system, many providers were not able to afford occupational therapy. Deanna explained, “So every basic agency get per diem,...so per patient, per daily to cover all that. So, I’m sure that there are many agencies that are unable to financial afford certain ancillary services.”

For other private sector settings, the Medicare capitation structure supported occupational therapy utilization. Working at both an adult-day medical center and in the community, Odessa explained she felt unrestricted by Medicare guidelines.

Well, I’ll be honest with you. It is the first and only place where I feel like I am fairly limitless. I don’t have to account to somebody for, you know, “Oh, how would I bill that service.”...I am, at least for our agency, able to decide what is the best use of my time.

Overall, the participants in the private sector observed that Medicare guidelines affected what services are available, utilized, and funded. Among home hospices, Medicare guidelines set up an opportunity for occupational therapy, but the per diem rate still limited occupational therapy utilization within hospice agencies. However, other

Medicare-certified agencies under a capitation system offered greater use and autonomy for occupational therapy at the end of life.

Public Sector. The VA is a public sector, non-Medicare funded health care provider. Per Dennis, the VA offered a form of “socialized medicine,” that provided longitudinal and comprehensive care:

Because the VA is probably the purest form of socialized medicine in the world, and we’re not billing based on, you know, tests, and we’re not being paid for procedures and things. We are not a fee-for-service model. We’re basically there to provide- the bottom line is providing the care, not generating a profit. So as a result, the care tends to be longitudinal and very patient-centered. And I think it’s more comprehensive.

According to Deanna, the VA, as a secondary insurance, supplemented treatment: The VA is the secondary insurance. So, basically you can have...vets who are on hospice for their cancer, and Medicare is paying for the hospice. But Medicare may say, “We are not going to pay for your chemotherapy or radiation, ‘cuz you are on hospice.” But because they have the VA benefit as a secondary insurance, the VA will actually continue to pay for chemo or radiation.

Occupational therapists who worked at the VA, typically felt the VA supported utilization in end-of-life care. When asked if insurance reimbursement specially affected occupational therapy use, Opal responded, “In my setting, no, because it’s VA. So, as far as I know, that’s not been an issue.” Occupational therapy participants also felt readily able to provide needed equipment to veterans as well. Per Odonna,

So through the VA, I'm very lucky because if I medically can justify it, like Hoyer lift, slings, wheelchairs, splints, commodes, I can order that through a catalog and then I bring it out, provide training, assist with set-up.

The VA appeared to support end-of-life care and utilization of occupational therapy, perhaps providing occupational therapists more opportunities than Medicare-certified home hospice agencies in the private sector.

At the local level, "The services that we offer in terms of the team and everything is mandated by Medicare," insurance highly affected end-of-life care services. Medicare requirements and reimbursement shaped what services were available and likely to be paid for. The VA system offered a more socialized health care system that enabled participants to provide longitudinal care into the end of life. In all, a place's insurance broadly shaped utilization of occupational therapy services at the end of life.

In summary, place described the context of care. The personal level, "It's to provide...the best service to people at the end of life," shed light on the how workplace missions defined workplace roles and guided services. At the intermediate level, "We have the ability to borrow from the home health discipline service line," reflected how larger organizations had more financial resources to support use of occupational therapy. At the local level, "The services that we offer in terms of the team and everything is mandated by Medicare," depicted how insurance reimbursement affected care decisions and actions throughout a health care setting. Together, place shaped care decisions and actions.

The Relationships Between Awareness, Adjust Focus, and Place

Using the paradigm analytic tool, the researcher considered whether the relationship between awareness, adjust focus, and place explained how the utilization of occupational therapy in end-of-care is determined. After establishing the context, the researcher analyzed the themes together under the conditions, action-interaction, and consequences (see Table 11). Analysis of the relationships between the three themes provided a framework of the occupational therapy referral process and direction for deeper analysis.

The context was a person dying from a terminal illness. With disease progression, the person experienced symptom burden, decreased quality of life, and/or functional loss. The decision maker sought to improve quality of life by decreasing symptom burden.

The conditions revolved around awareness. Decision makers considered occupational therapy if they were aware of how occupational therapy's scope of practice addressed a patient's needs. Based on varying levels of awareness of occupational therapy, the decision makers adjusted focus of occupational therapy to address the patient's functional level, specific needs, and goals. Through the lens of place, the decision makers further viewed occupational therapy with respect to the workplace mission, available resources, and insurance reimbursement.

Moving toward the next stage, action-interaction, decision makers made a referral action. Based upon place and awareness, the decision maker prioritized funds for occupational therapy, drew from other resources within the organization, or saved the resources for other services. Depending on these factors, the decision maker either placed

a referral or not. If the decision maker placed a referral, the occupational therapist adjusted focus based on awareness of occupational therapy's role in end-of-life care. Intervention responses included the occupational therapists helping patients meet patient-centered goals through adaptation and modification, deferring services to a more experienced therapist, or providing a traditional rehabilitative approach.

The consequences of these conditions and action-interaction varied. If the decision maker did not place an occupational therapy referral, the patient's occupational needs remained unmet or addressed by another service. If the decision maker placed an occupational therapy referral, the patient possibly had improved occupational engagement and patient/caregiver experiences. With a more rehabilitative approach, the patient may have been unable to meet the expectations of a rehabilitative program due to disease progression. The decision makers potentially conferred with the patient about treatment outcomes, made their own observations about outcomes, and integrated these experiences into their level of awareness for future patients.

By looking at the relationship between awareness, adjust focus, and place, the researcher determined a utilization process and possible outcomes. Awareness remained the central theme with adjust focus and place influencing awareness. Upon completing this axial analysis, the researcher needed to conduct deeper analysis of the various places among the participants to understand how this paradigm changes under different health care contexts.

Table 11*Paradigm of Awareness, Place, and Adjust Focus*

Context (Events, Set of Circumstances, or Conditions)			
A person was dying from a terminal illness. With disease progression, the person experienced symptom burden, decreased quality of life, and/or functional loss. The Decision Maker sought to improve the patient's symptom management.			
Theme	Conditions	Action-Interaction	Consequences
Awareness (Central)	<ul style="list-style-type: none"> Decision Makers had varying levels of awareness using OT to address pain, functional loss, safety, and occupational engagement. Decision Makers had varying levels of understanding of Medicare Hospice Benefit or insurance reimbursement. 	<ul style="list-style-type: none"> OT referral placed to increase QOL, safety, maximize function, and promote occupational engagement. No OT referral placed <ul style="list-style-type: none"> OT not seen as appropriate (rehab only, curative) EOL OT seen as non-reimbursable; patient discharged from hospice to have rehab Prioritized Medicare per diem toward other services. Referred other disciplines to address needs. No OTs was available 	<ul style="list-style-type: none"> OTs helped to improve a patient's symptom management and QOL through increased occupational engagement, positioning, safety, and/or caregiver training. OTs gets repeated referrals. Another service addressed patient's need. Patient's occupational needs remained unmet.

Theme	Conditions	Action-Interaction	Consequences
Place	<ul style="list-style-type: none"> Professionals strived to provide quality care. Workplace mission shaped goals of care. There were limited resources to provide EOL care (e.g. funds, employees, time, insurance reimbursement). 	<ul style="list-style-type: none"> Based on awareness, mission, funds, and/or OT services, Decision Maker prioritized funds/per diem or draws from other resources (e.g. home health OT) for OT services. Saved resources for other services 	<ul style="list-style-type: none"> Decision Maker met patient's occupational needs. Decision Maker did not meet patient's occupational needs.
Adjust Focus	<ul style="list-style-type: none"> Decision Makers had varying levels of understanding of how to adjust rehab focus and refer OT for EOL care. Decision Maker saw OT only as rehabilitative and curative. Decision Maker saw OT for specific services such as for fall prevention, safety awareness, caregiver training, and/or equipment provision. Decision Maker saw OT as a means to increase participation in meaningful and valued occupations. OTs may use environmental modifications and caregiver training. 	<ul style="list-style-type: none"> OTs adjusted focus to help patient identify and meet patient-centered goals at EOL. OTs did not know how to adjust treatment and may defer referral to another therapist. OTs viewed OT for rehab only and discharged patient for lack of rehab potential 	<ul style="list-style-type: none"> Patient received OT services and possibly had increased QOL and occupational engagement at the EOL. Patient was unable to meet expectations of a rehabilitation program due a declining state. Patient discharged with possible unmet occupational needs. Patient did not receive OT services due to lack of OTs able to provide EOL care.

Note. EOL = End-of-life; OT = Occupational Therapy; OTs = Occupational Therapists

Deeper Analysis Across Participants' Places

To gain richer understanding of the observed paradigm, the researcher examined how the paradigm varied across the participants' places by comparing the conditions, actions-interactions, and consequences of each setting (see Table 12). There were 10 identified places among the participants. The conditions were the participants' workplace missions, typifying the prompts for actions-interactions, and information that answered, "why, when, or how come?" Actions-interactions were the participants' responses or observations to their place conditions. Consequences were the outcomes of the occupational therapy referral. Four consequence themes emerged:

- community-based hospice: reliance on awareness
- non-traditional end-of-life settings: autonomous identification of end-of-life needs
- VA inpatient hospice: preventing over-utilization, and
- community-based continuum of care: good fit and strong utilization

Community-Based Hospice: Reliance on Awareness

Community-based hospices included formally defined end-of-life care provided at the patient's home, a residential care facility, or a skilled facility. Participants' workplace mission encompassed providing the best quality of care, managing symptoms, and honoring the life of the patient. Medicare-certified community-based hospice relied on the Medicare Hospice Benefit per diem for funding. Action-interactions involved the decision makers determining whether occupational therapy was a valued service for their patient and worth prioritizing their Medicare Hospice Benefit per diem. Decision-making

was further shaped by the place's financial funding and staff constraints. Consequences were that occupational therapy referral was highly reliant upon the decision maker's awareness of occupational therapy's distinct value to meet end-of-life care needs and inclusion under the Medicare Hospice Benefit. When possible, some community-based hospice agency called upon the VA to supplement occupational therapy services and address equipment needs for their veteran patients, outside of the agency's per diem.

