Social Work Awareness of Hospice Referral Barriers in the Veterans Health Administration

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ABSTRACT OF THE DISSERTATION

Social Work Awareness of Hospice Referral Barriers in the Veterans Health Administration

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Managed by an interdisciplinary team of healthcare professionals, hospice provides relief from pain and offers supportive services at the end of a patient's life. However, services are only provided for an average of 89.6 days (Medicare Payment Advisory Commission, 2021). This study explores the barriers to hospice and looks at how social workers are involved in and can better aid the referral process.

Sources of information for this study included secondary data from a Veterans Affairs Medical Center and first-hand semi-structured interviews with social workers employed there. An explanatory sequential mixed methods design was used to analyze a sample of 262 hospice/palliative care referrals at the VA Medical Center gleaned from 1250 records spanning 2015 to 2020. Demographics, hospice/palliative care consults, and social work documentation were analyzed in SPSS using frequencies and inferential statistics. Informed by this secondary analysis, semi-structured interviews were conducted with five social workers using a phenomenological approach. They were transcribed and analyzed through NVivo (2018).

Results showed that most of the hospice referrals at the VA Medical Center were accepted but the average length of stay on hospice was 29.5 days. The primary reason for barriers to hospice referrals was a lack of advance care planning conversations between surrogates and their medical team. Social workers were involved at varying levels and played differing roles depending on the team's dynamics and the social worker's comfort level.

These findings indicate the need for social workers to incorporate palliative care into their practice to help support patients in receiving medical care consistent with their values, goals, and preferences. Findings also suggest that social workers can explore their positions in interdisciplinary teams to take a more active role in providing education about hospice.

Keywords: hospice, Veterans Affairs, medical social work, palliative care, and social work

The Dissertation for the Doctoral (Program) Degree

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER ONE

INTRODUCTION

Everyone has preferences about their medical care and how they want to be treated if they become seriously ill. Discussing and documenting these preferences is often known as advanced care planning (ACP). If one’s wishes about the ways they would like to be cared are not documented, they may not be realized by family members or a health care team and one may lose the opportunity to express them. Social workers, even if they do not specialize in palliative care or hospice care, regularly work with clients who experience medical problems and end-of-life issues. Social workers can help patients navigate the healthcare system and assist them in carrying out their advanced care wishes (Berkman & Stein, 2017), even when including hospice care. The Department of Veterans Affairs (VA) is the largest healthcare system in the United States, with approximately 15,000 social workers employed, and has initiatives to address ACP, palliative, and hospice services (VA, 2021a). It is logical and wise to understand the role of the VA social workers in these initiatives and to explore the ways social workers can facilitate and help improve the ACP and hospice services for our veterans.

In this study, the history and challenges of ACP were explored, specifically related to hospice, barriers in hospice referrals in a veteran affairs medical center (VAMC). Additional topics explored included the timing of when social workers become involved in discussions with veterans, family members, and their interdisciplinary care teams about hospice referrals.

Definition: ACP

The National Hospice and Palliative Care Organization (NHPCO, n.d.) defined ACP as “making decisions about the healthcare you would want to receive if you’re facing a medical crisis" (p. 1). Sudore et al. (2017) offered a more comprehensive, multidisciplinary definition of ACP:

> (1) Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.
>
> (2) The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illnesses.
>
> (3) For many people, this process may include choosing and preparing another trusted person or persons to make medical decisions in the event the person can no longer make his or her own decisions. (p. 14)

Benefits of Hospice

ACP is especially needed when patients are incapable of making health care and or medical care decisions. That is, ACP can help determine healthcare treatment decisions and end-of-life care through a living will, durable power of attorney for healthcare, and do not resuscitate or do not intubate instructions (National Institute on Aging, 2018). There is evidence that ACP can reduce hospitalizations, improve quality of life, and increase the ability of both the medical team and family to respect the patient's wishes (Fulmer et al., 2018; Wang et al., 2017).

Because of unconsciousness, cognitive impairments, or inability to communicate, an estimated 40% of all adults who are hospitalized are unable to make their own treatment decisions (Raymont et al., 2004), with a large majority of critically ill patients unable to make decisions for themselves (Nelson et al., 2006). This is especially true with chronic illnesses, which the Centers for Disease Control and Prevention (CDC, 2021) described as "illnesses that last a year or longer and necessitate continuing medical attention or impedes daily activity, or both" (p. 1). Examples of chronic diseases include heart disease, Alzheimer's disease, cancer, and chronic lung disease.

Specifically, Alzheimer's disease is the sixth leading cause of death in the United States (CDC, 2020), with almost half of the nursing home population (47.8%) having some form of dementia (CDC, 2019). For the 44%–69% of nursing home residents with decisional impairment, health care agents and surrogates (including family members) are necessary (Kim et al., 2002). Conversely, health care agents may also be involved in advocating on behalf of patients who have retained their decision-making competence but choose to defer to family members (Vig et al., 2007).

Background Information About Palliative and Hospice Care

The Institute of Medicine (IOM, 2015), in their *Dying in America* report, defined palliative care as "care that provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families" (p. 56). The National Quality Forum (2006) defines hospice as:

> A service delivery system that provides palliative care for patients who have a limited life expectancy and require comprehensive biomedical, psychosocial, and spiritual support as they enter the terminal stage of an illness or condition. It also supports family members coping with the complex consequences of illness, disability, and aging as death nears. (p. 3)

Hospice care provides comfort care and can reduce unnecessary treatments (Mulville et al., 2018). Services can be offered in the home, assisted living facilities, nursing homes, hospitals, and hospice centers (National Institute on Aging, 2021). The attending and hospice physician initially approves hospice for the first 90 days, and it is renewed by the hospice physician (Medicare Payment Advisory Committee, 2021).

Benefits of hospice include patient satisfaction with care received and pain control (Kleinpell et al., 2016). Additional benefits of hospice service include reduced hospital use, fewer procedures (Mulville et al., 2018), and fewer transitions between multiple care levels (Benzar et al., 2011). Patients in 2011 experienced four or more transitions in their final 6 months of life (Wang et al., 2017). In a study by Bainbridge and Seow (2017), caregivers reported higher satisfaction ratings with hospice than hospitals in providing physical and emotional support. In addition to improving quality of life, hospice services increased the number of home deaths. In 2010, in the United States, 715,000 deaths occurred in the hospital (Hall et al., 2013). Studies have shown patients would prefer to pass away in the comfort of their homes, but only a small percentage can do so (Cao et al., 2020; Ernecoff et al., 2020). Hospitals can be lonely and uncomfortable, and patients often lack sleep and privacy (Bainbridge & Seow, 2017). Contributing factors affecting the ability to die at home can include multiple diagnoses and insufficient support for a patient's physical and medical needs (Bainbridge & Seow, 2017). In 2018, of those patients receiving hospice services, slightly more than 50% died in their homes (NHPCO, 2020).

Though there has been a steady increase in hospice services since its inception in 1983, in 2018, the average length of stay in hospice was 89.6 days, and the median length of stay was 18 days. Many patients receive hospice for 90 days or longer. Still, only 25% of patients receive the benefits of hospice services during their last week before death (Medicare Payment Advisory Commission, 2021). There are concerns that the referrals are being made too late in the course of illness (Bainbridge & Seow, 2017; Mulville et al., 2018) due to the lack of communication with the medical team (Benzar et al., 2011; Mulville et al., 2018) and a lack of coordination among all parties involved (Mulville et al., 2018). Ernecoff et al. (2020) studied hospice referrals of patients with cancer, dementia, and chronic kidney disease. Of the patients reviewed (*n* = 402), 42% received a hospice referral, with most of the referrals being made for patients with cancer (61%).

The National Coalition for Hospice and Palliative Care (2015) released a public comment requesting the 6-month life expectancy criteria be removed, as the criteria was arbitrary and not based on need. The National Coalition for Hospice and Palliative Care (2015) and the Medicare Payment Advisory Commission (2021) recommend earlier referrals to hospice so patients can benefit from a higher quality of life. The American Society of Clinical Oncology also recommends earlier referrals, and their clinical practice guidelines state palliative care should be initiated within 8 weeks of a terminal diagnosis (Ferrell et al., 2017; Osman et al., 2018) as earlier referrals can optimize quality of life and increase patient and family satisfaction (Christakis & Escarce, 1996).

Hospice provides supportive services to patients and families. A study of caregivers reported less stress and increased quality of life when patients received services from hospice 30 days or more (Stillman & Syrjala, 1999). Although there is no standard for length of hospice stay due to the variabilities in illness course, a study by Rickerson et al (2005), found 3 months to be an optimal length of time for patients and families to receive the benefits of hospice services. Dai et al. (2021) discovered improved quality of life when hospice care services were provided 8–60 days before death. Another study by Hui et al. (2014) considered palliative care referrals 3 months before death a late referral, although several studies defined late hospice referrals as 7 days prior to death (Diamond et al., 2015; Enzinger et al., 2014; Sedhom et al., 2021). Late referrals do not align with the values of hospice and can lead to poor outcomes as the focus of care may be managing death (McGorty & Bornstein, 2003) instead of managing medical and mental health care as a team (Smith et al., 2017). Bradley et al. (2004) studied caregivers and more caregivers experienced major depressive disorder when patients received hospice for 3 days or less.

Hospice provides multidimensional palliative care addressing a variety of pain control. This includes physical, emotional, and spiritual pain of the patient and family. Additionally, hospice has traditionally also addressed financial pain and bureaucratic pain. Bureaucratic pain is the very real stress and strain that patient/families experience in dealing with filing insurance claims. Hospices remove that area of bureaucratic pain as the hospice itself takes over such issues of reimbursement and insurance filings. In terms of financial pain, it is important to discuss the financial implications of hospice care. Taylor et al. (2007) compared the cost of care for patients during the last year of life with and without hospice services and discovered patients with hospice reduced Medicare expenses on average by $2,309 with the maximum benefit of $7,000 per patient at 8 weeks of hospice. Kelley et al. (2013) also completed a study on the financial benefits of hospice that showed a maximum savings of $6,430 per hospice patient when receiving hospice services 15–30 days and considering the savings associated with reduced hospitalizations.

History of Hospice

As part of ACP, hospice care services have a relatively new, yet complicated, history. This section provides a historical review of the formation, use, and evaluation of hospice services.

Beginnings 1963 and 1981

Hospice (also known as palliative care) concepts were founded by Cicely Saunders, a doctor, social worker, and nurse, who opened the first hospice house, St. Christopher's Hospice, in 1967, in London. Saunders provided compassionate and dignified care to dying patients by treating their pain with a team approach. "Clinical care, education, and research" (Clark, 1999, p. 730) were Saunders's hospice goals.

Saunders inspired the dean of the School of Nursing at Yale, Florence Wald, to resign her position and start the first hospice program in the United States, Hospice, Inc., in 1971. Wald and a team worked toward their vision of providing services that promoted community through a nursing-led interdisciplinary team, and they opened the Connecticut Hospice in Branford in 1974 (Buck, 2011). At the same time, Kubler-Ross (1973) published *On Death and Dying*, which explained the stages of grief based on her interviews with dying patients and their families. The year before, in 1972, Kubler-Ross spoke about dying with dignity at the U.S. Senate Special Committee on Aging (NHPCO, n.d.). These events were the start of a hospice movement.

Additional hospice organizations began to form, and national discussions led to the creation of the National Hospice Organization (NHO). The NHO released standards for hospice care a year after its creation in 1979. Leaders in hospice were able to obtain approval from the Health Care Finance Administration for a pilot program to study the benefits of hospice for patients and families and reduce spending on long-term care (Buck, 2011).

Established Services (1982–2005)

After a successful pilot program, the Hospice Medicare Benefit was approved as part of the Tax Equity and Fiscal Responsibility Act in 1982. It took some time for hospice agencies to meet regulations. The NHPCO (2007) estimated that, by 2005, 1.2 million people were receiving hospice services. Patients with cancer initially comprised most recipients, but that changed in 2005, with cancer referrals dropping to fewer than half. At the end of this period, the average length of stay in hospice declined from "70 days to less than 50 days" with "30% of patients receiving services for 7 days or less" (NHPCO, 2006, p. 92). Another critical policy was the 1990 Patient Self-Determination Act (1990), which introduced mandatory inquiry, information, and documentation about advance directives by health care facilities.

The IOM (1997) released reports in 1997 and 2003 about dying and how to provide care at the end of life. The 1997 report included several recommendations: (a) patients and families should be provided with ACP, (b) health care professionals and students should seek education and advocate for patients, (c) systematic and policy changes should be made to improve quality of life, and (d) discussions about end-of-life issues should continue. Subsequently, the IOM released a report in 2003 about the psychosocial needs of children and families of children who die (Field & Behrman, 2003). The IOM recommended health care professionals (a) conduct clinical research, (b) incorporate palliative care in medical care, (c) seek education, and (d) advocate for children (Field & Behrman, 2003).

Reforms Since 2014

The U.S. Department of Health and Human Services Office of Inspector General (OIG; Levinson, 2016) completed a report in 2016 detailing inappropriate billing in 2012 by hospice agencies, which cost Medicare $268 million. It was determined that hospice agencies, primarily for-profit, sent patients to general inpatient care—which is provided in skilled nursing facilities (SNF), inpatient hospice units, or the hospital—when they did not meet the criteria (e.g., for pain control or chronic symptoms). General inpatient care is more expensive than routine care and costs Medicare $672 per day per patient. The OIG also reported Medicare was sometimes billed for medications twice, once through the hospice agency and once through the patient’s Medicare Part D. Another area of concern was the coordination of care among the hospice team on behalf of the patient. According to the OIG report, not all members were involved in the care plan, and sometimes elements of the plan were missing (Levinson, 2016).

Between 2006 and 2013, there were several additional significant events, starting with the recognition of hospice and palliative medicine as a specialty by the American Board of Medical Specialties in 2006 (American Academy of Hospice and Palliative Medicine, 2006). Palliative care programs doubled in 6 years from 632 in 2000 to 1,240 in 2006 (Connor et al., 2007). In 2008, National Healthcare Decisions Day was created to promote awareness about ACP (IOM, 2015). That same year, the National Association of Social Workers (NASW) created the Advance Certified Hospice and Palliative Care Certificate with the National Hospice and Palliative Care Organization (NHPCO, formerly NHO; NASW, 2021).

In 2009, hospice services to children were addressed when the NHPCO released their pediatric palliative care standards (NHPCO, 2019a). Another important change was that Medicaid programs allowed children on hospice to receive curative treatment under the Patient Protection and Affordable Care Act (Lindley, 2011).

The IOM (2015) provided a report in 2015, noting an increase in hospice services but continuing problems with referring until the final days of life. The 2015 IOM report included several recommendations: (a) quality ACP discussions, (b) education for health care workers, (c) changes in policy to promote services for end-of-life care, and (d) public education. The following year, CMS (2018) approved physicians and qualified staff to bill for advanced care discussions with patients.

Challenges to Hospice Referrals

The challenges of completing advance care planning toward hospice services seem to be connected to the lack of knowledge of ACP that patients and family members have, the lack of awareness of those services by healthcare workers, and vulnerabilities in the healthcare system.

Patient and Family Awareness of Hospice Services

Rao et al. (2014) explored hospice awareness in the HealthStyles Survey from 2009–2010 (*n* = 7,946). Most respondents (67.8 %) expressed reservations about end-of-life care, but only 26.3% of respondents had completed their advance directives (AD), a form that names a surrogate to make medical decisions and can including a living will. The percentage of completed ADs was like Yadav et al's (2017) systematic review of studies completed 2011–2016 that determined 36.7% of the U.S. population had an AD. The main reason for the lack of ADs was lack of awareness, with the second reason being the belief their family members would make decisions for them. Participants who completed ADs were more likely to have at least one chronic disease, be older than 55, college-educated, and White. Other researchers have similarly found patients may be unaware of the various aspects of ACP (Seymour et al., 2004; Shaw et al., 2017; Vig et al., 2007), have misconceptions about hospice (Vig et al., 2010), or have conflicts with their cultural and religious beliefs (Barzagan, 2020). Many patients have not discussed ACP and life-sustaining treatments with their providers (Heyland, 2013).

