

DESIGNATED HOSPICE ROOMS IN NURSING HOMES:

A NEW MODEL OF END-OF-LIFE CARE

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The undersigned, appointed by the dean of the Graduate School, have examined the dissertation entitled

DESIGNATED HOSPICE ROOMS IN NURSING HOMES:
A NEW MODEL OF END-OF-LIFE CARE

Presented by Denise Lyn Swenson,

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ABSTRACT

An aging population, the prediction that approximately 40% of elderly Americans will die in a nursing home by the year 2020, and a paucity of nursing homes designed to meet the needs of dying residents is creating the perfect storm. In an effort to respond to this trend, innovative nursing homes are establishing designated hospice rooms. This qualitative study utilized a multi-method design to describe these unique settings. The study identified two major themes: specific physical environmental features present in designated hospice rooms; and a prevailing emphasis on accommodating the needs of family members. The findings from this study will be beneficial to nursing home owners and administrators, social workers, and architects dedicated to improving the end-of-life experience for nursing home residents and their families.

CHAPTER ONE: INTRODUCTION

An aging population, the prediction that approximately 40% of elderly Americans will die in a nursing home by the year 2020, and a paucity of nursing homes designed to meet the needs of dying residents is creating the perfect storm. In an effort to respond to this silver tsunami, innovative nursing homes are establishing designated hospice rooms to accommodate the end-of-life needs of residents and their family members. Attention to the physical, emotional, and psychosocial needs of nursing home residents and their families throughout the life cycle is a critical component of optimum care. In order to enhance the quality of life for dying nursing home residents and their families, compassionate, comprehensive end-of-life care is imperative.

Theoretical Background

Lawton (1990) proposed models of environmental docility and pro-activity. According to the tenets of the docility hypothesis, the environment serves as an important determinant of behavioral outcome as personal competence diminishes. In keeping with this premise, compensation for personal loss may be achieved via environmental support. Accommodations such as wheelchair access, enlarged print, or amplified lighting may serve as “environmental interventions that can foster behavioral outcomes that minimize the negative effects of age-related declines” (Lawton, 1990, p. 639).

Lawton’s (1990) pro-activity model proposes that people may deliberately and purposefully choose or create environmental conditions in order to satisfy personal needs and preferences. In this context, as personal competence increases, a variety of environmental resources may be utilized to satisfy one’s desires. Although each position

is unique in its premise, both suggest that elderly individuals often benefit from environmental supports and resources. While personhood and the environment are considered separate, distinct entities, both are part of a supra-ordinate system in which subject and object are changeable (Lawton, 1986, 1990; Nehrke et al., 1981).

Background/Rationale

Although the need for end-of-life care in nursing homes is acute and ubiquitous, very little empirical research is available to suggest which physical environmental features constitute an optimal setting for a peaceful, dignified death in a nursing home. A precursory review of the literature using key words “hospice room” and “hospice room and nursing home(s)” confirmed this phenomenon. Initially, 89 articles were identified. The search was further narrowed to those articles describing the architectural or physical environments of hospice rooms located in nursing homes. This limitation resulted in the selection of eight articles related to the physical environment of hospice rooms in nursing homes.

Issues related to privacy and dignity were prevalent in the majority of articles (Hyland, 2006; Kayser-Jones et al., 2003; Seale, 2007; Stewart, Teno, Patrick, & Lynn, 1999; Street & Love, 2005; Thompson & Parker-Oliver, 2008; Tofle, 2007). Privacy was closely associated with physical environments that replicated “home,” or through the creation of home-like environments for dying residents and their families (Street & Love, 2005). Privacy also contributed to independence, dignity, and emotional well-being for residents and their families (Tofle, 2007). Privacy was considered a moral commitment by nursing home professionals who were dedicated to ensuring that the wishes of dying

persons were honored (Street & Love, 2005). Noisy environments were noted as detracting from the respect and dignity of residents (Kayser-Jones et al., 2003).

The importance of private space, devoid of roommates and frequent interruptions, was considered a fundamental prerequisite for a dignified death in the nursing home setting.

Many articles referenced the importance of environmental factors in end-of-life care. Issues related to “home-like environments” and “comfort care” appeared frequently (Evans, Cutson, Steinhauer, & Tulskey, 2006; Hyland, 2006; Kayser-Jones et al., 2003; Parker-Oliver, Porock, Zweig, Rantz, & Petroski, 2003; Seale, 2007; Thompson & Parker-Oliver, 2008; Tofle, 2007). Environmental factors identified in studies included the following: (a) surfaces to accommodate family photos and keepsakes, enhanced acoustics, connections to nature, resident control of lighting and music, windows with a view (Evans et al., 2006; Tofle, 2007); (b) quiet, clean rooms and comfortable chairs (Kayser-Jones et al., 2003); (c) sofa-beds, clean bedding, coffeemakers, microwaves, and reading materials related to death and dying (Seale, 2007); (d) a kitchenette (Hyland, 2006); and (e) favorite music, aromatherapy, visits from pets, a space for worship and rituals, as well as a connection to nature through gardens (Thompson & Parker-Oliver, 2008; Tofle, 2007). None of the articles provided design guidelines of the physical environmental features recommended to promote an optimal environment for the dying experience.

Numerous articles suggested the importance of accommodating the needs of family members throughout the resident’s dying experience. Recommended provisions included creating private spaces for prayer, rituals, worship, and family gatherings, and extra chairs or cots for overnight stays (Thompson & Parker-Oliver, 2008). Other

suggestions included recliners, a quiet environment, and private space so families could visit comfortably (Hyland, 2006; Kayser-Jones et al., 2003). It was further proposed that grief and funeral planning information be readily accessible for family perusal (Seale, 2007).

Interestingly, the physical transition from a semi-private room to a hospice room was not always considered beneficial (Bern-Klug, Gessert, Crenner, Buenaver, & Skirchak, 2004; Reed, Roskell Payton, & Bond, 1998; Stewart et al., 1999; Wowchuk, McClement, & Bond, 2007). The change in physical environments often severed ties with staff who had routinely cared for (and about) the resident and resulted in a disruption in continuity of care (Stewart et al., 1999). As a result, dying residents and their families were transferred to new surroundings, devoid of familiarity and the presence of staff and roommates with whom they had often established supportive relationships and personal friendships (Blanchard, 2001; Ersek, Kraybill, & Hansberry, 1999; Happ et al., 2002; Moss, Moss, Rubinstein, & Black, 2003; Stewart et al., 1999; Wowchuk et al., 2007). It was suggested that a priori discussions are necessary to ensure that residents' wishes related to transferring to a hospice room, rather than dying in familiar surroundings, be addressed (Tang, 2003; Thompson & Parker-Oliver, 2008; Tofle, 2009; Tulskey, 2005).

The dearth of empirical literature related to physical environments that positively impact the dying experience for nursing home residents and their families suggests that further research is needed in order to establish evidence-based practices that promote "gerontopia –the ideal place where we would like to grow old and also die" (Tofle, 2009, p. 88). Preliminary research on this topic identified a scarcity of designated hospice rooms within nursing home settings. As the population continues to age, and nursing

homes increasingly become the site of death for the American populace, the cogent need for hospice accommodations that promote a *good death* will become paramount as healthcare professionals strive to care for dying individuals and their loved ones.

A good death will mean different things to different people. Some believe that a good death has occurred when the patient has accepted death; made peace with family, friends, and God; completed unfinished tasks; fulfilled cultural death rituals; and said good-bye (Bosek, Lowry, Lindeman, Burck, & Gwyther, 2003; K. E. Steinhauser et al., 2000). Others describe a good death as one that is free from distress and suffering; congruent with the wishes of the patient and family; and consistent with medical, cultural, and ethical standards (Easom, Galatas, & Warda, 2006). An attentive and resident-centered approach for dying residents and their families is also recommended as an optimal model for promoting a good death in the nursing home setting (Shield, Wetle, Teno, Miller, & Welch, 2005). Concomitantly, in order for residents to experience a good death specific to their individual preferences, it is imperative that they be afforded the opportunity to create their own gerontopia.

Need for Study

Americans are aging in epidemic proportions. The population of individuals 65 years of age and older totaled approximately 37 million in 2006; by the year 2030, this population will more than double to approximately 71.5 million (U.S. Department of Health and Human Services, 2008). By the year 2020, approximately one in six people will be 65 and older (O'Shaughnessy, 2008). As this phenomenon unfolds, millions of senescent Americans will be faced with the likelihood of leaving the comforts of home

and relocating to a nursing home where healthcare professionals will attend to their end-of-life needs.

By the year 2020, it is estimated that 40% of Americans will die in a nursing home (Chen, Chan, Kiely, Morris, & Mitchell, 2007; Lee, Leppa, & Schepp, 2006; Parker-Oliver, Porock, & Zweig, 2004; Teno, 2003). Death is often contrary to the mission and goals of most nursing homes. Nursing homes typically focus their efforts on restoring residents to their prior level of functioning or on maintaining their current physical abilities (Stewart et al., 1999; Teno, 2003; Thompson & Parker-Oliver, 2008; Wetle, Shield, Teno, Miller, & Welch, 2005). The chasm seems to occur when residents experience a decline in their physical or mental health, and death approaches.

Death in any setting can be a difficult transition for patients and their families (Thompson & Parker-Oliver, 2008; Walsh, 2001). It is well-documented that death in a nursing home is often less than ideal. Numerous studies have found that many nursing home residents die without the benefit of adequate pain medication, effective symptom control, or resolution to their emotional concerns (Asch-Goodkin, Caloras, Coloney, Kangas, & Wegryn, 2000; Bern-Klug, Gessert, & Forbes, 2001; Braun & Zir, 2005; Brenner, 2000; Casarett et al., 2005; Evers, Purohit, Perl, Khan, & Marin, 2002; Parker-Oliver & Bickel, 2002; Parker-Oliver et al., 2004; Parker-Oliver et al., 2003; Stillman, Strumpf, Capezuti, & Tuch, 2005).

Approximately one-third of nursing home residents die within the first 12 months of admission (Gillick, Berkman, & Cullen, 1999; Hoffmann & Tarzian, 2005; Parker-Oliver & Bickel, 2002; Parker-Oliver, Porock, & Oliver, 2006; Parker-Oliver et al., 2003). Despite this fact, few nursing homes incorporate accommodations for the dying

process into their structural design. The institutional environment characteristic of a typical nursing home setting includes noise, harsh lighting, semi-private rooms, and limited solitude (Forbes-Thompson & Gessert, 2005; Kayser-Jones, Chan, & Kris, 2005; Kayser-Jones et al., 2003). Dying residents and their families are often required to share this very personal and intimate experience with roommates and their visitors, devoid of privacy and serenity (Kane, 2001; Kayser-Jones et al., 2005).

Significance of Study

A substantial volume of literature exists related to the dying experience of those residing in a traditional nursing home setting – very little of which is positive or optimal. As agents of change, nursing home social workers are mandated to advocate for policies and evidence-based practices that can effectively change current nursing home protocols to best serve the needs of dying residents and their families. To that end, social workers must explore new and innovative alternative settings in order to determine which physical environments promote gerontopia for nursing home residents and their loved ones.

Social workers often serve as the conduit for social and institutional change. Nursing home social workers are in a unique position to dramatically redefine and enhance the dying experience for nursing home residents and their families by delivering comprehensive and compassionate psychosocial care to those who are dying and to their loved ones (Vourlekis, Zlotnik, & Simons, 2005). As the need for end-of-life care continues to grow exponentially, it becomes imperative that evidence-based practices be established to efficiently and effectively address the physical, emotional, and psychosocial issues related to death and dying. In addition, there is a growing need for environmental changes that will facilitate a *good death* for nursing home residents and

their families. According to the Social Work Code of Ethics, social workers are mandated to advocate for those they serve and to ensure that those who are among the most vulnerable are afforded the opportunity to die in an environment that is peaceful and dignified (National Association of Social Workers, 2004).

Statement of Purpose

Despite considerable research focusing on the end-of-life experiences of nursing home residents and their families, little is known about the effects of the physical surrounding as death approaches (Bosek et al., 2003; Kayser-Jones et al., 2003; Rice, Coleman, Fish, Levy, & Kutner, 2004). It has been suggested that a poor fit between the environment and an individual's needs and desires results in adverse outcomes such as negative behavior, decline in physical health, and depression (Sloane et al., 2002). The purpose of this in-depth study was to describe designated hospice rooms within nursing home settings. Specifically, the study utilized a structured observation guide derived from the Therapeutic Environment Screening Survey for Nursing Homes (TESS-NH), semi-structured interviews with nursing home staff, photographs, and field notes to describe, compare, and contrast the physical environmental features of designated hospice rooms within nursing homes. This study sought to answer the following research questions:

- What specific physical environmental features are present in designated hospice rooms within nursing home settings?
- According to nursing home staff, how useful are TESS-NH items in evaluating designated hospice rooms within nursing home settings?