Non-traditional End-of-Life Settings: Autonomous Identification of End-of-life Needs

Non-traditional end-of-life care settings included home health, acute care, oncology rehabilitation, skilled nursing care facilities, and an inpatient mental health setting. Participants' workplace missions included helping patients maintain dignity, function ability and autonomy, recover, adapt and improve to return to a normal lifestyle, and have access to holistic care. The inpatient mental health setting focused on mental health needs, while the other settings provided care under the curative, rehabilitative, and medical model. Within these conditions of care, patients who were at the disease end stages were not necessarily identified as being at the end of life. Occupational therapists were referred to evaluate patients to facilitate placement and provide recommendations for ongoing care. Depending on the setting and number of visits, occupational therapist participants provided occupational therapy interventions, were able to address end-of-life concerns, and/or make referrals for hospice and palliative care. Consequences were that end-of-life care occupational therapy provision was contingent upon whether the occupational therapist was able to autonomously identify end-of-life care needs, educate

providers on utilizing occupational therapy for end-of-life care, and make referrals for hospice and palliative care occupational therapy services.

VA Inpatient Hospice: Preventing Over-Utilization

The VA inpatient hospice setting included an inpatient ward that specifically provided veterans end-of-life care services. Care was fully covered by VA insurance. The participants' workplace mission focused on maintaining dignity, relieving suffering, and promoting quality of life. The occupational therapist was part of the primary care team and automatically referred for all patients upon admission. The actions-intentions were the occupational therapist was consulted to see all patients, including for issues not within occupational therapy's scope of practice. With regards to consequences, because the occupational therapist was part of the primary team and there were no funding constraints, occupational therapy was over utilized and not used effectively for its defined scope of practice.

Community-Based, Continuum-of-Care Settings: Good Fit and Strong Utilization

Community-based, continuum-of-care settings included community-based home health and hospice organizations, VA home-based primary care, and an adult care medical center with community-based services. For conditions, participants' workplace missions included improving a patient's symptom management and quality of life and helping them safely live at home until the end of life. These settings provided longitudinal care over an expanse of years and/or through the stages of palliative care into end-of-life care. Organizations tended to be larger, offering multiple services, in comparison to the smaller community-based hospice agencies. For action-interaction, the

organizations often valued occupational therapy as a means to support a patient's function to remain in the community and pooled funding and staffing resources to afford occupational therapy services (e.g., home health occupational therapist utilized to provide end-of-life care). Occupational therapists readily adjusted focus, by modifying the environment and enabling the patient to participate in meaningful occupation. Consequences were that occupational therapy was well utilized over a continuum of care to support the patient in the community until the end-of-life. Some participants reported working with some patients for 3 to 5 years until the patients' deaths. In comparison to the three other place groups (community-based hospice, non-traditional end-of-life care settings, and VA inpatient hospice), community-based, continuum-of-care settings appeared to have the best fit between the workplace mission and the role of occupational therapy, availing an opportunity for occupational therapist to support occupational engagement at the end of life.

Place highly influenced utilization of occupational therapy services. In community-based hospices, occupational therapy utilization hinged on the decision makers' awareness of occupational therapy and whether the decision maker prioritized use of the Medicare per diem toward occupational therapy services. In non-traditional end-of-life settings, occupational therapy utilization depended upon the occupational therapist autonomously recognizing and advocating for end-of-life care as there were limited external support for end-of-life care within a medical model. In the VA inpatient hospice setting, occupational therapy was valued, funded, and routinely referred, but such conditions facilitated over-referral and inefficient utilization of occupational therapy's

defined scope of practice. In community-based, continuum-of-care settings, the workplace mission of keeping patients as functional as possible in the community aligned best with occupational therapy. Of all the places, occupational therapy was most highly utilized in community-based, continuum-of-care settings. These findings suggest that occupational therapists need to promote awareness of occupational therapy's distinct therapeutic value in end-of-life care, clearly define its scope of practice, train occupational practitioners how to provide end-of-life care in various settings, and take advantage of the opportunity within community-based, continuum-of-care settings to support occupational engagement at the end of life.

Table 12

Deeper Analysis Matrix of Place

Place	Conditions	Actions-Interactions	Consequences
Community-Based Hospice			
Community-Based Hospice	<p>Participants desired to provide</p> <ul style="list-style-type: none"> • “the best quality of care” (Dean) • managing symptoms (Danielle) and • “honoring the life of the patient.” (Danielle). <p>Notes:</p> <ul style="list-style-type: none"> • Formally defined end-of-life care provided in the community 	<p>The team prioritized their per diem toward OT services based on their understanding of the Medicare Hospice Benefit and the role of OT.</p> <p>“Hospice forbids any therapy.” (Dean)</p> <p>“Even the people making the referrals and the agencies, think that the things that they bill for rehab patients have to be the same for hospice patients or they will not get covered. I will tell you that that is not true. Every single one of my visits has been paid for.” (Olympia)</p> <p>Community-based hospice looked to the VA for support.</p> <p>“It’s usually a collaboration [with the VA] because usually private sector OT and PT aren’t allowed to do the hospice unless it’s a hospice that has their own OT and PT.” (Deborah)</p>	<ul style="list-style-type: none"> • EOL care OT referral was dependent upon providers’ understanding of OT’s role and the Medicare Hospice Benefit. • Private-sector community-based hospice used VA resources for OT services.

Place	Conditions	Actions-Interactions	Consequences
	<p>(e.g. the patient's home, resident care facility, or skilled nursing facility). (Deanna)</p> <ul style="list-style-type: none"> Medicare-certified, private-sector community-based hospice received a per diem, per patient. (Deanna) 		
Non-Traditional End-of-Life Care Settings			
Acute Care	<p>Participants desired to</p> <ul style="list-style-type: none"> promote quality of life and (Obassi, Opal) and autonomy (Opal) 	<p>Acute care culture did not recognize the role of OT in EOL care.</p> <p>“The other part would be actually educating other colleagues about the role of occupational therapy in end of life and hospice care, because it is amazing to me the number of times I have heard, especially physical therapists and physicians say, ‘Well, they, they don't need any therapy services, now they're transitioning to hospice.’ Like, hold up. First of all, it's a part of</p>	<ul style="list-style-type: none"> The occupational therapist needed to autonomously identify EOL care, make referrals, and adjust focus.

Place	Conditions	Actions-Interactions	Consequences
	<p>Note:</p> <p>The occupational therapist participants evaluated occupational needs and made recommendations for the next stage of care. (Obassi & Opal),</p>	<p>the Medicare benefit. Second of all, here's all the ways that therapy can be utilized. And then I will list them in hospice care. So I think there's a lot of missed opportunities there.” (Obassi)</p> <p>The acute care environment was not conducive to EOL care.</p> <p>“I don’t think we clearly have the time...So, even the noise level, the amount of activity that goes on, the amount of time you have that you can spend with each person is not, I don’t think it should be for end-of-life.” (Opal)</p> <p>The occupational therapist needed to autonomously identify EOL issues, make referrals, and adjust focus of care.</p> <p>“I wrote it in my note twice because I saw the day before and yesterday, where I’m like, ‘Can we please get a palliative consult?’ And like nothing happens. I’m like, ‘Is anybody listening to what I am recommending?’” (Obassi)</p> <p>“So you kind of have to like, feel it out and figure out how much they understand about their condition...But I mean he was saying all the things, you know, ‘I don’t want to be a burden to my family. I’m ready to go.’ I mean, all these things. I was like, ‘Well, sounds like you bring in the hospice team, so you don’t be a burden on your family and live out the rest of your days, man.’” (Obassi)</p> <p>The acute care team deferred EOL needs to hospice and palliative care.</p> <p>“I think there’s a kind of a deferment to palliative or hospice care to handle the whole thing in a way like I’m not sure they</p>	<ul style="list-style-type: none"> • The acute care team deferred EOL needs to hospice and palliative care.

Place	Conditions	Actions-Interactions	Consequences
		think so much about the individual parts of what all that means.” (Opal)	
Adult Inpatient Mental Health Setting	<p>Participant worked to promote recovery, quality of life, and reintegration into the community. (Octavia)</p> <p>Note:</p> <p>Patients have mental health needs. Some have been at the hospital for 20 to 30 years. (Octavia)</p>	<p>The mental health care team was not be aware of EOL needs.</p> <p>“And I know people don’t associate you know psychiatric illness with end-of-life, but they age and they die and they have cancer and they have heart attacks and they have stroke just like anybody else.” (Octavia)</p> <p>The mental health setting was not fully supportive of EOL care.</p> <p>“So we do have a medical clinic, but I, I feel that the hospital really wasn’t setup for that, and it wasn’t set up for it’s not set up I believe for death and dying as a whole, and that causes me concern.” (Octavia)</p> <p>Occupational therapist brought a more holistic perspective of both physical and mental health needs to the mental health care team.</p> <p>“So I think that the way we interact with patients and find out about them and notice more not only cognitive things but physical things and knowing how the cognitive impairs the physical or how the physical will compromise the cognitive skills, where it’s not just the mental illness. So they see the patient more holistically, and in that way when we do our report, the team has found out things that they didn’t recognize.” (Octavia)</p>	<p>The occupational therapist needed to autonomously identify, address, and educate others on holistic EOL care issues.</p>