Despite the lack of communication with physicians about ACP, patients want information from their providers before making end-of-life decisions (Vig et al., 2010). Studies have shown patients and families want more communication from the medical team but are not given enough information, especially about poor prognoses at the end of life (Benzar et al., 2011; Ersek et al., 2021). Lacking information about prognosis and disease progression was a recurrent theme in the literature on patient and family ACP awareness. In the hospital, prognoses were sometimes vague or overly optimistic and lacked information about what caregivers should expect (Benzar et al., 2011).

Although patients rely on family members and caregivers to help make decisions, patients, caregivers, and surrogates in the Shaw et al. (2017) study did not share the same understanding of ACP terminology. There are also times when surrogates and family members disagree (Fulmer et al., 2018; Wang et al., 2017).

Health Care Worker Awareness of Hospice Services

One explanation for a reluctance to discuss palliative care and hospice is the physician's focus on curative medicine, leading to delays in hospice referrals until patients are close to death (Ernecoff et al., 2020). For hospice referrals, physicians must determine patients have a life expectancy of 6 months or less, which can be difficult for physicians to determine, accept, and communicate to patients and family members (Cherlin et al., 2016), especially with a noncancerous diagnosis (Cagle et al., 2019). Oncologists can provide a more accurate timeframe of end-of-life than most specialists in other medical fields. There is wide variability among physicians in their ability to determine life expectancy (White et al., 2016).

Another barrier to having palliative care conversations is a lack of education, with 30% of physicians reporting no training in ACP (Fulmer et al., 2018). Despite recognizing the value of ACP, very few physicians have been educated to engage in these complex conversations, and some report a lack of confidence with end-of-life discussions (Wallace et al., 2018). Similarly, in a study by Chuang et al. (2017), physician assistants (PAs) in a focus group reported a lack of training in communicating end-of-life discussions and uncomfortable feelings when holding such difficult conversations with terminally ill patients and their families.

Until 2016, health care professionals could not bill CMS for ACP discussions, but they are now considered a preventive service (CMS, 2018). Although there is now a specific Medicare payment code for ACP, physicians may believe it is insufficient for the extra time required for the comprehensive discussions of a patient’s treatment options (Otis-Green et al., 2019).

Vulnerabilities in Health Care System

When a patient does not have an ACP in place that includes a desire for hospice services, time constraints are the main reason there are no conversations with the patient in the medical setting (Fulmer et al., 2018; Pfeifer & Head, 2018; Singh et al., 2021). Making decisions about end-of-life care, especially in the hospital, can be challenging due to (a) medical complications; (b) increased urgency to make decisions; and (c) limited communication among patients, family, and medical staff (Bainbridge & Seow, 2017). Hospitalized patients must make difficult decisions about their healthcare and discharge plans in a short amount of time. In the most recent data reported by the Health Care Cost and Utilization Project (n.d.), there were 35.7 million hospital stays in the United States in 2016, with the length of stay for hospitalization averaging 4.6 days. In many cases, there may be limited opportunities during a hospital stay for the patient and their caregivers to work with the medical team on end-of-life planning and be referred to hospice services (Bainbridge & Seow, 2017).

In addition to a lack of time and training, Arnett et al.’s (2016) survey of health care workers in hospitals in Colorado also reported issues with (a) document retrieval and storage of AD’s, (b) role ambiguity about who would have discussions with patients about ACP, and (c) lack of facility support and guidance.

The Context of a Veteran Administration Medical Center

The United States has provided medical care to those wounded or injured while serving in the military since colonial times. In 1930, the VA was created to centralize benefits and medical services to military personnel. After World War II, in 1946, support for expanding medical benefits grew, and a veteran's health care system was formally established under the VA as the Department of Medicine and Surgery, which was changed to the Veterans Health Administration (VA) on May 7, 1991 (Oliver, 2007).

The VA is the country's largest comprehensive medical system, currently treating an estimated 9 million enrolled veterans each year. Veterans who were on active duty for at least 24 months and honorably discharged from the military are eligible to receive health care from the VA. The VA has an eight-group, priority-based enrollment system that determines copays and additional services based on disability rating and income. Priority groups are ranked 1 through 8, with 1 receiving the highest priority (VA, 2020a).

The VA (2021b) comprises 1,293 facilities, including 171 hospital centers and 1,112 outpatient centers. The VA is the largest cancer care provider and the largest provider of graduate medical education in the United States. The VA has also been considered a leader in developing geriatric and palliative care through training, relationships with academic programs, and the development of policies (Daratsos & Howe, 2007).

The VA served more than 8 million veterans in 2017, with most being 65 years or older (48%), White (73%), and male (91%); almost half had an annual income of $35,000 or higher (49%), with 47% reporting an annual income below $35,000 (Huang et al., 2018). In the population served, female veterans receiving services grew from 10% in 2000 to 22% in 2015, with a younger population (less than 65 years old) than males (Frayne et al., 2018). Delays in care for veterans led to the Veterans Access to Care, Choice, and Accountability Act of 2014 (Veterans Choice Act, 2014), which addressed wait times and staffing by providing veterans' healthcare services at non-VA facilities.

VA Directives

Every year, it is projected 21,000 veterans die in VA medical care (Veterans Health Affairs [VHA], 2017). Veterans' end-of-life care choices differ from that of nonveterans, with more veterans opting for do-not-resuscitate (DNR) orders and fewer having a durable medical power of attorney (Duffy et al., 2006). Only 5% of veteran decedents received hospice treatment in 2000, compared to 20% of Medicare decedents (Edes et al., 2007; Teno et al., 2013).

Starting in 1978, the VA recognized the need for more compassion and quality of life for dying veterans. In 1992, a directive was adopted by the VA to establish hospice teams. In 2002–2003, the VA Directive 2003-008 (Hospice and Palliative Care Workload Capture) and VA Directive 2003-034 (Palliative Care Consult Teams) established end-of-life care for veterans (Daratsos & Howe, 2007) to receive care within the VA or through hospice agencies funded by the VA or Medicare (Miller et al., 2017).

The Comprehensive End-of-Life Care Initiative was enacted between 2009–2012 to develop a sustainable infrastructure of palliative care services, education, and leadership with the VA. Though the CMS prohibits patients from receiving concurrent care (e.g., hospice and cancer-directed treatment at the same time; Mor et al., 2015), the Comprehensive Life Care Initiative allows concurrent care for veterans so they can continue to receive care for their illness while receiving hospice services (VHA, 2017).

The most recent initiative in the VA is the VA Directive 1004.03, *Life-Sustaining Treatment Decisions: Eliciting, Documenting, and Honoring Patients' Values, Goals, and*

Preferences was enacted in 2017 (VA, 2017b). This directive establishes standards for initiating, documenting, and supporting end-of-life goals and preferences for life-sustaining treatments, which the VA (2017b) defined as “a treatment that is intended to prolong the life of a patient who would be expected to die soon without artificial treatment” (p. 4).

Veterans End-of-Life Considerations

Veterans’ daily lives are substantially altered because of their military service, sometimes physically and often emotionally. Military experience also affects how veterans find meaning in their lives and at the end of their service (Ferrell, 2019). Veterans face emotional, existential, or spiritual distress as they near the end of their lives (Holland et al., 2014; Mor et al., 2015) due to fragmented relationships (Prince-Paul et al., 2014) and a need to better understand how their previous military experience influenced their faith, either negatively or constructively (Holland et al., 2014). Veterans have differing levels of military experience. Combat experience can cause veterans to struggle with moral trauma resulting from unpleasant loss or shame (Ferrell, 2019). Each veteran’s unique experience should be acknowledged, when considering or providing hospice services (Varilek & Isaacson, 2021).

Description and Justification of Study

In this study, the challenges surrounding end-of-life care discussions and barriers to hospice referrals among veterans were explored. Although there is no standard timeframe for hospice referrals, studies of the financial benefits of hospice services recommend services for 15–56 days (Kelley et al., 2013; Taylor et al., 2007). The researcher used a mixed methods design framed through a phenomenological perspective using an inductive approach by completing a retrospective secondary analysis of hospice referrals and interviewing social workers about their experiences with hospice referrals.

Relevance to Social Work

Social workers' values, including commitment to clients, self-determination, informed consent, and cultural and social diversity (NASW, 2021) align with the Patient Self-Determination Act of 1990. This act states healthcare organizations must (a) inform patients of their rights to make their own medical decisions, (b) document AD, (c) provide education, and (d) not discriminate based on AD completion. The IOM (2015) report, *Dying in America,* presented several issues relevant for social workers, such as cultural diversity in ACP. The report noted personalized care should be given to dying patients and identified specific issues to consider regarding (a) children, (b) people with cognitive impairments, (c) patients who are homeless, (d) physical and mental disabilities, (e) religion, (f) race, (g) ethnic and cultural groups, and (h) various levels of health literacy. The report's authors also recognized social workers as valuable members of interdisciplinary teams with values and skills that support end-of-life care. Currently, social workers play a significant role in ACP by providing education, advocating for patients (Fineberg et al., 2011), and completing AD's (Otis-Green et al., 2019; Wang et al., 2017). This study poses the following research questions:

1. What are the barriers to hospice referrals in a VA?
2. How and when are social workers involved with the hospice referral process?

Theoretical Constructs of this Study

The health belief model (HBM) clarifies the role of social workers in end-of-life discussions, specifically hospice referrals, because it provides suggestions for ways to employ social workers in conversations and implementations of ACP. The National Cancer Institute (2005) highlights HBM as a resource in understanding and working with individuals on behavior change. HBM is also a practical model in that it can explain why a problem exists (National

Cancer Institute, 2005). HBM constructs, therefore, could help identify the barriers related to end-of-life discussions and delays in hospice referrals.

Background of the HBM

The HBM was created in the 1950s by social psychologists Godfrey Hochbaum, Stephen Kegeles, Howard Leventhal, and Irwin Rosenstock with the then Public Health Service. The goal of the model was to explain why so many people failed to participate in illness prevention and detection programs (Rosenstock, 1974). Rosenstock noted the influence of Lewin on the development of HBM. According to Lewin's field theory, it is feasible to comprehend, predict, and change the behavior of individuals and groups by understanding the forces that influence their behavior (Back, 1992). Forces can be positive, negative, or neutral, with diseases being considered negative.

The founders of the HBM subsequently added an additional construct per Bandura—the concept of self-efficacy (Rosenstock et al., 1988). That is, Bandura (1974) defined self-efficacy as a belief in one's ability to exercise control over oneself and the events that affect one's life, and he argued that a strong sense of self-efficacy led to many advantages in life—from resilience to adversity to improved performance at work and school.

Theoretical Constructs of the HBM

Social psychologists developed HBM to predict and propose that individuals' beliefs about their susceptibility to disease—and their judgments of the benefits of attempting to avoid it—also theorized these beliefs influenced the willingness to act. In the following section, the six constructs that comprise the HBM are reviewed: (a) perceived susceptibility, (b) perceived seriousness or severity, (c) perceived benefits, (d) perceived barriers, (e) self-efficacy, and (f) cues to action (National Cancer Institute, 2005).

Perceived Susceptibility

Perceived susceptibility refers to the perceived risks of developing a sickness or condition. An individual's recognition of personal susceptibility to an illness varies greatly, with some being very concerned and others not being concerned (Rosenstock, 1974). Patients must believe there is a chance of contracting a disease before expressing interest in preventative testing (Glanz et al., 2008). As perceived susceptibility relates to ACP, Berzoff et al. (2020) recommend that emphasis should be placed on teaching social workers to understand their own challenges and wishes related to ACP before working with clients.

Perceived Seriousness or Severity

The perceived seriousness can be determined by the degree of emotional responses produced by the mere idea of sickness and the types of complications an individual believes a particular health condition will bring them. Medical complications can result in one's death, clinical complications can result in limited functioning, and social complications can result in a loss of employment or stress on family dynamics. Beliefs regarding a condition's gravity and outcomes can lead to action (Rosenstock, 1974). A mixture of susceptibility and severity can lead to a feeling of threat or danger (Glanz et al., 2008). An example of perceived seriousness that can influence ACP outcome is when a patient becomes seriously ill, and the social worker worries wishes may not be followed without an ACP discussion (Morrison et al., 2005).

Perceived Benefits

An individual's beliefs about the perceived benefits of various options for minimizing the disease danger will impact their behavior. Individuals with high susceptibility and severity beliefs are unlikely to take any recommended health intervention unless they also see it as a benefit in minimizing the threat (Glanz et al., 2008). According to social workers in Galgliardi and Morassael's (2019) study, promoting client self-determination by initiating ACP with patients adhered to the social work scope of practice and values. In an intervention that provided goals of care education in a nursing home that included social workers, family members of patients with dementia reported increased communication and trust, and healthcare providers were working toward the same objective (Hanson et al., 2017).

Perceived Barriers

An individual may believe completing a particular activity may reduce the risk of disease. Still, if that action is uncomfortable, costly, unpleasant, or traumatic, these perceived barriers can deter one from engaging in suggested behaviors (Rosenstock, 1974). Time and lack of support from medical providers have been found to be barriers for social workers in the hospital setting (Gagliardi & Morassaei, 2019) and dialysis centers (Berzoff et al., 2020). Additional obstacles for health care staff involved in ACP include logistical issues (Singh et al., 2021). Social workers or healthcare workers who anticipate that ACP discussions could be unpleasant due to strained family relationships may not initiate discussions (Bielinska et al., 2020).

Self-Efficacy

HBM incorporated Bandura's (1974) self-efficacy concept, which is the "belief in one's capabilities to organize and execute the course of action required to produce given levels of attainments" (Rosenstock et al., 1988, p. 3). To achieve change, individuals must believe they can implement change (Rosenstock et al., 1988). Bandura (1998) suggests that mastering experiences, vicarious experiences, social persuasion, and reducing people's stress reactions are ways to improve self-efficacy.

Henage et al. (2021) provided ACP training to physicians, physician assistants, and family nurse practitioners, resulting in a 27.5% increase in ACP discussions after the training.

Chan et al.’s (2020) survey of health care professionals, including social workers, revealed a link between training and increased ACP readiness. Compared to those who did not receive training, individuals who received education were more likely to find ACP meaningful and reported considerably higher levels of willingness and confidence in conducting ACP.

Cues to Action

The last construct considered important to the HBM model is a cue that triggers an individual to act. Cues can be internal or external stimuli, and they are difficult to measure (Rosenstock, 1974). Cues to take action to make an advance care plan could be triggered by transitioning from one setting to another, such as returning home from the hospital (Benzar et al., 2011). Another cue might be when an individual is provided with a new diagnosis (Combes et al., 2019).

Critiques of the HBM

One critique of HBM is its lack of integration among the constructs. This model does not specify the relationships among the six constructs, and there are no set guidelines for interpretation or prediction (Armitage & Conner, 2000). Additional missing components are the lack of consideration of culture and society (Davidhizar, 1983) and emotional influences on behavior (Glanz et al., 2008). That is, considerations of personal history and experience are less critical in HBM than the individual’s psychological state (Davidhizar, 1983). Inclusion of these issues would be beneficial because past experiences with the healthcare system can influence decisions about health. A final critique is that cues to action are challenging to capture and document, making it difficult to develop interventions based on the significance of a specific cue (Glanz et al., 2008). Individuals may not be able to identify which cue, internal or external, prompted their behavior change (Rosenstock, 1974).

Implications

This section includes exploration of the micro, mezzo, and macro implications of hospice delays and social worker involvement in palliative care or hospice referrals in a VAMC. The potential contributions to the literature and proposed research questions and methodology are also discussed.

Micro Level

Micro-level implications relate to the psychosocial barriers of hospice referrals. Reducing these psychosocial barriers may increase the frequency and timing of palliative care or hospice referrals so that veterans receive services are in concordance with their medical preferences. Social workers have opportunities to discuss ACP with patients and families in a variety of settings, such as nursing homes (Morrison et al., 2005), dialysis clinics (Berzoff et al., 2020), and hospital systems (Gagliardi & Morassaei, 2019). The results of this study help reveal how social workers' personal experiences with ACP, such as completing advance directives (Kwon et al., 2014), training, and knowledge of cultural diversity, can impact their work with individuals and families.

