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Hospice Social Workers' Perspectives on Place of Death Congruence: A Qualitative Study

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Hospice Social Workers' Perspectives on Place of Death Congruence: A

Qualitative Study

by

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MSW Clinical Research Paper
Presented of the Faculty of the
School of Social Work
St. Catherine University and the University of St. Thomas
St. Paul, Minnesota
in Partial fulfillment of the Requirements for the Degree of
Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

This qualitative research study was designed to explore place of death congruence among hospice patients from the subjective experiences and perspectives of hospice social workers. A semi-structured interview with nine hospice social workers served as the primary means of data collection within the present study. Using content analysis with descriptive phenomenology, dominant and underlying themes were identified, refined, and subsequently confirmed through a reliability check. From the establishment and verification of themes and sub-themes, the research questions were answered. The results of this study indicate that patients generally prefer to die in a place they call "home," including: private residences, skilled nursing facilities, assisted living facilities, and/or residential hospice homes. This research strongly indicates that caregivers are the *most* critical factor in achieving a home death. Not only must caregivers be willing, available, informed, and competent, they also must have the ability to flex their roles within the family system in order to achieve a home death. Several additional factors were shown to be important determinants in actual place of death including: culture, type of terminal illness and associated symptoms, safety, and finances. Hospice social workers often act as caregiver coaches in enabling home death by maximizing caregiver strengths and by building networks of support. Hospice social workers aim to enhance place of death congruence by completing effective assessments, providing a variety of supports, educating, and providing and exploring realistic options for patients and families. The findings of the current study support previous research as well as add depth and dimension to the existing understanding of place of death congruence. The findings of the present study presented numerous implications for continued hospice social work practice. The current study offered direction for the further study of end-of-life choices in order to better provide and facilitate exceptional care for individuals with terminal illness.

Acknowledgements

I would like to extend my profound appreciation to my committee members, Karen Carlson, Kristi Johnson, and Jeanne Schuller. I am immensely thankful for the time and energy you invested in my research over the last nine months. The expertise, experience, and insight you contributed was substantial and is greatly appreciated.

Thank you to all of the participants who shared their experiences. I am honored by your generous support, and I truly learned so much from each of your thoughtful responses. Thank you for the work that you do each day, your compassion and dedication has inspired and excited me to continue my professional work in hospice and palliative care.

Thank you, *most of all* to my family. My parents, Jane and John, have been incredibly supportive throughout my three years as a graduate student. I can say with absolute certainty that without your help, completing this research would not be possible. I feel I owe any success I may have to you. Thank you to my sister, Rose and to Nick Evans for your on-going encouragement and backing.

Finally, thank you to my Grandparents. I chose to pursue my graduate degree in the field of social work because of your influence. Thank you for demonstrating the importance of life-long learning, kindness, and compassion.

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It is often said that *home is where the heart is* and that *there's no place like home.* Indeed, even the word "home" conjures feelings of connection, familiarity, and a sense of "normalcy" (Brazil, Bedard, Krueger, & Heidebrecht, 2005, p.492). Undeniably, home not only represents a place where people feel "[safe] and a sense of belonging" (Tang & McCorkel, 2001, p.166), but also plays a part in shaping our very identity and provides an essential sense of comfort, consistency, control, and ease (Brazil, et al.; Tang & McCorkel).

The place one calls "home" is especially critical when considering end-of-life care and during the dying process (Bell, Somogyi-Zalud, & Masaki, 2010; Brazil, et al., 2005; Callanan & Kelley, 1992). Many scholars (Bell, et al., 2010; Brazil, et al.; Institute of Medicine, 2014; Tang & McCorkel) have posited that the place of death can significantly influence the overall experience of the dying and their loved ones, and has the potential to contribute to or detract from the quality of a person's final days (Brazil, et al.). A "good" death has often been defined as "one that is in general accord with patients' and families' wishes" (Weitzen, Teno, Fennell, & Mor, 2003, p.324) and in which a person is "treated as an individual, with dignity and respect; [is] without pain and other symptoms; [is] in familiar surroundings; and [is] in the company of close family and/or friends" (Department of Health, 2008; Paddy, 2011). Predictably, a "good" death is typically understood as one that occurs in the place the individual calls home (Gott, Small, Barnes, Payne & Seamark, 2008; Higginson & Sen-Gupta, 2000).

Although most people suffering from terminal illness prefer to die at home (Barclay, 2009; Gomes, Calanzani, Gysels, Hall & Higginson, 2013; Jenq & Tinetti, 2013; Weitzen, et al., 2003), more than three-fourths (76.2%) of deaths of individuals

ages 65 and older in the United States occur outside of private residences (Centers for Disease Control and prevention, 2010), highlighting a significant discrepancy (incongruence) between preferred place of death and actual place of death.

The nation's population is aging. In fact, it is estimated that the percentage of elderly individuals (ages 65 and older) will increase by 20% by the year 2025 (Administration on Aging, 2010). While our culture is certainly aging, people are also living longer due to advances in medical technology (Tang & McCorkle, 2001; Walsh, 2003), and thus the largest growth within the future population is expected to be among those over the age of 85 (McInnis-Dittrich, 2014). This group of the "oldest old" (McInnis-Dittrich, p.2) is furthermore the group requiring the most lengthy, expensive, and sustained care (Administration on Aging, 2010; Jenq & Tinetti, 2103; McInnis-Dittrich; National Hospice and Palliative Care Organization (NHPCO), 2012). Accordingly, it can be predicted that the number of individuals requiring end-of-life care will soar dramatically in the years to come and that the cost of providing this care will burden the United States' already hard-pressed health care financial system (McInnis-Dittrich; World Health Organization, 2004).

Separate demographic trends indicate that Americans are increasingly dying from serious chronic conditions such as heart disease, cancer, and chronic respiratory diseases (Gomes, et al., 2013; World Health Organization, 2004), signifying that "most people [could] expect a period of terminal illness to proceed death" (Gomes, et al., p.1.). Due in part to the upsurge in aging adults combined with increased chronic illnesses, hospice programs have seen expansion in program enrollment in recent years (Blackhall, Alfson, & Barclay, 2013). The growth in both aging adults and hospice utilization warrants

continued research in order to ensure patients are receiving the highest quality of end-of-life care.

Hospice is not a place, but rather a system of compassionate, terminal care that seeks "to provide people with the opportunity to die as they choose, deciding where, under what circumstances, with whom present, in what state of consciousness, and with what life supports [he or she desires]" (Tang & McCorkel, 2001, p.166). Hospice philosophy is grounded upon honoring patient choices, maximizing quality of life, and providing dignified and holistic care via a multidisciplinary team (Tang & McCorkle; Walsh, 2003). Despite the increasing cultural trend towards the medicalization of death (Bowling, 1983; Paddy, 2011), hospice care contrarily empowers individuals to remain at home for the dying process if they so choose (Tang & McCorkel).

The purpose of the present research is to explore and examine through a qualitative research design, place of death congruence from the perspective of hospice social workers. In addition, the current study seeks to understand end-of-life preferences and the extent to which hospice patients' preferences are actualized, factors that influence where hospice patients die, and how to improve congruency between preferred and actual place of death among hospice patients. In a broader sense, the current research aims to generate insight to the experience of hospice patients and challenges they encounter. Because the *place* in which individuals pass away has been recognized as factor related to the overall quality of end-of-life care (Tang & McCorkel, 2001), the current study ultimately seeks to enhance the quality of the hospice patient's final days, enabling patient preferences to be honored.

Literature Review

This literature review will focus on hospice care, preferred and actual place of death congruence, and factors that influence place of death. The review is separated into three corresponding sections, each discussing themes within current research.

Hospice Care

History

According to scholars, the word *hospice* was originally derived from "the Latin word *hospitium,* meaning a guesthouse for weary travelers" (Lamba & Quest, 2011, p. 282).

> Prior to the 20th century, death commonly occurred at home with care provided by family members and neighbors, supplemented by visits from a local physician. Caregiving in this earlier era was less of an option and more of an understood personal and family responsibility. Over time, Americans have increasingly gravitated toward hospitals and nursing homes for technological advances or nursing and respite care (Bellin, 2006, p.14).

Hospice care began in the 1960s with the work of the universally identified founder of the hospice movement, Dame Cicely Saunders (Lamba & Quest, 2011). Saunders established Saint Christopher's Hospice, the first hospice care facility that provided dignified, holistic, and comfort-focused care to terminally ill patients (Cicely Saunders Foundation, 2014). Saunders served as a nurse, social worker, physician, and taught and trained professionals specializing in terminal care, contributing significantly to the establishment and growth of end-of-life care knowledge and practice (Cicely Saunders Foundation; Lamba & Quest).

Although half of a century has passed since the founding of the Saint Christopher's Hospice, much of Dame Saunders' original philosophy remains at the heart

of contemporary hospice care practice. Hospice is not a place, but rather an

individualized and holistic system of care that utilizes a team approach to ensure comfort

and to address the unique needs of the patient and family (Lamba & Quest, 2011; Walsh,

2003). Hospice care is delivered to the patient in a place they call home, which can

include private residences, group homes, specialized hospice homes, assisted living

facilities, skilled nursing homes, and inpatient or outpatient hospital facilities among

others (Lamba & Quest; NHPCO, 2012; Walsh).

Who Does Hospice Care Serve?

Hospice care is for individuals who have been diagnosed with a terminal illness

and who have been given a medical prognosis of six months or less to live if the disease

runs its expected course (Medicare.gov). Currently, the great majority of hospice

admissions (80%) are for individuals over the age of 65 (Medicare.gov), although hospice

care can be appropriate for people of all ages.