Place	Conditions	Actions-Interactions	Consequences
Home Health	<p>Participants sought to</p> <ul style="list-style-type: none"> • help patients “adapt and improve” and • “return to a normal lifestyle.” (Imogene) <p>Notes: The team transferred patients at the end of life to hospice care. (Imogene)</p>	<p>OT referral for EOL care was contingent upon whether the physician and nurse see the need for OT.</p> <p>Janice: “It’s correct to say then that the use of occupational therapy is really contingent upon how much the nurse and the doctor understand... what occupational therapy can do and what the needs of the patient are?”</p> <p>Imogene: “Yeah, I would say that most definitely.”</p> <p>Influencer recommended OT for caregiver training prior to discharge from home health and transition to home hospice.</p> <p>“I recommend also sometimes that the OT... they can train the family before we discharge, and they don’t have our aid coming out anymore.” (Imogene)</p>	<ul style="list-style-type: none"> • EOL care OT referral was dependent upon providers’ understanding of OT’s scope of practice. • The team discharged the patients from home health and transferred them to hospice care to fully meet their EOL care needs.
Oncology Rehabilitation	<p>Participant sought to</p> <ul style="list-style-type: none"> • treat patients holistically and • increase patients’ “access to rehab services...into survivorship or end-of- 	<p>OT referral for EOL care depended on educating providers on OT’s role and the timing of the referral.</p> <p>“...if somebody has a stroke, there’s an immediate, obvious functional change. And so it’s clear to all providers like, ‘Oh, they need they need rehab here.’ But for an oncology patient, the decline is fairly subtle or can be fairly subtle.” (Orchid)</p> <p>“I do a quick family training session with the families so that they know how to safely transfer the patient because they’re just winging it at home. And I like to make the right recommendations for home health therapy and close that loop because the doctor is not doing that. And not, and not because</p>	<ul style="list-style-type: none"> • OT was well utilized within a medical model but not for EOL services. • The occupational therapist needed to be able to autonomously identify and advocate for

Place	Conditions	Actions-Interactions	Consequences
	life.” (Orchid)	they’re bad. They just aren’t looking at those things.” (Orchid) “But in the cancer literature world, you say all this cancer care continuum and a lot of times we go right into survivorship, and we forget that like end-of-life piece that could also pertain.” (Orchid)	EOL care in a timely manner.
Skilled Nursing Facility	<p>Participants sought to</p> <ul style="list-style-type: none"> “help [patients] maintain their dignity and their abilities to function in a safe environment.” (Osaka) <p>Notes: Occupational therapist participant often referred to evaluate and treat patients within a rehabilitative, medical model. (Osaka)</p>	<p>OT was readily referred for evaluation and treatment [rehabilitation] but not for EOL care.</p> <p>“I feel that I can only speak for my, my experiences, that a lot of times the medical team who, you know, they’re responsible for giving us our referrals to evaluate and treat. I think that they write off the abilities of somebody at the end-of-life to do something meaningful. I don’t know that the, that there is complete comprehension of our role in end-of-life care.” (Osaka)</p> <p>The team used rehabilitative OT to obtain Medicare placement for patients who may be better served by hospice services.</p> <p>“And so it’s like, you know, we can’t afford to live in a nursing home, and they need to, you know, quote unquote, buy time or establish a plan. So they often sign up for rehab when, as a therapist, you go and you’re like, ‘Oh, my God, they’re just blinking.’ Like there’s nothing, you know. And it’s not to be disrespectful, but it’s just kind of like, ‘What is it that you want me...’ you know, in that instance that you know that this patient is best served under hospice services for comfort and just end of life care versus trying to provide rehab services whereas rehab services, we have to go in every day.”(Irita)</p>	<ul style="list-style-type: none"> OT was well utilized for evaluation and rehabilitation services. The occupational therapist participant was limited in providing EOL care within a medical model. When the team was Aware of occupational therapy’s scope of practice for end-of-life, the occupational therapist participant was referred and

Place	Conditions	Actions-Interactions	Consequences
		<p>The medical model was not congruent with EOL care.</p> <p>“I’ve been in situations where I’ve seen, you know, physicians just say like there is absolutely no reason for therapy and that mindset of the medical model being curative and rehabilitative. It’s not congruent to what the end-of-life client needs.” (Osaka)</p> <p>Fellow occupational therapists did not know how to work with patients at the EOL.</p> <p>“The feedback has been like, ‘I never learned how to work with somebody that was dying.’ Like a lot of it is like hands off. I think that people get a little nervous about hurting somebody or causing more pain or causing more anxiety.” (Osaka)</p> <p>If providers and influencers understood OT’s scope of practice, they referred and utilized OT.</p> <p>“Sometimes the, whether it’s the nurses, the doctors, whoever it is that’s on that team. If they notice that there’s some kind of decline or if there’s concerns from the family, they’ll kind of mention that in the group setting. And that’s when sometimes, sometimes a nursing will say, ‘OK, we think she might benefit from some OT.’” (Orinda)</p>	utilized.
VA Inpatient Hospice			
VA Inpatient Hospice	Participants sought to <ul style="list-style-type: none"> maintain dignity and 	<p>OT was automatically referred for all EOL care patients. There were no reimbursement constraints.</p> <p>“...every patient that comes to the hospital it’s automatic triggered consult. So whether or not, I think we’re over used</p>	OT was over utilized and not used effectively for its defined scope of practice.

Place	Conditions	Actions-Interactions	Consequences
	<ul style="list-style-type: none"> a “sense of refuge...relieving suffering and promoting quality of life.”(David) <p>Notes:</p> <ul style="list-style-type: none"> Inpatient services were covered by VA insurance. Occupational therapist participant part of the primary team. (David) 	<p>sometimes.” (Ocean)</p> <p>OT referred for non-OT issues.</p> <p>Even if it’s has nothing to do with OT, we’ll get a consult. You know, a patient is tired of pressing the button because nursing didn’t come in, go call, you know, and fell from the bed. We get a consult. (Ocean)</p>	
Community-Based, Continuum-of-Care Settings			
Adult Day Health with Medical Center and Community-Based care	<p>Participants</p> <ul style="list-style-type: none"> helped “our elders in our community be able to remain living in the community 	<p>Occupational therapy was well utilized to support elders’ ongoing occupational engagement in the community over a continuum of care.</p> <p>“Our participants on average live about three to five years post-enrollment. And the idea is for them to be in our program until they pass away.”(Odessa)</p> <p>“And a lot of times that almost comes together with the comfort thing. My comfort almost goes into how to show your love, how</p>	<ul style="list-style-type: none"> Occupational therapy was aligned with workplace mission and was well utilized to support occupational engagement in

Place	Conditions	Actions-Interactions	Consequences
	<p>and</p> <ul style="list-style-type: none"> provided the best quality of life and health care through the end of their life.” (Odessa) 	<p>to try to provide care with as much comfort and love as possible and allowing the participant to also be involved in meaningful activities with them.” (Odessa)</p> <p>Reimbursement was based on the Medicare capitated system, allowing OT to make autonomous decisions.</p> <p>“Well, I’ll be honest with you, it is the first and only place where I feel like I am fairly limitless. I don’t have to account to somebody for, you know, “Oh, how would I bill that service.” I’m not trying to, you know, up charge productivity. I am, at least for our agency, able to decide what is the best use of my time.” (Odessa)</p>	<p>the community, over a continuum of care.</p>
Community-Based Hospice and Palliative Care	<p>Participants sought to</p> <ul style="list-style-type: none"> “improve symptom management” (Donna), “improve quality of life...by supporting them to find meaning...e mpower them to make decisions.” (Donatello) 	<p>OT referral for EOL care was contingent upon the provider’s level of understanding of the Medicare Hospice Benefit, OT’s scope of practice, and available funding resources from across the company.</p> <p>“...we found it hard as palliative providers to make an OT referral that would be reimbursed as opposed to if that OT referral came from primary care.” (Declan)</p> <p>“We’re the same company versus those companies where, for example, say at (a home hospice agency name), and they want a therapist, then they’re meeting to go and hire a therapist and pay a therapist their per diem, which their hourly contracted rate is \$65–\$75/hour, and then, that’s a large bill because they don’t have a lot of funds, where as we work together within the department, as the whole company.” (Irita)</p> <p>“We have the ability to doing home health, you know, the majority of our occupational therapy is on home health patients</p>	<ul style="list-style-type: none"> EOL care OT referral was dependent upon the providers’ understanding of OT’s scope of practice, the Medicare Hospice Benefit, and available funding sources. Providers used their per diem or drew from home health or other company

Place	Conditions	Actions-Interactions	Consequences
	Notes: Organizations were larger than community-based hospice and able to pool resources from different parts of the company. (Donna & Irita),	instead of hospice patients, and we have the ability to borrow from the home health discipline, service line.” (Donna) Treatment visits were closely monitored. “Our utilization is certainly monitored by staff that are in the office and might want to know more frequently than your weekly check in, you know, what’s the, what’s the plan here? You’ve seen this person for seven visits. Why are you, why are you still involved?” (Onassis)	resources. <ul style="list-style-type: none">Economic resources were closely monitored.
VAHBPC	Participants sought to “help our vets live their life out safely in their home.” (Omyra) Note: Participants saw veteran patients over a number of years prior to the veteran patients dying. (Obed, Oliveta, Omyra, Oreta, & Owen)	Occupational therapists were well utilized to support veterans’ occupational engagement in the community. “I think it goes back to the same thing that we have a very strong mission of having them stay safely at home. And it, so as OTs, we play a role in the safety part, the fall prevention, the equipment, the caregiver’s training for self care if needed.” (Omyra) “But our job is to try to go in and support the person aging, remaining in their home for as long as possible. So it’s a lot different than just traditional home health where they come in after a fall or a hospitalization, and they do more intensive services and then discharge. We’re always-when they’re in our program, they’re part of our care until the end of life time as long as they’re living at home.” (Obed) “...because I see occupational therapy as central to function, a, functionality, patients’ ability to, to perform the tasks of their every day. And in patients whose whole, you now, raison d’être per being in HBPC is that they have functional impairment and	<ul style="list-style-type: none">Occupational therapists were well utilized as part of palliative care and then segues into EOL care.The occupational therapist had the autonomy to see veterans and contract for services.