Mezzo Level

In addition to exploring the psychosocial reasons for delays, logistical barriers presented in the medical records and through interviews were explored. Social workers work within a variety of systems. This study may help social workers identify ways to reduce ACP barriers related to the systems in which they work, as identified in the introduction and literature review. Social workers may also find opportunities for leadership in their agencies to improve their processes (Otis-Green et al., 2019).

Macro Level

Systemic barriers to palliative or hospice referrals were explored during this study. This included assessing the level of training received by social workers have and the perceived impact of training on advance care planning and end-of-life care. The study results may be helpful in identifying the need for end-of-life training in organizations and the social work education curriculum.

Contributions to the Literature

This study adds to the literature on the current state of palliative care or hospice referrals at a VAMC and may help leaders recognize and understand changes in the frequency and timing of referrals and any challenges not previously studied. There are limited qualitative studies of nonpalliative care or hospice social workers about hospice referrals and end-of-life discussions. This study also adds to social work practice knowledge.

Methodology and Research Questions

A mixed methods design was used to study hospice referrals through (a) a retrospective secondary analysis of the electronic medical record of palliative and hospice consults and (b) qualitative interviews with social workers about their involvement with hospice referrals. The following research questions guided this study:

1. What are the barriers to hospice referrals?
2. How are social workers involved in hospice referrals?

CHAPTER TWO

LITERATURE REVIEW

In this study, the researcher explored the challenges of advance care planning (ACP), specifically hospice barriers, in a Veteran Affairs (VA) medical center and the involvement of social workers in the referral process. The literature review begins by examining policies in the VA that support quality of life followed by a chronological review of studies exploring the challenges in timely referrals of patients to palliative and hospice care and the unique needs of veterans and their family members. The chapter concludes with (a) an overview of social work involvement in end-of-life care, (b) a review of factors that influence social work comfort in ACP, (c) a review of studies of social workers in ACP, and (d) a look at the education and professional development of social workers.

Veteran's Administration

Veterans who receive services from the VA are at a higher risk of mortality than the overall veteran population. Those eligible for services have complex physical and emotional conditions (Holland et al., 2014), and it is estimated there are 21,000 deaths in VA medical centers every year (VHA, 2017).

Leaders of the VA have recognized the need for end-of-life care through the comprehensive end-of-life-care initiatives (2009–2012), which established palliative care services at all VA medical centers and allowed for concurrent treatment of illnesses even while receiving hospice services (VHA, 2017). The VHA Directive 1139, *Palliative Care Consult Teams (PCCT) and Veterans Integrated Service Network Leads* (VHA, 2017) requires all medical centers (a) have a palliative care team, (b) identify veterans who may qualify for palliative care and hospice services, (c) provide those services, and (d) document end-of-life preferences through the VHA Directive 1004.93, Life-Sustaining Treatment (LST) Decisions Initiative (VHA, 2020).

Concurrent Care

Haverhals et al. (2019) interviewed VA and non-VA hospice staff about concurrent care. Concurrent care allows providers to respect the wishes of the veteran and family member regarding treatments for terminal illnesses. The benefits of concurrent care are that veterans can continue to see their VA oncologist or other specialists, receive hospice services, and take time to consider treatment options. Some challenges noted by Haverhals et al. included difficulty coordinating care within different systems and acceptance of concurrent care. Difficulties exist among systems because there is no standardized process for medical care and billing across the VA, Centers for Medicare and Medicaid Services (CMS) systems, and hospice agencies. The mixed acceptance of concurrent care has led to an inconsistent adoption of concurrent care within the VA (Mor et al., 2015). At times, clinicians and staff in hospice had difficulty accepting concurrent care due to discordance in their beliefs regarding hospice and aggressive care. Although there were concerns about aggressive care, in their study of end-of-life care for veterans with advanced cancer, Smith et al. (2019), reported that cancer treatment did not increase with concurrent care in their study of end-of-life care for veterans with advanced cancer.

Aggressive Care

There are concerns that *aggressive care*, which can be considered as procedures, therapies, or settings with the purpose of extending life (Cohen & Deliens, 2012), leads to increases in mortality, poor quality of life, and emotional impact on patients and families (Gonsalves et al., 2011). The National Academy of Medicine and Society of Clinical Oncology do not support aggressive care; instead, they promote palliative care to increase management of symptoms and quality of life (Smith et al., 2019). Studies comparing aggressive cancer care in the VA to the private sector revealed the VA provided less aggressive care while the private sector had more hospitalizations and admissions to the intensive care unit (ICU; Gidwani-Marszowski et al., 2018; Keating et al., 2010). The VA also provides more palliative care and hospice services than the private sector (Olmsted et al., 2014). The VA's greater support for palliative care and hospice services can be explained by its focus on goals of care and end-of-life services (Gidwani-Marszowski et al., 2018). It has been shown that hospice services increase when discussed and documented in an LST note (Miller et al., 2021). Another reason for the differences between the VA and private sector regarding end-of-life services could be financial incentives for aggressive care within the private sector (Gidwani-Marszowski et al., 2018; Keating et al., 2010).

Hospice Within the VA

Although the VA provides less aggressive care than the private sector (Smith et al., 2019) and allows for concurrent care with hospice services, the rate of ICU admissions and the timing of palliative and hospice consults remains only about 2 weeks before death (Mor et al., 2015; Olmsted et al., 2014).

2002 and 2008, Active Cancer Deaths

Gonsalves et al. (2011) completed a retrospective study of veterans in a VA medical center (VAMC) in 2002 and 2008 who had active cancer. They compared the hospice and palliative care conditions surrounding the last 100 deaths of these veterans in both years. An important factor in the comparison between 2002 and 2008 is that, in 2003, the VAMC established a palliative care team. Veterans in 2008 received more aggressive care, including chemotherapy, hospital admissions, ICU admissions, and more deaths in the hospital. There were fewer hospice referrals in 2008 (*n* = 67) than in 2002 (*n* = 69), but veterans in 2008 received more hospice services with a palliative care consult.

2004–2011, Advanced-Stage Hepatocellular Carcinoma

Zou et al. (2018) completed a retrospective study of hospice use from 2004–2011 for veterans newly diagnosed with advanced-stage hepatocellular carcinoma (*n* = 597), a type of liver cancer with a limited survival rate. After receiving the hepatocellular diagnosis, only 40.8% received hospice referrals at that time, 32.5% received hospice later, and 26.7% never used hospice. Those who received hospice were an average age of 62, White (62.1%), managed by an oncologist (67.2%), had no additional insurance (47.2%), and lived in the southern United States (39.5%; Zou et al., 2018).

2004–2014 and 2009–2015, Advanced Kidney Disease

O’Hare et al. (2020) completed a qualitative text note analysis of veterans between 2004 to 2014 who had advanced kidney disease with hospice mentioned in their electronic medical records (EMR). Their study sampled 1,000 veterans and resulted in a review of 340 EMRs. The veterans who had hospice mentioned in their chart had higher diagnoses of cancer and dementia and more documentation that included mentions of palliative care, advance care planning, and home care. Hospice referrals were submitted when veterans were close to death and there were no available treatment options. The complexity of care at the time of the hospice referral made it difficult for the veteran to transition out of the hospital and the hospice agency to manage the veteran’s care at home. O’Hare et al. (2020) also found unclear interpretations of concurrent care and hospice services led to fragmented care and delay in hospice care.

Richards et al. (2019) completed a retrospective study of veterans with advanced chronic kidney disease who died in a VA facility from 2009–2015 (*n* = 9,993). They reviewed end-of-life care, dialysis, and family satisfaction of the last month of life, using the VA Bereavement Family Survey. Participants who died in a VA facility received aggressive care to extend life, with 54% of veterans spending 14 or more days in the hospital, 47% in the ICU, 36% receiving hospice services, and 38% receiving palliative care consults. Deaths by area included the ICU (31%), inpatient (27%), inpatient hospice or palliative care unit (26%), and nursing home (16%). Most veterans in this study did not receive dialysis (55%). Family satisfaction decreased with extended hospitalizations and intensive procedures. Family satisfaction increased when palliative care was consulted.

2007–2013, Advanced-Stage Lung Cancer

Sullivan et al. (2019) completed a retrospective study of veterans with advanced-stage lung cancer who died between 2007–2013 (*n* = 21,860) with palliative care consults. Palliative care consults were associated with increased deaths when referrals were made within 30 days of cancer diagnosis but were associated with longer survival when referred after 31 days. Most of the palliative care referrals in this study (76%) were initiated in the inpatient setting when veterans were acutely ill and death was imminent. Although the survival rate was shorter for these referrals, palliative care services decreased deaths in the hospital versus other settings. Benefits for those who had palliative care services for a more extended period included ongoing communication about preferences in care during different stages of illness. Sullivan et al. (2019) noted there were inconsistencies in the use of palliative care by VAMCs. Some VAMC's use of palliative care services was limited (5%), and some were higher (95%).

In the same study, Sullivan et al. (2019) focused specifically on hospice enrollment and discovered 70.3% of veterans were enrolled in hospice 27 days before death, and 14.7% were enrolled the last 3 days of life. Veterans with hospice services received radiation (36.6%) and chemotherapy (49%). Most hospice enrollees were White men, older (mean age of 68 years), with moderate to low income, higher functional comorbidity score, and Stage IV lung cancer. Variability was noted in geographic regions, with 77% hospice enrollment in the Southeast and 63.9% in the Northeast.

2008–2012, Surgical and Medical Specialties

Olmsted et al. (2014) completed a retrospective study of veterans who died between 2008–2012 (*n* = 191,280) with an acute inpatient hospitalization to determine the differences in referrals to palliative care and hospice for those followed by either medical teams or surgery teams. Veterans followed by the surgery team had fewer palliative care or hospice services (38.3% versus 41%) in their last year of life. Both groups' palliative care and hospice services increased (medical, 29% to 47%, and surgical, 19% to 24%), as did their number of days before referrals (medical, 22–25 days, surgical, 22–30 days). Surgical veterans tended to be male, younger, Black, and had more comorbid conditions.

2018–2019, Life-Sustaining Treatment

Miller et al. (2021) completed a retrospective study of veterans who had an LST note and died in 2019 with an inpatient hospital stay in the VA or a stay in a VA skilled nursing facility or community living center (CLC). The LST is a templated note in the medical record that addresses decision-making capacity, goals of care, and cardiopulmonary resuscitation status. The LST is completed with the veteran or their designated proxy decision maker. Veterans with comfort care preferences (80%) received less intensive care, consistent with their goals, with 57% receiving hospice services and reduced hospitalizations, including fewer ICU admissions (6% vs. 13% without LST).

Experiences of Family Members

2004–2010, Next-of-Kin Survey

Williams et al. (2016) interviewed the next of kin (NOK; *n* = 126) of veterans who had died 3–6 months prior between 2005 and 2010 to discuss comfort care services in the VA. The researchers identified a term, “ethic of heroism” (Williams et al., 2016, p. e1577) that conveyed NOK’s descriptions of the veteran’s patriotism and sacrifice in service. Military service was part of the veterans’ identities and influenced the family’s expectations of the VA’s services. NOK appreciated individualized care at the end of life as an act of recognizing the veteran’s military service. At times, NOK acted as an advocate for the veteran to ensure they received the care they felt the veteran deserved.

2007–2015, Caregiver Survey

Holland et al. (2014) studied the responses of caregivers who completed the Family Evaluation of Hospice Care survey (*n* = 560) between 2007–2015. Veterans were identified through medical records so researchers could compare responses of caregivers of veterans and nonveterans. Caregivers reported higher levels of sadness and anxiety in veterans, which Holland et al. suggested could be related to trauma from military service. Caregivers also reported a higher need for supportive services for the caregiver after the veteran died.

2009–2015, Advanced Chronic Kidney Disease Family Survey

Richards et al. (2019) completed a retrospective analysis of veterans with chronic kidney disease who died between 2009–2015 (*n* = 9,993) and reviewed the survey of family members’ views of end-of-life care from the Bereaved Family Survey, which had a 54% (*n* = 5,435) response rate. Family members reported low scores for aggressive care such as hospitalizations, surgical procedures, dialysis treatment, and deaths in the ICU. Families reported a higher quality of care when the focus was on comfort care and hospice services.

2011–2014, Deaths in VA Hospice or Palliative Care Unit

Carpenter et al. (2017) completed a retrospective study of veterans who died in a VA inpatient hospice or palliative care unit between 2011–2014 using the EMR and the Bereavement Family Survey (*n* = 5,592). Families reported a higher quality of care when palliative care consults were submitted 6 months before death, increasing in satisfaction starting at 1 week before death. The earlier palliative care referrals provided individualized care and ongoing communication about the progression of the illness and preferences in care. The earlier referrals also provided families with increased emotional care when spiritual support was provided through palliative or hospice care.

In summary, studies about hospice within the VA show an increase in quality of care when palliative care and hospice services are provided. Still, there are challenges in the timing of referrals and inconsistencies in the use of services.

Social Work Involvement in End-of-Life Care

Social workers in all settings will work with clients directly or indirectly impacted by illness and end-of-life (EOL) issues (Berkman & Stein, 2017; Otis-Green et al., 2019). Even if patients are considered terminal and are at the end of their lives, they may not receive advanced care planning (ACP), palliative care, or hospice care, so all social workers should be knowledgeable in end-of-life issues (Berkman & Stein, 2017).

Health social workers can integrate primary palliative social work skills into their practice, addressing the needs of chronically ill patients and aging populations (Sumser et al., 2015). Social workers can help patients and families through various settings and circumstances while providing education, counseling, support, and compassion to patients, family members, and the health care team (Otis-Green et al., 2019). In addition, social workers rely on their professional standards and the NASW code of ethics, which aligns with ACP. The following explores ACP studies involving social workers, as ACP encourages individuals to consider and communicate their future health care preferences for their medical care.

Survey Research with Medical Social Workers

Research on health care teams supports the presence of social workers on interdisciplinary teams. Still, there have been limited studies on social workers' responsibilities with ACP, as ACP has no standardized processes in place (Stein et al., 2017). Stein et al. surveyed social workers (n = 1,676) through the Social Work Hospice and Palliative Care Network and National Hospice and Palliative Care Organization to explore their involvement in ACP. The social workers in the study worked in community-based palliative care, inpatient palliative care, oncology, nursing homes, and private practice. Two surveys were completed with a second sample comprised of clinical social workers who saw patients (n = 456).

The study by Stein et al. (2017) showed palliative care social workers are involved in teams and provide education, discussions, and documentation. In the clinical social workers' study, 96.3% reported having ACP discussions, 93% reported leading discussions, and 67.8% reported documenting ACP. The study showed a difference in oncology and inpatient palliative care social workers who were less involved with the ACP process. The social workers who reported higher competencies also had more participation and led more ACP discussions (Stein et al., 2017).

Gutheil and Heyman (2011) surveyed NASW members (n = 844) in 2006 regarding their attitudes toward end-of-life planning. In particular, they asked about completion of a health care proxy, personal comfort, and professional training. In the study, social workers were grouped into (a) healthcare and aging and (b) general social workers. The social workers in healthcare and aging scored higher in all the areas. According to this study, social workers' attitudes regarding end-of-life planning are influenced by personal factors, such as individual completion of an end-of-life planning document, personal comfort with death, and years of experience. There was a significant difference in the group's continuing education, with 75% of the healthcare and aging social workers receiving end-of-life training versus around 33% of the general group.

A survey of social work students by Kwon et al. (2014) showed students had positive attitudes toward ACP and clients' self-determination. Students were willing to complete advance directives themselves and offer it to clients. The students' competence with discussions about death or life-sustaining treatments was related to experience with death. Another significant aspect of this study was race. Minority students were less comfortable with end-of-life issues. The writers noted this was important because social workers should be self-aware of their own cultural identity (NASW, 2015).

Intervention Studies with Medical Social Workers

Morrison et al. (2005) studied a half-day ACP training for nursing home social workers ($n = 4$). The intervention did not produce an increased number of advance directives but resulted in improved documentation of patient wishes so medical treatments were aligned with the patient's treatment goals. The researchers did not explore the social workers' level of experience or understanding as part of the study. Social workers were selected for the study based on their communication and counseling skills and frequent communication with patients and family members. Morrison et al.'s study was limited because of the number of participants, as one social worker left after the intervention. However, the study was significant because it reviewed chart documentation to capture the changes in treatment wishes. Only 5% of this documentation came from physicians remarking on ACP.