Demographics. In 2012, The National Hospice and Palliative Care Organization

(NHPCO), published an annual overview titled *Facts and Figures: Hospice Care in

America* in order to disseminate the "important trends in the growth, delivery, and quality

of hospice care across the country" (p.3). The report utilized a convenience sample of

hospice organizations that voluntarily submitted data to the national data set in creating

national estimates related to dying and hospice care. The NHPCO reported that in 2011,

56.4% of hospice patients were female, 39% of patients were over the age of 85 (as

compared to 16.3% 65-74 and 27.6% 75-84 years old), 82.8% were White/Caucasian, as

compared to 8.5% of patients who identified as Black/African American, and 6.2%

Hispanic or Latino, and 2.4% Asian, Hawaiian, and Other Pacific Islander. The same

report revealed that in 2011, a little over one-third of hospice patients were admitted into

hospice care under the terminal diagnosis of cancer (37.7%), followed by debility

unspecified (13.9%), dementia (12.5%), and heart disease (11.4%).

Current Trends

Hospice growth. Over the past decade, enrollment in hospice has grown

significantly (Blackhall, Alfson, & Barclay, 2013). Indeed, "the hospice industry has

been marked by substantial growth in the number of hospice programs and patients

served" (NHPCO, 2012, p.4). *Hospice Care In America*, indicated that 1,059,000

individuals passed away while enrolled in hospice care in 2011, and that nearly half

(44.6%) "Of all deaths in the United States were under the care of a hospice program"

(NHPCO, p.4). This increase in hospice utilization is understandable given that "hospice

care serves as a model for quality, compassionate care for those facing a life-limiting

illness" (Lamba & Quest, 2011, p.282).

Hospice underutilization. Despite the increase in hospice operation over the last

century, several experts posit that hospice care continues to be vastly underutilized

(Lamba & Quest, 2011; Tang & McCorkle, 2001; Weitzen, et al., 2003). Although

widely available, hospice care services are globally underutilized, as data indicates that

the median length of service is only about three weeks (Lamba & Quest; NHPCO, 2012).

Reasons for delayed admission in to hospice are diverse. Commonly, late enrollment

surrounds myths and misconceptions such as the belief that hospice services benefit only

those who are actively dying, that hospice care accelerates the dying process, and that

hospice is equivalent to giving up hope (Lamba & Quest, NHPCO). In addition, trends in research indicate that the reluctance of physicians to "prognosticate and communicate the resultant prognosis, unwillingness of patients to accept terminal illness" (Lamba & Quest, p.284), and racial/ethnic dynamics are factors important for considerations behind that underutilization of hospice services.

Hospice Philosophy & Guiding Principles

    Focused on life until death. Although the term *"hospice"* is generally associated with dying and death, hospice philosophy centers greatly on *living*, and helping individuals who are terminally ill (along with their families) pass through the journey toward death as comfortably as possible. Hospice care "neither hastens nor postpones death" (Tang & McCorkle, 2001, p.166) and "emphasizes quality of life and 'living until you die'" (Lamba & Quest, 2011, p. 282). Hospice care includes the provision of "the best available medical care and making the advances of recent decades fully available, so that all have the best chance of using their time well" (World Health Organization, 2004, p.7).

    Offers palliative and dignified care. Hospice care has been as described as palliative, in that it seeks to provide comfort rather than life-prolonging measures (Walsh, 2003) and considers "pain and symptom control [to be] paramount" (McInnis-Dittrich, 2014, p.298). Hospice is concerned with caring for, not curing patients, and seeks to "[begin] from the understanding that every patient has his or her own story, relationships and culture and is worthy of respect as a unique individual" (World Health Organization, 2004, p.7). Hospice care emphasizes dignity and self-determination so that "dying persons have the right to receive medication and services that will do all that is possible

to alleviate pain and suffering" (McInnis-Dittrich, p.298). The essence of hospice care

includes the belief that every individual has the right to die in a way that is self-

determined, dignified, and in which pain is effectively managed (Walsh, 2003).

Contests medicalization of death. Current trends indicate that end-of-life

hospitalizations are commonplace, but not necessarily appropriate (Bowling, 1983; Jenq

& Tinetti, 2013, Institute of Medicine, 2014). Medicalization of death has been defined as

the "determination to continue aggressive treatments for hopelessly ill patients" (Paddy,

2011, p.34). Although there have been significant growths in hospice utilization over the

last half century, the amplified availability of end-of-life services has not altered

America's cultural fixation on aggressive and curative care for terminal illness (Bowling;

Jenq & Tinetti; Paddy).

Negative outcomes surrounding overly medicalized death are well documented.

According to the Institute of Medicine (2014), terminally ill "Americans suffer needless

discomfort and undergo unwanted and costly care as they die, in part because of a

medical system ruled by 'perverse incentives' for aggressive care and not enough

conversation about what people want" (Sedensky, 2014, para. 1). Research additionally

suggests that the very doctors recommending life-sustaining treatment may be poorly

trained in terminal care, and that although professional guidelines encourage doctors to

discuss palliative options with patients, the "adoption of timely referral to palliative care

appears to be slow" (Institute of Medicine, Key Findings, p.1). Further, it has been

demonstrated that dying individuals commonly undergo "multiple transitions between

health care settings-including high rates of apparently preventable hospitalizations—

which can fragment the delivery of care and create burdens for patients and families"
(Institute of Medicine, Key Findings, p.1).

On the contrary, hospice care diminishes the medicalization of death by focusing on
enhancing quality of life, minimizing costs, and coordinating care among expert
professionals (Institute of Medicine, 2014; Jenq & Tinetti, 2001; Walsh, 2003). Hospice
care aims to operate free of the incentives present in clinical settings which encourage
doctors to "choose the most aggressive care" (Sedensky, 2014, para. 3), and to prolong
living through extraordinary means even with negative side effects. Hospice care also
assists patients and families to avoid the often traumatic experience of hospitalization, as
one of the major objectives of hospice is to allow dying individuals to remain at the place
they define as home by providing resources and support (Tang & McCorkle, 2001;
Walsh, 2003), and ultimately enabling them to "realize their preference of place of
terminal care and death" (Tang & McCorkle, p.167).

Holistic care provided by a multidisciplinary team. The dying process has been
identified as being physically, psychologically, emotionally, and spiritually taxing
(Oliver, Wittenberg-Lyles, & Demiris, 2008). In order to address the multitude of needs
at the end of life, and to provide comprehensive care, several individuals from a variety
of disciplines each specializing in their own aspect of care have been shown to be
essential (Oliver, et al.). According to the NHPCO's *Facts and Figures: Hospice Care in
America* (2012), hospice services available to each admitted patient are intended to be
tailored to the individualized needs of the person and family, by way of a team-oriented
approach.

Existing literature has posited that effective hospice care requires the intervention efforts of all disciplines in a universal manner or all-inclusive approach (Oliver, et al., 2008). Specifically, researchers have emphasized the collaborative practice of the interdisciplinary hospice team as a core feature of superior care (Wittenberg-Lyles, Oliver, Demiris, & Regehr, 2010). The interdisciplinary (or hospice care) team is comprised of physicians, nurses, social workers, home health aides, chaplains, volunteers, and can also include dieticians, music therapists, and occupational and physical therapists (Walsh, 2003; Wittenberg-Lyles, et al.). In a 2010 study, the collaborative process was demonstrated to have a positive impact on the quality of patient care and the overall experience of families, although it required a greater dedication of hospice staff time (Wittenberg-Lyles, et al.). The same study showed that without collaboration, role ambiguity ensued and gaps in contributions among various disciplines were created (Wittenberg-Lyles, et al.).

Role of the hospice social worker. Hospice social workers play an essential role within the hospice care team and are involved in many facets of end-of-life-care that encompass macro, mezzo, and micro levels of organization (McInnis-Dittrich, 2014; Walsh, 2003). Social workers are deeply committed to the values of social justice, importance of human relationships, and competence (National Association of Social Workers, 1999) and are "concerned about protecting an individual's' personal dignity and independence, especially in the face of a debilitating illness" (McInnis-Dittrich, p.310). Trends in the literature suggest that the role of the hospice social worker relate to assessing, advocating, educating, and intervening with hospice patients and their loved ones.

Assess. Social workers are instrumental in assessing and evaluating patient and family strengths, supports, and needs from a problem-solving lens (Walsh, 2003). Hospice social workers provide assessment throughout the dying journey from admission to bereavement and can provide assessment related to psychosocial functioning, mental health, sexuality, spirituality, risk, care plan development, and long term care planning (Hay & Johnson, 2011). These assessments lead to a better patient and family understanding and enable safety and the provision of person-centered and holistic care (Walsh).

Educate. Hospice social workers teach patients and families about the dying process and communicate and clarify end of life rights (Walsh, 2003). Further, social workers educate patients about how to describe pain, enhancing communication with healthcare providers (Walsh) and empower patients and families by informing them about available supportive resources. (McInnis-Dittrich, 2014; Hay & Johnson, 2011; Walsh).

Advocate. Hospice social workers advocate on behalf of patients and their families "making sure that health care providers are sensitive to and understand the needs of [the hospice patient] and family members" (McInnis-Dittrich, 2014, p.290). Social workers understand the complex cultural and structural concerns (such as institutional racism, discrimination, and poverty) that impact hospice patients, and advocate for quality care of vulnerable and oppressed populations (McInnis-Dittrich; National Association of Social Workers, 1999).

Intervene. Hospice social workers utilize clinical skills "to negotiate family conflict, facilitate goal-oriented team functioning, and provide emotional support for…the team

[patient,] and family." (McInnis-Dittrich, 2014, p.300). Additionally, it is the role of the

social worker to provide case management, individual and family counseling, facilitation

in life review, crisis intervention, and care conferences, and plan for the patient and

family's needs at end of life (McInnis-Dittrich, Walsh, 2003).