Findings from this study will contribute to the existing empirical knowledge related to the impact of end-of-life care for nursing home residents and their families, and

provide valuable insight into the existing physical environmental elements being utilized by nursing homes featuring designated hospice rooms. This information will be beneficial to social workers entrusted with providing holistic, innovative interventions designed to enhance the lives, and deaths, of those they serve.

Definition of Terms

For the purposes of this study, the following key constructs were defined as follows:

Gerontopia – Gerontopia is a word coined to describe an individual’s ideal environment in which to grow old and die. “The word is coined from the Greek words *geron*, referring to old age, and *topia*, meaning a place” (Brent, 1999).

Good death – A good death is a death experience that is in keeping with the resident’s and family’s end-of-life preferences.

Physical environment – The physical environment includes, but is not limited to, elements of structure, design, functionality, adaptive devices/technology, meaningful possessions, noise, lighting, privacy, and cleanliness.

Resident – A resident is an individual who resides in a nursing home.

Nursing home – A nursing home is a licensed, skilled nursing facility.

Hospice – Hospice is an interdisciplinary healthcare model designed to provide end-of-life care to individuals certified under the Federal hospice regulations as “terminal” (a life expectancy of six months or less) (Government Printing Office, 2000).

Designated hospice room – Although a designated hospice room can be found in a variety of settings, for the purposes of this study, a designated hospice room is a designated room within a nursing home reserved specifically for terminally ill residents and their families.

End-of-life care – End-of-life care is comfort care designed to address the physical, emotional, and psychosocial concerns of dying residents and their families. Comfort care does not include curative treatment or aggressive, life-prolonging measures.

Family members – Family members are those persons identified by the resident or nursing home staff as having a significant relationship with the resident, regardless of legal or biological status.

Assumptions

The premise of this study assumed that designated hospice rooms in nursing homes varied in their design, structure, functionality, and appearance. Further, it was assumed that designated hospice rooms differed from traditional semi-private rooms in a nursing home.

Limitations

The availability of designated hospice rooms in nursing homes was sparse. Further, the evaluation and accompanying photographs of the designated hospice rooms were dependent upon permission from the resident or family members occupying the space. Lastly, research was constricted to designated hospice rooms in nursing homes throughout the Midwest, thus, transferability is limited.

Delimitations

There are considerable ethical issues related to research methods in end-of-life care. The vulnerability of those who are dying, and their families, is a critical component to be considered (Takesaka, Crowley, & Casarett, 2004). Only those residents or family members willing and able to consent to the evaluation of their hospice room were included in the study. In response to issues of privacy and confidentiality, none of the

field observations or photographs included notes, images, or artifacts that identified the resident or family. In addition, through the use of direct observation and photography, the study was not exclusively reliant on the subjective self-reports typically associated with qualitative research. Also, the use of the revised TESS-NH survey instrument provided a structured, systematic evaluation tool which resulted in replicable processes and findings.

Summary

This chapter provided an overview of the study that was conducted. As such, the theoretical background and purpose of the study were introduced. In chapter two, a comprehensive literature review will investigate projections relative to the aging population, the current trends associated with dying in America, and issues related to death in a nursing home setting. Lastly, designated hospice rooms within nursing homes will be explored.

CHAPTER TWO: LITERATURE REVIEW

A silver tsunami is forecast as the baby boomer generation (those born between 1946 and 1964) enter senior citizenry. In response to this impending cataclysm, innovative alternatives to current models of end-of-life care are being developed. A comprehensive literature review was conducted to explore this phenomenon relative to the aging population.

Aging Population

Persons 65 years of age and older are the fastest-growing segment of the U.S. population (Dennison, 2008). In 2006, approximately 330 people each hour (or 7,918 each day) turned 60 years of age (U.S. Census Bureau, 2006). Individuals 65 years and older currently comprise approximately 12% of the U. S. population; by the year 2030, it is estimated that 20% of Americans will be 65 or older, an increase of approximately 34 million people (U.S. Department of Health and Human Services, 2007, 2008). A 147% increase in the 65-and-over population is predicted between 2000 and 2050; in comparison, the U.S. population as a whole will have increased only 49% during that same time period (Longley, n.d.a.). As the population continues to age, and baby boomers enter their final decades, millions of Americans will be faced with health concerns that require nursing home care and end-of-life expertise.

Theoretical Background

The connection between person and environment has been examined from various perspectives: Moos and Lemke studied the physical and architectural features of age-specific environments; Lawton examined nursing home design objectives; Calkins

reviewed environmental/behavioral issues; Cohen and Weisman researched the therapeutic goals of age-specific environmental dimensions; and Regnier and Pynoos analyzed environmental/behavioral principles (Lawton et al., 2000). Each perspective stresses the importance of the dynamic link between human need and the potential for the environment to fulfill that need. Lawton et al. (2000) suggest that the interdependence between personal need and environmental capability is a transactional unit rather than an interaction between separate elements. It is further posited, the more vulnerable we are, the more influential the environment becomes (Brent, 1999; Lawton, 1977, 1985, 1986, 1990; Moore, VanHaitma, Curyto, & Saperstein, 2003; Tofle, 2009).

Lawton (1990) proposed the environmental docility and pro-activity hypotheses to address the issue of person/environment in age-specific settings. He suggested that age-associated changes occur; however, they are relatively minor compared to the changes associated with poor health, reduced income, and social ageism (Lawton, 1990). The more vulnerable people are due to failing health and low competence, the more impact the environment has on them (Tofle, 2009). As a result, the elderly may choose to adapt to personal loss through environmental supports such as adaptive equipment and modified accommodations.

The environmental docility hypothesis has been defined as, “The less competent the individual, the greater the impact of environmental factors on that individual” (Moore et al., 2003, p. 472). The docility model asserts that as physical and mental health declines, environmental modifications and adaptive devices may be utilized to compensate for losses in competency, and may have a disproportionately stronger and more positive effect on impaired older people’s behavior (Lawton, 1985, 1990; Tofle,

2009). To that end, an incremental improvement in environmental quality could be monumental to a person with major limitations, just as a small decrease in quality could totally disrupt that same person's equilibrium (Lawton, 1986; Moore et al., 2003).

Lawton also proposed that "environmental effects on psychological well-being are stronger as a person's competence decreases" (Lawton, DeVoe, & Parmelee, 1995, p. 470). Persons with diminished capability are more susceptible to environmental influence and may experience heightened behavioral dependence on external conditions (Lawton, 1990; Lawton & Simon, 1968). Lawton (1990) further projected that the environment is a more potent determinant of behavioral outcome as personal competence decreases.

The environmental pro-activity model posits that people may intentionally construct environmental conditions in an attempt to satisfy personal preferences (Lawton, 1994). "The environmental pro-activity hypothesis suggests that as personal competence increases, the variety of environmental resources that can be used in satisfaction of the person's needs increases" (Lawton, 1990, p. 639). Pro-activity is demonstrated when persons attempt to change themselves or create an environment to meet a desired need or behavior (Lawton, 1985). Lawton (1985) further proposes that "environmental resources are likely to be better used by (and therefore more likely to be behavior-activating for) people of higher competence" (p. 507). Persons who are competent, alert, and oriented can either manipulate the environment independently or utilize adaptive resources to increase control of their surroundings and satisfy their personal preferences related to space and place – thus creating their own gerontopia.

Although each position is unique in its premise, both suggest a continuum of responses or behaviors (Lawton, 1977). Together, these models illustrate the dynamic,

reciprocal relationship between elderly persons and their environment (Moore et al., 2003). “The exercise of personal competence at any level may be promoted by an environment provided either by external circumstances or by personal choice” (Lawton, 1990, p. 639).

Aging in America

Accommodations for those nearing the end of life include a variety of options: home hospice, hospice facilities, assisted living/residential care/aging in place, hospitals, and nursing homes. Each of these settings offers unique benefits and limitations.

Home hospice. Most people would prefer to die at home (Asch-Goodkin et al., 2000; Hunt, 2001; National Hospice and Palliative Care Organization, 2004; Tang, 2003). The familiar surroundings of home and family may well provide the optimal experience for those who are dying. However, home hospice is not always feasible. Although persons in hospice may live alone, at some point in the disease trajectory, a full-time caregiver may be needed to meet the patient’s physical needs. If no such person is available, or if the caregiver is elderly or unable to fulfill the physical demands of caregiving, nursing home placement may become necessary.

Hospice facilities. Freestanding hospice facilities are an option for terminally ill patients when the support system at home is unable to meet the physical or emotional demands of caregiving, or if it is unsafe for the patient to remain at home without the assistance of full-time professional medical care. Although the availability and accessibility of such facilities is limited throughout the United States, 19.2% of hospice patients died in such facilities in 2007 (National Hospice and Palliative Care Organization, 2008; Verderber & Refuerzo, 2006). The focus of this research will target

traditional nursing home environments where 22.8% of hospice patients died in 2007 (National Hospice and Palliative Care Organization, 2008).

Assisted living/Residential care/Aging-in-Place. Assisted living settings, residential care facilities, and aging-in-place venues offer residents the opportunity to live in a home-like environment that provides meals, housekeeping, social activities and limited medical assistance (Kane, 2001; Oliver, 2001; Sloane et al., 2003). Unfortunately, as health declines and safety issues become a concern, many individuals are required to relocate to a nursing home that offers comprehensive medical services (Hunt, 2001; Stone & Reinhard, 2007). Concomitantly, the room and board costs associated with these settings is typically a private expense which may be prohibitive for many elderly individuals (Kane, 2001).

Hospitals. Hospitals were once the most common site of death for elderly patients (Bern-Klug et al., 2001). Recent changes in Medicare reimbursement limit hospital services to those for whom cure is no longer an option (Meier, Morrison, & Cassel, 1997; Morrison & Meier, 2004; Teno, 2003; Teno et al., 2004; Wallace, Cohn, Schnelle, Kane, & Ouslander, 2000). Patients who are allowed to remain in the hospital until death often experience a sterile, noisy environment, visiting restrictions, and inadequate symptom control and pain management (Prendergast & Puntillo, 2000; Verderber & Refuerzo, 2006).

Nursing homes. Approximately 4% of the U.S. population aged 65 and older live in nursing homes (Department of Health and Human Services, 2007). Currently, almost 24% of elderly Americans die in nursing home settings (Munn et al., 2008). By the year 2020, it is estimated that 40% of Americans will die in a nursing home (Chen et al., 2007;

Lee et al., 2006; Parker-Oliver et al., 2004; Teno, 2003). Residing in a nursing home is often the least preferred choice and the most costly option available for seniors (Kane, 2001; Oliver, 2001; Teno, 2003). Nehrke et al. (1981) suggest that institutional settings are rarely designed to be “optimal environments” for the elderly.

Dying in a nursing home is often contrary to the goals and mission of long-term care facilities. Most nursing homes focus their efforts on restoring residents to their prior level of functioning or maintaining their current physical abilities (Stewart et al., 1999; Teno, 2003; Thompson & Parker-Oliver, 2008). The chasm seems to occur when residents experience a decline in their physical or mental well-being and death approaches.

Death in the Nursing Home Setting

It is well-documented that death in a nursing home is often laden with complications (Hanson, Danis, & Garrett, 1997; Kane, 2001; Kayser-Jones et al., 2003; Vandenberg, Tvrdik, & Keller, 2005). It has been reported that 30% of seriously ill older adults would “rather die” than move to a nursing home (Kane, 2001). Many nursing home residents die without the benefit of adequate pain medications, effective symptom control, or resolution to their emotional or spiritual concerns (Asch-Goodkin et al., 2000; Bern-Klug et al., 2001; Brenner, 2000; Casarett et al., 2005; Evers et al., 2002; Parker-Oliver & Bickel, 2002; Parker-Oliver et al., 2004; Parker-Oliver et al., 2003; Wetle et al., 2005). Despite considerable research on the bio-psycho-social aspects of death in a nursing home, little is known about the effects of the physical surroundings as death approaches.

Although approximately one-third of nursing home residents die within the first 12 months of admission, few nursing homes incorporate accommodations for the dying process into their structural design (Gillick et al., 1999; Hoffmann & Tarzian, 2005; Munn et al., 2008; Parker-Oliver & Bickel, 2002; Parker-Oliver et al., 2006; Parker-Oliver et al., 2003). The institutional environment characteristic of a typical nursing home setting includes abrasive noise, offensive odors, harsh lighting, crowded rooms, limited provisions for families or visitors, and minimal solitude (Forbes-Thompson & Gessert, 2005; Kayser-Jones et al., 2005; Kayser-Jones et al., 2003; Schwarz & Brent, 2001). As the dying process unfolds, residents and their families are forced to navigate this sacred journey devoid of privacy and serenity (Kayser-Jones et al., 2005; Kayser-Jones et al., 2003).