Gagliardi and Morassaei (2019) conducted a study to provide ACP training to inpatient hospital social workers (*n* = 26) in Canada. Social workers were provided with a 1-day training, debriefings every 4 weeks for 4 months, and a pretest and posttest. Barriers to completing ACP discussed by the social workers were, again, having the time to devote to in-depth conversations, communication with the physician, and uncertainty of the patient's ability or willingness to discuss ACP (Gagliardi & Morassaei, 2019).

Participants showed that their competence in ACP discussions increased from "36% to 82%" after the training (Gagliardi & Morassaei, 2019, p. 802). In addition to the increased confidence, documented conversations in the medical record increased at the end of the study. The social workers in the study supported ACP and reported ACP was consistent with social work values and scope of practice. This also supported a consensus that health care workers see the benefits of ACP (Jimenez et al., 2018; Ke et al., 2015).

Studies addressing barriers to and training in advance care planning specifically for social workers are limited. However, Berzoff et al. (2020) carried out a study that provided training to renal social workers in dialysis clinics. Renal patients are a high-risk population, and those on dialysis are an average of 75 years old. Those with comorbidities have a 60% greater likelihood of death. Studies have shown only about 50% of patients on dialysis have completed an advance directive (Feely et al., 2016). Under the End Stage Renal Disease Conditions for Coverage mandate through CMS, patients have a right to be informed about advance directives. Social workers should assist if needed (Centers for Medicare and Medicaid Services, 2018).

The 17 social workers in Berzoff et al.'s (2020) study received an 8-hour training focused on "clinical practice, leadership, culture and spirituality, and legal and ethical issues" (p. 10). The training was led by a physician, social workers, and a lawyer through video conference. After the training, two social workers led an ongoing supervision group. Unfortunately, not enough posttests could be completed due to high turnover, with half of the staff leaving their positions, so the effectiveness of the training could not be evaluated. Although the validity of the training could not be determined, some useful information came out of the pretests about the specific issues social workers in the dialysis clinics had to consider. The main issue was renal social workers who were less experienced were more anxious about ACP discussions and were concerned about upsetting patients. Another issue was time. Half in the study reported concerns about finding the time to complete ACP discussion with high caseloads of up to 150 patients. Several noted having difficulty meeting with the nephrologist to discuss complex cases.

In an intervention by Singh et al. (2021), social workers were consulted to complete a medical durable power of attorney form. Care managers screened hospitalized patients and, if a medical durable power of attorney had not been completed in the previous year, a consult was sent to the social workers. Social workers were provided with a 1-hour training, and information was sent to hospital staff. The intervention resulted in a 13% increase in medical durable powers of attorney.

Education and Training

The Institute of Medicine (2015) report recommended health care workers improve their knowledge about end-of-life issues through education or certifications. Although NASW has established competencies and certificates, no social work certifications are needed to work in specialty fields such as palliative care or health care (Thiel et al., 2020). Literature reviews have supported the need for social workers and health care workers to receive training and ongoing communication about ACP, as few clinicians have been educated to engage in these discussions (Austin et al., 2015; Combes et al., 2019; Jimenez et al., 2018; Pearlman et al., 2005). Few organizations have prioritized the development of ACP programs, despite universal recognition of the relevance of ACP (Otis-Green et al., 2019). Social workers' understanding of ACP has not been received through educational courses or training, but, instead, skills have been developed by learning from colleagues and team members (Stein et al., 2017; Sumser et al., 2015). Health care providers who receive ACP training reported being more responsive and confident to promote ACP dialogues (Antonacci et al., 2020; Jimenez et al., 2018).

Weisenfluh and Csikai (2013) surveyed hospice and palliative care social workers (n = 1,169) recruited through end-of-life listservs and professional websites to study their professional activities and educational needs. Although most of the respondents (70%) were aware of the Advanced Certified Hospice and Palliative Care Social Worker certificate offered by NASW, only 11% had received certification. The social workers in the study had limited membership in end-of-life organizations, with 19.3% being members of the Social Work Hospice and Palliative Care Network and 25% members of the National Council of Hospice and Palliative Professionals. There was also limited conference attendance, with 45.3% attending hospice and palliative care conferences. Participants received most of their training from in-service trainings, local workshops, and online education. The barriers given for limited professional activity were cost, lack of related content, and lack of support from employers. Participants wanted training in direct care with patients and family members in grief, family dynamics, and cultural awareness and diversity.

Cultural Competency

Cultural competency is an area that necessitates more ongoing education. Social workers may have end-of-life discussions with persons of varying ages, disabilities, religious affiliations, ethnicities, cultural groups, immigrant status, cognitive levels, and literacy levels. NASW addresses cultural competency in the code of ethics (NASW, 2021) and the Standards and Indicators for Cultural Competence (NASW, 2015). NASW (2015) defined cultural competence as the

> process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic backgrounds, religions, spiritual traditions, immigration status, and other diversity factors in a manner that recognizes, affirms, and values the worth of individuals, families, and communities and protects and preserves the dignity of each. (p. 15)

Cultural differences and religious beliefs can be challenging when providing end-of-life care (Rajdev et al., 2018). Social professionals can help patients and families navigate the ACP process by employing cultural humility and awareness skills (Otis-Green et al., 2019). Francoeur et al. (2016) discussed social work assessment as an opportunity for social workers to explore spirituality or religious preferences with patients and families. Arthur (2015) noted cultural considerations are important for the lesbian, gay, bisexual, transgender population. Assessments can help determine what cultural issues or experiences impact the client’s current needs. Nedjate-Haiem et al.’s (2013) study of healthcare providers’ interactions with Latino patients showed advocacy and empowerment were needed when working with Latino patients due to language, medical terminology, and social and economic barriers. According to Combes et al. (2019), when discussing ACP with the frail elderly it is important to consider starting conversations early and reframing end-of-life discussions to focus on present and future care goals. For homeless individuals, trauma, loss, religion, and prejudice or abuse from health care providers may influence their perspectives on death and ACP (Hubbell, 2017; Tarzian et al., 2005).

Conclusions From the Literature

The VA has created initiatives to improve the quality of life for dying veterans. However, there are still opportunities to improve the frequency and timing of palliative care and hospice services. Social workers could assist with advocating for veterans to make their end-of-life preferences known. Still, it appears social workers' knowledge about how to communicate end-of-life goals is not sufficient (Gutheil & Heyman, 2011). Social workers and social work students' understanding of end-of-life care appears to be minimal, with social workers reporting that their knowledge of end-of-life care comes mostly from continuing education programs or peers (Wang et al., 2017). Training on end-of-life issues could help underprepared social workers provide dying patients and their families with individualized care (Gagliardi & Morassaei, 2019). NASW (2015) has supported social workers attempting to understand the cultures of those they serve and approaching each person with care and respect.

CHAPTER THREE

METHODOLOGY

Research Design

In this study, the researcher explored the challenges surrounding end-of-life care discussions and delays in hospice referrals in a veteran affairs medical center (VAMC). This mixed method study was conducted by initially analyzing secondary data from the VAMC's hospital database of hospice referrals. Then, a phenomenological approach, using interviews with social workers to formulate hypotheses about factors that lead to slow referrals to hospice, led to a better understanding of the factors from the secondary data.

The Veterans Health Administration (VHA) is the nation's largest employer of social workers (VA, 2021a). The VAMC in this study, which opened in 1932, is a 206-bed, level 1C teaching hospital with nearly 2,900 employees. An estimated 150 of these employees are social workers. The health care system serves 83,000 veterans each year and consists of a medical hospital, inpatient psychiatric facility, outpatient mental health department, and seven community-based outpatient clinics (VA, 2021b). VA medical centers are accredited by The Joint Commission, which certifies health organizations (VA, 2017; The Joint Commission, 2021).

Quantitative and Qualitative Approaches

Initially, a quantitative retrospective analysis of the existing data of hospice consults was considered, but, ultimately, a mixed methodology approach was used due to the advantages it afforded in exploring both quantitative and qualitative data to understand the complexities of the topic (Creswell & Creswell, 2020). Greene et al. (1989), in fact, affirmed the benefits of a mixed method approach, such as reducing biases and employing triangulation, which increases the credibility of results by using more than one approach to validate findings. An additional benefit is complementarity, which can provide different perspectives to enhance understanding of a phenomenon.

Hospital Records (Quantitative)

Secondary analysis, the review of information already collected (Thyer, 2010), is useful in supporting a research study. Direct observation may be unavailable, but data may be available to explore a phenomenon occurring simultaneously or in the past (Riedel, 2000). The retrospective data in this study were the secondary data obtained from the VAMC. The quantitative data collected in the study’s first phase were the hospice referrals submitted within the VAMC from 2015–2020 using the Veterans Health Information Systems and Technology Architecture (VISTA) program and data from the Computerized Patient Record System (CPRS). The researcher examined reasons for the inability to move forward with hospice services in CPRS, starting with the initial hospice consult submitted by a VA provider. Data related to the referrals included (a) date of palliative care/hospice consult, (b) date of completion of palliative care/hospice consult, (c) results of the palliative care/hospice consult, (d) do not resuscitate and do not intubate status, (e) life-sustaining treatment documentation, (f) completion of advance directives, (g) source of referral (e.g., primary care provider, specialty care provider), (h) hospice diagnosis, (i) date of death, (j) demographic information (e.g., age, race, marital status, insurance information, and service connection), (k) decision-making capacity of veterans, (l) involvement of surrogate decision maker, (m) aggressive care (e.g., hospitalizations, cancer treatment, and deaths in the hospital), and (n) social work involvement.

Statistical analysis was completed using SPSS. The retrospective data helped guide the qualitative phase by informing the focus and formulation of open-ended questions, which, in turn, helped expose interactions among the variables (Creswell & Creswell, 2020).

VA Social Workers (Qualitative)

Using a phenomenological approach, qualitative interviews were conducted with five social workers to provide depth and understanding to complicated issues of end-of-life care (Thyer, 2010). Husserl is attributed as the philosopher who first applied the ideas of phenomenology to social science (Moustakas, 1994). Patton (2014) explained the phenomenological approach as the researcher studying a problem through the emotions and interpretations of those involved in the phenomena toward a shared meaning of the experience. The VA social workers contributed to an understanding of the phenomenon of hospice referrals through interviews and synthesis of all information (Patton, 2014).

During these semistructured interviews, the researcher presented the topic of hospice referrals and gave the VA social workers an opportunity to describe and explain their relationships to the phenomenon (Moustakas, 1994). The information was analyzed several times, as recommended by Giorgi (1979), which led to the uncovering of themes and process information to help provide meaning.

Mixed Methods Design

An explanatory sequential mixed methods design was selected. Quantitative data from a retrospective analysis of VA data were collected in the first phase. The quantitative data collected helped guide the second phase through the questions asked during the qualitative interviews (Creswell & Creswell, 2020). Then, analysis of the qualitative interviews helped explain the quantitative data (Creswell & Plano Clark, 2017).

Sampling

Hospital Records (Quantitative)

Data from the VA VISTA program were used to capture all hospice consults from the VAMC from January 2015 through December 2020. This resulted in 834 referrals that were downloaded and renamed to maintain confidentiality. A random sample at a 95% confidence level with a 5% confident interval was used, and, thus, 262 records were randomly selected among the 834 records using the random sample feature in SPSS.

VA Social Workers (Qualitative)

In purposive sampling, individuals who can help the researcher understand the topic are chosen as participants (Creswell & Creswell, 2020). Considerations for the number of participants in a qualitative study are that the sample provides detailed and meaningful information about the topic (Creswell & Clark, 2017) and they represent the population (Bock & Sergeant, 2002). There were 140 social workers working in the VAMC; 70% were female and 30% were male. Thus, for the phenomenon of hospice referrals, the sample was comprised of five VA social workers (four female and one male). Social workers in the VAMC who were recruited had been assigned a caseload, provided case management services, and had worked at the VAMC for at least 5 years. Basic demographic data were also collected, such as age, education, and years of experience. Interviews were recorded through Zoom, transcribed, and then analyzed through NVivo. Handwritten notes were transcribed during the interviews to note any nonverbal communication.

This study incorporated three of Creswell and Creswell's (2020) strategies that indicate trustworthiness: (a) triangulation, (b) member checking, and (c) thick descriptions. Triangulation was attempted by comparing the themes revealed by the retrospective analysis and those revealed by the qualitative interviews (Creswell & Creswell, 2020). Member checking was carried out in this study by providing participants with the outcomes of the interviews. Thick descriptions (Geertz, 1973), which provide a complete and in-depth view of the topic, were presented through the descriptions and discussion of the topic and findings (Rodwell, 1998).

To clarify any potential biases, a statement was provided to participants about the researcher's employment at the VAMC and how the study results could be influenced by the researcher's history and experience with participants. Riedel (2000) provided guidelines for reliability and validity when working with secondary data, such as becoming familiar with the data and any weaknesses in the data, while also reviewing agency practices that may impact data gathering. The researcher remained aware of maintaining balance or fairness in participant representation and the analysis of results, an important characteristic of the constructivist approach.

Data Collection

Hospital Records (Quantitative)

In the study, the researcher explored the reasons for hospice delays and social work involvement in one VMAC. The VMAC is one of two VA medical systems that provides medical care for veterans in a southern state. Data from the VISTA program were used to identify all palliative care and hospice consults in the VMAC from January 2015 through December 2020. The electronic medical record (EMR) of all veterans with palliative care and hospice referrals from January 2015 through December 2020 were reviewed through the CPRS to capture recent information before the complications of COVID-19.

For this study, the following variables were obtained from the CPRS: (a) date of palliative care/hospice consult, (b) date of completion of palliative care/hospice consult, (c) results of the palliative care/hospice consult, (d) do not resuscitate and do not intubate status, (e) life-sustaining treatment documentation, (f) completion of advance directives, (g) source of referral (e.g., primary care provider, specialty care provider), (h) hospice diagnosis, (i) date of death, (j) demographic information (e.g., age, race, marital status, insurance information, and service connection), (k) decision-making capacity of veterans, (l) involvement of surrogate decision maker, (m) aggressive care (e.g., hospitalizations, cancer treatment, and deaths in the hospital), and (n) social work involvement.

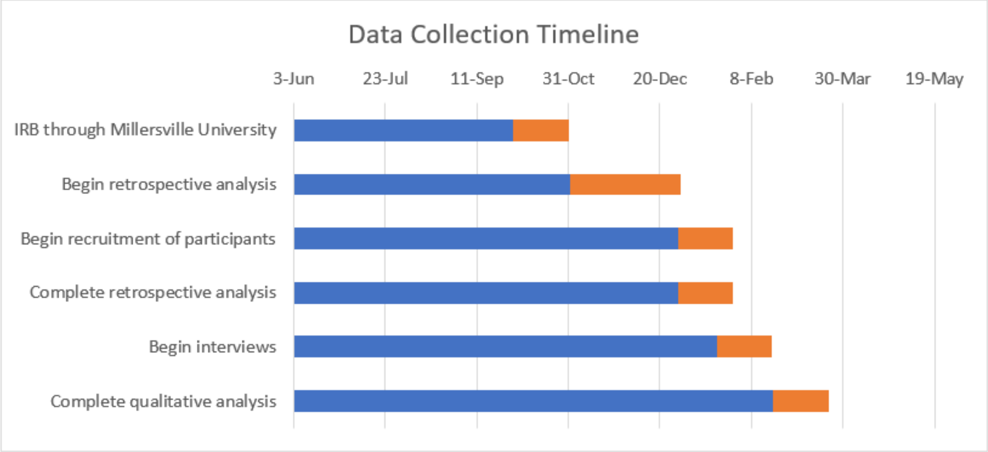
VA Social Workers (Qualitative)

An email was sent to the social work department to recruit participants who worked at the VA for at least 5 years and who directly provided case management services to veterans (see Appendix A). Participants were selected to reflect the gender population of the social work department.