Preferred and Actual Place of Death

Preferred Place of Death

The literature appears to be in agreement that most people, including those who are

terminally ill, prefer to die in the place they call home (Barclay, 2009; Beland, 2013;

Gomes, et al., 2013; Higginson & Sen-Gupta, 2000; Gomes & Higginson 2004; Tang &

McCorkle, 2001; Weitzen, et al., 2003, World Health Organization, 2004). The

preference for a home death appears to be more than a national trend, as empirical

research has demonstrated that the place a person calls home is the preferred place of

death in Italy, England, Australia, Israel, Japan, and Taiwan (Tang & McCorkle). Trends

suggest that individuals overwhelmingly express a preference to die at home because of

the associations that "home" has with physical and emotional comfort, familiarity,

privacy, normalcy (naturalness), and feelings of patient control (Gott, et al, 2008;

Higginson & Sen-Gupta; Tang & McCorkle). Although most literature supports the

preference toward home death, the range of individuals who indicate a preference to die

at home varies.

Higginson & Sen-Gupta (2000) conducted a "systematic literature review of the

preferences for place of [terminal] care and death among cancer patients" (p.287). "Five

surveys of the general public found that 50% or more of people [in the general public

preferred] to be cared for at home in advanced or terminal illness" (p.289). Further,

"Eleven of 13 studies reported a percentage of their sample preferring home care and/or

deaths all with majority of respondents preferring care at home" (p.297). The World

Health Organization (2004) similarly reported that nearly three-fourths of all respondents

across studies prefer to die at home and that "a range of studies have found that between

50% and 70% of people receiving care for a serious illness also say they prefer home care

at the end of life" (p.16).

Although the place a person calls home may be the preferred place of death, research

demonstrates that home deaths are not always achievable. Gott, et al. (2008) conducted

40 semi structured interviews with individuals ages 60 and older, who were diagnosed

with heart failure, in an effort to understand the palliative needs of this population.

Qualitative analysis revealed that while many participants expressed a preference to die at

home, "others identified that [dying at home] may cause a significant burden to their

family and therefore, it was not seen as a feasible option" (p.1120). In addition, "for

participants who lived alone, dying at home raised the possibility of dying alone"

(p.1120). The researchers concluded that despite the common belief that dying at home is

generally "viewed as an ideal place to die, it may not be preferred by [all] older people"

(p.1120.)

Preferences can change over time. Research suggests that preferences for place of

death are not static and often change. A trend within the research postulates that as illness

progresses, resources and conditions also change, and subsequently individuals'

preference for dying at home declines (Barclay, 2009; Gomes & Higginson, 2004;

Higginson & Sen-Gupta, 2000). Gomes et al. (2013) reviewed 15 studies tracking

changes in preferences for place of death of patients. Results indicated that "change in

preference were documented for [20% of patients] across 10 studies" (p.9). Higginson &

Sen-Gupta correspondingly found through systematic review that "preferences were

tempered by the change in choices the patient and family made with progression of

disease, passing of time, and services delivered" (p.299).

Actual Place of Death

Although the bulk of existing literature suggests that Americans prefer to die at

home, "the majority of deaths from all diseases/conditions in most Western countries

occur in a hospital" (National Center for Health Statistics, 2011; Tang & McCorkle,

p.166).

The National Center for Health Statistics (NCHS) (2011) collected place of death

data from 1989 to 2007 in the United States representing approximately "50% of all

deaths" (p.105). Place of death was defined by the NCHS as the place "where death was

pronounced and on the physical location of death, not the services they were receiving at

the time of death" (p.105). The NCHS reported that in 2007, among individual ages 65

and older, 23.7% died at home, while 35% died in the hospital as an inpatient, 27.9%

died in nursing homes, 5% in hospital outpatient, and 8% were identified as passing away

in "all other places" which included: dead on arrival, hospice facility, other, and

unknown. Rates of home deaths reported by the NCHS were up in 2007 as compared to

20.9% in 1997, and 15.2% in 1989.

Weitzen, et al. (2003) utilized the National Mortality Followback Survey

(NMFS), in order to better understand where people in the United States die. The survey

utilized death certificates to inform place of death including: acute care hospital, nursing

home, or home. Researchers used a "stratified random sample of 10,122 deaths occurring across 49 states in the US that were caused by chronic illness." Results indicated that "58% died in the hospital, 22% died at home, and 20% died in a nursing home" (Weitzen, et al., p.327).

The NHPCO reported that in 2011, 66.4% of deaths among hospice patients occurred in the "patient's place of residence" (2012, p.6). However, "place of residence" was operationalized as including private residences (41.6%), nursing homes (18.3%) and residential facilities (6.6%) in contrast to other studies that defined "home" as an individual's' private residence or as distinct from nursing homes. The same study reported that 26.1% of hospice patients died in a hospice inpatient facility and 7.4% of patients passed away in an acute care hospital (NHPCO).

The results from the NCHS report (2011) and the research of Weizen (2003) are highly useful, but broadly report using data from all deaths (NCHS) and from exclusively cancer patient deaths (Weizen), without specifying whether or not respondents were receiving hospice care services at time of death. Although the NHPCO (2012) reports specifically on place of death congruence among hospice patients, the report uses a different definition of "home" as compared to some aforementioned studies. Although much research exists surrounding place of death within the general population, research specific to hospice patients is notably less abundant, and home is defined using differing constructs. Further research is needed in order to explore, in greater detail, place of death among hospice patients.

Place of Death Congruence

Defining Congruence

Congruence has been defined as "the agreement between a patient's stated preferred place of death and actual place of death" (Bell, et al., 2010; Tang & McCorkle, 2003). Place of death congruence is important for health care professionals, families, and policy makers to consider as "honoring a patient's choice for place of death has been identified as an essential component in terminal care" (Bell, et al., p.591).

Place of Death Incongruence

An incongruence related to preferred and actual place of death has been consistently noted within research. In the systematic literature review conducted by Bell, et al. (2010), it was reported that within studies concerning the general population's preferred place of death, "50-90% of respondents preferred to die at home" (p.591), however, "in [actual] place of death studies, 10%-35% of patients died at home and 50%-60% died in hospitals" (p.591). Tang & McCorkle (2001) sought to "[review] the determinants of place of death among terminal cancer patients within published studies in hopes of shedding light on difficulties of dying patients and to realize their preferences for place of death" (p.165). Results from Tang & McCorkle's analysis of thirteen published studies revealed that "28%-89% (with an average of 59.5%) [of patients] under the home care services could die at home and 11-72% (with an average of 37.5%) of patients under such kinds of care died in the hospital" (p.167).

Holdsworth and Fisher (2010) sought to "explore recording rates of preferences, and the preferred and actual place of death among hospice patients" (p.1) using data

collected from 298 hospice patients over six months. Researchers reported an overall

congruence rate of 61.7%, (home 52.5%; hospice 86.2%; hospital 100%; and care home

50%). Surprisingly, the results of this study indicated that only one in four respondents

expressed a preference for a home death, while "58.4% [of respondents] had no

expressed preference for place of death" (p.1).

The incongruence in place of death is a major trend in current research and

proposes that multiple factors, including individual, relational, and structural matters

influence place of death (Tang & McCorkle, 2001, p.168.). Incongruence might also posit

that in some circumstances individuals lose control over the place of their final days

(Bell, et al, 2010; Tang & McCorkle). Although the aforementioned studies demonstrate

the existing dissonance between preferred and actual place of death, explanations for said

incongruence vary, and require further exploration.

Factors influencing actual place of death

The literature proposes that there are many determinants, as varied as individuals

themselves that contribute to each person's actual place of death. Indeed, "determinants

of place of death for terminal [patients] are a function of a complex interplay of personal

and cultural values, support network characteristics, and physical and medical factors, as

well as various health care system forces" (Tang and McCorkle, 2001, p.177). Some

recurrent influences contributing to place of death in the current literature include: the

utilization of hospice care, caregiver presence and ability, terminal diagnosis, and cultural

background (Beland, 2013; Gott, et al., 2008; Tang & McCorkle, 2001; Weitzen, et al.,

2003).

Hospice Utilization

In the systematic literature review conducted by Bell, et al. (2010), researchers discovered that both inpatient and outpatient hospice care utilization was associated with increased congruence surrounding place of death, and that hospitalization was associated with decreased congruence. Further, "of the 161 home deaths [included] in the study, 70% reported hospice utilization" (p.599), suggesting that the use of hospice services enables patient preferences for home death to be honored. Correspondingly, the analysis completed by Weitzen et al. (2003) revealed that of the deaths reported in the NMFS, for individuals "enrolled in hospice, three out of four died at home" (p.331), and that receiving hospice services was strongly associated with home death. Bell et al. (2010) posited that because hospice offers specialized care surrounding comfort and support, place of death congruence was positively impacted by hospice utilization. These results infer that the utilization of hospice services may better support the actualization of end-of-life preferences than among dying persons in the general public.

Social Support & Caregiving

Previous research indicates that the presence of a caregiver has a significant impact on place of death (Beland, 2013; Gott, et al., 2008; Paddy, 2011; Weitzen, et al., 2003). Existing empirical literature suggests that employing private caregiving services can be costly and thus is an unrealistic option for individuals living on a fixed income or with limited savings or assets. For family members, taking on the role of caregiver has been described as a "major undertaking" (Beland, 2013) and as "one of the most difficult (and oftentimes rewarding) tasks a family [member] will ever face" (Mcinnis-Dittrich, p.338).