Designated Hospice Room within a Nursing Home Setting

Hospice. Hospice care is provided in a nursing home as an alternative to curative or restorative care. Hospice services include pain and symptom management, along with emotional and spiritual support for residents and their families (Bosek et al., 2003; Chochinov, 2006; National Hospice and Palliative Care Organization, 2008; Verderber & Refuerzo, 2006; Welch, Miller, Martin, & Nanda, 2008). The presence of hospice in the nursing home setting also increases one-on-one interaction with dying residents and provides grief support to family members (Munn et al., 2008; Rice et al., 2004). In addition, the presence of hospice care in the nursing home setting was found to increase family satisfaction with end-of-life care (Welch et al., 2008).

Physical environment. The physical environment contributes to the possibility of a good death for residents and their families (Cohen, Boston, Mount, & Porterfield, 2001;

Kane, 2001; Kayser-Jones et al., 2005; Kayser-Jones et al., 2003; Lawton, 1990; Meador, Bykowski, & McGuire, 2000; Sloane et al., 2002; Touhy, Brown, & Smith, 2005; Verderber & Refuerzo, 2006; Wowchuk et al., 2007). A designated hospice room designed to accommodate comprehensive end-of-life care provides the space and quiet atmosphere residents and families desire (Kayser-Jones et al., 2003; Meador et al., 2000). In order to individualize the dying experience for residents and their families, family members are encouraged to personalize the room with family photographs and memorabilia; guests are granted 24-hour visitation privileges; comfortable chairs and a recliner are readily available; and the physical environment provides a home-like setting in close proximity to nature (Bosek et al., 2003; Evans et al., 2006; Hodgson, Landsberg, Lehning, & Kleban, 2006; Hyland, 2006; Kayser-Jones et al., 2005; Kayser-Jones et al., 2003; Meador et al., 2000; Parker-Oliver et al., 2003; Seale, 2007; Thompson & Parker-Oliver, 2008; Tofle, 2007). Additional recommendations include brightly lit hallways surrounded by windows; dining room tables with festive tablecloths, placemats, and place cards denoting residents' dietary preferences; courtyards with sitting areas and wheelchair accessible flower beds; enhanced acoustics; resident control of lighting and music; sofa-beds; coffeemakers; microwaves; aromatherapy; and accommodations for pets (Cohen, 2002; Evans et al., 2006; Forbes-Thompson & Gessert, 2005; Kayser-Jones et al., 2005; Seale, 2007; Thompson & Parker-Oliver, 2008; Tofle, 2007).

Privacy. Privacy and space are necessary so that residents can have time with their families and bring closure to their lives (Kane, 2001; Kayser-Jones et al., 2003). Privacy contributes to dignity, independence, and the emotional well-being of residents and their families (Chochinov, 2006; Chochinov, Hack, McClement, Kristjanson, &

Harlos, 2002; Cohen et al., 2001; Tofle, 2007; Verderber & Refuerzo, 2006). In contrast, noisy environments, a task-centered rather than a resident-centered approach, shared accommodations, and inadequate staffing patterns detract from the privacy, respect, and dignity residents and their families desire and deserve (Cohen et al., 2001; Forbes-Thompson & Gessert, 2005; Kane, 2001; Kayser-Jones et al., 2003; Lemke & Moos, 2001; Lindgren & Murphy, 2002; Wowchuk et al., 2007). Nursing home professionals consider privacy a “moral commitment” and a primary measure of quality of life for dying nursing home residents (Street & Love, 2005; Vourlekis et al., 2005).

Family. A fundamental principle of comprehensive end-of-life care, and hospice care, is to assure not only the well-being of the patient, but also that of the family (Engel, Kiely, & Mitchell, 2006; Hudson, Aranda, & Kristjanson, 2004; National Hospice and Palliative Care Organization, 2008). At end-of-life, family involvement is as crucial as any other type of care (Chochinov, 2006; Rhodes, Mitchell, Miller, Connor, & Teno, 2008; Verderber & Refuerzo, 2006). The presence of family members may have a calming effect even on unconscious, restless patients (Lee et al., 2006). The role of family members in the nursing home setting is subject to increased stress at the end of life, thus efforts to support and comfort family members is a critical component of quality care (Sloane et al., 2002; Wetle et al., 2005). Loved ones share memories, promote privacy, encourage affection, engage in religious rituals, and sustain the dying person’s worth, dignity, and legacy (Bosek et al., 2003; Tofle, 2007).

Death is almost always a family event, not just a solitary experience (Reynolds, Henderson, Schulman, & Hanson, 2002; Wowchuk et al., 2007). Families view the experience as it impacts their whole life. Although the resident’s experience ends with

death, the family's experience continues throughout bereavement (London, McSkimming, Drew, Quinn, & Carney, 2005). The death of a loved one may linger in the memories of those who witnessed the event. Relatives who observe a resident's obvious distress at the end of life may have complicated grief and difficulty adjusting to the loss (Lee et al., 2006). Not surprisingly, most families prefer compassionate care, provided by empathic, caring staff, over elaborate accommodations or state-of-the-art medical technology (Wetle et al., 2005).

Effects of Environmental Design and Physical Surroundings on the Dying Experience of Residents and Families

A review of the literature related to the effects of environmental design and physical surroundings at end-of-life resulted in minimal findings. Although the need for end-of-life care in nursing homes is acute and ubiquitous, very little empirical research was available to suggest which physical environmental features constitute an optimal setting. As the population continues to age, and nursing homes increasingly become the place of death for millions of Americans, the development and implementation of end-of-life accommodations becomes imperative. Concomitantly, as the need for hospice services increases, so does the need for accompanying architectural information (Verderber & Refuerzo, 2006).

A review of the literature focusing on end-of-life care in U.S. nursing homes resulted in the conclusion that "there is no empiric evidence that indicates a positive, pain-free dying experience in the long-term care environment" (Parker-Oliver et al., 2004, p. 154). Concomitantly, only Verderber and Refuerzo (2006) provided design guidelines of the physical environmental features recommended to promote an optimal

environment for the dying experience. Clearly, further research is needed to identify which environments constitute an optimal setting for a peaceful, dignified death in the nursing home setting.

Summary

Empirical research focusing on designated hospice rooms within nursing home settings is lacking. Most articles reported on the inadequacies of the nursing home environment; few articles provided insight into the optimal environment recommended to promote a good death. Although there is a substantial body of research related to dying in the nursing home setting, most of the information describes suboptimal conditions, and few recommendations were provided for improving the dying experience for residents and their families. Knowledge about designated hospice rooms may present innovative alternatives to current end-of-life models.

Chapter two highlighted that additional research is warranted to develop an evidence-based design for designated hospice rooms within nursing homes. Further, little consensus was found to support which physical environmental features should be incorporated into designated hospice rooms in nursing home settings. The next chapter will discuss how the study was conducted in terms of design, participants, and analysis.

CHAPTER THREE: METHODOLOGY

Current research suggests considerable opportunities for improvement in end-of-life care in nursing homes. The majority of empirical findings report on the substantial deficits in end-of-life accommodations and care in this setting. Very little research provides recommendations for improving the dying experience for nursing home residents and their families. The aim of this research was to (1) systematically describe specific physical environmental features of existing designated hospice rooms within nursing homes, and (2) determine how useful TESS-NH items were in evaluating designated hospice rooms. The study was conducted utilizing a qualitative, multi-method design to answer the research questions.

Participants/Unit of Analysis

The unit of analysis in this study consisted of designated hospice rooms located within nursing homes. Sampling consisted of ten Midwest nursing homes that incorporated a designated hospice room within their facility. Nursing homes were chosen based on a variety of factors in an attempt to achieve maximum variance. Inclusion was determined by the following criteria: licensed skilled nursing facility; contractual arrangement with hospice agency; profit vs. non-profit status; and urban vs. rural location. Given that some of the designated hospice rooms were occupied by residents receiving hospice services, those individuals became part of the observation process and were requested to consent to participate in the study. While residents were not the focus of the research and therefore not the unit of analysis, occupied environments and interaction between the humans and environment became part of the observation process.

As such, those residents occupying hospice rooms were asked to consent to the research study prior to evaluation of the premises. Copies of signed consent forms are part of the permanent records of the study. Consenting residents were judged by the nursing home staff to be competent to sign the document. Additionally, out of respect for the need for privacy during the final days before death, rooms occupied by imminently dying residents were excluded from the study.

Design

Snowball sampling techniques were utilized to identify nursing homes that featured a designated hospice room. The sample was obtained vis-à-vis various hospice-related listservs including, but not limited to, the Missouri Hospice and Palliative Care Organization, the Greater St. Louis Hospice Organization, and the Greater St. Louis Social Work and Healthcare Professional Organization. The listservs were used to contact hospice agencies, social workers, and healthcare professionals throughout the Midwest to request the names and contact information for nursing homes in their geographic area that featured a designated hospice room [Appendix A]. The administrators of those facilities meeting the inclusion criteria were solicited for participation via telephone contact. The researcher contacted each facility administrator by phone to explain the research project utilizing scripted information [Appendix B]. Administrators agreeing to participate were asked to sign two copies of the consent form acknowledging their voluntary participation in the study. One copy of the signed form was left with the nursing home administrator; the other signed copy became part of the permanent records of the study.

Data Collection

The use of qualitative data results in comprehensive information of high validity about a relatively small number of cases from the perspective of the subjects being studied (Hogle & Sweat, 2006). In this study, a structured observation guide that included descriptive items gleaned from the TESS-NH was utilized to systematically observe and describe specific physical environmental features of designated hospice rooms in each facility [Appendix C]. Semi-structured interviews with nursing home staff and photographic inquiry resulted in rich, descriptive data. In addition, the notations, observations and quotations recorded in the researcher's field notes further substantiated the findings. Hogle and Sweat (2006) suggest that the descriptions and direct quotations found in field notes serve to support the conclusions and interpretations of a study.

Observation guide. In order to systematically describe specific physical environmental features of each designated hospice room, a structured observation guide was developed utilizing the TESS-NH (Sloane et al., 2000) as a template. The TESS-NH is an observational instrument developed to assess individual environmental characteristics and is not a scale. Although this instrument (<http://www.unc.edu/depts/tessnh>) was originally designed for assessing the physical environment of institutional settings for persons with dementia residing in special care units, the authors suggest that TESS-NH items are useful in evaluating other specialty units (Sloane et al., 2002). Currently, no widely accepted measure exists for the evaluation of end-of-life environments, thus the researcher developed a structured observation guide utilizing information derived from the TESS-NH in order to describe

specific physical environmental features of designated hospice rooms within nursing homes [Appendix C].

The TESS-NH is a collection of descriptive items: (a) privacy/control/autonomy; (b) safety/security/health; (c) visual/tactile stimulation; (d) noise; (e) socialization; (f) orientation; and (g) personalization/familiarity/home likeness (Sloane et al., 2002). Within these categories, Sloane et al. studied individual elements such as unit autonomy; outdoor access; exit control; maintenance; cleanliness; stimulation lighting; and space/seating. Previous research indicates many of these factors are paramount to an optimal end-of-life environment (Bosek et al., 2003; Chochinov et al., 2002; Cohen, 2002; Evans et al., 2006; Forbes-Thompson & Gessert, 2005; Hodgson et al., 2006; Hyland, 2006; Kane, 2001; Kayser-Jones et al., 2005; Kayser-Jones et al., 2003; Meador et al., 2000; Parker-Oliver et al., 2003; Seale, 2007; Thompson & Parker-Oliver, 2008; Tofle, 2007; Verderber & Refuerzo, 2006).

Although the TESS-NH was modified based on the literature, its psychometric properties are important to note as the TESS-NH provides the foundation for the observation guide used in this study. Sloane et al. (2002) tested the TESS-NH on a variety of measures:

Inter-rater reliability. Inter-rater reliability between two raters was approximately 86.7% (range 41.7% to 100%). The Pearson correlation coefficients for continuous variables ranged from 0.33 to 1.0; kappas ranged from 0.13 to 1.0. Seven items had kappas less than 0.50 and two-thirds of the items had kappas greater than 0.70.

Test-Retest reliability. The overall subjective rating resulted in an intra-class correlation coefficient of 0.81. Environmental factors that were permanent (i.e. type of

floor surface) demonstrated higher levels of test-retest reliability with agreement above 0.8. Those factors more subjective in nature (i.e. presence of odors, adequacy of lighting, amount of dirt) resulted in moderate to substantial agreement.