The email included information about the study, how the information would be used, and the option to withdraw at any time (see Appendix A). Participants were given an informed consent form (see Appendix B). The interviews were conducted individually and recorded through Zoom using semistructured questions. The questions were based on the retrospective analysis, which helped determine the themes explored through the interviews. General questions were created and further developed based on the quantitative analysis. Observations of the interviews were handwritten and noted the setting of interviews, researcher reflections, and descriptions of the participants, as recommended by Creswell and Creswell (2020). The interviews were transcribed and coded as part of the process of developing themes through NVivo. The data collection timeline is presented in Figure 1.

Figure 1

Data Collection Timeline



Institutional Review Board

This study that included a retrospective analysis of the EMR and qualitative interviews of VA social workers was exempted from institutional review board review of the VAMC research department. The data collected were considered a process improvement project. A human subjects review protocol form was submitted to the Millersville University Institutional Review Board.

Data Analysis Methods

Quantitative Analysis of the Electronic Patient Record Data

In this study, secondary data was obtained from the VISTA program and the VA CPRS IBM SPSS (Version 25) was used to perform descriptive and exploratory data analysis and crosstabulation of the secondary data. Additionally, correlations among select interval/ratio level variables were used to detect significant relationships that may have been worth exploring in the qualitative interviews. Lastly, mean comparisons of delay times among demographic (group) variables were explored that lead to the development of the qualitative interviews.

Qualitative Analysis of the Interview Data

The quantitative data aided in the formulation of the qualitative interview questions because it led to identification of deviations in expectations or constraints in the flow of decision making. Thus, the qualitative interviews and researcher notes and observations were transcribed and coded in NVivo (2018) to develop an understanding of social workers' involvement working with veterans, families, and interdisciplinary teams in hospice referrals. An inductive thematic approach of engaging the data was used to analyze the data (Lincoln & Guba, 1985), followed by identifying codes that were developed into themes (Braun & Clarke, 2006). Both sets of data were analyzed separately and then studied by "connecting the quantitative results to the qualitative data collection" (Creswell & Creswell, 2020, p. 243). The qualitative interviews helped explain and illuminate the secondary data analysis (Creswell & Creswell, 2020). Member checking was incorporated by providing participants with the outcomes of the interviews and analysis. Participants reviewed and provided feedback on accuracy. The reasons found in the EMR for delays or refusal of hospice services were categorized into themes, which were ranked by how common or uncommon they were and then explored further through the qualitative interviews with VAMC social workers.

CHAPTER FOUR

FINDINGS

In this chapter, the quantitative and qualitative results of the study are described in detail. The quantitative data provided information from a randomized sample of hospice consults from the Veterans Affairs Medical Center's (VMAC) hospital database, and the qualitative data provided information from semi-structured interviews of social workers working in the hospital. This mixed methods approach was used to answer the research questions:

1. What are the barriers to hospice?
2. How are social workers involved in the process?

Quantitative Results

A sample of 262 hospice consults was analyzed from January 1, 2015 to December 31, 2020. This section describes the results of this analysis.

Demographics

Table 1 shows the descriptive statistics of the sample. The sample size reflected more males (96%) than females (4%) and fewer people of color (39%). This is consistent with the population the Veterans Administration (VA) serves, as White males (61%) are more prevalent than females (8%) and people of color (27%; Huang et al., 2018). Fewer than half of the veterans were married (40.8%), and the majority were divorced (24.4%), widowed (20.6%), single (11.8%), or separated (2.3%). Most had insurance coverage (86.3%) and had the choice of receiving medical care outside the VA, although 36 (13.7%) did not have insurance. The ages of the veterans ranged from 47 years to 101 years (*SD* = 10.639, *M* = 75.26) showing a bimodal distribution with a peak at 68 and 89 years (see Figure 2).

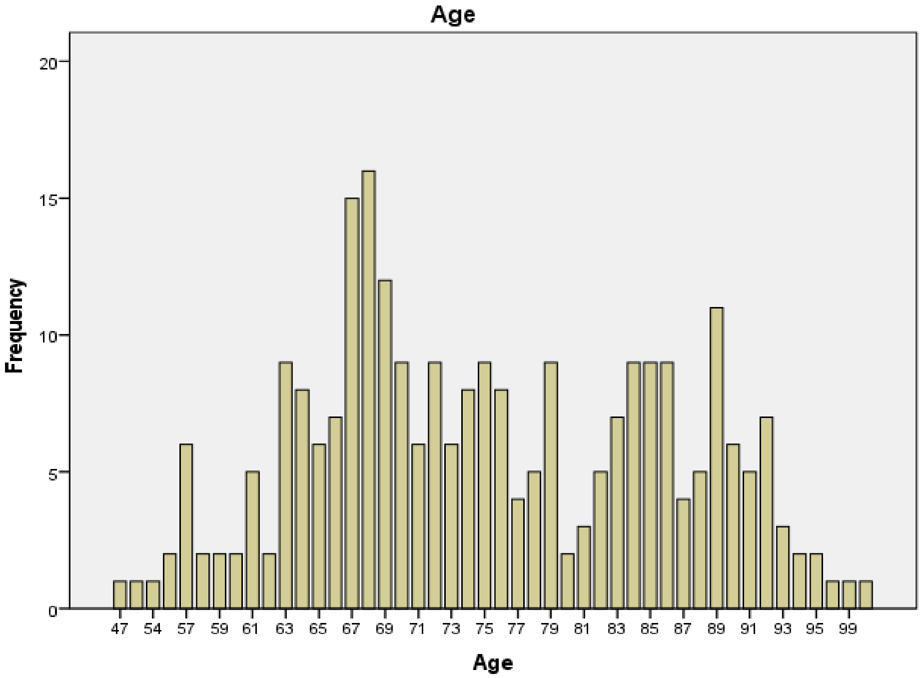
Table 1

Sample Demographics

Variable	*n*	%
Gender		
Male	252	96.2
Female	10	3.8
Race/Ethnicity		
White	159	60.7
Black	100	38.2
Hispanic	1	0.4
Native American	1	0.4
Native Hawaiian	1	0.4
Marital status		
Married	107	40.8
Divorced	64	24.4
Widowed	54	20.6
Single	31	11.8
Separated	6	2.3
Insurance		
Yes	226	86.3
No	36	13.7

Figure 2

Age at Time of Referral



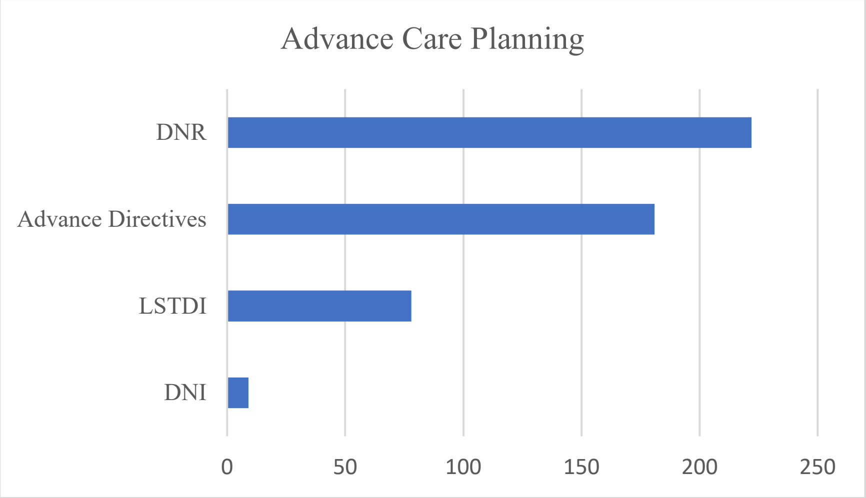
Q1. What are the Barriers to Hospice?

Advance Care Planning

Most patients had advance care planning in place (98%, *n* = 257) to include do not resuscitate (DNR; 84.7%, *n* = 222), advance directives (AD; 69.1%, *n* = 181), life-sustaining treatment decisions initiative (LSTDI; 29.8%, *n* = 78) and do not intubate (DNI; 3.4%, *n* = 9; see Figure 3).

Figure 3

Advance Care Planning

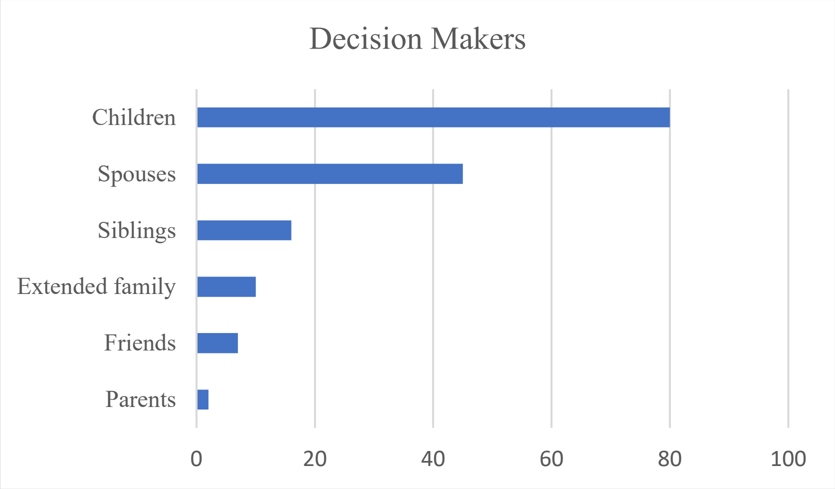


Decision Maker

Surrogates made more healthcare decisions (61.1%, *n* = 160) than patients themselves (38.9%, *n* = 102). Adult children (*n* = 80) made most of the decisions, followed by spouses (*n* = 45), siblings (*n* = 16), extended family (*n* = 10), friends (*n* = 7) and parents (*n* = 2; see Figure 4). In some cases (*n* = 24), the decision making changed from the patient to the surrogate during the consult. Dementia was noted in the primary medical history in almost a quarter of patients (22.1%).

Figure 4

Decision Makers

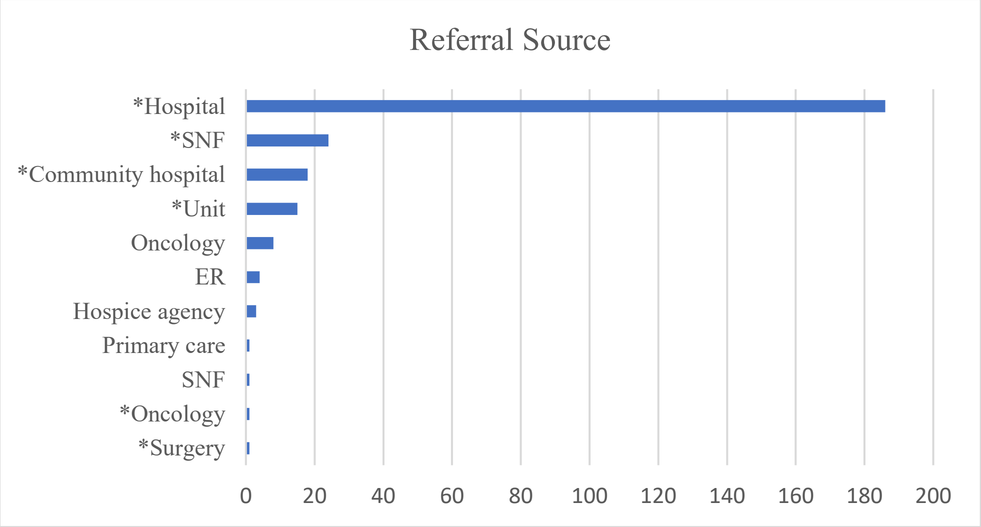


Consults

Most hospice consults were completed within 1 day (*M* = .97, *SD* = 1.09). Only a few consults (1.5%, *n* = 4) did not meet hospice criteria. Cancer (51.1%, *n* = 134) was the reason for more than half of the referrals. Most of the referrals were inpatient referrals (95%, *n* = 249), including community hospitals (*n* = 18). Inpatient consults in the VA were generated by the inpatient general hospitalists (*n* = 186), inpatient nursing home (*n* = 24), inpatient unit providers (*n* = 15), emergency department (*n* = 4) and inpatient oncologists (*n* = 1). Outpatient referrals (*n* = 13) included those submitted by the oncology clinic (*n* = 8), hospice agencies (*n* = 3), nursing homes (*n* = 1) and primary care (*n* = 1; see Figure 5).

Figure 5

Referral Source



Note. Sources with an * were inpatient referral sources.

Hospice

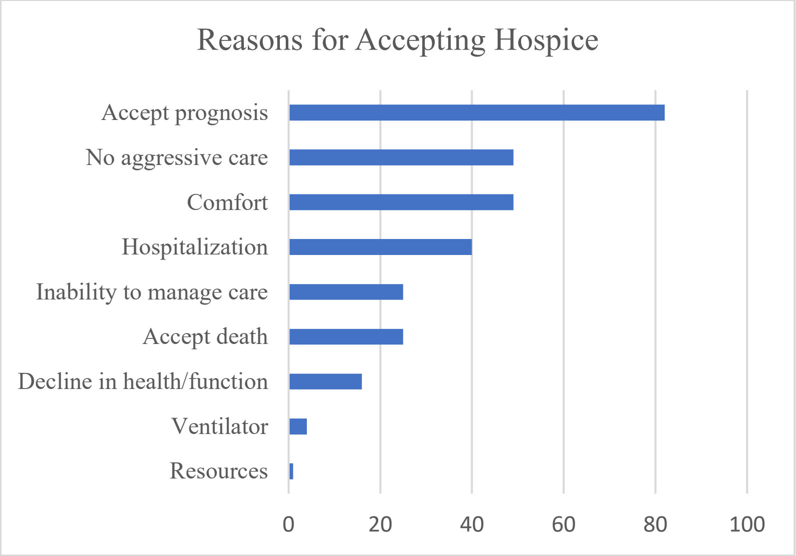
Most hospice consults (92%, *n* = 241) were accepted by patients and surrogates. Most patients and surrogates (95%, *n* = 252) had discussions with providers before the hospice team answered the hospice consult. Of those who accepted hospice, the majority (80.9%, *n* = 212) accepted the same day, although some (17.6%, *n* = 46) took longer to decide.

Acceptance

More than half (61.8%, *n* = 162) of the reasons for hospice acceptance were available in the records, but some (38.2%, *n* = 100) were not clear. The most cited reason for receiving hospice care was accepting the prognosis (31.3%, *n* = 82), followed by keeping the patient comfortable (18.7%, *n* = 49), not wanting aggressive care (18.7%, *n* = 49), recent hospitalization (15.3%, *n* = 40), inability to manage care at home (9.5%, *n* = 25), decline in health/functional status (6.1%, *n* = 16) and needing resources at home (.4%, *n* = 1; see Figure 6).

Figure 6

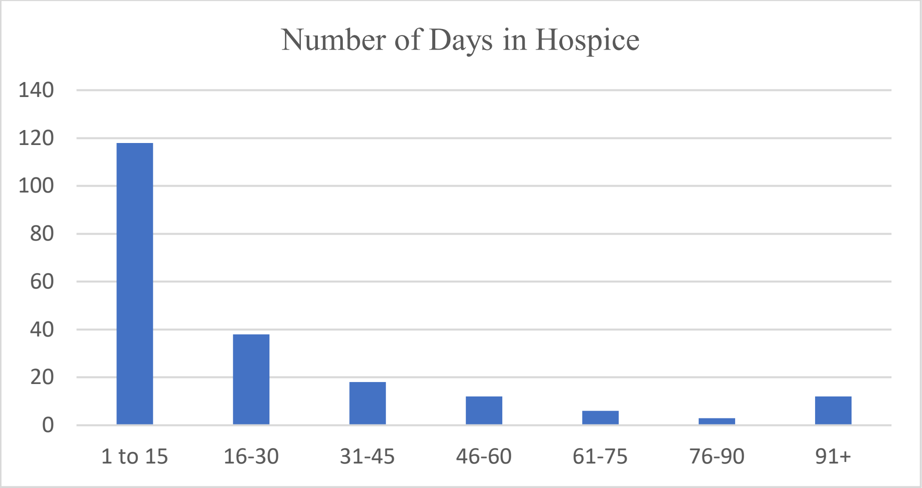
Reasons for Accepting Hospice



The number days in hospice ranged from 0 to 639 (*M* = 29.5, *SD* = 64.68), with 0 meaning hospice was accepted but these patients died before services could be started. Most patients received hospice services for 1–15 days (45%, *n* = 118), followed by 16–30 days (14.5%, *n* = 38), 31–45 days (6.9%, *n* = 18), (6.9%, *n* = 18), 46–60 days (4.6%, *n* = 12), 91+ days (4.6%, *n* = 12), 61–75 days (2.3%, *n* = 6), and 76–90 days (1.1%, *n* = 3; see Figure 7).