Because individuals who are dying from a terminal illness require an intense level of care and often become dependent (to some degree) on caregivers, "dying at home can cause hardship and distress for the patient and the carer" (Paddy, 2011, p.35). In fact, research suggest that it is not uncommon for caregivers to "refuse the possibility of a home death even though it [may be] the patient's preference" (Paddy, p.35), due to matters such as concurrent responsibilities and/or stressors (such as work, finances, or child rearing), age, and perceived and/or actual inability to support a home death (Paddy; Tang & McCorkle, 2001). Although a private residence may be the preferred place of death, supporting a home death without the proper resources and/or training could become problematic, trying, and has the potential to threaten the health of caregivers (Beland, 2013; Gott, 2011, p.36).

In research by Tang & McCorklel (2001), caregiver ability was positively correlated with place of death congruence among cancer patients. Similarly, Weitzen, et al. (2003) concluded that the availability of an appropriate caregiver, and caregiver burden were factors influencing place of death. One explanation for this finding is that for carers who do not receive the appropriate supports, coping may become a struggle leading to patient placement outside of the home (Beland, 2013).

Terminal Illness

Terminal illness is an influential factor in the determination of place of death; in part due to the fact that illnesses commonly associated with hospice enrollment (including cancer, congestive heart failure, and dementia) have varying functional trajectories, prognoses, symptoms, and accompanying comorbidities (Weitzen, et al.,

2003). Further, research indicates that common triggers of hospitalization are directly

related to some disease processes (Lamba & Quest, 2011).

Using the NMFS, Weitzen, et al. (2003) analyzed place of death and terminal

illness. Results indicated that "certain diseases with acute onset and rapid trajectory, such

as stroke or heart disease predicted dying an acute care facility. Heart disease deaths were

almost twice as likely and stroke deaths were more than three times as likely to occur in a

hospital, as compared with cancer deaths" (Weitzen, et al., p.332) and that "the odds of

dying at home [were] much lower for most non-cancer causes of death [as] compared

with cancer" (p.331). Weitzen, et al. concluded that "illnesses with a rapid decline predict

dying at home or in a nursing home compared with a hospital, whereas early functional

loss predicts dying in a nursing home" (p.332).

Race/Cultural Background

According to research, race and/or cultural background is an individual factor

contributing to a person's actual place of death, highlighting a significant social justice

issue. "In 2000, 82% of hospice patients in the U.S. were white; eight percent were

African American, two percent were Hispanic, two percent were identified as other, and

six percent were not classified by race or ethnicity" (The Hastings Center, 2003, p.39).

Similarly, Weizen, et al. (2003) found that African Americans were less likely to die at

home as compared to whites" (p.327) and that Caucasians were found to have "higher

proportions of deaths at home and in nursing homes than descendants of other races,

whereas more than 70% of non-Hispanic black persons, and 70% of Hispanics died in a

hospital compared with 55% of white persons" (p.327). Results from the research of

Higginson & Sen-Gupta (2000) likewise indicated a "significant [relationship] between preference for dying at home… and race" (p.298) with more whites dying at home as compared to other races.

The results indicating that Caucasians are more likely than that of any other racial group to experience death at home are surprising, particularly given that the "incidence of informal family caregiving increases in Asian-American, African-American, and Hispanic-American older adults" (McInnis-Dittrich, 2014, p.330). The increase in informal caregiving among culturally diverse individuals is partially "evidenced by culturally-specific attitudes about caregiving and a greater likelihood that older adults will reside with other family members prior to needing caregiving services" (McInnis-Dittrich, p.330). Nonetheless, the results of the aforementioned studies in conjunction with the growing evidence that nonwhites experience more pain and receive less care at end-of-life underscores the insidious racial disparities existing throughout the entirety of the lifespan (Walsh, 2003), and warrants continued research.

Conceptual Framework

The conceptual framework for the current research was based upon services provided by the hospice social worker and guided the creation of interview questions and qualitative data analysis. For the purposes of the current research, ecological systems theory and solution-based theory was used as conceptual frameworks.

Ecological Systems Theory

It is commonly agreed that human beings cannot and do not flourish in seclusion (Miley, O'Melia, & DuBois, 2013). The Ecological Systems (Eco-Systems) perspective is considered integrative and inclusive as it views "the behaviors of individuals, families, groups, organizations, local communities, and international societies as interconnected… [and] focuses on how people and their environment fit [together]" Miley, et al., p.31). Through the Eco-Systems perspective lens, humans are viewed as complex beings that both *evolve in* and *interact with* contextual environments (systems) bursting with compelling influences such as culture, ethnicity, socioeconomic status, power, oppression, and access to resources (Miley, et al.). Individual and family system functioning and the efficiency of greater social systems, are largely based upon "the relative balance or imbalance of resources, opportunities, and demands within and between these systems" (Miley, et al., p.36). Under the Eco-Systems perspective, it is important to consider the person as an individual as well as the various micro, mezzo, and macro systems in which reciprocal, person-in-environment transactions take place (Miley, et al.).

Humans are generally considered to be dynamic, complex, multifaceted, and engage in transactions; hospice patients are no exception. All patients are both *whole* in his or her own distinctive identity and a *part* of a many larger systems. In considering how to enhance place of death congruence, it is important to acknowledge and integrate a multitude of systemic interactions that reflect various levels of organization. Within system factors include the patient's terminal diagnosis and cultural background, both of which are factors that could be influential when considering place of death congruence. At the subsystem (micro) level, patients are often a part of a family and a household taking

on the roles of parents and grandparents, spouses, and friends. At the mezzo level of

system organization, transactions between hospice patients and their caregivers, the

medical system, the hospice agency, neighborhood and surrounding community systems,

must be considered as important interactional contributors to place of death. At the

societal level, access to resources and support networks, housing systems, financial

systems, social service systems, and cultural systems must be considered in the

achievement of final goals.

Solution-Focused Theory

Solution-Focused Theory focuses around the client, honoring their expertise,

resilience, and strengths (Miley et al., 2013). This theoretical model was developed in the

early 1980s in Milwaukee by Steve de Shazer and colleagues in a family therapy setting,

and has since been supported by empirical research and efficaciously employed within

therapeutic settings, social work, education, and business (Winbolt, 2011). Solution-

focused therapy has been described as a practical, goal-driven model that emphasizes

clear, concise, and realistic goal negotiations (Winbolt) and seeks to discover "solutions

and potentials for change [while] fostering a sense of optimism" (Miley, et al., 2013,

p.227).

Solution-Focused approaches are described as "collaborative and creative process

requiring the expertise of both [clients and professionals]" (Winbolt, 2011, p.21). By

working together, the patient and social worker "are far more resourceful and productive

than either would be alone" (Winbolt, p.22), and are better equipped to realistically

problem-solve and identify exceptions to the difficulty. Utilizing Solution-Focused

Theory does not mean solving the patient's problems, but rather is based around creating

positively-oriented conversations "towards some sort of positive outcome (or goal), albeit within the very real constraints some [patients] face" (Winbolt, p.23). "Finding out what the [patient] wants… and negotiating a course of action that is acceptable to them enables solutions to be constructed" (Winbolt, p.21).

Hospice care is a collaborative journey that seeks to honor and support patient goals. However, when it comes to place of death, this is not always possible. When individual, relational, or structural factors impact the placement of final days, hospice social workers often negotiate goals and pursue solutions to best support the patient and family. Within hospice care, tools such as Advance Directives and the Provider Order for Life-Sustaining Treatment (POLST) are often used to identify patient preferences and establish goals.

Methodology

Research Design

The purpose of the current study was to explore subjectively and ideographically, the perspectives of hospice social workers regarding place of death congruence. An exploratory qualitative study design was utilized by conducting semi-structured interviews that allowed participants to share experiential knowledge related to patient preferences, the role of the hospice social worker, impactful factors related to place of death among hospice patients, and the achievement of place of death congruence. Qualitative research "refers to the meanings, concepts, definitions, characteristics, metaphors, symbols, and descriptions of things" (Berg, 2007, p. 3), and was a good fit for the current study, as the research design facilitated the collection of rich exploratory data.

Sample

Nine, licensed social workers currently employed within a hospice care setting were selected to participate in the present study via convenience (availability) and snowball sampling. Participants ranged in terms of age, years of hospice experience, (participants averaged 5.2 years of experience), and in terms of hospice agency (four agencies represented). All participants were female. The current study focused on the participants' professional opinions and subjective experiences relating to the research questions, "What factors influence place of death congruence among hospice patients?" And "What is the hospice social worker's role in providing a congruent place of death among hospice patients?"

Protection of Human Subjects

A proposal of this qualitative study was written by the principal investigator and was reviewed and approved by a research committee. A protocol for the current study was additionally created by the principal investigator and submitted to the University of Saint Thomas Institutional Review Board (IRB). Following necessary protocol and proposal edits and secondary IRB approval, data collection officially began. For the purposes of this study, the researcher modified a consent form template that was originally created by the University of Saint Thomas. Once modified, this consent form (See Appendix B) was submitted to the IRB, edited, and approved. The first portion of the consent form specifically provided the participants with pertinent study information and addressed the purpose of the current research. The consent form also explained reasoning behind participant selection, outlined the research procedure, and explained

how the data would be collected, used, and protected. The form presented risks and

benefits of participation, discussed issues of confidentiality, and the voluntary nature of

the research. In addition, the consent form provided contact information for the

researcher, course instructor, and University of Saint Thomas IRB. The second portion

of the consent form contained the actual provision of informed consent, which was signed

and dated by both the researcher and all participants. Data collected by the researcher was

stored on a password-protected cell phone and will be destroyed by June 2015.

Data Collection

        In this qualitative study, a semi-structured interview consisting of ten open-ended

questions and several follow-up questions (See Appendix A), served as the principle

means of data collection. Questions were developed by the researcher following a review

of the existing literature regarding preferred and actual place of death within hospice

care. Interview questions centered upon the hospice philosophy of care, the role of the

hospice social worker, the preferred place of death and actual place of death among

hospice patients, and factors that affect place of death. All interviews were recorded

using a digital recording program on the principle investigator's personal cell phone, and

took approximately one half hour to complete. Six interviews were completed in-person

and three were conducted via telephone. In-person interviews were carried out in a

variety of comfortable and private settings including participant's homes and hospice

agencies/offices. The principal investigator additionally kept field notes throughout the

data collection process.