Place	Conditions	Actions-Interactions	Consequences
		<p>can't get to the clinic for most of them. Then OT is central to that. So, you know, whether that function is out about or just in the home." (Dennis)</p> <p>The occupational therapists had the autonomy to see veterans without a referral and contract services over a continuum of care.</p> <p>"So there are, we do not traditionally do treatment per say. We go in there and do an initial evaluation. If they need equipment or if we see an immediate need, we will provide that for them. If they need more treatment, if we notice in low endurance, if we're noticing that they need more assistance with ADL training or ther-ex then we will contract in an agency that comes to two times a week three times a week, but it's short term versus our program follows them literally until they go onto the nursing home where they pass away." (Oreta)</p>	

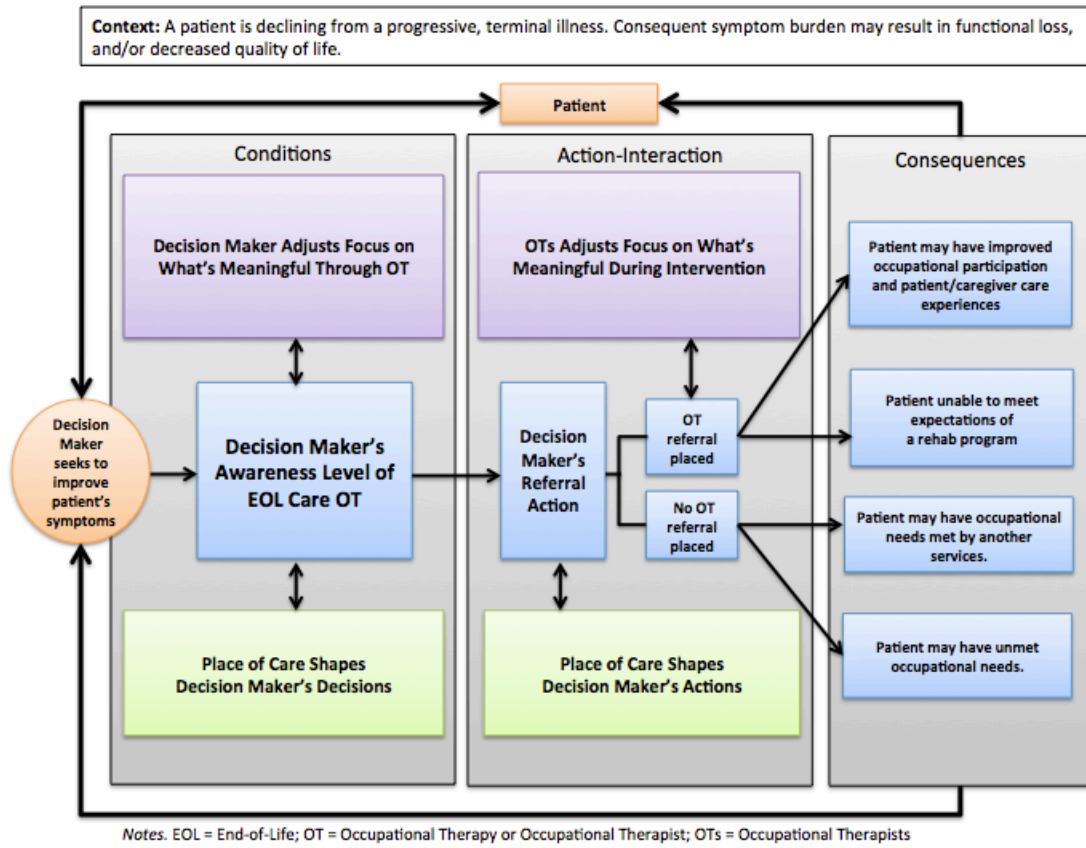
Note. EOL = End of Life; SNF = Skilled Nursing Facility; VAHBPC = Veterans Affairs Home-based Primary Care

A Model of Occupational Therapy Utilization in End-of-Life Care

Drawing upon open and axial coding of participants' experiences and deeper analysis across participants' place, the researcher developed the "Model of Occupational Therapy Utilization in End-of-Life Care" (see Figure 2). The starting point is the patient at the top of the model. In response to the patient's needs at the end-of-life care, the decision maker seeks to improve symptom management. The decision makers' use of occupational therapy is contingent upon their awareness of occupational therapy services at the end-of-life. Awareness is influenced by conditions of place and the decision maker's ability to adjust focus of occupational therapy services to meet the patient's needs. Based on awareness, adjust focus, and place, the decision maker decides whether to refer occupational therapy services. If the decision maker does not refer occupational therapy, predicted outcomes are that the patient's occupational needs will not be met or another service will address the needs. If the decision maker does refer occupational therapy, predicted outcomes are based upon the occupational therapist ability to adjust focus. The greater ability of the occupational therapist to adjust focus, the likelihood the patient will experience increased occupational engagement and satisfaction. The lesser ability to adjust focus, the likelihood the occupational therapist will defer the consult or provide a more traditional rehabilitative approach. In the context of progressive disease, the patient may not be able to meet expectations of a rehabilitation program. Consequences of this process filter into a feedback loop between the patient and decision maker, feed the decision makers' awareness of occupational therapy and influence future decisions whether to utilize occupational therapy in the future.

Figure 2

Model of Occupational Therapy Utilization in End-of-Life Care



Key Informant Feedback on the Model

Seven key informants provided feedback on the model. The researcher debriefed all comments with her PhD mentor. Four key informants felt the model generally reflected their experiences. Owen wrote, “[The model] captures attitudes, settings, patients goals, provider awareness, and accounts for many other factors that do need to be addressed. I could not see any way to distill that down any further than you have.” Omyra said, “[The model] looks comprehensive and well laid out. It reflect[s] my experience.” Donatello felt the model “reflects how we conceptualize our workflow,” but added wording suggestions such as including the patient is “declining” instead of dying in the context, “educate” to the phrase “train caregivers,” and “improve patient/caregiver care experience” to the consequence—“client may have improved occupational engagement and quality of life.” The researcher felt these comments reflected the data and integrated the feedback into the model. Davina stated, “Overall I thought [the model] quite concise and appropriate!” However, she had hoped that the researcher had added more on “the existential benefits that [occupational therapy] can offer to palliative care.” The researcher did not add this to the model, as the existential benefits of occupational therapy were not reflective of the collective experience of the participants.

Three key informants posed thought-provoking remarks about the model. Olympia noted, “What I do not see represented is the patient’s own awareness of the role of OT which can also lead to a decline of services.” She acknowledged though that “this may be directly tied to the decision maker’s awareness of OT’s role and ability to educate the patient on the benefits of OT, so it is represented in that sense.” The researcher did

not integrate this feedback into the model, as the study did not investigate the patient's experience. Second, Osaka suggested adding to consequences, "no change" or "increased experiences of physical and/or mental symptoms of progressive terminal illness." The researcher did not add these suggestions, as "no change" was inferred in "patient may (or may not) experience occupational engagement" and the progression of terminal illness is not an outcome of occupational therapy. However, Osaka's comments underscore that the researcher did not ask participants about their negative outcomes with occupational therapy. Third, Obassi expressed confusion over the use of "rehab" in the model, as "rehab" is "trying to fix the problem, whereas in an [end-of-life] case I would shift lenses to a palliative approach." The researcher acknowledged Obassi's comment and explained that the use of "rehab" was reflective of the data and the lack of awareness over occupational therapy's role in end-of-life care.

Summary

Based on the grounded theory analysis of 41 participants' experiences of the utilization of occupational therapy in end-of-life care, the researcher identified three themes—awareness of occupational therapy's role in end-of-life care, adjusting focus on what is important to the patient, and place of health care. Juxtaposing the themes across the participants' place, the researcher developed a model of occupational therapy utilization in end-of-life care. Awareness was the central theme while adjust focus and place influenced awareness and the decision maker's action to refer occupational therapy or not. Outcomes were highly influenced by the occupational therapist's ability to adjust focus of occupational therapy interventions to meet the patient's needs. Consequences of

the decision maker's referral action varied from the patient's occupational needs not being met to the patient experiencing improved occupational engagement. Consequences looped back to the decision maker and affected future occupational therapy utilization.

CHAPTER V

DISCUSSION

The central research question of this grounded theory study asked, “How is the utilization of end-of-life care occupational therapy services determined?” Study results yield answers and reflection points. In review of the first two research aims, findings indicate decision makers’ limited awareness of occupational therapy’s role in end-of-life care highly affected occupational therapy utilization, yet occupational therapists were able to address their patients’ occupational needs through their own occupational adaptation. For the third research aim, the developed model visually maps possible entry points to increase occupational therapy’s influence and create opportunities to share occupational therapy’s distinct value in end-of-life care. Looking further through the lens of the MOHO, this study underscores the MOHO as a model of practice for occupational participation at intermediate and local levels. Limitations are described. Implications for research, education, and advocacy are presented to consider how we may further occupational therapy in end-of-life care.

Research Aim 1: The Decision Maker’s Process

Decision makers determined utilization of occupational therapy based on their level of awareness of occupational therapy. Congruent with the literature, decision makers who saw occupational therapy as curative or rehabilitative and, consequently, not appropriate for end-of-life care, typically did not refer occupational therapy services (Knecht-Sabre et al., 2018). When decision makers had limited awareness of

occupational therapy, they referred occupational therapy for specific tasks such as fall prevention, caregiver training, or equipment issue (Eva & Morgan, 2018; Keesing & Rosenwax, 2011; Knecht-Sabre et al. 2018).