Figure 7

Number of Days in Hospice

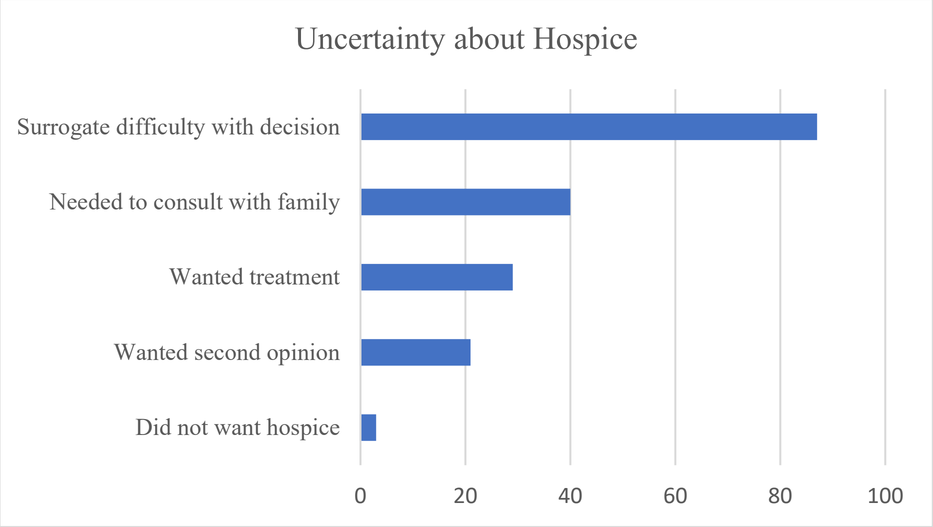


Uncertainty

Although 92% of hospice consults were accepted, the 8% of patients and surrogates who did not feel completely comfortable with hospice gave several reasons for their uncertainty. In many cases, the surrogate had difficulty making a decision (48.3%, *n* = 87), some had to consult with family or caregivers (22.2%, *n* = 40), and others wanted treatment (16.1%, *n* = 29) or a second opinion (11.7%, *n* = 21). A few stated they did not want hospice services (17%, *n* = 3; see Figure 8).

Figure 8

Uncertainty About Hospice

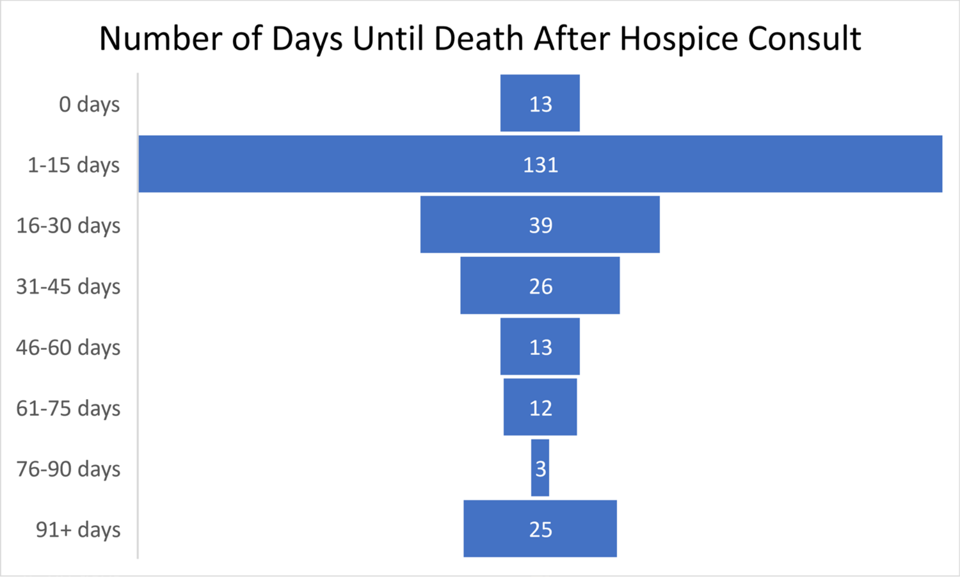


Deaths

The number of days until death after a hospice consult took place ranged from 0 to 819 (*M* = 4.61, *SD* = 100.65), following a skewed curve, with most deaths occurring between 1–15 days (*n* = 131), followed by 16–30 days (*n* = 39), 31–45 days (*n* = 26), 91+ days (*n* = 25). Small proportions experienced death at 46–60 days (*n* = 13), zero days (died the same day, *n* = 13), 61–75 days (*n* = 12), and 76–90 days (*n* = 3; see Figure 9).

Figure 9

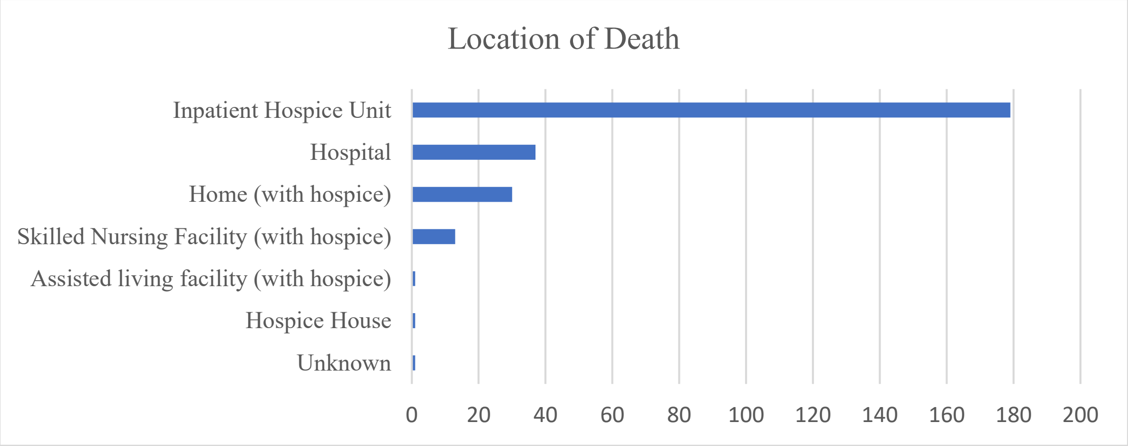
Number of Days Until Death After Hospice Consult



The location of deaths with and without hospice was tracked in medical records. Most deaths occurred in the inpatient hospice unit (68.3%, *n* = 179), followed by in the hospital (13%, *n* = 34), home with hospice (11.5%, *n* = 30), nursing home with hospice (5%, *n* = 13), assisted living facility with hospice (.4%, *n* = 1), a hospital in the community (.4%, *n* = 1), hospice house (.4%, *n* = 1), and unknown (.4%, *n* = 1; see Figure 10).

Figure 10

Location of Death



Q2. How are Social Workers Involved

Social Work Involvement

Social workers were involved in most cases (88.6 %, *n* = 227). There was more social work involvement with the inpatient referrals (*n* = 224, 85.5 %) than outpatient referrals (*n* = 3, 1.1%). The main reason social workers did not see the remaining patients was because they had a length of stay in the hospital of less than 4 days (65.7%, *n* = 23), and this was not sufficient time for social workers to get involved with hospice discussions. In terms of licensing, there was a similar rate of involvement between social workers who had their LMSW (39.6%, *n* = 104) and LISW (33.9%, *n* = 89) and cases where both groups were involved (14.1%, *n* = 37; see Table 2).

Table 2

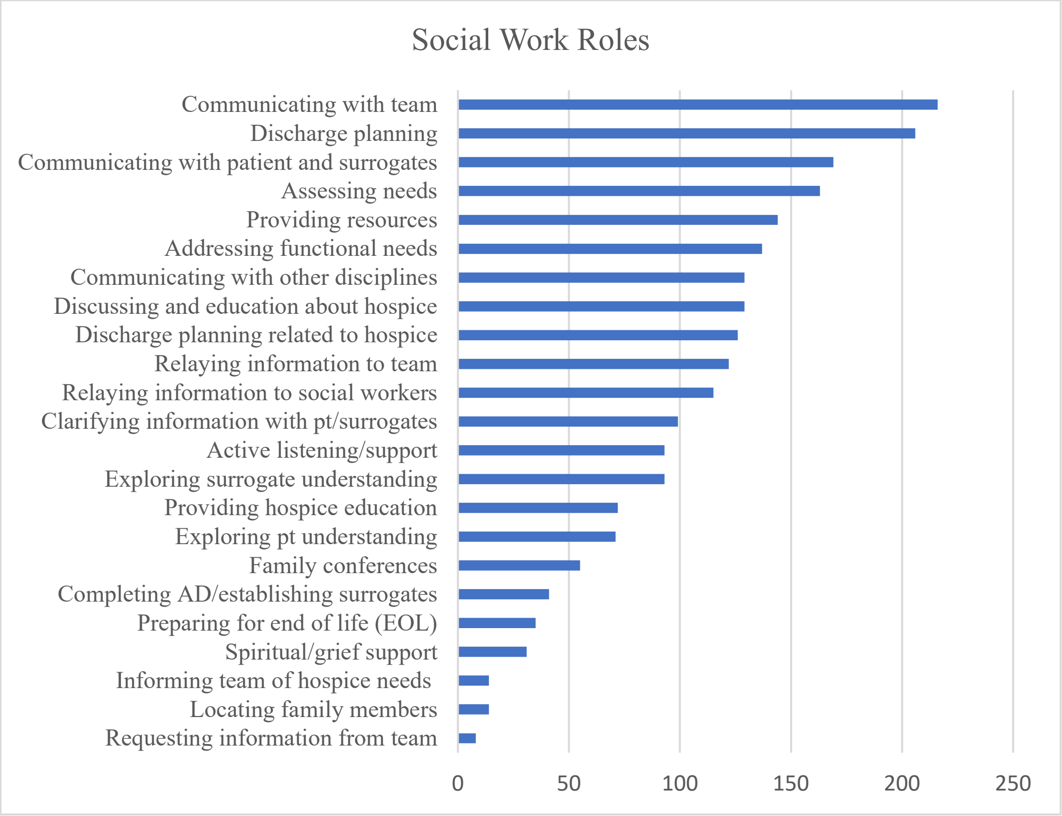
Social Work Involvement

Variable	*n*	%
Social work involvement		
Yes	227	88.0
No	35	12.0
Location of services		
Inpatient	224	89.95
Outpatient	3	23.07
License		
LMSW	104	39.6
LISW	89	34.0
Both	37	14.1

Social workers engaged in hospice discussions in two primary ways: (a) working with the interdisciplinary team and (b) working directly with the patient and surrogates. The most noted role was communicating with a team (82.4%, *n* = 216), followed by discharge planning (78.6%, *n* = 206), communicating with other disciplines (49.2%, *n* = 129), relaying information to the team (46.6%, *n* = 122), family conferences (21%, *n* = 55), informing the team of hospice needs (5.3%, *n* = 14), and requesting information for patient or surrogates (3.1%, *n* = 8). Social workers communicated with patients, surrogates, and family members (64%, *n* = 169). The most noted tasks for social workers were assessing needs (62.2%, *n* = 163), followed by providing resources (55%, *n* = 144), addressing functional needs (52.3%, *n* = 137), providing hospice education (49.2%, *n* = 129), discharge planning (78.6%, *n* = 206), discharge planning related to hospice (48.1%, *n* = 126), relaying information to social worker (43.9%, *n* = 115), helping patients and surrogates clarify/understand information (37.8%, *n* = 99), active listening (35.5%, *n* = 93), exploring surrogate understanding (37.8%, *n* = 93), providing hospice education (27.5%, *n* = 72), exploring patient understanding (27.1%, *n* = 71), completing advance directives/establishing surrogates (15.6%, *n* = 41), end-of-life support (13.4%, *n* = 35), spiritual and grief support (11.8%, *n* = 31), informing team of hospice needs (5.3%, *n* = 14), and locating family members (5.3%, *n* = 14; see Figure 11).

Figure 11

Social Work Roles



Inferential Statistics

Predictions related to the research questions are described in this section. Analysis was completed using chi-square tests.

Q1. What are the Barriers to Hospice?

Acceptance of Hospice

It was predicted that acceptance of hospice would vary based on marital status, race, decision-maker, diagnosis of dementia, completion of advance directives and social work involvement. Results showed an association between hospice acceptance and both marital status ($\chi^2 = 22.08$, $df = 8$, $n = 262$, $p = .005$) and decision-maker ($\chi^2 = 22.57$, $df = 12$, $n = 262$, $p = .032$). No associations were found between hospice acceptance and race ($\chi^2 = 4.44$, $df = 8$, $n = 262$, $p = .815$), dementia diagnosis ($\chi^2 = .863$, $df = 2$, $n = 262$, $p = .649$), completion of advance directives ($\chi^2 = .588$, $df = 2$, $n = 262$, $p = .745$), or social work involvement ($\chi^2 = 1.526$, $df = 2$, $n = 262$, $p = .466$).

Length of Stay in Hospice

It was predicted length of stay in hospice would vary based on age, diagnosis, source of referral, and location of death. There was no association between length of stay in hospice and age ($\chi^2 = 3113$, $df = 3080$, $n = 262$, $p = .330$). However, length of stay in hospice was associated with diagnosis ($\chi^2 = 4126.93$, $df = 3780$, $n = 262$, $p < .001$), source of referral ($\chi^2 = 751.26$, $df = 630$, $n = 262$, $p = .001$), and location of death ($\chi^2 = 560.37$, $df = 350$, $n = 262$, $p < .001$; see Table 3).

Table 3

Inferential Statistics

Prediction	Association	No association
Acceptance of hospice		
Marital status	x	
Decision maker	x	
Race		x
Dementia		x
Advance directives		x
Social work involvement		x
Length of stay in hospice		
Diagnosis	x	
Source of referral	x	
Location of death	x	
Age		x

Qualitative Results

The purpose of this study was to explore, through semi-structured interviews, social workers' awareness of barriers to hospice and the social workers' involvement in the hospice referral process. The questions for the interviews included the following:

- What is your comfort level in discussing end-of-life issues and hospice?
- Tell me about your last experience working with a patient or family with hospice.
- What are some typical responses patients or surrogates have when hospice is first discussed?
- What are some challenges in getting hospice set up?
- What are some reasons hospice was accepted?
- Tell me how social workers can support patients at the end of their life.

Description of Research Participants

Using purposive sampling, five participants were recruited from a VA hospital to explore their understanding of barriers to hospice and their roles with hospice as social workers. All were social workers with at least 5 years of experience at the VA, and all had a caseload. One participant was a veteran. As described in the methodology, participants consented to one-on-one semistructured interviews through Zoom with a follow-up phone interview to review research findings as a means of improving reliability and validity. Copies of the consent form were provided to the participants (see Appendix B). The participants completed a demographic questionnaire that provided the following information: gender, age group, race, licensure, certificates, years worked at the VA, and years worked as a social worker.

Participants included four females and one male. The ages of the social workers were 25–34 (*n* = 2), 35–44 (*n* = 1), 45–54 (*n* = 1) and 55–64 (*n* = 1). Three participants self-identified as White and two as Black. All had their social work license, with the majority having their independent license (LISW; *n* = 3). The remaining had a master's (LMSW; *n* = 2) in social work. Both LMSWs were pursuing independent licenses. One social worker had a certificate in gerontology and alcohol and drug addiction, one in health and mental health, and another in prolonged exposure and rational emotive behavior therapy. The five social workers practiced in various areas of the VA, including the hospital (*n* = 2), caregiver program (*n* = 1), community health program (*n* = 1), and post 9/11 veterans transitioning out of service (*n* = 1). Participants' years of employment at the VA ranged from 6–13 years. The total number of years each participant had served as a social worker ranged from 6–30 years. Three social workers had experience working outside the VA, but the VA was the first job for two. Several participants expressed preparing for end-of-life and hospice care was important. See Table 4 for demographic data. In the description and discussion that follow, participants are numbered and referred to with an S for social worker (S1, S2, S3, S4, S5).