Data Analysis

The purpose of the current study was to explore hospice social workers' perspectives on place of death congruence and factors that influence place of death through the development of sub-themes and dominant themes, and thus a descriptive phenomenology was utilized for data analysis. As previously discussed, a digital recording program was used to record the interviews with the study's participants. Following the interview, the recordings were meticulously transcribed and examined by the researcher using first-level coding as outlined by Padgett (1998). Upon first appraisal, the principle investigator worked inductively by completing content analysis via reading through all collected data iteratively, noting analytical memos, and identifying recurring concepts, themes, and words (codes). Once common codes were roughly identified, the researcher worked deductively by gathering the excerpts (content units) together in ways that related to overarching themes, similarities, and differences. Excerpts themselves were then analyzed and sorted into groups of similar meaning. It was expected that some excerpts would not be linked to exclusively one code, as some excerpts fit in to more than one theme and thus interpretation, reordering, refining, and broadening ideas to reflect the coded information was necessary.

Once first-level coding was completed, second-level coding, in which codes were translated in to themes and subthemes was employed (Padgett, 1998). Both manifest and latent content were identified and documented. All excerpts were then examined and compared across various responses. Themes important to the established research questions were identified, themes were compared for similarities and differences, relationships and trends among responses were assessed, and exceptions to themes were

compiled. Several concept maps representing various themes were additionally created in order to facilitate the grouping of themes in a meaningful way.

In order to enhance the present study's rigor and test for inter-rater reliability, the transcription of the interview was analyzed for codes and themes by a second, objective researcher. The reliability check confirmed the themes and sub-themes that were identified in the second-level coding process. The two researchers were in agreement regarding dominant themes and sub-themes that emerged from the data, and had similar ideas regarding the concepts relating to the overall research question. Both researchers found the codes to be logical and credible, and sampling, data collection, and analysis to be justified, which further increased rigor within the current study.

Results: Sub-Themes

Social Worker's Role

Participants were asked to discuss their role as a social worker within the hospice interdisciplinary team. Table 1 illustrates the sub-themes that participants identified as being included within their role.

Table 1
Frequency Distribution of Sub-Themes: Hospice Social Worker's Role

Sub-Themes: SW Role	*n*	%
Assess	6	67%
Educate	6	67%
Support	5	56%

Assess. Six participants (67%) stated that their role included completing assessments. Such assessments surround the patient, family, and/or caregivers, and are made on an on-going basis throughout hospice services. Participants identified the role of the social worker in completing assessments related to psychosocial needs of the patient, disease progression, the caregiver's ability to care for the patient, and to cope with stress/changes.

Educate. Six hospice social workers (67%) identified the importance of providing education as a part of their role. According to participants, most education provided by the social worker surrounds preparation, teaching patients and families "*what to expect*," and helping them to envision (what things will "*look like*"). Many of the participants discussed providing specific education surrounding hospice care (philosophy, team, and services), the terminal disease progression, and the dying process. Participants suggested that education also includes providing options, information, and connecting families with resources.

Support. Five participants (56%) discussed providing support as a part of their role within the care team. Providing "support" included concepts such as relationship-building with care recipients and other entities, listening, providing supportive counseling, and being present as changes and/or crises occur.

Hospice Philosophy

Participants were asked to discuss the philosophy of hospice care, as they understand it. Table 2 illustrates the sub-themes that participants identified as particularly important to the philosophy of hospice care.

Table 2

Frequency Distribution of Sub-Themes: Philosophy of Hospice Care

Sub-Themes: Philosophy of Care	*n*	%
Comfort	9	100%
Whole/Holism	4	45%
Quality	4	45%
Symptom Management	3	30%

Comfort. Nine participants (100%) identified comfort as an integral part of the hospice philosophy of care. Participants discussed that patients enter in to hospice care when aggressive interventions are not desired, or when curative options do not exist. Instead of seeking an antidote for a life-limiting disease, hospice patients seek physical, emotional, and spiritual comfort. One participant said "*almost everything we do as a hospice team involves providing comfort*."

Whole/Holism. Four participants (45%) discussed the holistic nature of hospice care and the usefulness of the interdisciplinary team in meeting the emotional, physical, and spiritual needs of patients and families. Participants described hospice care as a system of care that departs from the traditional medical model, and as an "*individualized approach*" in that care is tailored to the unique needs of each patient and family.

Quality. Four participants (45%) identified the element of quality when discussing the hospice philosophy of care. Participant discussed concepts such as making the most of life at the end of life, achieving end-of-life goals, and emphasizing comfort over life-prolonging measures.

Symptom Management. Three participants (30%) identified the management of terminal symptoms as an integral part of the hospice philosophy of care. Symptoms commonly identified as being managed by hospice care included: pain, agitation, restlessness, nausea, and anxiety.

Preferred Place of Death among Hospice Patients

Participants were in agreement that in general, if given the ultimate decision, hospice patients prefer to die in the place they call home. Participants differed in how they defined the concept of "*home*." According to responses, home can include a variety of settings including private residences, skilled nursing facilities, assisted living facilities, and/or residential hospice homes. Participants also discussed "*home*" as being understood as "*the place where the patient has been living consistently, wherever that place may be*."

Although participants were in agreement that most patients prefer to die in the place they call home, several hospice social workers cautioned that this is not *always* the case. One participant shared, "*in my experience, most of my patients prefer to die at home. But you know, it's not all of them. There are definite exceptions to that*." Participants discussed the tendency of patients to feel that they are a "*burden*" at home and to seek placement elsewhere to ensure that family members do not become caregivers. Several participants expressed that not all hospice patients are able to articulate their preferences, and that others have no choice in the matter. Another participant stated that often due to issues related to symptom management, "*there are some people who would rather go to the hospital, or to a place where there are professionals to help, such as a residential hospice or a skilled nursing facility*."

Why is Home Preferential?

Participants were asked to discuss plausible reason behind the preference toward home death. Table 3 illustrates the sub-themes that participants identified in discussing why home is preferential for death.

Table 3
Frequency Distribution of Sub-Themes: Why Home Preferential?

Sub-Themes: Why Home Preferential?	*n*	%
Family	6	67%
Familiarity	5	56%
Comfort	5	56%

Family. Six participants (67%) identified home as a place associated with family, thus making it preferential. Participants discussed that "*home*" is often where family gathers, and where the patient feels the greatest sense of support from loved ones. Three participants identified that home is where the patient's pets live; one hospice social worker stated lightheartedly, "*For some people it really is about being surrounded by their animals. They are just as much a part of the family [as the people]*."

Familiarity. Five participants (56%) identified the concept of familiarity in discussing why home is the preferred place of death for hospice patients. Participants indicated that when patients are able to remain in place for death, feelings of consistency are heightened. Participants identified home as a place where patients are surrounded by familiar people and pets, familiar objects, and inferred that familiarity often produces feelings of safety and security. Participant's responses revealed that a person's home can

be closely tied to feelings of identity, and several participants drew connections between being in a familiar setting and recalling pleasant memories.

Comfort. Five participants (56%) identified comfort as a factor that makes home the preferential place to die. Comfort included concepts surrounding physical and emotional comfort, feelings of control, and fear/misinformation.

Physical and emotional comfort. Participants discussed the physical comfort found at home. Comfort can be concrete: "*our home is our comfort, whether that is the pictures on the wall, or our favorite couch that we sit in, or making sure our family is around or our dog sitting on our lap*," and emotional: "*it's where we are surrounded by our network of safety*." The participant's responses suggested that the concept of home was associated with feelings of increased privacy and independence. Home additionally was described as "*comfortable because it's not institutional, and it's not sterile—it's lived in*."

Feelings of control. Participants indicated that comfort is associated with feelings of control and self-efficacy. One participant said:

> *I believe home is comfortable...because at home there is a sense of control. When you're in your environment, you are in control of the situation, and there might be a feeling of a loss of control, so to speak when you're in someone else's home. There's someone else running the show, and I think when so much is taken already from people throughout the disease process, [dying at home] is the one thing they can still control.*

Fear/Misinformation. Contrasting comfort, two participants discussed fear and misconceptions surrounding end-of-life experiences outside the home. Two participants discussed the comforts of home being linked to a lack of knowledge regarding other alternatives. One participant stated, "*I think that there is a lot of fear and dislike associated with nursing homes, and I think sometimes people think that's their only option, so [given that choice,] they want to be at home.*"

Factors Influencing Place of Death: What is needed for a Home Death?

Participants were asked to discuss the factors that are needed in order for a patient who prefers to die at home to actually die at home. Table 4 illustrates the sub-themes that participants identified as essential for achievement of place of death congruence.

Table 4
Frequency Distribution of Sub-Themes: Factors Needed

Sub-Themes: Factors Needed	***n***	**%**
Caregivers	9	100%
Support	5	56%
Education	3	30%

Caregivers. Nine participants (100%) discussed the need for caregivers in achieving a preferred home death.

Willing and able. Participants inferred that not only must caregivers be willing, but they also must be *emotionally*, *physically*, and *financially*, able to provide care. Caregivers need to be "*capable and comfortable*," in providing 24-hour-a-day, seven-day-a-week care. According to participants, caregivers must be specifically comfortable

administering medications, providing personal cares, completing physical transfers, and

being on-call at all times. One participant said:

> *I don't think it's even that they just need to be willing, but I think they also have to*
>
> *be competent. It's an ability that family members have to have, to be able to*
>
> *provide end-of-life care. Not everyone can do that. Whether it's due to physical*
>
> *limitations or any other kind of emotional discomfort. Some loved ones really*
>
> *want to be able to do it, but when it comes down to it, they're just not able to*
>
> *emotionally. Or they're not physically capable of transferring them, and bathing*
>
> *them, and doing a lot of the physical cares*.

