Re-conceptualizing the Information Use Environment: Enablers of and constraints to human information behavior in hospice care volunteerism in the southeastern Appalachian region

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DEDICATION

I dedicate this dissertation to all hospice care personnel, who willingly and continuously give their time, energy, effort, and hearts to comfort those who, though they fade, never really leave us; and, to Mom and Dad.

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ABSTRACT

Hospice care has seen an explosive growth in the last decade, with 42% of all deaths in 2010 in the US occurring under the care of a hospice program. A central aspect of hospice care is (unpaid) volunteer work, which is unique among other types of volunteer work in that it is strictly regulated by the Medicare hospice benefit, in which 94% of all hospices currently participate. As a cost-saving measure, Medicare requires that at least 5% of total patient care hours are undertaken by volunteers. However, hospice care faces a number of challenges, including a rapidly aging society that increasingly relies on hospice care; volunteer recruitment and retention; volunteers' uncertainties about their role in hospice care; and a lack of consistent and accurate information-sharing among the hospice team, including the volunteer. Therefore, it is crucial that the origin of the hospice volunteer's knowledge gaps be identified so as to determine how best to address hospice volunteer retention and recruitment. This study adapts Robert Taylor's concept of the information use environment (IUE) and Anthony Giddens's structuration theory in order to identify and explore the information behavior of the hospice volunteer coordinator. Twenty-one interviews of hospice care volunteer coordinators were conducted over a two-year period in East Tennessee, northern Georgia, and western North Carolina. A major finding of this study reveals that a power structure imbues both hospice care volunteerism as an IUE and the information behavior of the volunteer coordinator. Implications for library and information science are discussed, and recommendations are made for future research.

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CHAPTER 1: INTRODUCTION AND STATEMENT OF THE PROBLEM

Background

The population of the United States is rapidly aging. The 2010 US census report states that just over 40 million Americans were aged 65 and older, with women outnumbering men by almost a two-to-one ratio (US Department of Commerce 2010). Moreover, in the decade between 2000 and 2010, the population of aged adults 65 and older "increased at a faster rate (15.1 percent) than the total US population (9.7 percent)," with more of that same population of adults existing in 2010 than in any previous US census (US Department of Commerce 2010). Additionally, according to a 2002 report issued by the United Nations Department of Economic and Social Affairs (UNDESA), the number of persons in the United States age sixty and older is expected to almost triple to 107 million by 2050 (due mostly to decreased fertility rates alongside increased mortality rates) (UNDESA 2002). Accordingly, adults age sixty and older are this nation's fastest-growing population segment, and, in 2002, the U. S. government spent five times as much on healthcare for older adults as it did on children (U.S. Department of Health and Human Services 2008b). Older adults (defined in this study as those age sixty-five and older) are expected to face a variety of health-related complications, typically resulting from disease (e.g., diabetes) and injury (e.g., falls) (Centers for Disease Control and Prevention [CDC] 2007).

The increasing prevalence of chronic illness has resulted in many older adults facing end-of-life health issues (World Health Organization 2004). Indeed, a 2007 CDC report identified the "alleviation of end-of-life suffering" as a *key area* where the public health arena can help make significant improvements in the quality of life. According to the CDC report,

> ". . . with innovations in medical technology and treatment, quality of life and of dying have become increasingly important societal concerns. While end-of-life issues have steadily gained recognition in the health care system as an important area to address, the

> public health community has only recently come to recognize this as an area requiring its involvement. End-of-life issues share characteristics that are similar to other public health priorities, namely a substantial burden (e.g., universal incidence), a major impact on the individual and family members (e.g., effect on caregiver health), financial costs for individuals as well as society, and the potential to prevent suffering associated with the dying process. . .” (2007)

End-of-life care also has received recent attention in the popular media. A 2009 series of articles in *The New York Times* about end-of-life care reported on issues such as incarceration during end-of-life care and the delicacy with which end-of-life care physicians deliver dismal prognoses. The *Times* also reported that in 2009, Medicare paid more than $12 billion for hospice beneficiaries, up from $2.9 billion in 2000 (Rau 2011), signaling that the last decade has seen an explosive growth in palliative and hospice care programs in the US (as reported by Morrison, Maroney-Galin, Kralovec, & Meier 2005; Connor 2008). The Medicare Hospice Benefit also was recently a central topic on the financial-planning talk show “The Suze Orman Show” (Orman 2012).

According to the National Hospice and Palliative Care Organization (NHPCO), the overwhelming majority of patients who received hospice and palliative care in 2011 were adults age 65 and older (83%), with an estimated 1.58 million patients received hospice and palliative care in 2010 (NHPCO 2011). Across all age groups, slightly more females than males are hospice or palliative patients (56% vs. 44%, respectively), with Caucasians comprise 94% of patients in 2007 (NHCPO 2011). Meanwhile, the National Hospice Foundation (2011) reports that the number of hospice and palliative programs nationwide is on the rise, with approximately 5,150 currently in existence; according to the NHPCO (2011), the majority of hospices are freestanding agencies that deliver home hospice care, the remainder being either part of a hospital system, a home health agency, or a nursing home.

An important aspect of hospice and palliative care is the interdisciplinary team that administers such care, which generally includes a physician, a nurse, and a bereavement counselor (Capezuti, Siegler, & Mezey 2008, p. 416). A highly valuable component of hospice care is the volunteer worker, who typically assists with such tasks as office work (e.g., answering telephones) and services to patients (e.g., personal care), although they might also work as fundraisers, consultants, and board members (Forman et al. 2003). Accordingly, volunteers are widely recognized as essential to the interdisciplinary team of care (Forman et al. 2003, p. 96), and have been described as the "backbone of the hospice movement" (Finn Paradis & Usui 1989) and the "life-line of hospice" (Patchner & Finn 1987).

The Problem

Despite its contribution to hospice care, hospice care volunteerism is not without its challenges. As the largest payee of hospice care, Medicare *requires* that hospice care agencies receiving Medicare payment document their efforts to recruit, train, and retain volunteers as part of the agencies' overall cost-savings measures, since volunteers, including those that, other than the physician, might otherwise work a paid position are required to perform a minimum of five percent of the total paid hours devoted to a patient by a hospice care team (US Department of Health and Human Services 2008a), making hospice care volunteerism unique among all other types of volunteer work (NHPCO 2011). Compounding the situation is that hospice volunteers continue to express a need for and request training and education beyond their pre-service training, with the quality of training a factor in whether a volunteer chooses to stay in a particular hospice agency (see, e.g., Chevrier, Steuer, & MacKenzie 1994; Worthington 2008).