Use of TESS-NH in Non-Special Care Unit (SCU) settings. The mean global ratings for non-SCUs were 6.46 for 204 SCUs, 5.31 for 80 non-SCU dementia units, and 6.93 for 45 non-dementia units.

The ease of use and applicability of the TESS-NH was beneficial in describing end-of-life environments. The survey was designed to be completed by someone with modest levels of knowledge and experience related to person-environment concepts. In addition, the survey was intended to be completed in approximately 30-45 minutes by walking through the physical space (Sloane et al., 2002). The established survey instrument, along with the ease of the survey design and the wide array of survey item descriptors, increased the likelihood that the findings would be valid, trustworthy, useful, and transferable (Johnson & Turner, 2003; Payne, 2007). Thus, a structured observation guide derived from elements of the TESS-NH was developed to describe designated hospice rooms within nursing homes [Appendix C].

Interviews. Data collection included semi-structured interviews with nursing home staff. Zeisel (2006) states that interviews based on environment-behavioral research typically ask “how an individual feels about, perceives, or otherwise reacts to a particular environment or situation” (p. 227). Ten interviews were conducted with various nursing home professionals including five administrators, three directors of nursing, three registered nurses, one director of admission, and two social workers. Some interviews included multiple staff members. Interviewees were asked to sign two copies of the

consent form acknowledging their voluntary participation in the study. One copy of the signed form was left with each interviewee, the other signed copy became part of the permanent records of the study. Each of the interviews was conducted in person and ranged from 30 to 60 minutes in length resulting in a total of 35 pages of transcription. The open-ended, semi-structured format of the interview guide utilized for this study [Appendix D] was beneficial in obtaining responses that were in-depth, insightful, and specific to the research questions. Further, the format offered an opportunity to probe, explore, and confirm responses (Johnson & Turner, 2003).

Digital photographs. In addition to the information gleaned from the observation guide and interviews, detailed digital photographs were taken to analyze, compare, and contrast the design variances and similarities of designated hospice rooms. A total of 224 pictures were taken. On average, 18 pictures were taken of each site. The hospice rooms were photographed from multiple angles in an effort to record each room's unique design and environmental features. Careful consideration was given to avoid photographing family photos or other identifiable artifacts. The digital photographs did not include identifying images of residents or their family members.

Digital photographs offer many advantages. They can be downloaded onto computers and made available to others for analysis and discussion. Likewise, they can be "convenient and captivating during oral presentations" (Zeisel, 2006, p. 168). Digital photographs are also easily grouped and regrouped for further examination. Finally, photographs serve as visual "field notes" intended to support research findings (Shenk & Schmid, 2002).

The use of photography as a qualitative research method is established in the literature (Harper, 2003; Kanstrup, 2002; Shenk & Schmid, 2002; Silverman, 2005; Zeisel, 2006). Harper (2003) purports that the invention of the camera allowed persons to see a more profound reality than what was visible with the naked eye. Photographs can be a source of inquiry and a mechanism for presenting research findings (Shenk & Schmid, 2002; Zeisel, 2006). As a form of inquiry, photographs, in conjunction with other methodologies, can provide a detailed record of a specific place (Zeisel, 2006). Photographs can also be used to present research findings to diverse audiences. Shenk and Schmid (2002) suggest photography offers a new “way of knowing” and accommodates a variety of learning styles.

Field notes. Detailed field notes were compiled during and immediately after each site visit in an effort to capture the researcher’s instantaneous impressions and observations. The field notes included notations, observations, and direct quotations specific to each setting. Hogle and Sweat (2006) suggest that the field notes characteristic of qualitative research are the equivalent of a completed set of questionnaires in survey research. As such, field notes lend support to the researcher’s findings and interpretations (Emerson, Fretz, & Shaw, 1995; Hogle & Sweat, 2006).

Valuable information was gleaned through the complementary, multiple-methods triangulation of descriptive observation, interviews, photography, and field notes. The observation guide provided a structured, systematic evaluation of selected physical environmental features of each designated hospice room, thus establishing replicable processes and findings. The semi-structured interviews provided narrative that was beneficial in understanding the perspective of nursing home staff regarding the physical

environmental features of designated hospice rooms. The photographs provided visual support to the research findings. Finally, an analysis of the field notes created throughout the study served to provide further explanations and insight via notations, observations, and direct quotations. Together these complementary methods support and strengthen each other and provide a clearer understanding based on the combination of methodologies (Shenk & Schmid, 2002).

Data Analysis

Data from the structured observation guide, interviews, digital photographs, and field notes were systematically analyzed to identify common themes and to answer the research questions. Analysis followed a constant comparative method.

Observation guide. A structured observation guide derived from the TESS-NH survey instrument was utilized to collect data at the nursing homes [Exhibit C]. Data was amassed through direct observation of each designated hospice room. The observation guide was completed via the researcher physically walking through each room and recording the presence or absence of specific physical environmental features listed on the observation guide. Completed copies of each facility's observation guide became part of the permanent records of the study. Once all site visits were completed, a spreadsheet was created to organize the data and to categorize and describe particular physical environmental features of the designated hospice rooms in each of the ten Midwest nursing homes. The spreadsheet was beneficial in conducting a comparative analysis of the hospice rooms individually and collectively. Specific physical elements were identified utilizing a systematic process involving categorization. Categories were

developed based upon constant comparative analyses. Category development continued until analysis of all ten nursing homes was complete.

Interviews. All of the interviews were recorded and transcribed verbatim for purposes of analysis. The transcripts became part of the permanent records of the study. Information gleaned from the interviews was used to support or refute the findings of the structured observation guides, digital photographs, and field notes. Upon completion of data compilation and analyses, initial coding was developed based upon a priori codes of privacy and dignity; room size; personalization of room; home-like setting; close proximity/access to nature; and family accommodations. Throughout the coding process, the following emergent codes were identified: enhanced amenities intended for family use only; control of lighting, temperature, and sound; restroom features; and flooring. A constant comparative methodology was utilized until all data sources had been evaluated, compared, contrasted, and coded. Lastly, specific domains were identified based on the themes identified in the research findings. Those findings will be discussed in detail in chapter four.

Digital photographs. Digital photographs of each designated hospice room provided additional data. The digital photographs were downloaded and filed according to the respective facility represented. Printed copies of the photographs became part of the permanent records of the study. Analysis of the photographs followed a constant comparative method based upon the a priori and emergent codes. Concomitantly, the photographs were utilized to conduct a collective comparative analysis of all facilities studied. Lastly, specific photographs were selected according to the pertinent domains identified by the analysis of the observation guides, interviews, and field notes. The

photographs were also chosen based on their ability to best represent and exemplify the topics being addressed.

Field notes. Hand-written field notes for each site visit were transcribed verbatim. Both the hand-written and typed field notes became part of the permanent records of the study. Field notes, including notations, observations, and quotations were entered into the Excel spreadsheet along with the findings from the observation guides.

Protection of Human Subjects

This study was approved by the University of Missouri Health Sciences Institutional Review Board. The unit of analysis in this study was designated hospice rooms located within nursing homes. As such, there was no risk to human subjects identified. Occasionally, the designated rooms were occupied by residents receiving hospice services. In such instances, those residents became part of the observation process. When this occurred, the researcher explained the purpose and intent of the research and requested the resident's consent to participate in the study. Copies of the signed consent forms became part of the permanent records of the study.

Validity Structure

Issues related to validity have plagued qualitative research for decades (Adcock & Collier, 2001; Fortner & Christians, 1989; Johnson, 1997; Johnson & Turner, 2003).

R. Burke Johnson (1997) proposes a number of strategies to promote qualitative research validity including: low inference descriptors, triangulation, data triangulation, and peer review. Each of these strategies was utilized in the present study:

Low inference descriptors. Low inference descriptors include descriptive phrases closely mirroring the participants' accounts and the researcher's field notes. Low

inference descriptors were provided via direct quotations gleaned from verbatim transcripts of interviews. The researcher's field notes also served as low inference descriptors.

Triangulation. Triangulation is the process of "cross-checking" information and assumptions through the use of multiple procedures or sources. Triangulation was achieved through the use of various interview sources including nursing home administrators, directors of admission, nurses, and social workers. In addition, multiple methodologies were used to obtain data.

Data triangulation. Data triangulation involves the use of multiple data sources to explain a phenomenon. A structured observation guide, semi-structured interviews, digital photographs, and field notes provided data triangulation.

Peer review. Peer review involves discussions of the researcher's interpretations and assumptions with others. Periodic peer debriefings with a fellow doctoral student provided discussions related to the researcher's processes, interpretations, and conclusions. In addition, the dissertation committee chair provided feedback related to the researcher's processes and analyses. Member checking was facilitated by the Medical Director of a hospice agency and by a nursing home staff member who participated in the interview process, both of whom agreed to review the research findings for face validity.

Summary

This chapter detailed the qualitative, multi-method design employed to answer the research questions. A review of the various methodologies was presented. The study design, participants, and analyses were also described. In addition, the data collection and data analysis processes were reviewed. Lastly, issues related to validity were addressed.

Chapter four will present detailed findings of the study based on information gleaned via the observation guide, semi-structured interviews, digital photographs, and field notes detailed in this chapter.

CHAPTER FOUR: FINDINGS

The previous chapter provided an in-depth explanation of the methodological processes utilized in this research. A structured observation guide, semi-structured interviews, digital photographs, and field notes were analyzed to formulate responses to the following research questions:

- What specific physical environmental features are present in designated hospice rooms within nursing homes?
- According to nursing home staff, how useful are TESS-NH items in evaluating designated hospice rooms within nursing home settings?

To that end, designated hospice rooms in ten nursing homes throughout the Midwest were studied utilizing a qualitative, multi-method design. A structured observation guide derived from the Therapeutic Environment Screening Survey for Nursing Homes (TESS-NH) was instrumental in determining the presence of specific physical environmental features present in designated hospice rooms [Question 1]. Digital photographs and field notes were also beneficial in describing the physical environments of each hospice room, individually and collectively. Lastly, semi-structured interviews were conducted with nursing home staff to determine how useful the TESS-NH items were in evaluating designated hospice rooms within nursing home settings [Question 2].

An analysis of all data sources netted two major themes: specific physical environmental features present in the designated hospice rooms; and a prevailing emphasis on accommodating the needs of family members. Issues related to the physical environmental features present in the designated hospice rooms included:

- Privacy and dignity
- Room size
- Personalization of the room
- Flooring
- View of nature
- Control of lighting, temperature, and sound
- Restrooms/Bathrooms.

The second theme emphasized the importance of accommodating the needs of family members throughout the dying process. Such efforts were enhanced via specific physical environmental features present in designated hospice rooms along with special accommodations and amenities intended to provide family comfort. In this chapter, each of these themes will be explored using data obtained from the observation guide, interviews with nursing home staff, digital photographs, and field notes.

Sample Characteristics

Efforts to identify nursing homes that incorporated designated hospice rooms were tedious. The researcher utilized snowball sampling techniques to query hospice staff, nursing home staff, professional organizations, and private individuals in an effort to identify and locate such facilities. Nine of the facilities included in this study were located on the Kansas/Missouri border, the Iowa/Missouri border, and in central Missouri; one facility was located in Illinois. Once the homes were identified and approval to visit was obtained, the researcher drove 883 miles to conduct the actual site visits and interviews.

Most of the nursing homes were approximately 30 years old. As such, the majority featured an environment similar to most clinical institutions. Although all of the facilities incorporated an attractive reception area complete with comfortable chairs and a home-like ambiance, points beyond the guest area included double-loaded corridors,

overhead public address systems, semi-private accommodations, and communal dining areas. Shiny, linoleum flooring in the halls, dining areas and resident rooms, fluorescent lighting, and vinyl upholstery added sterility to the general atmosphere.

In comparison, all of the designated hospice rooms had been established within the past six years, most as recently as 2007 and 2008. Three of the facilities, all located in rural areas, had established an entire wing dedicated to palliative care. Conversely, the facilities located in urban areas had developed one, sometimes two designated hospice rooms, despite the fact that the census in those facilities was considerably larger.

Seven of the nursing homes offered their designated hospice room(s) to all residents regardless of payer source; both private pay and Medicaid reimbursement were accepted. Only two facilities restricted use of the designated hospice room(s) to those paying privately. Those same facilities charged an additional, albeit “nominal” fee for occupying the designated hospice room(s). One of the facilities was not currently utilizing the designated hospice room due to its physical location within the facility. A summary of the sample characteristics can be found in Appendix E.

Findings

The findings from this study will be presented in terms of the two major themes identified by the data: specific physical environmental features present in the designated hospice rooms; and a prevailing emphasis on accommodating family members.