Role flexibility. In enabling a home death, participants discussed the obligation

for family members (caregivers) to flex in their roles within the family system.

Participants stated that often, adult children must flex between the role of the child, or

care recipient, to the role of caregiver. "*You know there's a huge dignity issue there and a*

lot of dynamics within the family there too. So, when adult children are suddenly helping

mom to the bathroom and wiping her bottom, that's a huge role reversal, some folks just

can't do that." Participant's responses revealed that changes in roles could become

overwhelming for family members, and have the potential to cause a placement outside

of the home.

"It takes a village." Many participants strongly asserted that more than one

caregiver is absolutely required in order to avoid burnout/caregiver exhaustion and to

make a home death a realistic option. One participant stated, "*If there's a sole caregiver,*

that's problematic because the toll on the caregiver is really extreme. The care becomes

24-seven for an ongoing period of time." Participants suggested that not only is one

caregiver not enough, but that in actuality, *three* caregivers are necessary in order to

provide effective end-of-life care.

> *You know we talk a lot about three caregivers being ideal. About the fact that,*
>
> *there's a reason that professional caregivers work eight hours, and then are off*
>
> *16 hours, and then come back and do another eight hours. We say ideally, it's a*
>
> *three-person job.*

Two participants remarked that end-of-life caregiving at home "takes a village." One

participant noted:

> *In order for a home death to happen, people need to be comfortable proving*
>
> *personal cares, and managing medications, being in that caregiver role all the*
>
> *time. It's just key. And having people that will give them break. It's really just*
>
> *about that large support system and just that number of people. It really does take*
>
> *a village.*

Support. Five (56%) of participants discussed the need for support in achieving a

preferred home death. Participants discussed the requirement for *systems of support* for

caregivers in preventing burnout. Responses indicated that this type of "*network*" can be

based within the family or the community, and can be supplemented by the hospice care

team. One participant inferred that there is strength in numbers stating:

> *The number of caregivers that can be actively involved is really critical because*
>
> *that translates into how much support the caregiver will get in reaching the goal*
>
> *and allowing the patient to stay at home. So if there is a spouse and children and*
>
> *other people involved in the actual day-to-day care it becomes a lot more*

possible, or you if they hire in additional hours of care privately, that make home

death more do-able also.

Education. Three (30%) of participants discussed the need for education in achieving a preferred home death.

Preparation. Participants suggested that the education needed in order to attain a home death should prepare caregivers and "*paint the picture*" of what end-of-life care really is, and what disease progression might "*look like*." Two participants referred to educating with "*conversation*." One participant stated,

It's really important to have that conversation with the family members and

educate them and make sure that they understand what's all to come. So

educating them on what the dying process is going to look like and how much

care somebody might need towards the end-of-life.

Specifically, participants expressed the demand to communicate that patients are often bed-bound, incontinent, and need round-the-clock medication administration during the dying process.

Addressing misconceptions. In addition to preparing caregivers, participants suggested that education was critical in order to dispel misconceptions surrounding home deaths.

I think when a patient says, 'I want to die at home' they don't… well it's very rare

for them and family to be able to know what the last weeks might look like. When

they are totally bed-bound, they need medications around the clock, so I think,

that a huge conversation that I as a social worker start to have.

Another participant said, "*families will say, 'well we want dad to be at home,' but when*

you start to talk about what that will look like... you know, what does caring for someone

at home while illness progresses really look like?"

Participants discussed how families often do not expect the patient's condition to

decline, another area in which education is required.

People say, 'I'm not comfortable taking my dad to the bathroom!' and I totally, I

get that. But you know, maybe dad is up and moving around and able to mobilize

right now, so family likely doesn't even comprehend what the end will look like. I

think people; they can't even wrap their heads around a loved one starting on

hospice, much less about the deathbed scenario. You know it's just so hard to

wrap your head around.

Factors Influencing Place of Death: What are Barriers to Home Death

Achievement?

Participants were asked to discuss the barriers in achieving a preferred home

death. Table 5 illustrates the sub-themes that participants identified as barriers to place of

death congruence.

Table 5

Frequency Distribution of Sub-Themes: Barriers to Home Death Achievement

Sub-Themes: Barriers	*n*	%
Caregivers	9	100%
Terminal Symptoms	8	89%
Safety	4	45%

Caregivers. Nine (100%) of participants identified an absence of caregivers as a barrier to the achievement of a preferred home death. Responses indicated that often adult children (potential caregivers) do not live in the same state as their parents, and are only able to visit from time to time. One participant shared emphatically, "*Location! Location is a huge barrier. I mean if [the caregiver] is living out of state, and there's a life-changing event, [will the caregiver] be able to get home? Maybe not.*" Without the presence of caregivers, patients who wish to remain at home are often unable to do so due to safety concerns. One participant noted:

> *Some of our patients don't have family involvement and don't have people around to help them and if they don't have that support network around them, then when it comes to end of life, it's not really a safe option for them to remain at home and alone.*

Participants inferred that in most instances, available caregivers become unavailable due to burnout or because the needs of the patient become overwhelming. One participant said, "*The care needs can become really hard. Especially with our older folks, for example an elderly spouse who is the sole care provider for the patient. You know, they're just not able to do it.*" Further, participants submitted that many caregivers

do not have flexible jobs that allow for vacation time to provide continuous care, or are financially unable to take a loss of wages from missed work hours.

Terminal Symptoms: Eight (89%) of participants identified end-of-life symptoms as a barrier to place of death congruence. Responses indicated that often, terminal symptoms exceed the ability of caregivers within the home setting. Specific symptoms that were indicated by participants as hard to manage in at home included psychosis, extreme agitation/restlessness, impulsivity, pain, memory loss/cognitive deficits, and wandering/falls. "*Sometimes the symptoms get hard to watch, and so family gets very overwhelmed, with what they are witnessing and being a part of, and maybe feel inadequate in what they are providing.*" Participants specifically discussed the loss of sleep that caregivers often experience as being particularly trying. One participant stated:

> *I had a patient who was experiencing some terminal agitation, and falling a lot and just became too much for [the caregiver]. This caregiver had to be on-guard at all hours and wasn't getting much sleep, as he was up all night and sleeping all day. [The caregiver] had to be constantly watching him and making sure that her dad didn't get up and then fall...exhausting!*

Safety: Four participants (45%) identified issues related to safety as a barrier to the achievement of a home death. In many cases, participants indicated that patient safety is often closely tied to terminal symptoms, physical environment, and/or absence of caregivers.

Falls. Many participants discussed falls in relation to safety and ability to remain at home for death. One participant shared empathetically,

Something that really prevents people from having their end-of-life experience at home is safety concern. When people start falling, I see it over and over again. Caregivers say, "Oh well, if [the patient] falls, I'll just pick him up," and it's like "no, he's 200 lbs. and isn't able to help you at all." And then, sure enough the patient falls and [the caregiver] calls the nonemergency medical people to come over to pick [the patient] up from the floor. Families will start crying and say 'I just realized, I couldn't get him off the floor.' That's always a deal-breaker for staying at home, crises just like that.

The responses of participants indicated that some terminal symptoms such as agitation or wandering are particularly tied to falls in the home. One participant spoke about the connection between falls and facility placement stating, "*There are a lot of times when people become agitated and become a risk for falls. Or you know they are wandering and they really need to be like on a locked unit, that's the time we might look at moving the patient to a different setting.*"

Absence of caregivers. Many participants indicated that safety is also closely connected to the presence of caregivers.

If a patient is living with an elderly spouse, and you know the daughter can come over to check on them at night, but, the spouse can't physically transfer them on their own during the day or can't physically move them to change them or something, then [the patient's safety] becomes a concern.

Factors Influencing Place of Death: Psychosocial Factors

Participants were asked to identify and discuss psychosocial factors that are especially influential in determining where a hospice patient dies. Table 6 illustrates the variables that participants identified psychosocial factors that impact hospice patient's place of death.

Table 6
Frequency Distribution of Sub-Themes: Psychosocial Factors

Sub Themes: Psychosocial Factors	***n***	**%**
Culture	9	100%
Finances	8	89%
Progression of Illness	4	45%

Culture. Nine participants (100%) indicated that culture is a psychosocial factor that effects where hospice patients die. Culture included concepts such as cultural background, American cultural values, and the culture that exists within a family system.

Cultural background. Several participants discussed the ways in which a patient's cultural background influences their place of death. Several hospice social workers discussed cultural preferences for Hmong patients, although participants had conflicting perspectives regarding the preferences themselves. One participant recalled, "*I worked with many Southeast Asians, and some of the Southeast Asians don't want to die in their home, because then the evil spirits will then inhabit the home,*" while another participant explained, "*the Hmong and other Asian populations, they take care of their families at home, most often. There's always outliers, but that has been my experience.*"

Yet another participant stated, "I *know that for some of the Hmong families that I have worked with, it was very important for that person to stay home*."