Meanwhile, other vital, although not legally required, documentation continues to lag: findings from grant-funded research apportioned specifically to hospice care volunteerism report that volunteers' effects on patient outcomes remain inaccurately documented, which is likely to have "a negative impact on future investments in hospice volunteer programs" (University of Virginia Health Sciences Center 1998; see also Morris, Wilmot, Hill, Ockenden, and Payne 2012).

Moreover, Medicare does not stipulate or designate the responsibility of volunteer recruitment, training, retention, or documentation thereof to a specific person on the hospice care team (US Department of Health and Human Services 2008a); this responsibility can fluctuate within an agency, causing some volunteers to experience unclarified lines of authority, as well as role ambiguity, resulting in volunteer stress and burnout (Paradis, Miller, & Runnion 1987; Paradis & Usui 1989; Glass & Hastings 1992; Berry & Planalp 2009). Additionally, as with all types of volunteerism, volunteerism in hospice care fluctuates in terms of the number of those who volunteer their time to hospice care patients; in 2010, 458,000 volunteers provided 21 million hours of service, with sixty percent committing their services directly to patients (NHPCO 2011).

Nevertheless, interdisciplinary collaboration, which, at least conceptually, includes the volunteer, is an approach to hospice patient care also mandated by Medicare as a cost-savings measure (USDHHS 2005). However, patient-related hospice care interdisciplinary team meetings have been found to be subject to "inaccurate, incomplete, or out-dated [sic] information," often resulting in "different levels of access to information sources" by each team member (Demeris, Washington, Oliver, & Wittenberg-Lyles 2008). This confirms previous findings, most notably those of DeFord (2003), who found that hospice and palliative care

interdisciplinary team meetings typically are led by physicians and therefore are clinical in nature, and thus can undermine information-sharing among hospice team members (e.g., updates about a patient's condition). The disparity in information flow and access to information during interdisciplinary team meetings can be particularly damaging to the volunteer, since the overseer of the volunteer, as a paid, professional member of a hospice care agency team, is the volunteer's primary source of information, guidance, and support (Dunlop & Hockley 1990; Forman et al. 2003).

In sum, despite being identified as crucial to hospice care both philosophically, historically, and legally, hospice care volunteerism faces immediate, substantial, and unyielding structural pressures: an aging society that increasingly relies on hospice care and the volunteerism therein; legal requirements for volunteers to encompass at least five percent of total paid hours worked on behalf of a patient; legal requirements for hospice care agencies to document their efforts to recruit, train, and retain volunteers; volunteers' call for continuous training; dire warnings that hospice volunteer programs are in serious danger of being abolished if volunteers' effects on patient outcomes continues to remain obscure or unknown; volunteers' uncertainties about their roles in hospice care and about their hospice agency's "pecking order"; and the inherent potential of a lack of consistent and accurate information among the hospice care team, including the volunteer and his or her overseer.

Inarguably, then, hospice care is a robust information environment in which volunteers find themselves in the dubious position of being at the heart of hospice care, which has been found to prolong the quality of life of terminally-ill patients (NHPCO 2011), while captive to a tenuous system of information bottlenecking and gatekeeping. More so, the volunteer lacks the authority to effect profound change in his or her access to information, other than periodically requesting

ongoing training, while at times uncertain as to whom on the team is the volunteer's "go-to" person. Therefore, we need to unravel the path by which the volunteer acquires information so as to identify volunteers' knowledge gaps and how they might affect the volunteer's ability to serve a hospice care patient with the full compassion and caring called for by hospice care philosophy. However, since the overseer of the hospice volunteer has been found in previous research as the main source of information for the volunteer, and because the overseer is responsible for recruiting, training, and retaining the volunteer, we must first explore the information behavior of the overseer as it occurs according to the aforementioned structural pressures (e.g., Medicare requirements) that currently bridle hospice care volunteerism.

Just as importantly, we also must explicitly identify the overseer of the volunteer, as well as the element or those elements in a hospice care setting that enable and constrain his or her ability to access information. As noted earlier, whoever is charged with the task of overseeing the volunteer at times is not obvious even to the volunteer, a dilemma that can impede the flow of information between the overseer and the volunteer. Moreover, identifying the elements within hospice care that facilitate or prohibit the overseer's ability to access to information is key to determining that which might produce the volunteer's knowledge gaps and thus affect his or her decision to remain as a volunteer in hospice care.

Purpose of the Study and Research Questions

The primary purpose of this study is to identify and describe the overseer of the volunteer in hospice care, as well as his or her information needs, and the ways in which he or she seeks and uses information in order to resolve those needs. A secondary purpose is to determine to what extent the information behavior of the overseer of the volunteer could translate into whether a

volunteer continues to participate in hospice care. A third purpose of this study is to derive a theoretical framework of human information behavior within a broad social context, a research aim called for by Hargittai and Hinnant (2006, p. 55) and Nichols and Twidale (2011, p. 205), and bluntly characterized by Jaeger and Burnett (2010, p. 4) as "frustratingly rare" in library and information science. The fourth and final purpose of this study is to explore whether the IUE contains dimensions yet to be discovered. As such, this study poses and explores the following research questions (RQ):

RQ1: Who is the overseer of the volunteer in a hospice care setting and what is his or her work-related profile?

RQ2: What are the information needs of the overseer of a volunteer in a hospice care setting?

RQ3: How does the overseer of a volunteer in a hospice care setting seek information?

RQ4: In what way(s) does the overseer of a volunteer in a hospice care setting use information?

RQ5: What enables the information behavior of an overseer of a volunteer in a hospice care setting?

RQ6: What constrains the information behavior of an overseer of a volunteer in a hospice care setting?

Significance of the Study

The importance of this study lies primarily in exploring the context in which it occurs, i.e. hospice care, and the structural pressures that continue to assault hospice care. As noted earlier, increasing numbers of terminally-ill people rely on hospice care in their final weeks of living, and that number continues to increase, with just over one million patients relying on hospice care in 2010.