Physical Environmental Features of Designated Hospice Rooms

In interviews conducted with nursing home staff, the designated hospice rooms were consistently described as “soothing,” “calming,” and “comfortable.” Staff reported that the rooms were “tailored to residents’ specific needs at end of life.” Another staff

member remarked, “It’s more peaceful, designed to be more for the person that’s dying and for their families.” The most notable physical elements observed or cited included privacy and dignity; room size; personalization of the room; flooring surfaces; view of nature; control of lighting, temperature, and sound; and restroom/bathroom accommodations.

Privacy and dignity. Staff considered privacy paramount to an optimal end-of-life experience for residents and their families. The privacy of the designated hospice room(s) provide respite from the “noise and hustle and bustle” of a typical nursing home environment. As one administrator explained, “You can always bring in what you need but you can’t always get the sound and the noise away. It’s easier to control what comes in than what’s surrounding you so separateness is probably the biggest thing.” Although all of the rooms were private, in contrast to the semi-private accommodations found in most nursing homes, many of the facilities made a deliberate decision to retain the privacy curtains typical of semi-private rooms. The curtains provided additional privacy and dignity for the resident during bathing and personal care.

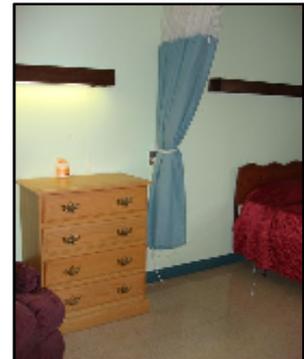


Figure 1. Facility # 2
Privacy Curtain

Quiet was a common theme among nursing home staff when describing the designated hospice room(s): “It’s kind of a busy hall but something about the room keeps it quiet.” One administrator lamented, “Some days they feel a little too quiet for me.” Likewise, there was concern that the designated hospice room may result in residents feeling “isolated or lonely.” Several of the hospice rooms were located on halls that had been designated as palliative care wings. As such, the halls were “quieter and less

congested.” Interestingly, although the researcher recognized the *quietness* of many of the rooms, there were no appreciable absorbing surface materials such as carpet, window treatment, or acoustical tile accountable for this phenomenon.

Upon entering several of the rooms, the researcher experienced an ineffable aura of reverence and sacredness that was palpable. There was an almost instantaneous stillness that had not been present prior to crossing the threshold, regardless of where the room was located within the facility, and despite the absence of discernable environmental traces or clues to explain the sensation. Similarly, one staff member remarked, “There’s just really something very special and sacred about this space.” Conversely, noise and clutter often influenced the environment. Areas that were cluttered

or crowded with equipment, supplies, or personal possessions affected the ambiance of the room. Likewise, none of the nursing homes incorporated built-in oxygen or suction mechanisms in the designated hospice rooms. As a result, portable oxygen concentrators often served as an audible interruption to the tranquility of the room.



Figure 2. Facility # 7
Crowding

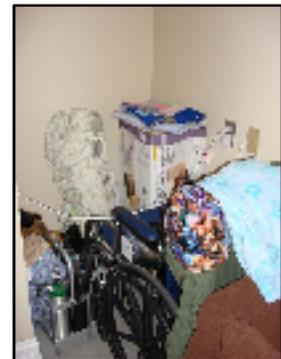


Figure 3. Facility # 4
Clutter

Room size. Room size was frequently cited by nursing home staff as one of the most beneficial aspects of the designated hospice room(s). All of the designated hospice rooms were private; however, most had been converted from semi-private rooms to private rooms as evidenced by the environmental traces of multiple overhead lights, and the duplicity of closets, sinks, counter tops, and dressers.

The smallest room was 15'5" X 10'5":



Figure 4. Facility # 1



Figure 5. Facility # 1



Figure 6. Facility # 1

The largest room was 21' X 15'5":



Figure 7. Facility # 6



Figure 8. Facility # 6



Figure 9. Facility # 6

Many of the rooms utilized the increased space to provide additional seating and upgraded furnishings such as armoires, dressers, and kitchenettes. In many instances, the size of the room resulted in a home-like setting – a notable improvement over the typical nursing home environment.

Personalization of the room. Staff frequently stressed the importance of the residents' option to personalize the room: "I saw almost their whole living room come in. Their favorite chair; their pictures; their bookcases with the things they liked. It just looked like their living room with their bed in it." Another staff member exclaimed, "One family pulled up in a U-Haul."

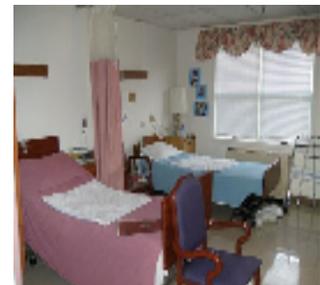


Figure 10. Traditional Semi-Private Nursing Home Room



Figure 11. Facility # 2 Personalization

Many of the comments regarding the personalization of the hospice rooms focused on attempts to create a “home-like” environment vs. the typical nursing home or institutional environment:

If they’re in a normal nursing home setting or hospital environment, there’s just too many other things going on - the sounds, the noises, odors, the whole thing. Sometimes it’s just not a very pleasant environment. Whereas, a designated area, you don’t just focus on the room; you focus on the surfaces, on the location.

As one staff member aptly explained, “This is their home, and if you can’t physically die in your own home, this is as close to home as we can get for them.” The designated hospice rooms featured a variety of accommodations and surfaces for the display of personal items.



Figure # 12. Facility # 2



Figure # 13. Facility # 8



Figure # 14. Facility # 9

The following were frequently observed or mentioned as items used to personalize the room:

- Furniture (dressers, desks, beds, bookcases)
- Comfortable chairs (recliners, sleeper chairs, rockers)
- Appliances (televisions, refrigerators, microwaves)
- Personal photographs
- Bedding (special pillows, hand-made quilts, comforters, bedspreads, afghans)
- Music
- Alarm clock
- Stuffed animals

The presence of family was considered imperative to the personalization of the designated hospice rooms. There were consistent references to the role family members played in decorating and personalizing the residents' rooms:

“The family went to great pains to bring [his] favorite things;”



Figure 15. Facility # 9
No Family Involvement



Figure 16. Facility # 9
Family Involved

“Some people bring a lot of stuff and some people don't. It depends on the family;” “If the family's not involved ... they don't look as home-like; those rooms look very bare.”

Anticipated length of stay was also mentioned as a determining factor in the personalization of the room:

It depends a lot sometimes on how long the new person is expected to be with us. Sometimes we get 'em from the hospital and they only give 'em a few days. I think that's the big factor is the time, what time they have left.

Direct observation yielded an array of decors and furnishings in some rooms as compared to the sparse surroundings evidenced in others. Nursing home staff confirmed that such discrepancies were a result of family involvement, or lack thereof.

Flooring. Flooring surfaces varied amongst the rooms. Most rooms utilized beige or grey linoleum; a few of the rooms had commercial carpeting. One facility featured mahogany laminate flooring with inlaid carpeting. An obvious difference in noise levels based on flooring materials was not observed. However, the decor was noticeably enhanced in the room that included the laminate flooring and inlaid carpeting.



Figure 17. Facility # 6
Carpet and Laminate Flooring

View of nature. All of the designated hospice rooms included at least one functioning window. In fact, a number of nursing home staff mentioned the importance of functioning windows “so that the spirit can be let out of the room after the resident dies.” Only one nursing home offered direct access to nature via sliding glass doors in the resident’s room. However, the researcher noted that the large expanse of glass created by the sliding doors resulted in a cold, barren aperture rather than an inviting passageway to nature.

It was frequently noted through direct observation that a *view of nature* and a *view of the outdoors* were not always synonymous. Quite often, the resident’s *view of nature* included a view of the parking lot, utility meters, or fences. It was not unusual for the view to include nothing more than a grassy area devoid of trees or flowers.

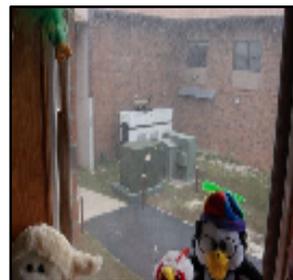


Figure 18. Facility # 1
View of Outdoors



Figure 19. Facility # 6
View of Outdoors

Two facilities included concrete patios with gazebos and outdoor furniture.



Figure 20. Facility # 3
View of Outdoors



Figure 21. Facility # 9
View of Outdoors

Only one facility featured a beautiful courtyard complete with a wooden arbor covered in lush vines and flowering plants.



Figure 22.: Facility # 2
View of Nature

Control of lighting, temperature, and sound. Control of the elements was almost always restricted to staff and family members rather than residents. Switches, thermostats, and television remotes were often inaccessible to the resident primarily due to physical location or issues related to crowdedness. The researcher noted that many of the rooms featured light fixtures that had been relocated or replaced in an attempt to provide lighting that was less harsh or abrasive. Many of the rooms utilized wall sconces or lamps rather than ceiling fixtures. One room featured recessed lighting complete with heat bulbs that were located directly over the resident's bed in order to provide additional warmth during times of bathing

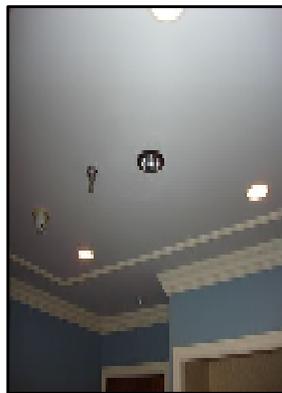


Figure 23: Facility # 6
Recessed Lighting

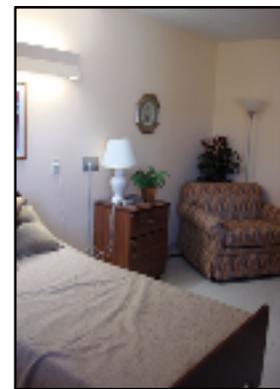


Figure 24: Facility # 8
Alternate Lighting

and personal care. Only fixtures mounted directly behind the bed were controllable by the resident via a pull-chain affixed to the light.

Temperature control was often restricted due to the physical location of the heating/air conditioning unit. Most rooms featured wall-mounted systems that provided both heating and cooling functions. The researcher noted that the resident's bed was often located directly in front of the heating/cooling unit. Quite often, control of the temperature mechanisms was not accessible to the resident due to issues related to mobility, distance, and crowding.



Figure 25. Facility # 1
Temperature Control

Residents' control of sounds was typically negated by their inability to adjust noise levels. The researcher consistently noted that when rooms were occupied, regardless of whether the resident was present, awake and oriented, asleep, or unresponsive, televisions or radios were frequently voluminous. The residents' ability to adjust the volume on televisions or radios was often compromised by their inability to access the remote control for the television or to reach the radio or television controls. Quite often, the television remote or radio was located on a piece of furniture, a shelf, or a table that was not within the resident's reach. Interestingly, on more than one occasion, nursing home staff made special mention of the fact that alarm clocks were provided in the designated hospice room(s), the purpose or intent of which was not divulged.

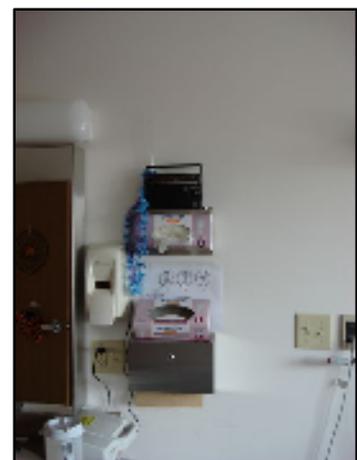


Figure 26. Facility # 1 – Radio,
Call Button, Water, Light Switch
Inaccessible to Resident

Restrooms/Bathrooms. Restroom/bathroom accommodations varied. Most of the designated hospice rooms included private restrooms. One bathroom featured a bathtub that was described as being “really just for the family.” A few facilities had remodeled the bathrooms to include a roll-in shower, thus allowing wheelchair accessibility. In addition, two facilities had installed medicine cabinets in the hospice room to accommodate personal grooming items and toiletries, thus increasing the oft negligible counter surfaces found in most residents’ rooms.



Figure 27. Facility # 7
Counter Space

Summary. A summary of the findings related to the physical environment are included in Appendix F.

Family Accommodations

The second theme identified by the study suggests a prevailing emphasis on accommodating the needs of family members throughout the resident’s dying process. The findings confirm the importance of attending to the needs of those most intimately affected by the loss of a loved one: “The focus is on family. Everything depends on the family’s wishes;” “The room is prepared for family support rather than the dying patient.” These sentiments reveal a common theme among nursing home staff. All of the interviewees emphasized the importance of the designated hospice room as it related to family comfort: “By the time the patient gets here, it’s really for families.”

Privacy and dignity. All of the nursing home staff discussed the importance of family privacy at end-of-life. As one nurse explained, “Everything depends on the family’s wishes.”