Table 4

Demographics of the Social Workers

Variable	*n*
Gender	
Female	4
Male	1
Age	
25–34	2
35–44	1
45–54	1
55–64	1
Race/Ethnicity	
White	3
Black	2
License	
LISW	3
LMSW	2
Areas of practice	
Hospital	2
Caregivers	1
Community health	1
Post 9/11 veterans	1
Years of experience in VA	
5–7	2
8–10	2
11–13	1
Years of experience total	
5–7	2
8–10	0
11–13	2
14+	1
Specialized training in EOL	
Yes	1
No	4

Qualitative Data Collection

An email was sent to the social work department requesting volunteers who met the inclusion criteria of working at the VA for at least 5 years, providing case management services, and having a caseload of patients (see Appendix A). Five participants responded to the email.

Consents were obtained (see Appendix B), and then individual interviews were set up. Interviews ranged from 30 minutes to 50 minutes and were recorded through Zoom. Interviews were then transcribed and coded in NVivo. Reliability was achieved by writing detailed notes, memos, and transcribing audio recordings of the interviews (Creswell & Poth, 2017).

Interview questions were developed from the quantitative analysis to gain a deeper understanding of the challenges surrogates and families experience when making decisions and to explore the research questions. Codes were identified from interview transcripts, revealing some themes were present in all the interviews, and some were not. Member checking was completed by reviewing the outcomes of the interview with each participant. All participants validated the themes that emerged.

The following semistructured questions were asked during the interviews:

1. What is your comfort level in discussing end-of-life issues and hospice?
2. Tell me about your last experience working with a patient or family with hospice.
3. What are some typical responses patients or surrogates have when hospice is first discussed?
4. What are some challenges in getting hospice set up?
5. What are some reasons hospice was accepted?
6. Tell me how social workers support patients at the end of their life.

Research Question 1—Barriers to Hospice

An overview of the three themes related to barriers to hospice can be found in Table 5. The most common theme to emerge when investigating barriers to hospice was the Lack of Conversations about end-of-life care and hospice. This theme had 100 references in NVivo. Three subthemes surfaced in the interviews helped explain the lack of conversations about hospice. These were Families Not Having Discussions, Hesitancy of the Medical Team to Discuss Hospice, and Lack of Follow-Up. The second most common theme to appear in the interviews was Challenges Making Decisions with subthemes of Death Happening Suddenly and Struggling With Decisions. Death Happening Suddenly included two subthemes which where, Difficulty Processing the News and Not Seeing Patients in Person. The third prominent theme in the interviews was Misperceptions of Hospice with subthemes of Culture, Giving Up, and Unfamiliarity With Services.

Table 5

Barriers to Hospice

Themes	Subthemes	Subthemes
Lack of Conversations	Families Not Having Discussions Hesitancy of Medical Team to Discuss Hospice Lack of Follow up After Hospice is Discussed	
Challenges Making Decisions	Death Happening Suddenly	Difficulty Processing the News Not Seeing Patients in Person
	Struggling With Decisions	
Misperceptions of Hospice	Culture Giving Up Unfamiliarity With Services	

Theme: Lack of Conversations

Families Not Having Discussions. The subtheme of Families Not Having Discussions was identified 40 times in the interview transcripts. Interviewees provided several examples of patients being in denial of their situations and unwilling to plan for the future. S2, for instance, recalled a veteran who was given a terminal diagnosis but would not talk to his family:

> He had a wife and three children. I tried to have a conversation with him and bring up things he could expect and encouraged him to talk to his wife. His decisions were going to impact his family. He said no and put his fingers in his ears.

All five social workers provided stories about family members having difficulty making medical decisions for patients who could not make their own decisions. S3 relayed a story about a patient who was recently remarried:

> I learned that so many of the children were not prepared, and they didn't have a conversation, and then he had a new wife who was going to be the decision maker. This was an instance where the nurse called the social worker to keep the peace.

S1 also described conflict with family members: "The people that haven't had a discussion," S1 suggested, "I think you have more of a conflict there. I've seen more conflict with those families than with families who have already had this discussion." S4 gave an example of an estranged daughter who was not aware she was the veteran's health care power of attorney (HCPOA):

> The daughter wasn't involved in the veteran's life in the last 10–20 years. There hadn't been any communication. She wanted to hear what was written and what the preferences were because, at the time when I was reviewing it with her, the veteran was intubated. She was receptive, just based on what was written, but not everyone feels that way.

S2 worked with younger veterans and stated she had several who became ill or had accidents yet had never had discussions or anything written about their preferences. S5 remembered one family taking several weeks to decide on hospice because the veteran and family had not had any discussions:

> He was fully independent before he was hospitalized, and he was diagnosed with esophageal cancer that was really aggressive. It was a shock for the veteran and then family. Then he wasn't able to make decisions. We had a lot of end-of-life and goals of care conversations, and it took me arranging several family conferences with the team and specialty providers.

Although the estranged daughter S4 mentioned previously was comfortable making decisions based on a living will, four social workers said families were more comfortable making decisions when they had a direct conversation with the patients. Those four social workers all stated having an advance directive or written documents helps with the decision, but three of these social workers believed the helpfulness of written preferences depends more on the person making decisions. S4 explained having a conversation with the patient gives the surrogate "ease of mind and know[ledge that] I heard it directly from him. [Decisions about hospice are] not just something the social worker or doctor is reading to me." S4 also mentioned surrogates must make complicated decisions. "The decisions get difficult," S4 said, "and I'm not sure if you would naturally have conversations about blood transfusions, organ donation, being put on life support, [or] dying naturally. Also, to talk about funeral services and what you want [is not easy]."

The Hesitancy of the Medical Team to Discuss Hospice. The second most referenced subtheme under Lack of Conversations was the Hesitancy of the Medical Team to Discuss Hospice due to their goal of sustaining life and personal discomfort of the topic. Two social workers worked with providers who had difficulty discussing hospice. S2 stated, "I think some providers, I mean for me, they have been uncomfortable having the discussion, but it is so important and allows the patient to have some control." S1 also shared the idea of knowledge giving patients control:

> We all have a meaningful life but, most people can have a meaningful death too if we could say, I really cannot do anything else for you, let's talk about what your options are. Some people will continue, no matter what, but some people will stop and consider their quality of life and try to do things that they wanted to do if someone would have engaged with them early on in the process.

Lack of Follow-Up. When patients are provided with a terminal diagnosis and hospice is mentioned, there may be a lack of follow-up*,* meaning hospice is presented as a possibility and the patient and families are left to think about it without anyone returning to explain or discuss it with them. This lack of explanation and information becomes a barrier. Three social workers touched on this theme a total of 11 times. These social workers had experience in outpatient settings where there is less interaction with providers. S2 stated, "I'm not sure how social workers could intervene more with the providers, but when you tell someone they are eligible for hospice, that should be the start of the conversation and not the end of the conversation." All three social workers talked about wanting to be more involved in the process after providers discuss hospice with patients. S1 said empathically, "It's not like when someone gets that news, they are thinking clearly. It can be upsetting, so having to think about it and any follow-up would help."

Challenges Making Decisions

As revealed in interviews with the five participants, the second barrier to hospice was the Challenges of Making Decisions*,* which yielded 40 references in NVivo. The medical team, surrogates, and patients are all interconnected but moving at different levels and speeds towards understanding and making decisions. The main subthemes were Death Happened Quickly and Disagreement*s*, which will be discussed below.

Death Happened Quickly. All five social workers shared stories of patients diagnosed with a terminal illness who declined quickly without hospice services or experienced a limited time only in hospice. Four participants talked about the difficulty processing the news, and three social workers discussed loved ones not being able to see the patient in person.

Difficulty Processing the News. All the social workers spoke about the difficulty for surrogates in accepting the news of their loved one dying and processing grief to move forward with making important decisions for patients. S5 provided an example of families being surprised: "It came out of nowhere for the family. He did pass from his terminal illness. So, very quickly, hospice had to be introduced, discussed, and it was a lot for the family to process and understand." Surrogates and families can have different reactions, as explained by S4:

> The daughters were very caring and understanding, not to say the son wasn't, but I think he struggled more with the whole situation and no matter what you presented, he had difficulty with it. He had some sort of resistance to everything, like he was not in a good place, which I could understand.

S1 explained, for some family members, the resistance to hospice can be a reaction to grief: "The granddaughter was not receptive to hospice because she wasn't receptive to the fact that her granddad was going to die."

Not Being Able to See the Patient in Person. Three social workers recalled families not knowing how sick patients were because they had not seen them. Two of the social workers brought up the challenge presented by the COVID-19 global pandemic. Regarding families not allowed to visit patients in-person in the hospital, S4 explained: “It makes a difference and there’s a difference between seeing someone in person versus by video. I think it helps when they can’t tell them how they are feeling.” S2 brought up a personal story about her mother being in hospice. She was surprised when her father told her hospice was ordered, “We talked on the phone, but I had not physically seen her for a time. I just never really understood how sick she was.”

Disagreements. Four social workers mentioned family disagreements as a barrier to hospice because they posed a challenge to the decision-making process. S3 explained disagreements could be the result of displaced aggression, saying, “I think a lot of contentious energy, not only are they sad with grief, but it’s the fact that things aren’t in place and that causes another type of grief and negative energy.” Although all the social workers supported having advanced directives and end-of-life documents in place, three stated the surrogate makes the decision and determines how they want to proceed. Yet, even when there is a surrogate, S1emphasized the family wants to be involved. S1 described her family: “We have HCPOA’s, but everyone wants to make a decision but it’s not their role. They can advise and recommend, and some will say they don’t agree, but ultimately, it’s up to the surrogate.*”* S1 stressed the surrogate knowing what the patient wants does help:

> I find that it’s dependent on the decision-maker and what discussions they’ve had with the patient about end-of-life care. If there have been some real discussions about what they want and what their wishes are, then they are more apt to be in line with I know my mom or dad would not want this so I’m going to go with comfort care.

Misperceptions of Hospice

The third barrier to hospice discussed in the interviews was misperceptions patients and caregivers have of hospice. NVivo made 25 references to this theme in the interview transcripts. The main subthemes provided were Giving Up and Unfamiliarity With Services, which are discussed below.

Giving Up. Three social workers reported hospice is, at times, associated with giving up. S1 believed patients and family members may have seen other people who died after receiving hospice for a short time.

Furthermore, three social workers indicated they have seen a connection between patients giving up and patients' religious beliefs and cultural practices. S1 stated:

> I'm African American, too, and I'm going to own this statement myself. This concept of religion and believing in miracles and if you pray hard enough and you do all of these things, God is going to make a way.

Based on her experience, S5 reached out to the chaplains and asked about religion; she said, "I have noticed that some African American families, it takes much more time and they take in spiritual and religion as well and they may not want to make any decisions, because it's in God's hands."

Unfamiliar with Services. All social workers reported providing education about hospice to their patients, but three reported patients and families do not realize the benefits of hospice services. S1, S2, and S5 had positive personal experiences with hospice. S2 experienced hospice services the day her mother died. S2 said she had misperceptions, too, but she was appreciative of hospice:

> I did not understand what a benefit hospice was. The hospice nurse came to start care right after my mother died. She helped us with so much, like getting a funeral set up and getting rid of the equipment in the home. We weren't prepared for all that. She did more for me and my dad than I could have hoped for. Otherwise, it would have just been us trying to scramble to figure it all out.

S2 shared what she has told many families:

> People will tell me they don't need hospice because they're not giving up. I tell them the last thing you want to do is wait until the very end because hospice could be out there for 6 months establishing relationships and helping with pain management. They could have chaplains and social work and all those services in place versus hours before they die.

Research Question 2—How Social Workers are Involved in the Process

Two main themes emerged in the interviews when trying to understand how social workers are involved in hospice. The first theme Working With the Team, yielded 39 references in NVivo. The second theme Providing Education and Support had 26 references.

Working With the Team

All five social workers talked about working with a team in different areas. However, it was clear from the interviews that each area and team had its own process and level of social work involvement at the start of hospice discussions. S1 worked in an outpatient setting and was comfortable talking to her nurse practitioner. "I would sometimes say to the nurse practitioner, who was the main person, have you considered talking to the family about hospice, and, in some cases, I even went with her, and we had family meetings together." S1 said the family meetings were a good opportunity for her to understand the patient's medical needs and support the patient and the team by discussing the resources available through hospice. S1 commented she was glad she had that relationship with the nurse practitioner so she could bring up the idea of hospice, saying, “The way the system is built, the social workers do a lot of the discussions and talking to people about it, but we are not the ones that actually put these consults in.”

On the other hand, S5 worked in inpatient and outpatient settings and stated she was rarely involved in the outpatient setting unless the patient needed a referral to a nursing home or inpatient hospice. In S5’s inpatient experience, she worked closely with the team and was involved in the start of discussions and throughout the process. S5 talked about the team working together to get a veteran home on hospice:

> He was not going to make it in the next 6 hours, so we had to come together as a team to make this happen for the veteran and the family and their wishes. There were a lot of barriers for transport and his oxygen needs, but we were able to get it set up through the VA and the hospice agency, so he was able to pass away at home like the family wished.

Three social workers mentioned setting up family conferences as part of their role. The social workers talked about reaching out to other disciplines to coordinate care, and two specifically remembered working with chaplain services. Two of those three social workers discussed working closely with the family and the team to ensure everyone communicated and got the information they needed.

Providing Education and Support

The second theme, Providing Education and Support, was mentioned by all five social workers. All five social workers stated they provide education about hospice and offer veterans the opportunity to complete advance directives. Two social workers talked about being present for the patient and family members to support them in understanding their current situation. Several interviewees shared personal experiences. Three of the social workers who had personal experiences with hospice talked about how they feel they can relate to patients and families based on their life and work experiences. S4 did not share a personal experience with hospice but explained he is comfortable providing information about hospice but prefers not to due to his military background:

> We had deaths during our deployments to Iraq, and, during those times, we didn’t really process anything. It’s like this happened. Well, we have to move on to the next thing. Even when we lost 20 in one day, we didn’t have a ceremony for a couple of weeks, so that affects me now still and the processing of it.

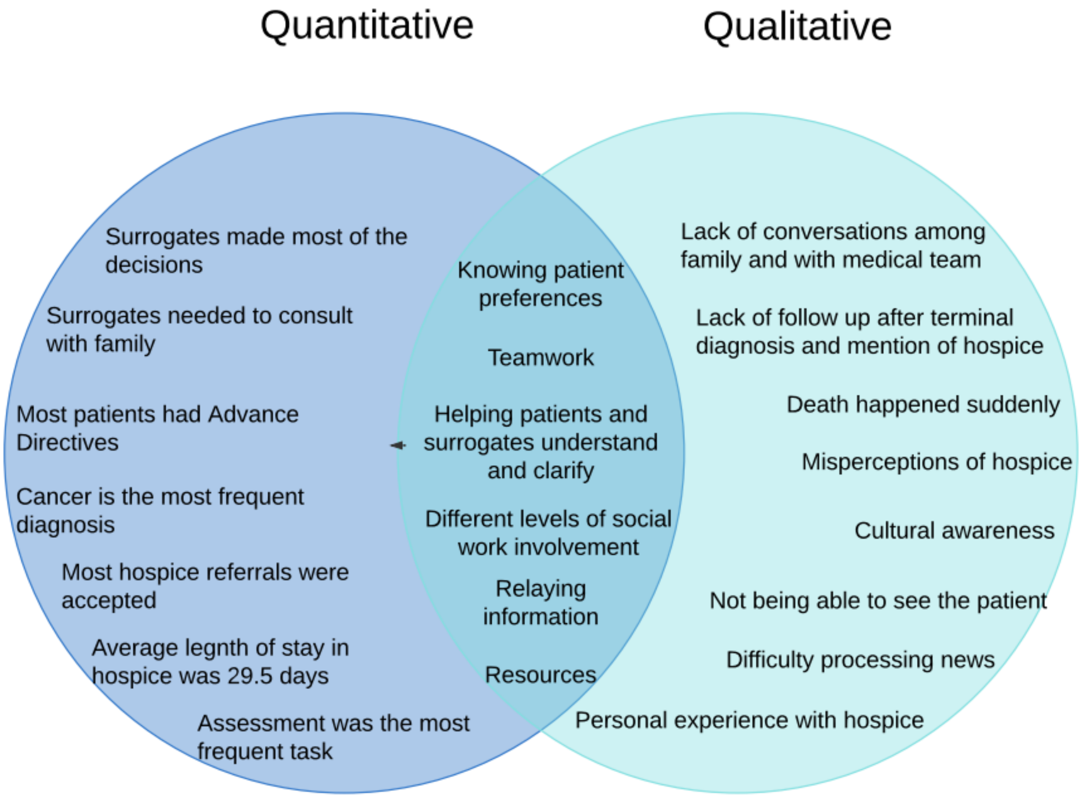
Summary

Although most of the veterans in this study received hospice, the average length of stay of patients who received hospice was 29.5 days, significantly lower than the national average of 89.6 days (Medicare Payment Advisory Commission, 2021). The quantitative and qualitative data in this study highlighted the importance of patients having conversations with their surrogates about their preferences in end-of-life care (see Figure 12). Surrogates made most of the decisions, but even when an advance directive was completed, they had difficulty deciding on hospice or treatments when they were not entirely confident about what the patient wanted.