A theme among participant's responses related to the impact of culture suggested that compared to "*Americans*," other cultures, specifically, African Americans, Hispanics, East Asians, and Somali individuals, are both better able to rally systems of support, and facilitate death at home. One participant explained:

> *I have certainly noticed that other cultures do a much better job of caring for loved ones in the home than Americans. And you know I did an admission the other weekend for a Hispanic family, and it's like "Placement!? That's not even a conversation. That's not even something that needs to be talked about." You know, "the plan B option is that we would [be the primary caregivers]."*

American culture. Values from American culture surrounding death and dying emerged as an influential factor in determining where patients die. Specifically, participant's responses suggested that the generation gap, ageism, and the tendency of Americans to value individualism and mobility are impactful factors in place of death congruence. One participant shared:

> *As a culture, we are so…mobile. And I think issues of cultural mobility come in to play in a big way. You know, kids don't live in the same state as their parents-- you know, the kids will be here and mom and dad are down in Florida, or vice versa. And… as we become more mobile as a culture, I believe our ability to facilitate home deaths declines.*

Another participant discussed the importance of remembering that other cultures are often interdependent valuing formal or informal family, rather than individualistic valuing self-promotion. The participant expressed, "*not everyone is focused exclusively on work and doing better for ourselves. A lot of cultures really value caring for their elder. Families say, 'we take care of each other, that's just what we do.'*"

Culture within a family system. Participants also identified culture within the family system as impactful in determining place of death among hospice patients. Specifically, participants mentioned the family's ability to cope and to adapt to change. "*It's really about the whole family system and even the functioning of the family and the patient before the diagnosis. And just how they do with stress and how they manage it.*" In addition, the amount of support present with a family, relationship dynamics, and communication style were distinguished as influential. One participant stated:

> *So if there's a very strong support system, the whole family, supportive family, present and available then that's very positive. The more distant and disengaged families, or families with history of domestic violence or alcohol or other drug use, usually that impacts on the family's ability to sustain caregiving for any length of time and impacts place of death.*

Another participant shared:

> *Trust among family members and how their relationship was before hospice is influential. Sometimes it's more structural, like family dynamics. Like we have had situations with adult children, where they were estranged for a number of*

years and then they get back into their parent's life and then they start to die and it's just too much emotionally for them to be around these people.

Finances. Eight participants (89%) discussed the influence of finances in determining where hospice patients die. According to participants, having money buys patients and families options at the end of life. With money, families can hire private caregivers to ensure burnout does not occur, or can relocate the patient to a home-like hospice home facility, which can be exceptionally expensive. Further, money allows for the preservation of roles within the family system. One participant commented, "*Having money is really nice because that allows the family to just be family and then have that hired help there to provide the professional care.*"

One participant discussed misconceptions related to the cost of end-of-life care, and what a burden money can be throughout the dying process stating:

Money is such a stress for families. So stressful. People are just shocked when they hear that hospice does not provide 24-hour room and board. That we don't pay for that and neither does Medicare. Because people always think of hospice as a place you go. "Well, I thought Medicare covered hospice?" Well, yes Medicare does pay for it, but it's not a place you go. It's a service. There's just so much misinformation out there.

Progression/Course of terminal Illness. Four participants (45%) identified the patient's terminal illness and/or illness progression as significant in determining place of death. Responses indicated that the course of a given disease is highly unique to the individual, and involves many additional aspects. Some participants recognized illnesses

that present with a quicker onset and produce a rapid decline as more likely to cause a

placement or hospitalization, while other participants identified a slow disease

progression as exhausting and wearing on caregivers leading to a placement outside the

home. One participant thoughtfully summed:

> *While many patients and families express the desire to die at home, it can be*
>
> *difficult for that to happen with respiratory diseases, particularly COPD, with*
>
> *certain cancers, and end-stage dementia with behaviors. These are all diseases*
>
> *that take a heavy toll on the primary caregiver. The patient can be*
>
> *demanding/anxious with COPD, or the patient can be in intractable pain, which*
>
> *is really hard for families to watch, or the patient can be uncooperative, and*
>
> *confused, with interrupted sleep patterns. The glacially slow or erratic diseases*
>
> *are also very wearing on caregivers, like Alzheimer's can be so gradual with no*
>
> *end in sight, Lewy Body dementia disease progression can be very erratic with*
>
> *very good days and then very bad days, which can be a roller coaster for the*
>
> *caregiver.*

Enhancing Place of Death Congruence

Participants were asked to discuss what hospice social workers can to in order to

enhance place of death congruence. Table 7 illustrates the sub-themes that participants

identified.

Table 7

Frequency Distribution of Sub-Themes: Enhancing Place of Death Congruence

Sub-Themes: Enhancing	*n*	%
Support	9	100%
Educate/Converse	8	89%
Options	3	30%

Support. Nine participants (100%) indicated the concept of support in discussing

how hospice social workers might enhance place of death congruence. Participants

suggested that hospice social workers often provide psychosocial and emotional support

to patients and families throughout the dying process as changes and crises arise. In

addition, participants inferred that hospice social workers help and show support for the

decisions and preferences of patients and caregivers, "*letting them know that the hospice*

team will follow them wherever they go, and that we will support the decisions they make

and just kind of come alongside of them and help them through it." Participants also

highlighted the importance of recognizing, maximizing, and affirming the strengths and

abilities of caregivers. "*People just need to hear 'you're doing a great job.' I just really*

think that simple things like that are helpful. Validating, 'we ask a lot of you as a

caregiver, and you've really adapted and are doing a great job.'" Further, hospice social

workers aim to enhance place of death congruence by developing, supplementing, or

"*buffing up support networks*" and through advocacy.

Educate/Converse. Eight participants (89%) discussed education in addressing

the question of how hospice social workers might enhance place of death congruence.

Specifically, participants discussed having on-going conversation with patients and

families about death and dying. One participant stated, "*we have that conversation with*

patients, like 'this is what it's going to look like at end of life.' Providing education on

disease processes, and on what to expect so that what they see isn't out of nowhere." Another participant said that hospice social workers aim to enhance place of death congruence by "*being the provider of the information. Having discussions, like 'if you*

choose this route, here is what you will need to look at. And if you choose this route, it

might look like this...'" Hospice social worker's responses revealed that education framed as a conversation may be more effective in communicating with patients, families, and other entities. One participant shared, "*it's really critical to know how to best deliver the*

information that's needed and how patient and family will best receive it."

Options. Three participants (30%) identified providing options in discussing the ways in which hospice social workers can foster a preferred home death. Participants spoke about the need for patients and families to have choices at the end of life and to have the necessary resources to support their goals related to place of death.

As social workers, we come up with plan B options, so giving the family a list of

resources, giving them people they can call if they need to bring people into caregiver, or

getting them connected with respite care on the weekends if they needed it.

Another participant expressed, "*we help our patients and families to weigh*

options, pros and cons of potential choices." Social workers stated that options must be realistic for the patient and family and that social workers should explore such options objectively with those they service.

> *It helps to let people know that there are options out there. That there are always*
>
> *options in the background. As we are kind of caching them to make caregiving*
>
> *work at home, also letting them know that there is something that we can do if this*

doesn't work, and that it's not [the caregiver's] fault, and it's not a reflection on

their abilities. This is the disease's fault, not their fault. Exploring options is

always good.

Results: Dominate Themes

The results of the current research suggests several overarching themes.

Significance of Caregivers

This study's results reinforce the significance of caregivers and strongly indicate

that caregivers are the *most* critical factor in achieving place of death congruence.

Caregivers were named by *all* participants as both an essential factor needed for a home

death to occur, and in discussing barriers to a home death (absence of caregivers).

Participants asserted that not only must caregivers be willing, available, informed, and

competent, they also must have the ability to flex their roles within the family system in

order to achieve a preferred home death. Typically, three caregivers are needed to

provide continuous end-of-life care, and a system of support is ideal for facilitating a

home death. Family members who have flexible jobs or financial means are better

positioned to successfully provide care at home, however burnout is a frequent cause of

placement outside the home. Without caregivers, patients often face safety concerns

making a preferred home death unattainable.

Significance of Disease

The results of the current study suggest that place of death congruence is strongly

related to a medical diagnosis. It appears that place of death depends greatly on the type

terminal illness the individual has, the course of the illness, and what symptoms are

present. Participants indicated that the progression and/or course of the illness is a

psychosocial factor that often impacts place of death, that terminal symptoms regularly become a safety concern and/or barrier to place of death congruence, and that managing terminal symptoms is an integral part of the philosophy of hospice care.

Significance and Emotionality of Place

The results of the current research indicate that when it comes to the end of life, place of death is a critical and emotional consideration. Most hospice patients prefer to die at home, or in the place where they have been living, as it is the most socially supportive, comfortable, and familiar setting. Private residences are often associated with warmth, comfort, and family, while skilled nursing facilities, are feared and linked to negative connotations. Results indicated that issues surrounding place of death are often connected to feelings of guilt. Family members often experience guilt when the decision is made to move a loved one out of the home, and conversely, patients may also feel guilty for inflicting the "*burden*" of in-home caregiving upon their family members.

Misconceptions and Need for Education

This study clearly accentuates the vast existing misconceptions and the need for education surrounding death and dying. Participants asserted that most individuals have misconceptions about what hospice care is, or have little knowledge about the philosophy of care and/or the services that hospice provides. In addition, misconceptions exist regarding what the dying experience entails and what end-of-life caregiving demands. This research further asserts that many misunderstandings related to options for place of death exist, and fears and misconceptions surrounding nursing homes are particularly prevalent.

Social Workers as Supportive Coaches

This study reveals that hospice social workers often act as caregiver coaches in facilitating place of death congruence by maximizing and affirming caregiver strengths, facilitating ongoing conversations, and by building networks of support. Hospice social workers aim to enhance place of death congruence by completing effective assessments, providing a variety of supports, advocating on behalf of patients and families, educating, and providing and exploring realistic options for those they serve at end of life.

Discussion and Implications

The results of the current research both support and contradict previous literature regarding place of death congruence. The majority of analyzed data from this study is not only in agreement with previous studies concerning place of death congruence, but additionally enhances the existing empirical research by focusing on the perspectives and subjective experiences of hospice social workers, thus adding depth and dimension to the current understanding of the topic of interest.