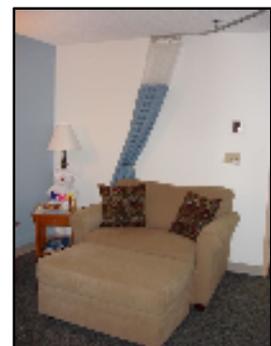


Figure 28. Facility # 7
Family Privacy

The fact that there were separate, designated areas specifically for family members of dying residents was considered beneficial: “The designated hospice room is set up so that the family members can be in the room with them when they are in the actual dying process, or even if they’re not. They want their family close with them.” It was further noted that the privacy afforded by the designated hospice room(s) assuaged family guilt or worry about disturbances to, or from, a roommate:

The family can feel comfortable, stay as long as they want, spend as much time as they want. The family has privacy. If they want to be here through the entire dying process...they have that option in a comfortable setting. Family and friends can feel that they are truly part of this person’s dying process.

Room size. The size of the hospice room was seen as an influential factor relative to the comfort of families.

One nurse explained that the designated hospice room differed from a traditional room in a nursing home “because it is set up for the patient and the family to be together.” A facility administrator explained

it this way, “There’s more distance from the bed if family wants to sit in a chair or table and talk, or watch a little TV, or catch up on the news.” It was also noted that the increased space accommodates large families and multiple visitors. Nursing home staff often considered the home-like environment to be as important for families as residents:

I think that when families come to that time and when this room is a fit for them, it’s perfect in that they can come here. They can feel like they are in a home environment and have an intimate experience with those that they love without feeling intruded on as well as without being uncomfortable and feel like they’re in a hospital kind of setting, which nursing home rooms can sometimes seem that way.



Figure 29. Facility # 6
Family Accommodations

When asked what was least beneficial about the hospice room, the same staff member replied, “It’s least beneficial in that it’s not home in that families are still having to juggle the emotion of walking through this huge, large building to get to this room. It’s still very much a facility.”

Private accommodations for family members. The private accommodations for family members were addressed vis-à-vis sleeping arrangements, private family rooms, and amenities not typically offered in the nursing home setting. Families were often provided cots, roll-a-way beds, or sofa-sleepers to accommodate overnight stays.

One nursing home offered a private bedroom located in close proximity to the hospice room(s). Several of the designated hospice rooms were equipped with small dining tables and chairs to accommodate meals and family gatherings.



Figure 30. Facility # 9
Family Bedroom

A few of the nursing homes offered separate family quarters located near the hospice room(s). Several facilities provided furnished family rooms including sofas, chairs, televisions, games, books, and puzzles. These rooms were often used by residents and family members as an extension of the resident’s private room: “It’s a quiet place where they can go; it’s more secluded than our lobby area.” The family rooms were often used to provide respite, or to host family gatherings, dinners, or visits with guests.

Several family rooms included seating for as many as 15 people.



Figure 31. Facility # 9 - Family Room



Figure 32. Facility # 10 – Family Room

Amenities. All of the nursing homes provided some type of amenities for the family members of dying residents. Several of the designated hospice rooms were equipped with microwaves and refrigerators for family use. Comfort carts were also used to provide beverages, snacks, books, games, music, etc. One of the facilities offered its kitchen to family members during their stay.



Figure 33. Facility # 9
Dining Area

On numerous occasions, staff mentioned that “special linens” and “fancy towels” were provided for family use only. One staff member remarked, “The administrator gets upset when patients use the special linens and towels intended for families.”



Figure 34. Facility # 4
“Fancy Towels”



Figure 35. Facility # 3
Family Bathroom

Likewise, staff frequently mentioned that the private bathrooms in the designated hospice rooms were “really just for family,” and not intended for resident use.

Summary. A summary of the findings related to accommodating the needs of family members is included in Appendix G.

Summary

Chapter four revealed the findings from this study. Through the use of direct observation, semi-structured interviews, digital photographs, and field notes, two major themes emerged. The first theme identified specific physical environmental features present in designated hospice rooms. The second theme addressed the importance of accommodating the needs of family members. Chapter five will focus on answering the research questions and provide further discussion of the findings as they relate to social work practice and policy implications. Further, the findings will be compared and contrasted with Lawton’s proposed models of environmental docility and pro-activity to establish and develop links between the research findings and the existing theories. Lastly, challenges to the implementation of designated hospice rooms in nursing homes and topics for future consideration will be explored.

CHAPTER 5: DISCUSSION

The previous chapter provided a thorough discussion of the research findings from this study. An analysis of all data sources netted two major themes: specific physical environmental features present in the designated hospice rooms; and a considerable emphasis on accommodating the needs of family members. Chapter five will summarize the key findings of the study; discuss Lawton's models of environmental docility and pro-activity as they relate to the research findings; explore possible constraints to the establishment of designated hospice rooms; and propose practice and policy recommendations intended to generate future knowledge. Findings from this study will contribute to the existing empirical knowledge related to the design and development of designated hospice rooms within nursing home settings in an effort to enhance the dying experience for residents and their families.

Summary of Key Findings

The intent of this study was to answer the following research questions, each of which will be addressed separately:

Research Question 1: *What specific physical environmental features are present in designated hospice rooms within nursing homes?*

Through the use of a structured observation guide, semi-structured interviews, photographs, and field notes, specific physical environmental features were identified in the designated hospice rooms. The fact that all of the designated hospice rooms were private and larger than a traditional semi-private room was noteworthy. Nursing home staff indicated that the spaciousness of the designated hospice rooms enhanced residents'

privacy and dignity while providing families with an array of comforts and accommodations.

Personalization of the environment was strongly emphasized. The type or quantity of personal belongings was not as consequential as the fact that the rooms were designed to accommodate such items. All of the rooms provided tables, shelves, bookcases, or window sills on which to display personal keepsakes or mementos. Each of the rooms had ample wall space to accommodate family photos or artwork. Additional touches of home were provided via special bedding, favorite foods, and visits from pets.

The institutional atmosphere typical of most nursing homes was often contrasted with specific physical environmental features present in the designated hospice rooms. The hospice rooms were noted as being quieter and more peaceful. The harsh, sterile environment commonly associated with a nursing home environment (Schwarz & Brent, 2001) was almost nonexistent in the designated rooms. It was obvious that great care and consideration had gone into the planning and implementation of each and every room as a means of enhancing the dying experience for residents and their families. In fact, the “hospice suites” in one particular facility were funded and furnished by two families who had encountered a less than optimal end-of-life experience. In an effort to improve the experience for others, the families chose specific colors, furnishings, and amenities to create an atmosphere of comfort. The sky-blue hue of the walls, the coordinating window treatments, and the contrasting white baseboard trim resulted in an aesthetically pleasing environment. The deep, rich mahogany furniture added a stately ambiance. Further, the inclusion of accents such as lamps, vases, and artwork brought warmth and character to the decor. Amenities such as a microwave, coffeemaker, television, and DVD player

provided a home-like atmosphere. Nursing home staff confirmed that the designated hospice suites were greatly appreciated by residents and families who have occupied the rooms during the dying process: “I think that all of the feedback that I’ve gotten from families who use this room is extremely positive. They just love these rooms.”

Finally, it was interesting to note that several of the rural nursing homes had established palliative care wings, whereas the urban facilities had not. One hypothetical explanation for this oddity may be the greater likelihood of a freestanding hospice facility in the urban areas, thereby reducing the need for additional designated hospice rooms in the nursing homes located in cities with larger populations. Nonetheless, the fact that three of the rural facilities featured entire wings dedicated to palliative care was impressive. These types of accommodations serve to address the deficits in end-of-life care well documented in previous research (Asch-Goodkin et al., 2000; Bern-Klug et al., 2001; Braun & Zir, 2005; Brenner, 2000; Casarett et al., 2005; Evers et al., 2002; Parker-Oliver & Bickel, 2002; Parker-Oliver et al., 2004; Parker-Oliver et al., 2003; Stillman et al., 2005).

Despite the many benefits associated with the physical environmental features of the designated hospice rooms, there remain aspects for future consideration. Interestingly, the environmental features of designated hospice rooms were often negatively impacted by the aging physical structures of many of the nursing homes studied. Most nursing homes in the Midwest are approximately 30 to 40 years old (C. Parsons, personal communication, December 12, 2008). As a result, many of the features listed on the structured observation guide were not incorporated in the designated hospice rooms due to feasibility and expense. For example, none of the designated hospice rooms included

built-in oxygen or built-in suction despite the fact that those adaptations provide a considerable reduction in noise and greatly enhance the peacefulness and serenity of the physical environment. As one administrator lamented, “The cost associated with installing that type of equipment would be just too expensive for most facilities, plus you’d have to rip out walls and install all new duct work. That’s just not gonna happen.” As older facilities consider remodeling, attention to visual features that promote a comfortable, peaceful, and dignified setting is suggested. A purposeful selection of specific colors, fabrics, furnishings, and accents will greatly enhance the atmosphere in most nursing home rooms without resulting in a financial hardship for facility owners or administrators.

Prior research indicates that the ability to personalize one’s physical environment is an important component of quality end-of-life care. LaTour (2007) suggests that “symbols and mementos can invoke past feelings of care and comfort” (p. 34). However, this study revealed that not all facilities welcome resident or family efforts to personalize the room as evidenced by the statement, “We’re very protective of the space.” Given the importance assigned to this issue by the nursing home staff and previous research, it may behoove those facilities to consider ways in which residents and families can create a home-like environment specific to their end-of-life wishes.

Despite the many benefits and amenities identified by nursing home staff, the physical transition from a semi-private room to a designated hospice room was not always considered beneficial. Relationships with roommates, confidence in certain nursing home staff, and familiarity with the environment were frequently cited as reasons to decline disturbing the status quo. Financial considerations were also a determining

factor: “If they don’t want to pay for it, then that’s their option;” “For some families it’s not as valuable sometimes.” The exact cost of occupying a designated hospice room was not made available to the researcher.

In addition, family size was an issue: “There may just be one loved one [family member] who’s really the one who’s spending the time and so the La-Z-Boy next to the bed is plenty if they feel comfortable with that.” A priori discussions are an important part of advance care planning in order to ensure that residents’ wishes related to transferring to a hospice room, rather than dying in familiar surroundings, are addressed. Although there were examples cited of residents and families declining to move to the designated hospice room(s), the overall consensus of nursing home staff was that the hospice rooms were the preferred setting for the majority of dying residents and their families.

As previously mentioned, there was a notable disparity among the facilities in regard to a *view of nature* vs. a *view of the outdoors*. Although all of the rooms incorporated a functional window, the view was not always pleasing despite the fact that a view of nature or direct access to nature has been suggested to enhance positive feelings and reduce fear and anxiety (LaTour, 2007). The existing structures of many of the nursing homes did not include large windows or passages to nature. Facility owners and administrators are encouraged to evaluate their exterior premises and to develop healing gardens, nature paths, flower beds or landscaping techniques that enhance the outdoor environment (Evans et al., 2006; LaTour, 2007; Thompson & Parker-Oliver, 2008; Tofle, 2007).

Lastly, it was disconcerting to note that residents often lacked control of their physical surroundings. Although the rooms were obviously designed to enhance privacy and comfort, the residents' inability to control the elements was problematic. The researcher observed that call buttons, television remotes, radios, water pitchers, and telephones were rarely within the residents' reach. Even issues related to the "special linens" and "fancy towels" were dictated by nursing home staff rather than residents.

Research has shown that autonomy is a vital aspect of self-worth (Collins, Goldman, & Rodriguez, 2008; Everett, 1993; Menn & Whitlatch, 2007). Although privacy and pleasant surroundings are beneficial, a sense of mastery over the environment is a critical component of humanity, regardless of age or physical well-being. The findings from this study were often in direct opposition to these principles. Healthcare professionals often focus on making sure the environment meets a person's basic physical and safety needs – sometimes failing to take into account a person's social needs. Nursing home staff and family members are encouraged to peruse a resident's room before leaving to ensure that the resident has easy access to the call button, telephone, and other controls. Ultimately, remodeling efforts should ensure that controls are accessible to residents regardless of their physical limitations or ability to ambulate.

Research Question 2: According to nursing home staff, how useful are TESS-NH items in evaluating designated hospice rooms within nursing home settings?

The second research question involves input from nursing home staff as to the usefulness of TESS-NH items in evaluating designated hospice rooms. Although the survey was originally designed for use in evaluating dementia units, it has been suggested that the instrument may be effective in assessing other types of specialty care units

(Sloane et al., 2002). The original TESS-NH survey instrument was modified for this study in an effort to enhance its applicability to designated hospice room settings [Appendix C]. To that end, an extensive list of specific physical environmental elements was developed for use in evaluating the premises. In keeping with the instrument's original intent, the assessment process was completed in a relatively brief period of time (30-45 minutes). The actual process involved walking through the designated hospice room(s) at each nursing home and recording the observation of particular elements. As such, the survey instrument was useful to the *researcher* in identifying selected physical environmental features of designated hospice rooms. However, those findings do not answer the specific research question: According to *nursing home staff*, how useful are TESS-NH items in evaluating designated hospice rooms within nursing home settings?