Social workers' roles were identified in both studies as varying in different practice areas and team dynamics. Social workers frequently communicated with patients and surrogates, and, when they were part of an interdisciplinary team, they helped relay information to both the patient and the team. Social workers provided support and resources, which included hospice, but most of the hospice information was provided as a team.

Figure 12

Combined Findings



CHAPTER FIVE

DISCUSSION

Hospice can help dying patients improve their quality of life by providing comfort care and supportive services to patients and family members. Often, surrogate decision makers, who may be family members, decide whether, when, and where a patient receives hospice. Social workers provide services in many areas of health care and work closely with patients, surrogates, family members, and the medical team. The following discussion combines the results of the quantitative and qualitative data from this study to explore the two research questions:

1. What are the barriers to hospice?
2. How are social workers involved?

The results of this mixed methods study about barriers to hospice, social work roles, and the implications for social work are explored in this chapter.

Barriers to Hospice

Two main barriers to hospice emerged from the quantitative and qualitative data, which were surrogates making decisions and knowing patient's preferences.

Surrogates Making Decisions

In the retrospective quantitative analysis, patients and surrogates accepted 92% of the hospice consults offered. Most of the decisions were made by surrogates (61.1%, $n = 160$) on the same day (80.9%, $n = 212$). Surrogates making most of these decisions is consistent with Raymont et al.'s (2004) study that showed 40% of hospitalized patients could not make medical decisions.

According to the medical records, the main two reasons for uncertainty about hospice were difficulty making a decision and needing to consult with family. The importance of this was noted in the interviews, where the social workers also noted challenges making decisions as their second highest barrier to hospice. Although many veterans had advance directives (AD; 69.1%) in this case study, having an AD did not make a significant difference in the acceptance of hospice or the length of stay. Marital status was the only variable that was associated with the acceptance of hospice, with fewer than half of the patients being married (40.8%). Another factor to consider is most of the patients were inpatient (95%, *n* = 249), and patients and surrogates had to make decisions quickly. Although there were outliers, the length of stay in hospice for the patients in this study (*M* = 29.5 days) was lower than the average length of stay (*M* = 89.6 days) reported by the Medicare Payment Advisory Commission (2021).

Knowing Patient's Preferences

The quantitative data about AD aligned with most social workers' views that having an AD was helpful, but it was more critical that surrogates knew what the patients wanted for their end-of-life care. In Rao et al.’s (2014) survey, many participants did not complete an AD (26.3%) because they left it up to the family to decide. This study had a higher percentage of patients with completed AD’s (69.47%, *n* = 181) than Rao et al.'s (2014) study with 26.3% completion of AD and Yadav et al.'s (2017) studies showing 36.7% of the U.S. population with AD;s. However, this study shows many families and surrogates have not had discussions with patients, so they have difficulty making decisions about hospice care. A few of the social workers mentioned surrogates had to make complicated decisions about life-sustaining treatment, which supports Shaw et al.’s (2017) findings that surrogates did not share the same understanding of end-of-life terminology as patients. The social workers in this study recognized surrogates not knowing a patient's care preferences was a barrier to accepting hospice; the most coded word was *hospice* (*n* = 159), and the second most coded word was *knowing* (*n* = 110).

Social Work Involvement in Hospice Referrals

The quantitative and qualitative data showed that social work involvement in hospice referrals depends on the dynamics of the interdisciplinary team and licensure of the social worker.

Teams

Social workers in the quantitative study were involved in most of the cases that had hospice consults (88.6%, *n* = 227), but there was less involvement with outpatient referrals (23.1%, *n* = 3). Inconsistency in social work involvement was addressed by three social workers who had experience in a few areas of the medical center. Stein et al.'s (2017) study addressed variability in social work involvement, even among palliative care social workers. In this study, the team was one of the factors that impacted the level of social work involvement.

Both quantitative and qualitative data about roles showed a significant role for social workers was to work with a team. Social workers contributed to the team by acting as a bridge between patients and surrogates and between the various professional disciplines involved in each case. Based on analysis of the medical charts, social workers spent more than half of their time communicating with team members (82.4%), discharge planning (78.6%), working with surrogates and family members (64.5%), and assessing needs (52.3%). During interviews, social workers also mentioned working with a team. They noted their roles of being available to answer and ask questions for patients and surrogates (*n* = 9), setting up and being involved in family conferences (*n* = 8), being the primary contact for the patients (*n* = 6), working with chaplains (*n* = 3), and coordinating services (*n* = 3). The two social workers who had inpatient experience discussed the team working together with patients and surrogates as both challenging and rewarding. Three social workers who had outpatient experience addressed the lack of follow-up after patients were given a terminal prognosis or after hospice was initially mentioned.

In this study, social workers worked with teams and families, but there was no standard role for social workers in the hospice referral process. Instead, social workers adjusted to the needs of the patients and surrogates and the dynamics of the team. The role ambiguity in this study was a finding of Arnette et al.'s (2016) study of health care teams in which physicians had the most discussions about advance care planning, but most of the team members supported nonphysicians having those discussions.

Hospice Education

Social workers in the study were active in educating and discussing hospice with patients and helping patients and surrogates navigate the healthcare system. The medical records also demonstrate providing education about hospice is an important part of the social workers' job. In the medical records, differences in how much a social worker engaged in hospice education depended on licensing. Social workers who had a LISW (*n* = 32) provided 20.6% more individual hospice education than those with an LMSW (*n* = 26), but social workers with an LMSW (*n* = 51) had 9.3% more general discussions about hospice with patients and surrogates about hospice than LISWs (*n* = 56) individually and with groups. Other roles social workers performed—mentioned in both the medical records and interviews—included helping patients and surrogates obtain information, helping patients and surrogates clarify their understanding of the situation, relaying information to the medical team, and providing information and resources.

Implications for Social Work

The findings in this study can be used to inform medical social workers of the need to seek education to incorporate palliative care in their practices with all patients and surrogates, especially those with a chronic illness or are actively dying. There are currently no standard requirements for medical social workers or palliative care social workers (Thiel et al., 2020). The interviewed social workers talked about becoming comfortable with hospice and the dying process through internships (*n* = 2), learning from peers, and personal experiences (*n* = 3). Only one interviewed social worker had a certificate in gerontology. Because there are no professional standards for medical social workers, social workers should follow the NASW (2021) Code of Ethics value of education and training to increase their skills in working with patients of all ages, and their families, to help them have conversations about medical preferences. Encouraging patients to consider and share their medical treatment preferences with their families aligns with the social work value of self-determination (NASW, 2021) and the Patient Self-Determination Act of 1990 (Congress, n.d.).

Social workers are valuable members of interdisciplinary teams. Social workers are skilled in assessments, active listening, communication, and collaboration. Social workers can take a systems perspective, which can help the team understand diverse patients, complex family dynamics, and also identify weaknesses within the team that may be barriers in providing end of life care. Social workers can take a leadership role in guiding the team in the values outlined by the NASW Code of Ethics, including dignity and worthiness of the person and the importance of human relationships (NASW, 2021). In this study, only 5% of the referrals were from an outpatient source. Social workers could educate outpatient sources about how social workers could collaborate with providers to ensure patients and surrogates receive information about the benefits of hospice.

In the interviews, social workers noted religious beliefs were sometimes the source of misperceptions about hospice. Advance care planning discussions about hospice education should consider religion, culture, ethnicity, and family beliefs. Taking these factors into consideration follows the NASW Code of Ethics (2021) standards of cultural competency.

Limitations

This mixed methods study had several limitations. The quantitative information was reviewed several times, but only by the researcher. The researcher was also the only person to code the semi-structured interviews in NVivo.

There were an appropriate number of participants for a phenomenological study ($n = 5$). Still, the number was relatively small, and it cannot be assumed their experiences are representative of all social workers in the VAMC or outside the VAMC. The study focused on social workers' perspectives and did not include those of other interdisciplinary team members. Moreover, the study examined only one VA medical center, and these findings may not represent other VA medical centers or other hospitals.

Through journaling and member checking with those interviewed, reflexivity helped guard against biases (Creswell & Creswell, 2020). The researcher is a licensed clinical social work supervisor at the VA medical center and identifies as an Asian woman with 20 years of experience in medical social work.

Future Research

Although retrospective studies that reviewed medical record documentation within the VA have been completed, there have not been any that specifically reviewed social work documentation and interviewed social workers.

To address the limitations of this study, future research should incorporate medical record documentation from other disciplines. Also, interviews with individuals in other disciplines within the VAMC would provide more perspectives on working with patients, families, and social workers.

The level of social workers' licensure was reviewed in the medical records. Still, the qualitative data did not explore the difference level of licensure has on working with patients and surrogates. It would be good to explore that further in interviews. The participants in this study had practiced in the VA for 5 years or longer, so it may be helpful to examine the perspectives of new social workers.

In this study, only one participant was a veteran, and he shared some of his experiences being in the military. Future studies could explore social workers' perspectives with a military background and look at how death and grief are experienced and processed by those in service.

Conclusion

This study revealed, in an inpatient setting, many decisions about hospice are made by surrogates (61.1%) and not by patients. The quantitative data revealed a difference in acceptance of hospice based on who made the decisions. The qualitative data also showed surrogates had difficulty making decisions if they did not know what the patient wanted, even if an advance directive had been completed.

Although most hospice consults are accepted (92%), the average length of stay in hospice from 2015–2020 was 29.5 days. The quantitative data revealed source of referral, diagnosis, and location of death impacted the length of stay in hospice. Qualitative data provided some clarity on the challenges of discussions among patients, families, the medical team, and the misperceptions of hospice.

This study provided insight into the roles of social workers in the referral process. There was a difference in involvement based on the referral source, as social workers were involved in most inpatient referrals (88.6%) but less in outpatient (23.1%) referrals. Social workers worked closely with patients and the team to ensure information was being shared and received. The role of the social worker, specifically in hospice referrals, is varied as it depends on the setting, dynamics of the team, and the level of comfort of the social worker. The social workers interviewed explained their comfort in discussing hospice from internships, learning from peers, and personal experiences, but not through continuing education training or classes.

The founder of hospice, Cicely Saunders, was a social worker, doctor, and nurse who envisioned an interdisciplinary team approach to helping dying patients alleviate their pain (Clark, 1999). Social workers in healthcare, the second largest group of social workers (U.S. Bureau of Labor Statistics, 2021), can refine their roles in various settings in teams so they can help patients and surrogates understand the benefits of hospice and support patients in receiving medical care that is consistent with their values, goals, and preferences.

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APPENDIX A

Recruitment Message

Email Send Time: 8:00 a.m.

Subject Line: Participate in social work interviews about hospice referrals

Email Body Text:

Dear Colleague:

I am working on a process improvement project to understand social work involvement in end-of-life planning to improve timely hospice referrals. Would you like to help? To see if you are eligible, please read the requirements below:

- Men and women who have worked at a VA for 5 years or more
- Those who work directly with veterans
- Ability to schedule a 1:1 interview by Zoom as your time permits

Interviews will be confidential and will be used in a DSW dissertation. Participants will receive no compensation, and your participation in this study is voluntary and you can withdraw at any time. If you fit these requirements and are interested in helping, please email me.

Shin Yun, LISW

APPENDIX B

Consent to be Part of a Research Study

Title of Project: Delays in Hospice and Social Work Involvement
Principal Investigator: Shin Yun, doctoral student, Millersville University
Faculty Advisor: Dr. Curtis Proctor

You are being asked to participate in a study. To participate, you much be a social worker who has worked in the VAMC for at least 5 years. Taking part in this research project is voluntary.

Important Information

Things you should know:

- The purpose of this study is to understand the barriers in hospice referrals and how social workers are involved with the process. If you choose to participate, you will be asked to meet by Zoom with the principal investigator, Shin Yun, for an interview that may last 60–90 minutes. Then, you will be asked to meet with the investigator a second time for 30–60 minutes to review the outcomes of the study.
- There are no known risks or discomforts associated with this research.
- The study will attempt to improve processes at the VA to improve the referrals to hospice.
- This study may not have any potential personal benefits to you.
- Taking part in this research is voluntary. You do not have to participate, and you can stop at any time.

Please take time to read this entire form and ask questions before deciding whether to take part in this research project.

Purpose of the study

The purpose of the study to understand the barriers in hospice referrals and how social workers are involved with the process

What will happen if you take part in this study?

If you agree to take part in this study, you will be asked to meet with the principal researcher by Zoom to discuss issues related to the delays in hospice referrals and social work involvement. The first Zoom sessions should last 60–90 minutes. Then, you will be asked to meet with the investigator a second time to review the findings of the study. The second Zoom session should last 30–60 minutes. The Zoom sessions will be recorded and transcribed. Your responses will be confidential.

How could you benefit from the study?

Although you will not directly benefit from being in the study, others might benefit because referrals to hospice could be increased, leading to more comfortable end-of-life care.

How will we protect your information?

The information you provide will be confidential and will not be associated with your name or other identifying information. The results of this study will be published in the investigator's dissertation and may be used in presentations or published in journals. We will protect the confidentiality of your research records by assigning a number to your information. Your name and other information that can directly identify you will be stored separately from the data collected as part of the project. It is possible other people may need to see the information we collect about you. These people work for Millersville University or VAMC.

What will happen to the information we collect about you after the study is over?
We will not keep your research data to use for future research. Your name and other information that can directly identify you will be kept secure and stored separately from the research data collected as part of the project.
We may share your research data with other investigators without asking for your consent again, but it will not contain information that could directly identify you.

Compensation
Participants will not receive compensation for being a part of this study.

Your participation in this study is voluntary
It is totally up to you to decide to be in this research study. Participation in this study is voluntary. Even if you decide to be part of the study now, you may change your mind and stop at any time. You do not have to answer any questions you do not want to answer. If you decide to withdraw before this study is completed, please inform the principal investigator.

Contact information for the study team and questions about the research
If you have questions about this research, you may contact:
Shin Yun, xxxxx@millersville.edu, xxx-xxx-xxxx, principal investigator
Dr. Curtis Proctor, xxxxx.xxxxxx@millersville.edu, xxx-xxx-xxxx, dissertation chair

Contact information for questions about your rights as a research participant
If you have questions about your rights as a research participant or wish to obtain information, ask questions, or discuss any concerns about the study with someone other than the researcher(s), please contact the following:
Millersville University of Pennsylvania Institutional Review Board
Dr. Rene Munoz, Director of Sponsored Projects and Research Administration
PO Box 1002
Millersville, PA, 17551
Phone: xxx-xxx-xxxx
Email: xxxx.xxxxxx@millersville.edu

Your consent:
By signing this document, you agree to be in this study. Make sure you understand what the study is about before you sign. We will give you a copy of this document for your records. We will keep a copy of the study records. If you have any questions about the study after you sign this document, you can contact the study team using the information provided above.

I understand what the study is about, and my questions so far have been answered. I agree to take part in this study.

Printed Subject Name

Signature Date