Secondly, healthcare itself continues to be a major political battleground, *with Medicare front and center in the battle,* due mostly to the program's funding challenges, coupled with rapid and continuous increases in enrollment. Medicare is administered by the Centers for Medicare and Medicaid Services (CMS), itself a component of the Department of Health and Human Services (HHS), although Medicare eligibility and the processing of Medicare payments is determined by the Social Security Administration (SSA) (U.S. Social Security Administration 2012). Medicare is funded by two trust funds designated solely for Medicare and comprised of various sources of funding (e.g., employee payroll taxes; taxes paid on Social Security benefits) (U.S. Social Security Administration 2012). By 2020, Medicare spending is projected to be $932 billion, totaling approximately five percent of the nation's gross domestic product (GDP), and reflecting seventy-nine million enrollees (Geithner, Sebelius, Solis, Astrue, & Berwick 2010). Moreover, with the nation's two major political parties' relentless sparring over their approaches to health care in general and to Medicare in particular, especially in terms of its funding and enrollment ratio, hospice care, as it falls under the Medicare benefit, deserves special attention.

Meanwhile, the nation is aging quite rapidly and is just now encountering the first wave of "baby boomers" collecting Medicare (Census Bureau 2011). Medicare requires, by law, that hospice volunteers make up for at least five percent of total paid hours devoted to a patient by a hospice care agency. Pair those societal macro-constraints with hospice care micro-constraints, such as the disruption of the flow of information of the hospice interdisciplinary team and how those disruptions affect hospice volunteer retention, as well as the hospice volunteer's oft-occurring uncertainty about to whom he or she should turn when needing information, and the need for this study becomes ever apparent.

Concurrently, many human information behavior researchers in LIS continue to call for and incorporate social contexts of the behavior into their studies. This study appropriately heeds that call and thus adds to a growing body of research that theorizes about human information behavior beyond its cognitive domain, and, additionally, by moving beyond mere categorization of human information behavior (i.e., a typology of need, seeking, and use) and actually discovering the *meaning* (i.e. theory) behind that behavior, a much-needed approach, given prominent LIS researchers' noting of theories of human information behavior as being "… still at the modeling stage" (see, e.g., Bates 2006, p.3). Accordingly, this study allows for exploring information behavior in a broad social context, called for many by LIS researchers (see, e.g., Taylor 1991; Frohmann 1994; [Frohmann quoted in] Raber 2003, p. 182).

Finally, this study is needed because it draws direct attention to the hospice volunteer's knowledge gaps in providing comfort to a hospice care patient, a decidedly under-studied aspect of such a vital aspect of hospice care. Although hospice care was founded on the concept of volunteerism, itself a common topic in hospice care research, studies that explore health- and medical-related volunteerism as it relates to human information behavior have yet to emerge, despite the surge of health-related information behavior in LIS within the last decade. Therefore, this study adds a unique but important demographic (i.e., the volunteer) to human information behavior research.

Conceptual Framework

The conceptual framework for this study is the information use environment (IUE). Robert Taylor (1986) identifies an IUE as "the set of those elements that affect the flow of information messages into, within, and out of any definable entity . . . ; and that determine the criteria by

which the value of information . . . will be judged in those contexts" (pp. 34-35). The IUE emphasizes the social context of all routine action related to information use and the value of that information at a particular time (Taylor 1986, p. 35). The IUE also has been identified as a major conceptual development in human information behavior studies (Pettigrew, Fidel, & Bruce 2001).

Taylor defines the IUE according to four major components: "People," or classes of professionals whose need for and use of information is highly similar; "Problems," or uncertainties from which an information need arises; "Problem Resolutions," or steps taken to resolve a problem, and "Setting," or those elements in an organizational structure that impose enablers and/or constraints on the information behavior that occurs within that structure.

The IUE is a conceptualization of Taylor's "value-added approach" to information systems, which calls for information behavior research to focus less on information systems and more on the users of those systems. Bilal (2007, p. 39) notes that a user-centered approach to the study of information systems has occurred over the last two decades, wherein "… the user has become the center of the information seeking process." For its part in that emergent paradigm shift in information systems research, the IUE functions as Taylor's framework for parsing human information behavior as it occurs in an organizational setting. However, Rosenbaum (1993) argues that the IUE should be expanded because it focuses on organizational structure at the expense of the information behavior that occurs within it, and thus remains system-centered, a distinct irony, given Taylor's objections to privileging the system over the person, and that those objections generated the concept of the IUE in the first place.

To reconcile this (presumably unintended) outcome of the IUE, Rosenbaum (1993) calls for the IUE to incorporate Anthony Giddens's theory of structuration, hereafter known as

structuration theory. Structuration theory focuses on how "the structural properties (i.e., rules and resources) of social systems are both the medium and the outcome of the social practices that constitute those systems" (Giddens 1979, p. 69). According to Giddens, *social systems* are comprised of *routinized social practices* produced and reproduced by knowledgeable actors within a specific time and space who are aware of the intended consequences of their actions, while *structures* are the rules and resources that bind those social practices into systems in a virtual time and space and which are continuously reproduced vis-à-vis the unintended consequences of the actions of those actors (see Figure 1). Structures do not have a physical existence; rather, they are virtual orders that are always evolving and that exist as routinized activities in which rules are applied and resources are manipulated. Moreover, structures not only are products of human action, but also are enablers of or constraints to human action, and are of three types: *legitimation,* or structures that produce a moral order; *domination,* or structures that imbue power; and *signification,* or structures that produce meaning.

In short, vis-à-vis their respective rules and resources, structures "express forms of domination and power" and both enable and constrain human action (Giddens 1984, pp. 18, 25). Rules are of two types: procedural, or those that determine the ways in which a particular practice is performed; and moral, or appropriate forms of social interaction deemed as such by actors ("agents") who are cognizant of their actions. Resources also are of two types: allocative, or tangible goods and commodities that allow for power to be wielded; and authoritative, or people and organizations that wield power.