Nursing home staff rarely mentioned the majority of elements listed in the TESS-NH survey. In fact, there were only four items that were consistently identified during the interview process: (1) space for the display of personal items; (2) accommodations for visitors; (3) accommodations for overnight guests; and (4) amenities for families. Individual characteristics of the room, including cleanliness or functionality, were seldom acknowledged. The specific room size, proximity to nurses' station, lighting, ventilation, restroom accommodations, presence or lack of built-in medical equipment, and enhancements such as wireless Internet access, cable hook-up, or outlets for chargers went unmentioned. Instead, the interviews revealed an overriding emphasis on accommodating the physical needs of family members.

As a result of these findings, there was little indication that the nursing home staff found the TESS-NH items useful in evaluating designated hospice rooms. Rarely did

their responses to interview questions or their substantial focus on family accommodations coincide with items listed on the TESS-NH instrument. Thus, the modified survey instrument appears ineffective in evaluating designated hospice rooms. The results indicate that future survey instruments place a greater emphasis on the environment, furnishings, and amenities dedicated to enhancing the family's experience, with less emphasis on actual room characteristics.

Theoretical Implications

As previously outlined, this study was guided by the theoretical background of M. Powell Lawton's proposed models of environmental docility and pro-activity. The docility model contends that as people age and physical and mental health declines, the elderly are more dependent on environmental circumstances (Lawton, 1986). As a result, environmental supports may be needed to compensate for personal loss.

Conversely, Lawton's (1990) pro-activity model proposes that elderly individuals may purposefully and deliberately choose or create environmental conditions in order to satisfy personal needs or preferences. In this context, as personal competence increases, numerous environmental resources can be utilized to satisfy one's needs or preferences. The more competent the individual, the less dependent the person is on environmental circumstances (Lawton, 1986, 1994). Lawton suggests that the agent of environmental change may be the person or forces outside the person such as staff or family (Lawton, 1985, 1990).

The findings from this study neither proved nor disproved either of these hypotheses. The study, as it was conducted, did not include input from residents or family members regarding their efforts to modify or adapt the environment to compensate for

personal competencies. Likewise, information regarding the adaptation of the environment to satisfy personal needs or preferences was not investigated. Future research is recommended to identify the role residents and family members play in modifying the environment of designated hospice rooms to address the competencies of those who reside in these settings.

Social Work Implications

Social workers often serve as the conduit for social and institutional change. As the need for end-of-life care continues to grow exponentially, it becomes imperative that evidence-based practices be established to effectively address the physical, emotional, and psychosocial issues related to death and dying. In addition, there is a growing need for environmental changes in nursing home settings that will facilitate a dignified and peaceful dying experience for residents and their family members. M. Powell Lawton (1990) posits, the more vulnerable we are, the more impact our environment makes. Social workers are mandated to advocate for those they serve and to ensure that those who are among the most vulnerable are afforded the opportunity to die in an environment that is dignified and respectful.

The role of social work in nursing homes includes advocacy for residents' rights and dignities; case management; facilitation of effective communication between physicians, nursing home staff, residents, and families; staff education; conflict resolution; decision-making; psychosocial and emotional support for residents and families; assistance with advance care planning and ethical dilemmas; and bereavement services (Bern-Klug, 2006; Bern-Klug et al., 2004; Bosek et al., 2003; Gruneir, Miller, Lapane, & Kinzbrunner, 2006; Hilliard, 2004; Kramer, Christ, Bern-Klug, & Francoeur,

2005; Lacey, 2005a, 2005b, 2006; Mezey, Miller, & Linton-Nelson, 1999; Munn & Zimmerman, 2006; Reynolds et al., 2002; Solloway, LaFrance, Bakitas, & Gerken, 2005; Teno et al., 2004; Touhy et al., 2005). In response to the national agenda for social work research in palliative and end-of-life care (Kramer et al., 2005), social workers must further the profession by conducting evidence-based research that supports the benefit of social work interventions at the research, practice, and policy levels. According to Kramer et al. (2005), “Social work is the most broadly based profession in relation to contexts of care for people who have a life-threatening condition or have experienced a death in their social network or a profound and traumatic loss” (p. 419). Despite a contingency of approximately 600,000 social work professionals throughout the United States, social work research is underrepresented in federally sponsored funding (Kramer et al., 2005). In order to preserve their role as vital members of the healthcare industry, at a time when legislation, economics, and cost containment are threatening their continued existence, social workers must participate in federally funded research intended to advance the profession and improve the lives of those they serve.

Similar to other healthcare professions, social workers are in need of continuing education specific to the emotional, psychological, and spiritual issues related to end-of-life care (Bern-Klug, 2006; Bern-Klug et al., 2004; Lacey, 2005a, 2005b, 2006; Mezey et al., 1999; Munn & Zimmerman, 2006; Touhy et al., 2005). In “A Report to the Profession and Blueprint for Action” (Vourlekis et al., 2005), numerous recommendations were proposed to enhance social work interventions in nursing homes. Among the proposed suggestions were initiatives to develop field practica opportunities in nursing homes to provide a venue for practice-academic partnerships, and a recommendation to encourage

collaborative efforts with academic nursing and medical colleagues focused on nursing home practices. Additional recommendations suggested specific research endeavors related to nursing home practices and outcomes.

Despite their considerable contribution to the lives of others, social workers have traditionally advocated much more effectively for their clients than for their profession. In order to retain their status as essential and respected healthcare professionals, social workers must support and further their profession through research, continuing education, and evidence-based practices that promote effective psychosocial care - to do less will jeopardize the social work profession and the well-being of the most vulnerable and oppressed members of our society.

Challenges to the Concept

There are a number of challenges associated with the establishment of designated hospice rooms in nursing homes. Each of these constraints offers opportunities to improve the status quo.

Death-denying culture. In order for a good death to occur, dying must be anticipated and acknowledged. Americans are uncomfortable acknowledging death or discussing its inevitability (Bern-Klug, 2006; Bern-Klug et al., 2004; Biola et al., 2007; Furman, Kelly, Knapp, Mowery, & Miles, 2007; Gessert, Elliott, & Peden-McAlpine, 2006; Kayser Jones, 2002; Meyers, Moore, McGrory, & Sparr, 2004; Osman & Becker, 2003; Rice et al., 2004; Travis, Moore, Larsen, & Turner, 2005; Wetle et al., 2005). Likewise, admitting a person to a nursing home is often considered a failure on the part of the family to provide for their elderly loved ones, even though there are times when a person's physical care requires more medical expertise than families can provide at home

(Bern-Klug, 2006; Evans et al., 2006; Kane, 2001; Teno et al., 2004). Further, death in the nursing home is often not planned for, discussed, or acknowledged when it occurs (Braun & Zir, 2005; Forbes-Thompson & Gessert, 2005; Parker-Oliver et al., 2006).

Open and honest communication is needed to dispel the many myths and misconceptions associated with nursing homes and hospice services. Events such as the National Health Care Directives Day are valuable in furthering end-of-life discussions through public forums and town hall meetings. The events also offer individuals an opportunity to meet with social workers to discuss their end-of-life wishes and to complete their Health Care Directive, thus providing valuable direction to family members or friends who may be called upon to make sure the patient's wishes are honored.

Culture of nursing homes. A culture change within the nursing home industry is overdue. It has been shown that a "top-down" approach to changing nursing home culture is most effective in implementing new programs (Rice et al., 2004). The Eden Alternative and the ideas of the Pioneer Network (innovative concepts designed to individualize and modernize nursing home environments), revisions to corporate nursing home policies and procedures, and individual nursing home efforts are focusing on improving the quality of life, and death, for residents and their families (Kane, 2001; Parker-Oliver et al., 2006; Thompson & Parker-Oliver, 2008). Finally, regulations that support a "compliance centered" rather than a "client centered" approach to end-of-life care need revision (Forbes-Thompson & Gessert, 2005).

Marketing efforts. There is a crucial need for public service and marketing programs that educate families about end-of-life care, hospice services, and the role of the nursing home in providing care when the patient's needs can no longer be met

adequately in the home environment (Bosek et al., 2003; Casarett, 2005; Kane, 2001; Mezey et al., 1999; Rice et al., 2004; Wetle et al., 2005). The majority of nursing homes in this study did not incorporate information about the designated hospice room(s) in their marketing materials. It was frequently noted that the “marketing person” was responsible for acquainting the community and area hospitals about the availability of the room(s). Only a few facilities had brochures or printed materials that included verbiage about the designated hospice room(s). Those interviewed discussed the perplexities of advertising a room for dying in juxtaposition with marketing efforts that focus on enhancing independence, restoring physical function, and improving quality of life:

I don't see people declining to move to the designated hospice room; I see them declining HOSPICE [emphasis intended]. I'd say families decline hospice off the get-go because of how it's presented, I think, by the physician, or the hospital, or the facility. I think some people hear, 'We'll give you a private room to die in.'

One administrator revised marketing materials in response to public misconceptions:

“I felt the word *palliative* was misunderstood and I started taking it out of the marketing. They just plain don't get it.” Conversely, if marketing efforts were successful in acquainting individuals with the benefits of a designated hospice room, there may be a greater response than most nursing homes could accommodate given the fact that many only had one such room in their facility.

Lack of reporting structures. Although it was encouraging to locate ten designated hospice rooms throughout the Midwest, their existence was not easily identifiable. As previously detailed, the researcher spent copious amounts of time in communication with social workers, hospice personnel, and other healthcare professionals in order to locate such facilities. Despite the fact that there are national, state, and local resources available to identify nursing homes, no such reporting mechanism is in place to locate those

nursing homes that feature a designated hospice room within their facility. The development of such a reporting system would greatly benefit families pursuing nursing home placement for loved ones nearing end of life.

Issues related to prognosis and admission criteria. Death is difficult to discuss and even more difficult to predict. Given the uncertainty of death, physicians and nursing home staff are encouraged to err on the side of referring a resident to hospice earlier rather than later. End-stage progression is rarely acknowledged in the nursing home setting, despite data that suggest that 30% of those admitted to a nursing home will die within the first year of admission (Porock, Oliver, Zweig, Rantz, & Petroski, 2003). It is imperative that healthcare professionals become more adept at identifying not only those likely to die within the next six months, but also those whose death is imminent.

In interviews with nursing home staff, most believed their facility's admission criteria for the designated hospice room(s) would follow the Medicare hospice guidelines related to the resident's terminal status. Many of the staff reported using a "first come, first serve" basis when determining admission criteria. The imminence of death was also frequently noted as being a determining factor in the admission process; however, there were instances reported where residents lived longer than expected. Nursing staff recalled meeting with families to broach the very delicate issue of moving a resident out of the designated hospice room in order to accommodate someone whose death was more imminent:

We tell them, 'Someone else is very ill and needs this room now and we're going to move your loved one to another room until she or he becomes more terminally ill and then they are welcome to go back to the room but right now this family needs it really, really bad.'

It was further noted that predicting length of stay posed a substantial challenge given that most nursing homes had only one designated hospice room available. Residents and family members were often offered the room when nursing home staff judged the resident to be within “four-to-six weeks of death.” Staff noted that when residents did not die within that timeframe they were either relocated to a different room within the facility, or a semi-private room was converted to a private room in order to accommodate the needs of multiple residents at end of life. The fact that residents receiving hospice sometimes live longer than expected was not an unknown phenomenon to nursing home staff:

If they’re admitted on hospice it doesn’t mean they are a fit for that room because I’ve had too many that come in on hospice and they end up being here for eight, nine, ten months. It’s supposed to be the end-of-life room so in the best of worlds, it would be somebody that would only be in there a week or two but of course we don’t have that premonition. We’ve had several that have stayed too long [laughter].

None of the nursing homes in this study had written policies and procedures specific to the designated hospice room(s). Although written guidelines may be helpful, the unpredictability of death remains a key factor in issues related to prognosis and admission criteria.

Financial constraints. Issues related to financial impact may pose the greatest barriers to the implementation of designated hospice rooms in nursing homes. Medicare does not pay for room and board in a nursing home; Medicaid pays for a semi-private room for those who qualify for services based on financial need, albeit at a rate that is typically below operating costs (C. Parsons, personal communication, December 12, 2008). The expense of a *private* room must be assumed by the resident or family, regardless of payer source. Even though, as one administrator stated, “It’s just the right

thing to do,” when a nursing home converts semi-private rooms to private hospice rooms, revenue is reduced. Rather than being reimbursed for two residents’ room and board, the facility receives half that amount. Likewise, when a resident receiving Medicaid is placed in a private designated hospice room, the nursing home does not receive additional reimbursement for those accommodations.