An aspect of decision makers' awareness was the ability to adjust focus of the occupational therapy referral. When decision makers, such as Donatello and Donna, were more aware of possible and meaningful outcomes with occupational therapy and knew how to adjust focus of the occupational therapy referral to meet the client's specific occupational needs, there was increased utilization and financial allotment for occupational therapy services as speculated by Halkett et al. (2010). Adjusting focus of occupational therapy services aligns with palliative rehabilitation which utilizes rehabilitative services to maximize independence in self care and functional mobility in support of the patient's values and goals at the end of life (Barawid et al., 2015; Montagnini et al., 2020; Padgett et al., 2018). However, decision makers varied their approach from palliative rehabilitation, as palliative rehabilitation is performance-related and "function-directed care" (Padgett et al., 2018, p. 221) while the decision makers focused away from performance outcomes and more on meaningful participation through use of environmental supports (e.g., equipment or caregiver assistance) even in the last days of life. Given people at the end of life find "continuing occupational participation" most important at the end of life (von Post & Wagman, 2019, p. 1), the present findings suggest occupational therapists need to educate decision makers on how to adjust focus of occupational therapy to promote occupational participation in alignment with the priorities of terminally ill patients.

Second, the place of care influenced use of occupational therapy. Here, the word, “place,” alludes to health geography, a subdiscipline of human geography that “views health from a holistic perspective encompassing society and space...[conceptualizing] the role of place, location, and geography in health, well-being, and disease” (Dummer, 2008, p. 1177). As Giesbrecht et al. (2018) noted in an ethnographic study of place-based experiences of formal health care settings at the end of life, there are disparities in end-of-life care by how “programs, policies, and healthcare spaces and places have been designed, which target and cater to particular populations groups” (p. 44). In this study, place affected available occupational therapy services. Depending on place, decision makers had different role expectations of occupational therapists as to what services they provided. Congruent with Eva and Morgan’s (2018) findings, occupational therapists in acute care typically facilitated discharge planning. Community-based occupational therapists were often referred for equipment issue, caregiver training, and safety awareness.

Place also influenced service funding. Congruent with the literature, many decision makers at smaller hospice agencies felt that there were insufficient funds to pay for occupational therapy services with the Medicare Hospice Benefit per diem (Henry, 2020). In contrast, some decision makers at continuum care settings, such as a combined home health and hospice agency, pulled from their home health staff to afford occasional use of a hospice occupational therapist. The variance in funding per place underscored Keesing and Rosenwax’s (2013) assertions that occupational therapists “need to

demonstrate the value of their services from a cost/benefit view point” across a variety of care environments in order to promote utilization (p. 372).

Decision makers’ awareness of occupational therapy determined occupational therapy utilization in end-of-life care. Awareness was further shaped by the ability to adjust focus of the occupational therapy referral to support occupational participation. The expectations and financial demands of place highly influenced the availability of occupational therapy services. In order to increase utilization, study findings suggest the occupational therapy profession needs to educate decision makers on the scope of occupational therapy in end-of-life care and how to adjust focus of services to support occupational participation, rather than performance, as the patient continues through the various stages of the dying process. Greater awareness may increase understanding of occupational therapy’s value across a variety of settings and consequently broaden the range of occupational therapy’s services and increase funding allocation (Halkett et al., 2010; Keesing & Rosenwax, 2011).

Research Aim 2: Interaction of Occupational Therapist and Decision Maker

Research Aim 2 addressed how the interaction of the occupational therapists and the decision makers affected service utilization. As the study progressed, findings not only identified the occupational therapists’ interaction with the decision maker but also with place. Regarding decision makers, the occupational therapists developed an occupational adaptive response to still provide end-of-life care and support occupational participation despite limited external support and awareness from decision makers.

Regarding place, occupational therapists' alignment of the place with occupational therapy's scope of practice greatly influenced service utilization.

Development of an Occupational Adaptive Response

Occupational therapists met the demands of their place and the occupational needs of their patients through occupational adaptation. From the perspective of the MOHO, occupational adaptation is having the occupational competence to sustain an occupational identity while negotiating the changing demands of the environment over time (Bowyer, 2019; de las Heras de Pablo et al., 2017). Occupational therapists in this study expressed an occupational identity as an agent of occupational participation for their patients. For community-based participants, there was a particular occupational identity, as Omyra stated, to help patients "live their lives out safely in their home." Occupational therapists demonstrated occupational competence, maintaining this occupational identity by using their performance skills to accommodate the changing demands of their patients' functional decline through the dying process.

The components of the occupational therapists' adaptive response are broken down here through the lens of the MOHO. For volition, personal experiences may shape what one finds important and feels effective doing (Lee & Kielhofner, 2017b).

Occupational therapists often cited the death of a loved one as grounding for their end-of-life care work and realized their self-efficacy to provide effective occupational therapy by witnessing positive outcomes with their patients. For habituation, the occupational therapists' role was to provide occupational therapy services. As mentioned under Research Aim 1, study findings found that place often shaped role expectations of the

occupational therapists (e.g., acute care therapists facilitated discharge planning). Within the role of occupational therapist, participants used clinical skills, or performance skills, consistent with the literature to treat dying patients, such as

- finding what is important to the patient at the end of life (AOTA, 2016),
- providing patient-centered interventions (Hammill et al. 2014; Mills & Payne, 2015),
- integrating environmental modifications (e.g., equipment, caregiver education) to provide external supports for ongoing occupational participation (Yeh & McColl, 2019),
- focusing on occupational participation instead of occupational performance, to accommodate the patient's loss of function (Ashworth, 2014; Chow & Pickens, 2020), and
- evolving goals as the patient functionally declines (Hammill et al., 2014).

Occupational participation results in occupational adaptation (de las Heras de Pablo et al., 2017). Occupational therapists upheld their occupational identity as agents of occupational participation by facilitating occupational adaptation in their patients. Walder and Molineux (2017) noted people with chronic illness, major illness, or injury fostered occupational adaptation after turmoil and loss through developing competence, finding motivation, and becoming confident in occupations. In this study, occupational therapists described helping people develop competence, as Ocean said, "being able to...do something," becoming confident, as Oliveta added, "helping the patients meet their goals," and finding motivation, as Olympia stated, by still experiencing joy. These

findings reflect previous studies of occupational therapists in end-of-life care who supported end-of-life occupational participation by enabling the patient to identify meaningful goals, providing them choices, and prioritizing activities with the patient through the dying process (Pizzi, 2015; Tavemark et al., 2019). Occupational therapy provided a means to not only cope but also adapt to the dying process through sustained occupational engagement.

Alignment with Place

The alignment between place and occupational therapy's scope of practice also affected utilization. Deeper analysis of place indicated the greater the alignment, the greater the utilization of occupational therapy. In comparison of the various places, occupational therapists working in community-based settings were the most utilized, as the workplace mission of enabling patients to remain at home aligned well with occupational therapy's mission to enable occupational participation. This alignment supports Mills and Payne's (2015) speculation that occupational therapy could be integral with enabling people to remain at home until the end of life. In contrast, occupational therapists in non-traditional end-of-life care settings were the least referred for end-of-life care, as the curative, medical model did not support holistic, end-of-life care.

Occupational therapists needed to independently identify, provide end-of-life care interventions, and/or refer for hospice and palliative care services. The relationship between alignment with place and utilization underscores the importance of fit between occupational therapy's scope of practice and the environment to maximize occupational therapists' efficacy to support participation (Fisher et al., 2017). This study identifies a

strategy to increase service utilization—developing occupational therapy end-of-life care in areas that fit occupational therapy’s strengths such as places with awareness of occupational therapy’s scope of practice to support occupational participation, a larger organization that can sustain a range of services, and a workplace mission to support aging in place over a continuum of time and into the end of life.

In summary, there remains a gap between the occupational therapists’ positive experiences enabling end-of-life occupational engagement and decision makers’ awareness in the referral process. Although the role of occupational therapy is not well understood in end-of-life care, occupational therapists appeared to still facilitate occupational participation through occupational adaptation in themselves and in their patients. Occupational therapists seemed to have a volitional compass that drove them to support occupational engagement at the end of life with clinical skills that accommodated their patients’ changing needs as they functionally declined. Further work is needed to close the gap in occupational therapy utilization by promoting greater awareness of occupational therapy’s unique value to facilitate occupational adaptation to cope with the dying process. One strategy may be to concentrate efforts where occupational therapy best aligns with place—community-based, continuum-of-care models of care.

Research Aim 3: Development of a Model

The third research aim was to develop a theory to comprehensively describe the utilization process and enhance understanding. A model is presented and must first be tested in order to further develop a theory. The model of occupational therapy utilization in end-of-life care offers a visual map of the occupational therapy utilization process.

From this vantage point, we can see possible entry points into the occupational therapy utilization process through the patient, decision maker, and the occupational therapist. Reflection on the developed model and review of the literature offer direction to increase occupational therapy utilization in end-of-life care.

The context of this phenomenon was the patient functionally declining due to a progressive terminal illness. Maintenance of functional ability underscores wellbeing, being able to “meet basic needs, learn, grow, and make decisions, be mobile, build and maintain relationships, and contribute to society” (D’cruz & Banerjee, 2020, p. 5). Functional loss in the context of life-limiting disease may result in dependency on others, withdraw, and social isolation (Hellerstedt-Börjesson et al., 2016). In a literature review of existential suffering in the palliative care setting, Boston et al. (2011) noted loss of social role functioning may lead to existential suffering or distress. From a survey of people who request physician aid in dying, two of the top five reasons to terminate one’s life were loss of independence and inability to care for one’s self (Ganzini et al., 2009). There is existential suffering in functional loss.