The principal goal of structuration theory is to connect knowledgeable agents with social structures as a means of resolving what Giddens saw as the central problem in social theory: that it treated human action and social structure separately, resulting in what Giddens considered to

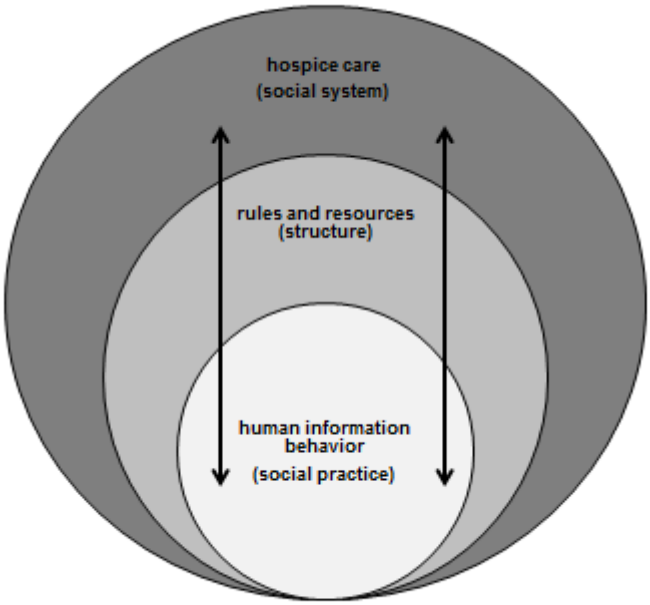

FIGURE 1. THEORY OF STRUCTURATION APPLIED TO HOSPICE CARE VOLUNTEERISM

be unnecessary tension in social research between macro (structural) and micro (agency) approaches to social science research. Accordingly, Giddens argued that structure and agency should be equally considered to explain social life (Giddens 1984, p.139). For Giddens, therefore, the bridge between human action and social structure lies in the *social practices* performed by agents within a social structure, and it is the bridging of the gap between structure and agency that Rosenbaum (1993; 1996) argues is *key* to rendering the IUE as a user-centered approach to studying human information behavior.

As for the ways in which the IUE is specifically conceptualized in this study, "People" refers to the overseer of the volunteer and his or her work-related demographic profile, i.e. the length of time he or she spent as a coordinator; the number of patients being cared for at the time of the interview; the number of volunteers at the time of the interview; and the efforts by which each

coordinator recruited and retained the volunteers. "Problem(s)" is conceptualized as the overseer's information needs, as well as his or her attempts to satisfy those needs, or resultant seeking behavior. Although this conceptualization differs from Taylor's definition of problem, i.e. an *uncertainty* that generates information need, the interview guide for this study did not stipulate between "problem" and "need," which meant that there was no method of demarcating or coding the data for "problem" and "need." Additionally, information seeking is subsumed under "Problem" in this study because it is an activity identified by some models of information seeking as being automatically generated by an information need (see, e.g., Wang 2011, pp. 17, 19). In short, Taylor defines a problem as an uncertainty that precludes and thus generates an information need, while this study, drawing upon the flexible nature of qualitative approaches to research, defines "problem" as the information need itself, since information need, and not its antecedents (e.g., uncertainty) is of primary concern to this study. Conversely, "Problem Resolution" is conceptualized as Taylor explicitly proposed; that is, a resolution to a problem is considered in this study as the purpose for which information is used by a coordinator.

Finally, "Setting" in this study refers to enablers of and constraints to information behavior. For Taylor (1992), "setting" in the IUE specifically refers to "physical context" and the ways in which the mutability of that context "affects [i.e. enables and constrains] the way [people] seek and use information" (1992). Similarly, Giddens argues that human interaction and the context in which it occurs (i.e. structure) continuously shape and re-shape, or produce and reproduce, one another. Taylor's concept of setting and Giddens's theory of structuration both focus on enablers of and constraints to human action, which renders the enabler-constraint duality as *the* tie that binds the IUE and structuration theory.

It should be noted that while this study does take the liberty of reconceptualizing the IUE beyond the scope called for by Taylor by enjoining it to structuration theory, incorporating pieces of conceptual and theoretical frameworks and re-formulating established conceptual frameworks is an accepted approach in qualitative research, since all conceptual and theoretical frameworks are constructed from other frameworks by borrowing pieces of those frameworks so as to build a new one (Maxwell 2005, p. 35)

Definitions

hospice care: Medicare-approved physical, mental, and/or emotional care and support given by an interdisciplinary team of paid professionals and unpaid volunteers to 1) a terminally-ill person who has been referred to such care and support by a doctor, and/or 2) to the terminally-ill person's primary caregiver(s)

overseer of a volunteer in a hospice care setting: a chaplain, bereavement counselor, team assistant, volunteer coordinator, volunteer services manager, or volunteer manager who is a paid member of the hospice care interdisciplinary team and who is responsible for the recruitment, training, management, supervision, and retention of an unpaid hospice care volunteer

hospice care volunteer: an unpaid person in a hospice care setting who assists in either indirect or direct care and support of a terminally-ill person, whose efforts are required by Medicare standards to account for at least five percent of the total paid hours devoted to hospice care, and who does not volunteer for a professional role that otherwise might be paid

information need: an information-related knowledge gap that arises for the overseer of a volunteer in a hospice care setting during the course of his or her efforts to recruit, train, supervise, manage, and retain volunteers and that prompts information-seeking and/or use behavior

information seeking: activity exhibited by the overseer of a volunteer in a hospice care setting that reflects an attempt to satisfy an information need or needs and that involves consulting and/or comparing sources of information

information use: the mode or method by which the overseer of a volunteer in a hospice care setting utilizes information derived from his or her information-seeking activity

enabler (of information-seeking): a person, resource, organization, Medicare standard, or HIPAA standard that resolves an information need or needs of the overseer of a volunteer in a hospice care setting and/or that helps in broadening his or her hospice care–related knowledge base

constraint (to information-seeking): a person, resource, organization, Medicare standard, or HIPAA standard that prompts the information need or needs of an overseer of a volunteer in a hospice care setting, as well as his or her subsequent information-seeking behavior, and that temporarily or permanently suspends or prevents the broadening of his or her hospice care–related knowledge base

moral rule: a course of action taken by the overseer of a volunteer in hospice care that is grounded in his or her individual sense of right and wrong and is external of an explicit, written policy of his or her respective hospice agency but that does not violate that policy, and that informs the information seeking and use activities of the overseer

procedural rule: a course of action taken by the overseer of the volunteer in hospice care that is grounded in his or her abiding by or adhering to an explicit, written policy of his or her respective hospice agency, and that informs the information seeking and use activities of the overseer

allocative resource: a material object that grants power either to the overseer of a volunteer in hospice care or to the corporate administrator(s) of his or her hospice agency, and that is used by the overseer to resolve an information need

authoritative resource: a member of the hospice care team, including the volunteer; a hospice care patient; a patient's family; another overseer of the volunteer; an admissions nurse; or an object consulted for information by the overseer of the volunteer in hospice care