Further, Medicare reimbursement favors restorative care, with its highest reimbursement rate being directed toward intensive rehabilitation services (Teno, 2003; Thompson & Parker-Oliver, 2008; Travis et al., 2002; Zerzan, Stearns, & Hanson, 2000). Lower reimbursement is provided for personal care and symptom management; thus, the reimbursement for restorative services such as physical therapy or skilled nursing is greater than those allowed for end-of-life care (Porock et al., 2003; Touhy et al., 2005). A report released by the Office of Inspector General (OIG) stated that hospice care provided in nursing facilities costs Medicare considerably more on average than hospice care offered in other settings (Office of Inspector General, 2007). Organizations such as the Centers for Medicare & Medicaid Services, the National Hospice and Palliative Care Organization, and other hospice-related entities are skeptical of these findings (“MedPAC considers whacking hospice with 'blunt instrument',” 2008; Office of Inspector General, 2007). The OIG report states that further analyses will occur in order to determine the “appropriateness of payments for hospice care for beneficiaries in nursing facilities” (iii). The current emphasis on budgetary constraints and reduced government funding has resulted in increased nursing home regulatory and public scrutiny, and fewer financial resources with which to implement new and creative alternatives to the current models of end-of-life care in nursing home settings. It is imperative that national and state hospice

organizations educate government officials and politicians about the fiscal, operational, and medical benefits of hospice services, and advocate for continued financial support of hospice services delivered in nursing homes.

In response to the ubiquitous financial challenges facing nursing homes, various innovative programs have been developed to defer costs. In this study, six of the ten nursing homes partnered with hospice agencies or private individuals to establish the designated hospice room(s). In some instances, hospice agencies had completely furnished the rooms; in other cases, specific equipment or furniture had been donated by a hospice agency. The OIG has voiced concerns related to practices that may suggest inappropriate relationships between hospices and nursing homes (Office of Inspector General, 1997, 1998). The fact that many of the designated hospice rooms associated with this study were established as a result of collaborative efforts between the nursing homes and various hospice agencies may pose concerns “that some decisions about patient care can be potentially influenced by financial rather than clinical factors” (Office of Inspector General, 1997, p. ii). Given the severity of such implications, nursing homes may want to consider alternative sources of financial support such as federal, state, and local initiatives that encourage designing green environments or that promote renewable energy and energy efficiency.

Topics for Future Consideration

Legislative efforts. Legislative efforts are crucial to improving the quality of life and death in nursing homes. Federal funding must be allocated to renovate existing facilities, and to develop new structures that are designed to accommodate the needs of dying residents and their families.

New construction of housing can be designed with high-tech environmental control: doors, windows, blinds, security, temperature and communication. Unfortunately, these architectural solutions take deliberate advanced planning and are expensive. The extensive modification of existing housing to incorporate high-tech control is also problematic and costly (Tofle, 2009, p. 79).

Without adequate financial support for the development of designated hospice rooms, nursing homes will be forced to maintain the status quo – practices that research indicates are grossly ineffective and inadequate in meeting the needs of dying residents and their families.

Reporting structure. Given the relative novelty of designated hospice rooms within nursing homes, it is understandable that there are no federal or state guidelines specific to these settings. Having experienced firsthand the complexities involved in locating such entities, the researcher proposes that a reporting structure be developed in order to locate nursing homes that feature a designated hospice room in their facility. Without such a tracking system, individuals and families may not be able to access these distinct accommodations. When designated hospice rooms become more prominent within the nursing home industry, future regulatory efforts could promote a national rating system similar to that which was recently initiated for nursing homes (Anstett, 2008). However, as with any suggestion for increased regulatory influence, there is trepidation that nursing homes may experience increased sanctions and restrictions in an environment that is already highly regulated.

Further research. Lastly, additional social work research is needed to determine what constitutes the optimal dying environment for nursing home residents and their families. Despite the frequency of death in nursing homes, the end-of-life experience has been studied less there than in other sites of death (Munn et al., 2008). In order to obtain

a clearer understanding of what residents, families, and healthcare professionals deem important at end of life, empirical research is needed. Studies concentrating on the role of personalization could also provide valuable insight. Quasi-experimental and retrospective studies that investigate the experiences of families whose loved one died in a traditional semi-private nursing home room, as compared to dying in a designated hospice room, could provide valuable insight into the benefits of one setting versus another. Likewise, a structured observation guide designed specifically for designated hospice rooms would provide an assessment tool for healthcare professionals, individuals, or families interested in evaluating and comparing these specialized settings.

Summary

The predictions related to aging and dying in America are daunting. Although research is clear about what the future holds for senescent Americans, little is known about how nursing homes will respond to the end-of-life needs of millions of elderly residents and their families. Although nursing homes offer a variety of services, the expense of nursing home room and board may be unaffordable for elders on a fixed income or for those who do not qualify for Medicaid. In addition to financial limitations, bed availability, limited privacy, and the institutional environment may diminish the possibility of a good death in these settings. “Empirical evidence defining a good death would assist efforts to improve end-of-life care by documenting the breadth of preferences of dying residents and their families (Karen E. Steinhauser et al., 2000).

Verderber and Refuerzo (2006) suggest that architects must create palliative environments that are designed “as a means of reinforcing personal independence, autonomy, and dignity and to relieve unnecessary suffering” (p. 4). The authors

encourage collaboration between those who design the environments and those who inhabit the settings in order to maximize individualization and personal preferences. The desperate pleas of, “I want to go home!” often heard in nursing homes are not demanding a location, but rather, a nostalgic yearning for the feeling of home (Tofle, 2009). To that end, nursing home environments, and designated hospice rooms in particular, must incorporate physical environmental features that promote autonomy, privacy, dignity, tranquility, and personal preferences – thus achieving gerontopia.

Conclusion

Few of us will have a say in where we die. For many, death will occur in a nursing home. In order to ensure that a meaningful, dignified setting is available to enhance comfort and dignity as death approaches, it is imperative that nursing homes begin modifying existing structures or developing new environments to accommodate the needs of dying residents and their families. Ultimately, is it not possible that a warm and welcoming environment designed specifically to enhance individual preferences, privacy, dignity, and autonomy at end of life may also be the optimal environment for those among the living?

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Appendix A

Sample Email to Hospice Administrators and/or Social Workers

Dear Administrator/Social Worker:

By way of introduction, I am a social worker currently pursuing my doctorate in social work with an emphasis in end-of-life care. My dissertation topic involves a study of designated hospice rooms within traditional nursing home settings.

I am writing to request your assistance in identifying nursing homes in your geographic area that feature a room designated specifically for hospice patients and their families. If you are aware of such facilities, please forward the facility name and contact information to me via return email so that I may contact the facility and request their participation in my study. With your permission, I would like to provide your name as the source of this information.

I sincerely appreciate your time and attention to this request.

Appendix B

Sample of Telephone Script to Nursing Home Administrator

Dear Administrator:

I am a social worker currently pursuing my doctorate in social work with an emphasis in end-of-life care. My dissertation topic involves a study of designated hospice rooms within traditional nursing home settings. Jane Doe, the social worker from Happy Endings Hospice, has advised that your facility features a designated hospice room within your facility.

I am calling to request your permission to visit your facility and to incorporate the findings from my visit into my dissertation. The purpose of my visit would be to systematically describe the hospice room at your facility. This process would involve describing and photographing the designated hospice room, along with interviewing nursing home staff. I have a copy of the preliminary Coding Sheet for Content Analysis of Observations/Photographs and the semi-structured interview questions available for your review and consideration. In appreciation for the respect and privacy of your residents and their families, photographs and field notes will not contain identifying information or images. Consent from the individual/family member of those occupying the designated hospice room will be obtained prior to observation and data collection.

I sincerely appreciate your consideration of this request. If you are willing to participate, I would be happy to send you a copy of my dissertation proposal outlining the exact process along with documentation of IRB approval from the University of Missouri. Is there a specific date or time that would work best for you?

Appendix C

Coding Sheet for Content Analysis

Physical environmental elements	Description
Year facility was built	
Licensed skilled nursing facility	
Contractual arrangement with hospice agency	
Profit or Non-profit	
Urban or Rural location	
Location within facility	
Private room	
Room size	
Width of doorways	
Proximity to nurses' station	
Bookcases/Shelves for personal items	
View of nature	
Access to nature	
Private restroom	
Handicap accessible restroom	
Roll-in shower	
Wall space for artwork/pictures	
Non-institutional bedding	
Lighting	
Ventilation	
Noise	
Built-in suction	

Built-in oxygen	
Cleanliness	
Functional windows	
Patient/Family control of lighting	
Patient/Family control of temperature	
Patient/Family control of music/TV/DVD/VCR	
Amenities (i.e. coffeemaker, microwave, food)	
Accommodations for visitors	
Accommodations for overnight guests	
Accommodations for pets	
Space for worship/rituals	
Wireless Internet available	
Outlets for cell phone/laptop chargers	
Additional Comments:	

Appendix D

Semi-structured Interview Guide

How is the designated hospice room different from a traditional room in the nursing home?

How does the designated hospice room improve the dying experience for residents/families?

Do residents/families ever decline the opportunity to move to the designated hospice room? Why?

What types of things do residents/families bring into the room to make it more “home-like” or comfortable?

What would you do to improve the designated hospice room?

What is most beneficial about the designated hospice room?

What is least beneficial about the designated hospice room?

Are there special policies and/or procedures specific to that room? (i.e. 24 hr visitation, overnight guests, pets)

Do your marketing or advertising campaigns include a discussion of the hospice room?

Are you planning to develop more hospice rooms?

Appendix E

Summary of Sample Characteristics

FACILITY INFORMATION	# 1	# 2	# 3	# 4	# 5	# 6	# 7	# 8	# 9	# 10
Year Built	1982	1960's	1970's	1986	1993	1976	1988	1970's	1970's	1960's
Year Hospice Room Added	2004	2007	2004	2007	2008	2003	2007	2008	2008	2007
Skilled beds/hospice beds	110/16	120/1	120/1	101/1	96/2	420/2	162/1	180/1	72/12	90/12
For Profit	X	X	X	X	X			X	X	X
Payer Source for room*	Both	Both	Both	Both	Private	Private	Both	N/A	Both	Both
Urban or Rural	Rural	Rural	Urban	Rural	Rural	Urban	Urban	Rural	Rural	Rural

*Both includes private pay and Medicaid

Appendix F

Summary of Findings Related to the Physical Environment

Physical environmental feature	Findings
Privacy and dignity	Rooms were quieter than traditional rooms; privacy curtains enhanced residents' dignity
Room size	All rooms were private; increased room size accommodated personal furnishings and provisions for family
Personalization of the room	Rooms were personalized via photographs, personal possessions; family involvement crucial to personalization efforts
Flooring	Most rooms utilized vinyl flooring, some had carpeting; room with wood laminate and carpeting was impressive
View of nature	Very limited views of nature; only two rooms featured a scenic view
Control of lighting, temperature, and sound	Resident control of elements was minimal; lighting was often modified; noise from TV/radios was pervasive
Restrooms	Two rooms had roll-in showers; built-in medicine cabinets increased counter space

Appendix G

Summary of Findings Related to Family Accommodations

Family accommodations	Findings
Privacy and dignity	Private rooms allowed for increased family privacy; relieved concerns of disturbing a roommate
Room size	Facilitated family gatherings, accommodated large families and multiple guests
Private accommodations	Private bedrooms and family rooms dedicated for family use; overnight accommodations were provided
Amenities	All facilities offered amenities for families including comfort carts, meals, special linens, and fancy towels

VITA

Denise Lyn Swenson was born in St. Charles, Missouri. She graduated from McCluer Senior High School, Florissant, Missouri, in January, 1970. In 1998, she graduated Summa Cum Laude with a Bachelor of Arts degree in Social Work from Lindenwood University in St. Charles, Missouri. Following her undergraduate work, Denise attended the University of Missouri in Columbia, Missouri, where she received her Master of Social Work degree in 2001. After completing her Master's degree, Denise worked as the Admission Coordinator at Missouri River Hospice in Columbia, Missouri, from 2001 until 2006. During that time, she attended the University of Missouri on a part-time basis taking courses directed toward a Doctorate in Philosophy. In 2007, Denise returned to the University of Missouri as a full-time student to complete her doctoral education. Upon completion of her academic studies, Denise joined Missouri Cancer Associates, LLC, in Columbia, Missouri, in January of 2008, as a medical social worker. She successfully defended her doctoral dissertation on April 10, 2009 and graduated from the University of Missouri in Columbia, Missouri with a Doctor of Philosophy degree in May, 2009.