As seen in these participants, decision makers desired to ease patients’ suffering. In the model, there are bilateral arrows, indicating the collaboration between the patient and decision maker. The literature and study interviews suggest decision makers acknowledge functional loss may cause suffering but may not be fully aware of its existential ramifications. In a study of what general practitioners define as unbearable suffering, there was variance whether physicians considered irreversible functional loss in the absence of pain, as unbearable suffering (van Tol et al., 2010). In their systematic

review of psychometric properties of suffering measurement instruments in palliative care, Gutiérrez-Sánchez et al. (2020) identified six assessments, but only one measured the impact of functional loss on suffering. There remains a gap between the decision maker understanding the impact of functional loss and more holistically addressing a patient's suffering.

In the model, occupational therapists are not involved in the occupational therapy utilization process until service referral. Their entry point of influence is contributing to patients' outcomes and shaping the decision makers' level of awareness. To increase referrals specifically for occupational therapy services, the occupational therapist needs to demonstrate how occupational therapy decreases existential suffering and provides comfort by enabling participation in personally identifying occupational roles.

Occupational therapists can address critical needs and priorities of terminally ill patients. Lowe et al. (2020) found advanced cancer patients prioritized upholding their social responsibilities, or roles, even the minimal levels, to maintain a sense of purpose, contribution, accomplishment, identity, and locus of control. From their scoping review of what is important to patients with a life-limiting illness, von Post and Wagman (2019) similarly found patients desired to maintain previous occupational patterns, feel needed, be involved in their social environment, leave a legacy, and live as fully as possible. Occupational therapists can play a distinct role in end-of-life care by promoting wellness through occupational participation at the end of life (AOTA, 2016, 2020).

Fisher (2013) asserts that to establish a unique identity, occupational therapists need to be consistently occupation-centered to impart, "the core importance of

occupation- meaningful doing” (p. 164). Assessments and interventions must be occupation-based to distinguish occupational therapy from other interdisciplinary team members (Fisher, 2013). Goals are to be patient-centered and occupation-focused (AOTA, 2016; Forsyth, 2017), measuring outcomes in occupational participation rather than occupational performance (Ashworth, 2014; Chow & Pickens, 2020).

Participation is “involvement in a life situation” (World Health Organization [WHO], 2001, p. 14) and may include “observing an occupation, engaging in partial or adapted performance, or directing others’ performance” (Koenig, 2014 as cited in Chow & Pickens, 2020, p. 5). Occupational therapists have been found to support occupational participation by building a rapport with the patient to identify what their wishes are, guiding goal setting based on available supports and abilities, prioritizing activities together, and making adaptations or accommodations to allow for ongoing engagement (Tavemark et al., 2019). Patients may continue to participate in valued roles by varying their routine such as doing only part of a housekeeping task and asking for assistance with the remaining tasks (de la Heras de Pablo et al., 2017). When patients are unable to satisfactorily participate, they may benefit from exploring and trying new occupations in a safe environment with the occupational therapist (Lyons et al., 2002).

Outside of the model, occupational therapists may need to market services and provide education on the benefits of occupational therapy to address the gap between the decision maker’s awareness and the patient’s occupational needs. The literature suggests occupational therapists may be more effective facilitating change by focusing on decision makers’ attitudes, motivation, and readiness as well as practical logistics. Within the

palliative care literature, Kam et al. (2010) investigated oncology providers' referral process for psychosocial support and found providers are less likely to refer for psychosocial services due to negative attitudes toward discussing support needs. Letizia and Jones (2012) found nurse practitioners were more receptive to palliative care training when instructors were sensitive to a nurse practitioner's level of motivation and readiness to accept new information. When considering an education program to promote occupational therapy, occupational therapists may need to consider what attitudes decision makers have that limit referral (e.g., not seeing occupational therapy as a means to decrease suffering), identify key motivating factors for their target providers (e.g. greater quality of life through being able to participate in daily life), and note the provider's readiness to accept new information. After connecting with decision makers and establishing the value of occupational therapy in end-of-life care, the occupational therapist needs to set-up a clear logistical path for referral. Based on the findings from their survey and focus group of referring providers, Phipps and Cooper (2014) suggested clarifying the referral process, establishing a clear communication channel (e.g., regular meetings or accessibility through phone or email), and providing an information packet on the range of interventions occupational therapy offers with illustrative case studies.

The model of occupational therapy utilization in end-of-life care offers a visual overview of the utilization of occupational therapy in end-of-life care. Surveying the developed model and drawing strategies from the literature, occupational therapists may more effectively promote occupational therapy by conveying to providers how functional loss may contribute to suffering, show how occupational therapy may reduce this

suffering through enabling occupational participation, address barriers to the referral process, and offer occupation-based interventions to distinguish occupational therapy's unique value in end-of-life care. Further testing of the model, however, is required to verify the validity of constructs to predict the phenomenon.

Reflection on the Results and the MOHO

The WHO included the concept of participation in the International Classification of Functioning, Disability, and Health (ICF) to increase understanding of people living with disabilities (Larsson-Lund & Nyman, 2017; WHO, 2001). In an exploration of occupation-based models and the relationship between participation and occupation, Larson-Lund and Nyman (2017) found the MOHO used the term “occupational participation” consistently with the ICF definition of participation but questioned whether the MOHO supports occupational therapy practice and research beyond the personal level. The MOHO has been used at the immediate level such as to provide a theoretical framework for recovery with schizophrenia with community-dwelling adults (Tan et al., 2020) and to promote positive long-term impact on therapeutic reasoning among occupational therapists in cancer rehabilitation (Bowyer et al., 2019). In the “Results and Research Aims” section, it was also established through the MOHO how occupational therapists enabled occupational participation in their patients at the immediate context. There remains a paucity of evidence of use of the MOHO at the local level. The following attempts to address Larson-Lund and Nyman's (2017) question of whether the MOHO frames occupational participation at the local level by establishing how the

MOHO framed occupational therapists' occupational participation within their health care systems.

For this study, the occupational therapists were within the local level of their health care system. Decision makers' responses to interview questions, based on components of the MOHO, built an aggregate picture of the health care system. Each decision maker was an occupational being encompassing volition (e.g., workplace mission, attitudes, and values), habituation (job roles), and performance (job duties and skills) components within an environmental context (social, regulatory, and financial demands), and embedded in the social environment of the health care system. Decision makers depicted the health care system dominated by the medical model as in Irita's commentary, "Rehab is to get better, hospice is to die" or heavily shaped by the insurance reimbursement system as reflected in Danielle's words, "everything is mandated by Medicare."

Within this local level, occupational therapists negotiated the complexities of their health care system, dealing with a limited number of occupational therapists trained in end-of-life care, securing reimbursement for occupational therapy services, or advocating for end-of-life care occupational therapy services where occupational therapy in non-end-of-life care settings. Participation in occupational roles are good indicators of a person's involvement in society, as roles encapsulate how we self-identify ourselves in society and the societal expectations of our behavior (Haglund et al. 2017). If one is able to uphold an occupational role or identity, they are able to successfully perform the actions required to fulfill the role (de las Heras de Pablo et al., 2017). All occupational therapists were

observed developing an occupational adaptive response at the intermediate level and still providing some level of occupational therapy with patients at the end of life. However, participants' level of success fulfilling occupational roles and providing occupational therapy services at the local level varied by place.

Addressing Larson-Lund and Nyman's (2017) inquiry of whether the MOHO addresses occupational participation at the local level, this study illustrates that the MOHO provides a theoretical framework to help organize the participants' responses and experiences, establish an aggregate view of health care at the local level, and capture occupational participation within this context. Through the MOHO, we can see the complexity and size of the local level and the occupational therapists' level of occupational participation. Further research using the MOHO may help determine ways to change attitudes and policies at the local level, influence health care, and possibly increase utilization of occupational therapy.

Limitations

This study had the following limitations. There were a small number of influencers to represent a broader interdisciplinary team perspective. The researcher speculates that many interdisciplinary team members did not realize their level of influence during team meetings or through their documentation to make recommendations for service referrals, especially when they do not readily use occupational therapy services. Second, the study only included occupational therapists who provided some level of end-of-life care occupational therapy services, shifting the occupational therapy perspective toward more successful occupational therapy service

utilization. When asking occupational therapists about their roles, the researcher also did not inquire about negative outcomes to provide a more balanced view of clinical outcomes. Third, only two pairs of participants worked together (Dennis and Omyra; Irita and Orinda), capturing the shared complexity of two care locations; consequently, the study did not include different perspectives of the same phenomenon experienced by each participant, across the various settings.

Implications

Results from this study have the following implications for research, occupational therapy education, and advocacy. Future research may expand understanding of the occupational therapy utilization in end-of-life care by

- testing developed model constructs (e.g., investigating if modification of awareness, place, or adjust focus increases occupational therapy referral),
- conducting a hermeneutic circle of occupational therapy utilization of one interdisciplinary team to gain multiple perspectives of the same phenomenon,
- probing for the negative outcomes of occupational therapy to get a more balanced view of occupational therapy in end-of-life care,
- incorporating the patient and family's perspectives,
- exploring how occupational therapy's alignment with place affects utilization to develop strategies to promote utilization and inform occupational therapy education, and

- investigating the efficacy of occupational therapy to alleviate existential suffering through occupational participation.

Occupational therapy education may be enriched by

- providing an occupation-centered curriculum (Fisher, 2013; Hooper et al., 2020) that integrates understanding of the physiological and psychosocial needs during the dying process (Chow, 2018) and is applicable across multiple care settings,
- focusing on occupational participation to achieve person-centered outcomes, rather than performance, in the context of decline (Ashworth, 2014; Chow & Pickens, 2020), and
- establishing an occupational therapy board certification to solidify occupation-based in end-of-life care.