Specifically, the results of the current study support the existing literature surrounding hospice philosophy and the role of the hospice social worker. The results of the current study support the existing literature by and Walsh (2003), Lambda & Quest (2011), and McInnis-Dittrich (2014) in describing the hospice philosophy of care as one that is focused on the dying process, provides holistic support for the patient and family, honors patient choices, and emphasizes comfort over life-prolonging measures. The importance of the interdisciplinary team that was highlighted in the research of Oliver, et al. (2008), and Wittenberg-Lyles, et al. (2010) is additionally echoed in the current study's data.

The results from the current research closely mirror previous literature by

McInnis-Dittrich (2014) and Walsh (2003) surrounding the role of the hospice social

worker. Both the current study and previous research posit that hospice social workers

make assessments, provide education, advocate, and intervene (provide support,

counseling, relationship-building).

The results of this study are in agreement with previous research by Barclay

(2009), Beland (2013), Gomes, et al. (2013), Higginson & Sen-Gupta (2000), Gomes &

Higginson (2004), Tang & McCorkle (2001), Weitzen, et al. (2003), and the World

Health Organization (2004) which posit that *home* is the preferred place of death for

dying individuals. Themes from the current research suggest that individuals prefer to

die at home because of the associations that "home" has with family, physical and

emotional comfort, familiarity, and feelings of patient control, which is consistent with

the research of Gott, et al. (2008), Higginson & Sen-Gupta, and Tang & McCorkle.

Empirical literature postulates that preferences for place of death often change.

Similarly, within the present study, the theme of change was ever present. The current

research suggests that individual's preferences can change, as can the course of terminal

illness, availability of caregivers, resources, and family dynamics.

This study's results are similar to that of previous research centering on factors

that influence the actual place of death. The current research found that caregivers are the

most critical factor in effectively facilitating a home death. The essentialness of

caregivers is in-line with the research of Beland (2013), Gott, et al. (2008), Paddy (2011),

and Weitzen, et al. (2003). The current study also indicated finances, terminal illness, and

cultural background, as influential in determining actual place of death, which is similar

to the findings of previously discussed research by Weitzen and Higginson & Sen-Gupta (2000).

One point of diversion between the literature and present study's data developed regarding the role of culture in place of death. Cultural background was determined to be impactful in relation to actual place of death in both the present study and in previous research. However, while the results of previous studies of Weitzen, et al. (2003) and Higginson & Sen-Gupta (2000) indicate that Caucasians are more likely than other racial backgrounds to die at home, the current research indicated that non-whites are better at rallying systems of support, and are better able to support and facilitate home deaths. In addition the current study adopted a broader understand of "culture" to include the influence of American culture (generational gaps, ageism, independence, and mobility) and culture within a given family system (communication, dynamics, relationships, roles).

Strengths and Limitations

The current research employed a qualitative design and content analysis in order to examine the preferred and actual place of death among hospice patients and includes strengths and limitations. The present study was be qualitative, and thus was be effective in exploring, conceptualizing, and in theory-building around a topic that is deserving of research (Institute of Medicine, 2014; Monette, Sullivan, & Dejong, 2011; NHPCO, 2012). The questions used in the interview were developed using previous research, which facilitated effortless comparison between former and current studies. The present research was strengthened by the use of content analysis, which has been described as "virtually unobtrusive" (Berg & Lune, 2012, p. 375) and considerably nonreactive. The

study additionally was cost-effective and feasible for one researcher to effectively carry

out (Berg & Lune). Six of the interviews were conducted in-person and three were via

phone. During the in-person interviews the principal investigator was able to focus on

both verbal and nonverbal behavior, thus minimizing misperceptions of the data and

ultimately enhancing face validity (Monette, et al.). The principle investigator carefully

recognized and assessed personal values and expectations prior to completing the

interview in order to reduce observational bias (Monette, et al.). Further, the use of open-

ended questions ultimately fostered a deeper and more insightful picture of the data that

was collected. Research validity was strengthened by the use of computerized audio

recording, transcription, field notes, and participant confidentiality agreement (Monette,

et al.).

The limitations of this study must be considered when evaluating the significance

of findings within this research. Because this study used content analysis and is

qualitative, it was not be effective for testing or determining causal relationships,

statistical significance, or in defining the frequency or proportion of a phenomenon,

limiting the results (Berg & Lune, 2012). The results of this study lack precision and

structure. The qualitative design of the study make data replication challenging and

implausible, and the data itself highly individualized (lacks generalizability).

Additionally, this study did not exercise probability sampling in participant or question

selection (Monette, et al., 2011) and employed only nine hospice social worker's

viewpoints, thus limiting explanatory power "that often comes from a large sample size"

(Monette, et al., p.253). In an effort to reduce bias, future research might utilize the

responses of additional licensed social workers, or individuals from a discipline other than social work, such as a hospice nurse, hospice aide, physician, or chaplain.

Implications

The current findings present numerous implications for future research and for hospice social work practice. As it was passionately asserted by the research participants, end-of-life decisions are never simple, neat, or easily deciphered. Acquiring knowledge and understanding of how to best care for hospice patients is fostered through continued research (both qualitative and quantitative), and is becoming increasingly critical as the number of people who enroll in hospice continues to grow.

As advocates and professionals involved in the care of our steadily increasing aging population, it is imperative for hospice social workers to honor patient and family preferences and to provide choices, support, and education related to place of death. This study highlights the *enormous* burden that is placed on caregivers who seek to enable home deaths. As our population continues to age this concern must be addressed, and future policy decisions should consider issues of cost efficiency surrounding dying at home versus dying in an institution, such as a hospital or nursing home. It will be imperative that hospice social workers understand how to best support caregivers, thus enabling them to meet the patient's end of life goals related to place of death. Hospice social workers must also provide education and translation in order to assuage potential concerns, address the individualized needs of the patient and family, as well as recognize and amend potentially dangerous or unfavorable situations. Future research should focus around these issues. Although end-of-life decisions are complex, emotional, and obscure, the present research offers a direction for the future study of hospice care and place of

death congruence in order to better facilitate and deliver exceptional care for individuals

and families facing terminal illness.

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Appendix A

Letter of Informed Consent

Consent Form

University of St. Thomas

GRSW 682 Research Project

Hospice Social Worker's Perspectives on Place of Death Congruence among Hospice Patients: A Qualitative Research Study: A Qualitative Research Study

IRB# 670188-1

I am conducting a study about the preferred and actual place of death congruence among hospice patients. I invite you to participate in this research. You were selected as a possible participant because of your occupational experience in this topic. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Florence Wright, a graduate student at the School of Social Work, College of St. Catherine/University of St. Thomas and is supervised by Dr. Karen Carlson.

Background Information:

The purpose of this study is to explore, examine, and gain a better understanding of place of death congruence among hospice patients from the point of view of the hospice social worker.

Procedures:

If you agree to be in this study, I will ask you to do the following things: Participate in a semi-structured interview and answer 8-10 open-ended questions (some with additional follow-up questions) regarding hospice care, the role of the hospice social worker, and place of death congruence, reserve between 30 and 45 minutes to complete the interview itself, consent to be audio-recorded throughout the duration of the interview, consent to have findings put into a de-identified report that will be publicly available (will not contain any identifying information), and consenting to having the de-identified interview responses viewed and interpreted by this researcher and one classmate during a reliability exercise.

Risks and Benefits of Being in the Study:

The study has minimal risks. The interview will focus on your professional opinion, experience, and views about hospice care, the role of the hospice social worker, and place of death congruence among hospice patients. Steps will be taken to protect personal information, confidentiality, and privacy.

The study has no direct benefits.

Confidentiality:

The records of this study will be kept confidential. Research records (research data) will be kept in a password-protected file within the principle investigator's personal cell phone. I will delete any identifying information from the transcript including your name and place of employment (name of hospice agency or organization). The audio recording and transcript will be physically destroyed by June 15th, 2015.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. You may skip any questions you do not wish to answer and may stop the interview at any time. Your decision whether or not to participate will not affect your current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work. If you decide to participate, you are free to withdraw at any time without penalty. Should you decide to withdraw, data collected about you will not be used. Please let me know by April 1st, 2015 if you wish to withdraw from this study.

Contacts and Questions

My name is Florence Wright. You may ask any questions you have now. If you have questions later, you may contact me at XXX-XXX-XXXX. You may also contact my instructor, Karen Carlson at XXX-XXX-XXXX the University of St. Thomas Institutional Review Board at 651-962-6038 with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study and to be audiotaped.

_____ _____

Signature of Study Participant   Date

_____

Print Name of Study Participant

_____ _____

Signature of Researcher   Date

Appendix B

Interview Questions

1.   How long have you been a hospice social worker?
2.   Could you tell me briefly about your role within the interdisciplinary team?
3.   Could you describe briefly the philosophy of hospice care as you understand it?
4.   In your experience, where do hospice patients prefer to die? Could you give me a rough estimate of what percentage of your patients express a preference to die at home?
5.   In your experience, where do hospice patients typically die? Could you give me a rough estimate of what percentage of your patients die at home? In a hospital?
6.   Could you tell me about why some patients prefer to die at home? (What is it about "home" that makes it preferential?)
7.   Could you tell me about the factors that are needed in order for a hospice patient who expresses a desire to die at home to actually die at home? (What things need to be in place for a preferred home death to occur?)
8.   Could you tell me about any barriers that exist in reaching place of death congruence among hospice patients? (If someone expresses a preference to die at home, what barriers might prevent them from doing so?)
9.   Could you identify any psychosocial factors that are especially powerful in influencing the patients' decision about where to die? Are these more powerful than the actual physical/medical implications of dying at home?
10. In your experience, what can a hospice social worker do to enhance place of death congruence? In other words what can you do to help ensure that a patient who wants to die at home is able to reach that goal and actually die at home?