Scope and Limitations

This study sought and acquired the participation of twenty-one overseers of the volunteer in licensed hospice care agencies in the southeastern portion of the Appalachian region of the United States (US). Data was collected in the Southern and South-Central sub-regions of Appalachia, and, specifically, in East Tennessee, northern Georgia, and western North Carolina (see Figure 2).

The sub-regions in which the interviews took place are defined according to the Appalachian Regional Commission, a federally-, state-, and locally-funded partnership that uses economic indicators to addresses critical healthcare challenges and "high incidence of life-threatening diseases" within the entire Appalachian region (Appalachian Regional Commission 2011). The

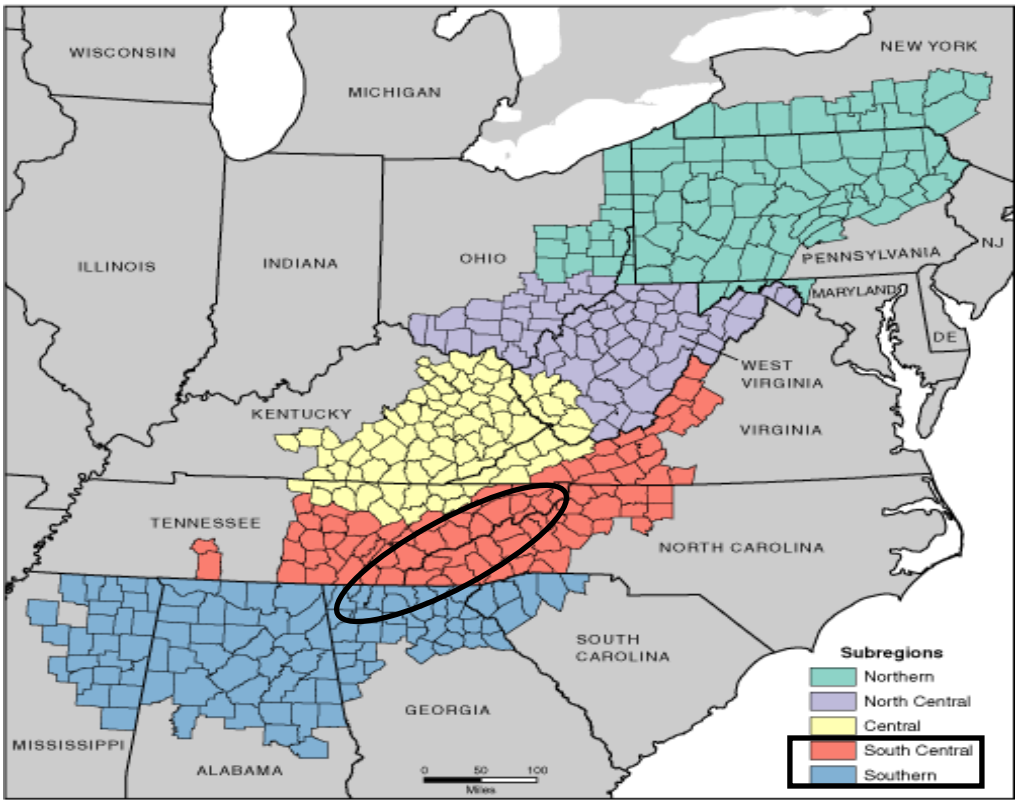

FIGURE 2. THE SOUTHERN AND SOUTH-CENTRAL SUB-REGIONS OF THE APPALACHIAN REGION

Southern and South-Central sub-regions and three of the states that those regions partially encompass (i.e. Tennessee, Georgia, and North Carolina) were chosen because the location of those states allowed ready access to the participants in person by the researcher. Moreover, the Southern and South-Central sub-regions not only are culturally diverse, but also experience health-related disparities according to demographic factors like race, age, and socioeconomic status (Halverson 2004; Paskett, Fisher, Lengerich & et al. 2011), which allows for the

possibility of accessing data that would be richer in detail than would data that reflected a more homogenous geographic locale or mere differences in state law.

This study also is limited to the reporting of general information that any given overseer of the hospice volunteer would likely need, seek, and use as a matter of routine, and *not* specific patient information that is sensitive in nature, i.e. that would identify a particular patient and that would thus violate the 1996 Health Insurance Portability and Accountability Act (HIPAA) regulations were such information to be disclosed to the researcher.

Ethical Concerns

Great effort was exerted to ensure that none of the questions in the interview guide would elicit specific patient information. For example, none of the questions asked a participant to divulge specific patient information. Additionally, a hard copy of HIPAA regulations was present at all interviews in case a participant wanted to verify whether an interview question or answer violated those regulations. Therefore, no foreseen risks existed. However, participants were free to decline to answer a question or to withdraw from the interview altogether at any time. As it so happened, none of the participants declined to answer a question or withdrew from an interview.

CHAPTER TWO: REVIEW OF THE LITERATURE

End-of-Life Care

End-of-Life care issues have been the focus of much debate for the past thirty years among providers, medical ethicists, and policymakers, as well as the public at large. The debate has centered on important questions about what constitutes quality of life at life's end and withdrawal of life-sustaining treatments (Gostin 2005). Studies that focus on end-of-life care are found in a variety of dimensions, including location of care (e.g., nursing homes) (Eersek & Wilson 2003), education (e.g., medical students' perspectives) (Wear 2002), and patient competency for discussion of end-of-life care (Buss, Alexander, Switzer & et al. 2005).