Advocacy for occupational therapy in end-of-life care may be furthered by

- educating providers on the coverage of occupational therapy services under the Medicare Hospice Benefit,
- lobbying lawmakers for a separate Medicare Hospice Benefit per diem for occupational therapy services,
- presenting on the role of occupational therapy in end-of-life care at multi-disciplinary conferences,
- publishing research and opinion papers in journals outside of the occupational therapy profession (e.g., palliative care, gerontology, amyotrophic lateral sclerosis, or oncology journals), and

- forming a registry of available end-of-life care occupational therapists.

Conclusion

This grounded theory study investigated how the utilization of occupational therapy in end-of-life care is determined, through the lens of the MOHO. A developed model suggests utilization of occupational therapy services is contingent upon the decision maker's awareness of the role of occupational therapy in end-of-life care and influenced by place of care demands and the decision maker's ability to adjust focus of the occupational therapy referral to accommodate the patient's goals and dying process. This study also provided an example of occupational participation of the occupational therapists themselves providing intervention in end-of-life care at the intermediate level and interfacing with their health care system at the local level. There remains a gap between decision makers' awareness and utilization of occupational therapy to support the occupational needs of people living with life-limiting illness. Further research, occupational therapy educational reforms, and advocacy are warranted to increase greater occupational therapy utilization and support meaningful occupational engagement at the end of life.

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APPENDIX A

Interview Question Matrix for Hospice Care Decision Makers

Research Question	Interview Questions for Hospice Care Decision Makers	Question Type	MOHO Elements		Analysis Category		Question Evaluation
How do hospice care decision makers determine which services to offer?	Where do you work? • Describe your workplace. • What community does (workplace) serve? (Who are your clients?) • What is the workplace mission?	Background Demographic	Environment		Context		
	What is your role? • What are your job duties?	Knowledge	Habituation		Context		
	What types of decisions do you make regarding hospice care services?	Behavior	Performance		Context		
	How do you determine what services to offer?	Behavior	Vol	Perf	Conditions		
	What makes a service valuable?	Opinion	Volition		Actions-interactions		
What are the demands and expectations of hospice care service decision-making?	Does (workplace)'s mission influence how you decide what service to use? If so, how?	Opinion	Vol	Envi	Context		
	Regarding hospice care service decision-making, what outcomes tell you that you: • did a good job? • need to make changes?	Opinion	Vol	Envi	Context	Actions-interactions	
	If you had to eliminate services, how would you determine which to keep and which to cut?	Behavior	Vol	Perf	Conditions		
How do hospice care	Have you worked with an occupational therapist before?	Knowledge	Environment		Context		

Research Question	Interview Questions for Hospice Care Decision Makers	Question Type	MOHO Elements		Analysis Category			Question Evaluation
decision makers view hospice occupational therapy?	<ul style="list-style-type: none"> If so, what area of care did you work with the occupational therapist? How would you describe what occupational therapists do? 							
	Do you have an occupational therapist on your current hospice team? <ul style="list-style-type: none"> If so, what services does your occupational therapist provide? If not, why has (workplace) chosen not to use occupational therapy services? 	Knowledge	Environment		Context	Conditions		
	If you had to eliminate services, would you cut occupational therapy services? <ul style="list-style-type: none"> If so, why? If not, why not? What would make occupational therapy a valued service worth saving? 	Opinion	Volition		Conditions	Consequences		
How does the interaction of hospice care decision	(Ask if workplace has OT) How has having an occupational therapist on your	Opinion	Vol	Environment	Context	Action-interaction	Consequences	

Research Question	Interview Questions for Hospice Care Decision Makers	Question Type	MOHO Elements		Analysis Category			Question Evaluation
makers with occupational therapy influence what hospice services are provided?	team affected the services provided by (workplace)?							
What are the barriers and facilitators of occupational therapy utilization?	In your opinion, what are the barriers to using occupational therapy in hospice care?	Opinion	Environment		Context			
	In your opinion, what facilitates use of occupational therapy?	Opinion	Environment		Context			

APPENDIX B

Interview Question Matrix for Hospice Occupational Therapists

Research Question	Interview Questions for Hospice Occupational Therapists	Question Type		MOHO Elements		Analysis Category		Question Evaluation
How does the interaction of hospice occupational therapists with the hospice institutional context affect the occupational therapist's (1) sense of efficacy (volition); (2) role perception (habituation); and (3) skill acquisition/competence (performance) to provide hospice occupational therapy services?	Where do you work? <ul style="list-style-type: none"> Tell me about (workplace). What community does (workplace) serve? (Who are your clients?) What is (workplace)'s mission? 	Background Demographic		Environment		Context		
	What is your role? <ul style="list-style-type: none"> What are your job duties? Where do you perform your job duties? 	Knowledge		Habituation	Environment	Context		
	How do you feel about your job? <ul style="list-style-type: none"> What gives you most satisfaction in your role? What are you most proud about your role? (What are the sources of your pride and satisfaction?) How do you feel 	Opinion	Feelings	Volition		Conditions	Actions-interactions	

Research Question	Interview Questions for Hospice Occupational Therapists	Question Type		MOHO Elements			Analysis Category		Question Evaluation
	<p>able to meet the needs of your workplace and clients? Please explain.</p> <ul style="list-style-type: none"> How do you feel your team views your role and contributions? Do feel you are being utilized to your full potential in your role? If not, why? If so, how so? 								
	<p>What skills do you need to do your job?</p> <ul style="list-style-type: none"> What experiences have prepared you for your job? How does your workplace support acquiring new skills for your job? If so, how? If not, how could your workplace support you more? 	Opinion	Knowledge	Performance			Context	Conditions	
How does the interaction of hospice	<ul style="list-style-type: none"> There is limited use of occupational 	Opinion	Behavior	Vol	Perform	Envi	Consequences	Conditions	

Research Question	Interview Questions for Hospice Occupational Therapists	Question Type		MOHO Elements			Analysis Category		Question Evaluation
care decision makers with occupational therapy influence what hospice services are provided?	therapy in hospice. How have you been able to advocate for hospice occupational therapy? (How have you been able to increase use of occupational therapy?) <ul style="list-style-type: none"> • Since you joined the team, do you feel your team has changed? If so, how? If not, why not? • How does the occupational therapy perspective impact what type of services are offered at your workplace? 								
What are the barriers and facilitators of hospice occupational therapy utilization?	<ul style="list-style-type: none"> • What limits use of occupational therapy at your workplace? • What promotes use of occupational therapy at your workplace? 	Opinion		Volition	Environment		Context		

APPENDIX C

Auditor Guide for Trustworthiness

Case #1 _____ Case #2 _____ Case #3 _____ Date _____ Auditor's Initials _____

Auditor Guide for Trustworthiness

Consider all three cases together and then answer the guiding questions.

Audit Area	Suggested Evidence Areas	Guiding Questions	Yes	No	Notes and reference of evidence which address guiding questions
			--- --- --- ---	--- --- --- ---	
Dependability	Raw Data	Do the categories reflect the data?	Yes	No	
	Process Notes		--- --- --- ---		
	Data Reduction/Analysis	Are there sufficient data to support decisions?	Yes	No	
	Data		--- --- --- ---		
	Reconstruction/Synthesis	Are main groups of data addressed?	Yes	No	
			--- --- --- ---		
		Are differences between participants addressed?	Yes	No	
			--- --- --- ---		
		Are similarities between participants addressed?	Yes	No	
			--- --- --- ---		
Confirmability	Raw Data	Does the relative weighting given to the categories reflect the data?	Yes	No	
	Process Notes		--- --- --- ---		
	Data Reduction/Analysis	Do examples fairly represent the data?	Yes	No	
	Data		--- --- --- ---		
	Reconstruction/Synthesis	Are data interpretations substantiated?	Yes	No	
			--- --- --- ---		
	Raw Data	Are the categories distinct from each other?	Yes	No	
	Process Notes		--- --- --- ---		

Case #1 _____ Case #2 _____ Case #3 _____ Date _____ Auditor's Initials _____

Audit Area	Suggested Evidence Areas	Guiding Questions	Yes --- --- --- --- No Mark an X on the scale	Notes and reference of evidence which address guiding questions
	Data Reduction/Analysis	Is the method of analysis clear?	Yes --- --- --- --- No	
		Do categories support saturation?	Yes --- --- --- --- No	
	Process notes Raw Data	Does the researcher emphasize use of the participants' wording in the data?	Yes --- --- --- --- No	
		Is there sufficient explanation of the researcher's processes?	Yes --- --- --- --- No	
		Does inquirer accommodate negative examples?	Yes --- --- --- --- No	
Credibility	Process notes • Methodological Journal • Trustworthiness Section	Is there triangulation?	Yes --- --- --- --- No	
		Is there peer debriefing?	Yes --- --- --- --- No	
		Is there member checking?	Yes --- --- --- --- No	

Compiled by Janice Kishi Chow, DOT, MA, OTR/L, Tina Fletcher, EdD, MFA, OTR, and Noralyn Pickens, PhD, OT, 5/5/2020

Corbin, J., & Strauss, A. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (4th ed.). SAGE.

Halpern, E. S. (1983). *Auditing naturalistic inquiries: The development and application of a model*. [Unpublished doctoral dissertation], Indiana University.

Lincoln, Y.S., & Guba, E. G. (1985). *Naturalistic inquiry*. SAGE.

APPENDIX D

Audit Trail Guidelines For Trustworthiness: Directions

Audit Trail Guidelines For Trustworthiness

Directions

Goal:

Establish trustworthiness by determining if there is a substantiated and supported trail that connects the data with the identified categories and themes.

Attachments:

- Prospectus (for overview of the study)
- Audit Trail Classification Guide (table of contents)
- Auditor Guide for Trustworthiness (the evaluation form)
- Audit Area Locator (where data is located for each participant)
 - OT4 Ophelia
 - D4 Daniel
 - I2 Irene
- OneNote Notebook (digital notebook with data) Link:
(link omitted for privacy)

Directions:

- Review Prospectus to orient to the study
- Review Audit Trail Classification Guide to orient to data organization
- Review the Auditor Guide for Trustworthiness to see evaluation areas
- Review the Data for each participant in the OneNote Notebook
- Fill out the Auditor Guide for Trustworthiness, considering all three participants together

How to View OneNote Notebook:

- The Notebook is organized with the same tabs as the Audit Trail Classification Guide (see Figure A)
- Look up the audit areas listed on the Audit Area Locator for each participant.
- **To run a file search** and gather the data for you (see Figure B)
 - Go to a section (e.g. Methodological Notes)
 - Use Control + F
 - Type in search term (e.g. OT4 Ophelia)
 - Below the search box, select “Section”
 - List of areas in that section will appear

Figure A: One Note Tabs

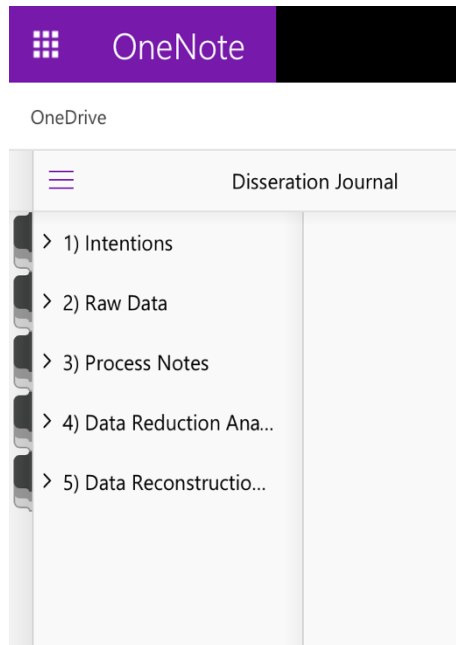
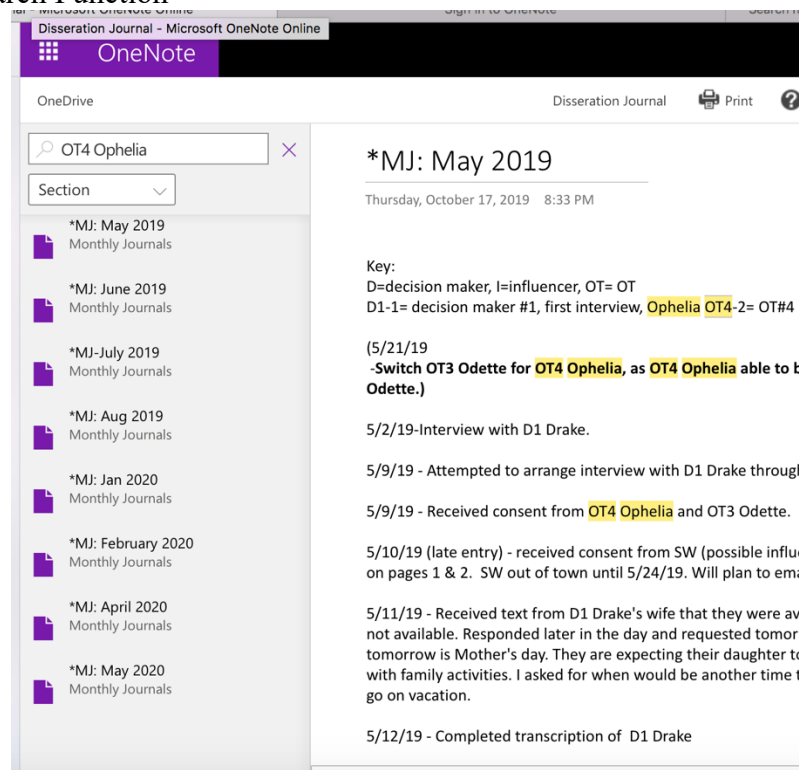


Figure B: Search Function



Filling out Auditor Guide:

- Mark an X on the scale for your answer
- Just give your first inclination
- Don't worry if unable to answer the question; make a note why

Case #1 _____ Case #2 _____ Case #3 _____ Date _____ Auditor's Initials _____

Auditor Guide for Trustworthiness

Consider all three cases together and then answer the guiding questions.

Audit Area	Suggested Evidence Areas	Guiding Questions	Yes	No	Notes and reference of evidence which address guiding questions
			--- --- --- ---	--- --- --- ---	
Dependability	Raw Data	Do the categories reflect the data?	Yes	No	
	Process Notes		--- --- --- ---	--- --- --- ---	
	Data Reduction/Analysis	Are there sufficient data to support decisions?	Yes	No	
	Data Reconstruction/Synthesis		--- --- --- ---	--- --- --- ---	
		Are main groups of data addressed?	Yes	No	
			--- --- --- ---	--- --- --- ---	

Thank you!

Freely call or text with any questions.

APPENDIX E

Audit Trail: Categories and File Types

Audit Trail: Categories and File Types

Audit Trail Category	File Types
(1) Intentions	(A) Proposal (B) Prospectus
(2) Raw Data	(A) Transcripts (B) Field notes (FN)
(3) Process notes	(A) Methodological Notes <ul style="list-style-type: none"> Monthly journals (MJ) – main logistical journal Reflections (RN) (B) Bias Notes (C) Procedural Notes (D) Trustworthiness Notes <ul style="list-style-type: none"> Logistics Peer debriefing Member check notes Auditor guides Auditor feedback
(4) Data reduction and analysis	(A) Open Coding (Define categories) <ul style="list-style-type: none"> Identify excerpts (line-by-line coding) Form codes (group excerpts) Identify conceptual headings (group similar codes) Create categories (group conceptual headings) (B) Notes (e.g. working hypotheses, concepts, or hunches)
(5) Data reconstruction and synthesis	(A) Axial coding (Determine relationships between categories within context) <ul style="list-style-type: none"> Context - events, circumstances, conditions Conditions - why, when, & how come? Action-interaction - meaning given to conditions Consequences - anticipated outcomes (B) Deeper Analysis <ul style="list-style-type: none"> Relationships between conditions, action-interaction, and consequences Range of conditions Range of possible outcomes Variance of actors and perspectives Effects of Micro conditions Effects of Macro conditions

Compiled by Janice Kishi Chow, DOT, MA, OTR/L, Tina Fletcher, EdD, MFA, OTR, and Noralyn Pickens, PhD, OT, 5/5/2020

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Lincoln, Y.S., & Guba, E. G. (1985). *Naturalistic inquiry*. SAGE.

APPENDIX F

Example Audit Area Locator (OT4 Ophelia)

Audit Area Locator: Case # OT4 Ophelia

- **Link to OneNote Notebook** “Dissertation Journal”: (Link omitted for privacy)
- **To run a file search**
Click onto a section (e.g. Methodological Notes)>Control + F>type in search term, type **OT4 Ophelia**>Below the search box, select “Section”

Audit Area	Subcategory	Location/Dates Dated entries listed in parentheses.	Notes
Raw Data	Transcripts (Tr)	Tr: Ophelia OT4	Transcripts only, no coding. OT4-1=Interview #1 OT4-2=Interview #2
	Field Notes (Fn)	Fn: Ophelia OT4 (5/28/19, 6/15/19, 7/2/19) Fn: Daniel D4 (7/14/19) Fn: Ollie OT1 (5/21/19)	
Process Notes	Methodological Notes: Monthly Journal (MJ)	MJ: May 2019 (5/9/19, 5/13/19, 5/20/19, 5/21/19, 5/24/19, 5/28/19) MJ: June 2019 (6/9/19, 6/11/19, 6/12/19, 6/15/19, 6/16/19, 6/22/19, 6/24/19) MJ: July 2019 (7/2/2019) MJ: Aug 2019 (8/20/19) MJ: Feb 2020 (2/6/20, 2/7/20, 2/8/20) MJ: April 2020 (4/6/20)	These are logistical notes of day-to-day events.
	Methodological Notes: Reflection Notes (RN)	RN: May 2019 (5/28/19, 5/30/19) RN: June 2019 (6/1/19, 6/3/19, 6/6/19, 6/15/19)	

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		<p>RN: July 2019 (7/2/19, 7/3/19, 7/14/19)</p> <p>RN: Nov 2019 (11/7/19)</p> <p>RN: Feb 2020 (2/8/20, 2/11/20)</p>	
	Bias Notes	Bias journal entries from 8/20/19–5/10/20. OT4 not specifically referenced.	Bias journal located under this tab. This info will not be listed under “Search This Notebook” as OT4 not specifically referenced in bias notes.
	Procedural Notes	Coding Strategies (2/6/20, 2/7/20, 2/8/20)	
	Trustworthiness	Member Check Ophelia OT4 (2/8/20)	
Data Reduction/ Analysis	Open Coding	Open Coding (1/2/20–4/26/20) (2/6/20, 2/7/20, 2/8/20)	This info will not be listed under “Search This Notebook” as OT4 not specifically referenced. Provides a broader view of the open coding process (1/2/20 to 4/26/20).
	Notes	Notes: 11/7/19–4/9/20)	This info will not be listed under “Search This Notebook,” as OT4 not specifically referenced. “Notes” journal working hypotheses, concepts, or hunches.

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Data Reconstruction/Synthesis	Axial Coding	Under Axial Coding tab: (4/19/20, 4/21/20)	This info will not be listed under "Search This Notebook" as OT4 not specifically referenced. Illustrates the axial coding process.
	Deeper Analysis	Under Deeper Analysis tab: (4/19/20, 4/21/20)	This info will not be listed under "Search This Notebook" as OT4 not specifically referenced. Illustrates the deeper analysis process.