In recent years, public health departments at federal, state, and local levels have become vital in managing long-standing public health concerns (e.g., chronic disease prevention); however, end-of-life care has been overlooked considerably as a matter of public health (Rao, Alongi, Anderson & et al. 2005). As such, many experts continue to advocate for more attention to be placed on end-of-life care in the public health sphere (see, e.g., Ferrell, Grant, & Virani 1999; Bradley, Cramer, Bogardus & et al. 2002; CDC 2007).

Hospice Care

The concept of hospice care has been documented as far back as Homeric times (8th century BC). The word "hospice" was first used in Europe during the Middle Ages "to identify a place that provided shelter to travelers or crusaders on their journeys" (Eng 1993). The first modern (i.e., post-industrial) hospice opened in France in the mid-nineteenth century (Dunlop & Hockley 1990). In the West, (Dame) Cicely Saunders, a British nurse, along with renowned American psychiatrist Elizabeth Kubler-Ross, are widely credited with fostering the prevailing position that

terminally ill patients have complex needs that must be addressed by the medical community (McDonnell 1986, pp. 3-4; Forman, Kitzes, Anderson & et al. 2003, pp. 3-5). In 1982, in the United States, the Congress created a Medicare benefit, which was made permanent in 1986 (NHPCO 2011).

The National Hospice and Palliative Care Organization (NHPCO) (2011) reports that in 2010, there were 5,150 hospice providers tending to 1,580,000 patients. Historically, hospice care was hospital-based, although many nursing home and home-care agency programs have been initiated within the last decade (Capezuti et al. 2008); still, most hospice care occurs in a patient's home (Larsen & Lubkin 2009, p. 522). For 2010, the NHPCO estimated that forty-two percent of all deaths in the US were under the care of a hospice program (2011).

A key component to hospice care is the organizational structure of the hospice care team, which can vary according to the characteristics of the communities it serves; i.e. several models of hospice care exist depending whether that care is received in one's home, a nursing home, a hospital, or a private agency (Larsen & Lubkin 2009, p. 22). Moreover, the hospice benefit of Medicare, with its accompanying regulations, creates yet another alternative for the structure of the hospice team, i.e. by law, the team must include a physician, a nurse, a social worker, and a bereavement counselor, but Medicare does allow for the addition of home health aides, volunteers, and volunteer coordinators (U.S. Department of Health and Human Services 2008).

While the physician and nurse are responsible for treatment of symptoms and for pain management, the social worker assists with emotional and support, as well as management of resources, insurance, and legal issues (Capezuti et al. 2008). The bereavement counselor provides support to help the family of a patient normalize grief, and to refer high-risk families to specialists (Forman et al., 2003; Capezuti et al. 2008). For their part, volunteers and home health

aides provide a bevy of services, including entertainment, respite care, running errands, and office work, while the volunteer coordinator acts as a liaison between the volunteers, and the patients and interdisciplinary team (Forman et al. 2003, p. 93).

It should be noted here that hospice care typically is defined as a team-oriented method for the delivery of competent, compassionate, and consistent end-of-life care to people who have been diagnosed with a terminal illness, who are not in search of a cure for their illness, and who have six months or less to live. Hospice care differs from palliative care in that those patients who receive the latter often do so for a cure with help from medical professionals and can receive curative treatment at any time during their illness, regardless of their life expectancy upon diagnosis. A comprehensive review of relevant literature revealed that often, "hospice care" and "palliative care" are used interchangeably; however, this study is limited to hospice care only, for two reasons: 1) the Medicare Hospice Benefit provides broad coverage for hospice care but not for palliative care, and 2) all hospice programs that accept Medicare payment must be licensed and must operate according to Medicare standards (American Hospice Foundation 2010; U.S. Department of Health and Human Services 2010).

Volunteerism in Hospice Care

Within the last decade, the U.S. has seen a steady rise in the numb of Americans who participate in volunteerism. Over sixty million Americans volunteered in 2011, with a .5 percent increase between 2010 and 2011, with health-related environments comprising eight percent of all environments in which volunteerism occurs (U.S. Census Bureau 2011; U.S. Department of Labor 2012). In terms of hospice care, approximately 458,000 volunteers donated their time at hospices throughout the U. S. in 2010 according to the most recent data collected (NHPCO

2011). Typically, a hospice volunteer performs a variety of caregiving tasks, including shopping, minding children, and sitting with families in order to give them a break from care (Dunlop & Hockley 1990, p. 39; National Hospice Foundation 2009).

Most studies that have focused on volunteerism in hospices have centered on the experiences and issues faced by hospice volunteers, including *burnout* (Brichacek 1988), *personality characteristics* (Caldwell & Scott 1994; Claxton-Oldfield & Banzen 2010), *age as a factor in volunteer responsibilities* (Black & Kovacs 1999); *the meaning of being a hospice volunteer* (Kovacs & Black 2000; Andersson & Ohle´n 2005), *satisfaction with volunteering* (Finkelstein 2008), *stress* (Dein & Abbas 2005; Claxton-Oldfield & Claxton-Oldfield 2008a; 2008b), *ethical issues* (Berry & Planalp 2009), and the *motivations for volunteering* (Planalp & Trost 2009); and on various perceptions of hospice volunteerism, including *those of patients* (Claxton-Oldfield, Gosselin, & Claxton-Oldfield 2008), *families of patients* (Claxton-Oldfield, Gosselin, Schmidt-Chamberlain, & Claxton-Oldfield 2009; Block, Casarett, Spence, Gozalo, Connor, & Teno 2010), *and* hospice care nurses (Claxton-Oldfield, Hastings, & Claxton-Oldfield 2008).

Hospice Volunteer Recruitment, Training, and Retention

Other relevant research forms a loose collection of studies that focus on volunteer recruitment, training, and retention, of which representative examples follow. For instance, Werner, Chard, Hawkins, and Marshall (1981) studied a hospice training program in northern Michigan in terms of how volunteer coordinators selected volunteers and the teaching methods that were used to train the volunteers. Caty and Tamlyn (1983) developed a hospice care volunteer recruitment profile, while Lamb and de St. Aubin (1985) established guidelines for screening potential hospice volunteers. Lister and Ward (1985) explored a hospice training

program developed for youth who wished to offer support to bereaved peers (versus the traditional patient support in which volunteers are normally engaged). Jimenez and Jimenez (1990) drew upon hospice care to propose a model of training and support for people afflicted with AIDS. Lafer and Craig (1993) surveyed more than one hundred volunteer coordinators in order to develop a tool for measuring volunteer performance. Erb (2001) described factors (e.g., cognitive, behavioral) that characterized hospice volunteer retention. Finally, in 2003, Salmon, Deming, Kwak, Acquaviva, Brandt and Egan reported the results of a volunteer coordinators' national needs assessment, to which more than 200 trainers responded, and that was used to develop a nationwide curriculum for hospice volunteer coordinators.

Similar research that focuses on the overseer of the volunteer is in the form of guidelines for training or enrichment and impact of the training experience (see, e.g., Wilson 2000; Egbert & Parrott 2003; Scherwitz, Pullman, McHenry, & Ostaseski 2006; Claxton-Oldfield, Crain, & Claxton-Oldfield 2007). Meanwhile, hospice care volunteers continue to express a desire for ongoing training and education, both of which long have been identified as being of high interest to volunteers (see, e.g. Wamboldt-Downe & Ellerton 1986; Scott & Caldwell 1996; Wilson 2000; Planalp & Trost 2008; Wittenberg-Lyles, Schneider, & Oliver 2010; Jovanovic 2011; Lavenburg & Bernt 2012) and major factors in volunteer retention (see, e.g., Chevrier, Steuer, and MacKenzie 1994; Worthington 2008).

Information-Related Studies in Hospice Care

An exhaustive literature search for research that focuses on information-related studies in hospice care yielded only a handful of results. For example, DeFord (2003) found that hospice and palliative care interdisciplinary team meetings typically are led by physicians and therefore

are clinical in nature, and thus can undermine information-sharing among hospice team members (e.g., updates about a patient's condition). Lin and Tsao (2004) identified six domains of information needed by family caregivers of terminally-ill cancer patients. Wittenberg-Lyles (2005) examined how hospice healthcare professionals share patient-related psychosocial information, while Demeris, Washington, Oliver, and Wittenberg-Lyles (2008) explored information access, exchange, and documentation during an interdisciplinary hospice team meeting. Finally, Fourie (2008) studied information behavior of hospice patients (and their family members) in hospice care in South Africa.

Human Information Behavior

Human information behavior typically is defined as the "totality of human behavior in relation to sources and channels of information, including both active and passive information seeking, and information use" (Wilson 2000). Human information behavior research dates back to 1948, at the Royal Society Scientific Information Conference, wherein papers were presented that discussed scientists' seeking and use of documents and of the library (Wilson 1999). Two decades later, research that focused on scientists' information use began to investigate their information needs (Wang 2011, p. 15). Since then, a plethora of LIS studies have addressed not only professionals' information behavior, but also the information behavior of everyday citizens (Vakkari 2008a). These studies have resulted in a distinct corpus of research in LIS that continues to be fertile ground and that increasingly explores information behavior associated with everyday life (see., e.g., Savolainen 2008, p. 6; Fisher & Julien 2009, p. 325) and with organizational structures in general (see. e.g., Taylor 1991; Rosenbaum, 1996; Wilson 1996;

Sonnenwald 1999, pp. 177, 180), the latter of which is explicitly identified as "underdeveloped" on a "theoretical level" (Spink & Cole 2006, p. 235).

A plethora of LIS studies address information human information behavior according to a particular context, in which information needs initially can arise (Wilson 1981) according to situational factors (e.g., time and resource constraints) (Choo, Detlor, & Turnbull 2000, p. 6). A comprehensive literature review (Vakkari1997; Courtright 2007) found that the context of such behavior was primarily considered in terms of occupation; of these, social scientists and engineers comprised the majority who were studied (see, e.g., Ellis, Cox, & Hall 1993; Bruce, Fidel, Pejtersen, Dumais, Grudin, & Poltrock 2003; Fidel & Green 2004; Tenopir & King 2004; Allard, Levine, & Tenopir 2009). However, *scholars* (see, e.g., Bates 1996; Wang, Dervos, Zhang, & Wu 2007; Tenopir, King, Edwards, & Wu 2009); *professionals* (see, e.g., Lundeen, Tenopir, & Wermager 1994; Urquhart 1999), including *managers* (MacKenzie 2003) and *farmers* (Timko & Loynes 1989), also have been widely studied as information seekers. Other notable contexts in which human information behavior is researched include the World Wide Web (see, e.g., Bilal & Kirby 2002; Bilal 2004; Rieh 2004) and social and demographic characteristics of information seekers (see, e.g., Mehra & Braquet 2007a).

Case (2008, p. 26) notes that a salient aspect of the context of human information behavior is the organization in which the behavior occurs, and is particularly important in organizational settings because it is often the first step in organizational change efforts (Johnson 1996, p. 3) and adaptation to new conditions that might arise (Choo 1998, p. 26). Organizational settings tend to be volatile; thus, information is crucial to decision-making and problem-solving (Choo 1998, p. 24). Moreover, information can be a form of social support that allows for managing organizational life (Johnson 1996, p. 3).

Models of Information Seeking

According to Marchionini, information seeking is a type of problem-solving that includes "recognizing and interpreting the information problem, establishing a plan of search, conducting the search, evaluating the results, and if necessary, iterating through the process again" (1992). Models of information seeking typically are expressed as frameworks wherein a person recognizes an information need, after which he or she engages in one or more activities intended to resolve the need to at least some satisfactory extent, upon which new information needs might emerge, thereby re-generating one or more activities intended to resolve those new needs. While a discussion of models here could suggest a positivist approach to this study, the information seeking models discussed are not meant to imply *a priori* knowledge on the part of the researcher of the information-seeking activity of the participants in this study; instead, the discussion of information seeking models is included here to ensure the comprehensiveness and relevance of the literary framework that supports this study.

Although many models of information seeking exist in LIS research, this section discusses four models of information seeking that are oriented toward organizational settings so as to explicitly consider the information seeking models most relevant to this study. For example, Ellis, Cox, and Hall (1993) and Ellis and Haugan (1997) identified and compared the information seeking activities of academic researchers in the social and physical sciences and in engineering, discovering common characteristics of information seeking undertaken by academic researchers (e.g., "Starting," or the means by which an academic researcher begins the process of satisfying an information need). Meanwhile, Bystrom and Jarvelin (1995) explored task complexity and its effect on the information seeking and use of and by public administration workers, generating a model of information seeking that suggests a "systematic and logical" interdependence

between the complexity of tasks and the sources of information used to accomplish those tasks. In contrast, Leckie, Pettigrew [Fisher], and Sylvain (1996) analyzed empirical studies conducted on information-seeking behavior in order to derive a model of information seeking relevant to health care professionals, engineers, and lawyers, yet generalizable to "professionals in any field." Finally, Johnson [J. D.], Donohue, Atkin, and Johnson [S. H.] (1995) developed the Comprehensive Model of Information Seeking (CIMS) to explain information channel usage. The model was tested in health and organizational situations, and is organized around three categories of variables, i.e. "Antecedents," "Information Carrier Characteristics," and "Information Seeking Actions."

Health-Related Human Information Behavior

Health-related human information behavior is increasingly taking shape and form as an avenue of research within the entirety of LIS research devoted to human information behavior (Wilson 1997; Johnson 2003; Case 2008, p. 265). However, a survey of health information-seeking behavior studies by Lambert and Loiselle (2007) revealed that such behavior is difficult to conceptualize or operationalize. Meanwhile, the sheer volume of studies that focus on such behavior, including those that are external to LIS, seemingly numbers into the thousands. This fact cannot be understated; however, to include all of those studies here would be cumbersome for the reader. Therefore, because this study is based on human information behavior (which typically falls under the purview of LIS), and because this study emphasizes issues related to health and healthcare as it pertains to a hospice environment, relevant literature was surveyed and selected for inclusion based on one or two of two criteria: that a cited study is an empirical and grounded in LIS; or that it is an empirical study about health-related human information

behavior that specifically targets older adults *or* terminally ill people, since, statistically, they are most likely to potentially use or be using hospice services, respectively, and thus are direct or indirect beneficiaries of the information behavior of the overseer of the hospice care volunteer. This criteria for selection and inclusion ensured that as much relevant literature as possible is present so as to support and justify the rationale for this study without over-saturating the entire review with studies that fall outside LIS in general and health-related human information behavior specifically.

Health-related human information behavior in LIS has emerged in a variety of domains; these include *alternative medicine* (Owen & Fang 2001); *consumerism* (Baker & Pettigrew [Fisher] 1999; Khalil 2001; Detlefesen 2004; Abrahamson, Fisher, Turner, Durrance, Turner 2008; Harris, Henwood, Marshall, & Burdett 2010); *demographic characteristics* (Warner & Procaccino 2004; Hughes-Hassell, Hanson-Baldauf, & Burke 2008; Peña-Purcell 2008; Yoo & Robbins 2008); *diseases and genetics* (Huber & Cruz 2000; Johnson, Andrews, & Allard 2001); *library use* (Hughes-Hassell, Hanson-Baldauf, & Burke 2008; Xie & Bugg 2009; Harris, Henwood, Marshall, & Burdett 2010); *World Wide Web and Internet use* (Detlefsen 2004; Boissin & Docsi 2005; Meischke, Eisenberg, Rowe, & Cagle 2005; Hardt & Hollis-Sawyer 2007; McMillan & Macias 2008; Peña-Purcell 2008; Yoo & Robbins 2008; Chu, Huber, Mastel-Smith, & Cesario 2009; Taha, Sharit, & Czaja 2009; Xie & Bugg 2009); *healthcare professionals, workers, university faculty, and students* (Owen & Fang 2001; Bryant 2004; Andrews, Pearce, Ireson, & Love 2005; Boissin & Docsi 2005; Cooper & Urquhart 2005; Dee 2005; Korjonen-Close 2005; Landry 2006; McKnight 2006; Wallis 2006; Wessel, Tannery, & Epstein 2006; Jackson, Baird, Davis-Reynolds, Smith, Blackburn, & Allsebrook 2007; Nail-Chiwetalu 2007; Martinez-Silveira 2008; Hider, Griffin, Walker, & Coughlan 2009; Kloda &

Bartlett 2009); and *internationally* (Boissin & Docsi 2005; Mooko 2005; Leung, Ko, Chan, Chi, Chow 2007; Martinez-Silveira 2008; Garcia-Cosavalente, Wood, & Obregon 2010).

Meanwhile, the corpus of research of health information-seeking behavior of older adults continues to increase, a fact salient to this study given that in 2010, eighty-three percent of hospice care patients were age sixty-five and older (NHPCO 2011). Earlier studies of older adult health information behavior are centered primarily on topics such as the health information needs of retired women (see, e.g., Chatman 1992); how age affects older adults' use of health information (see, e.g., Wagner & Wagner 2003); and older adults' overall information-seeking behavior, including health (see, e.g., Wicks 2004). However, more recent literature has focused overwhelmingly on whether and the extent to which older adults' health information behavior involves use of the World Wide Web and the Internet (see, e.g., Meischke, Eisenberg, Rowe, & Cagle 2005; Hardt & Hollis-Sawyer 2007; Lwung, Ko, Chan, Chi, Chow 2007; McMillan & Macias 2008; Chu, Huber, Mastel-Smith, & Cesario 2009; Taha, Sharit, & Czaja 2009; Xie & Bugg 2009). Conversely, studies of the health information behavior of terminally-ill older adults are far fewer in number; those that do exist seemingly focus on these adults' need for information about a specific disease, typically cancer (see, e.g., Clayton, Butow, & Tattersall 2005; Innes & Payne 2009), as well as general end-of-life health information needs (see, e.g., Baker 2004).

Information Use

Fisher and Naumer (2006, p. 93) posit that human information behavior research historically focused on what were known as "use and user studies," i.e. those that focused on the use of information sources and users' demographic characteristics. However, information use currently

is considered by some to be a woefully under-studied aspect of information-seeking behavior (Vakkari 1997; 2008a), even while it has long been identified as a major component of the trifecta that typically characterizes human information behavior (i.e., need, seeking, and use), no matter the context in which that behavior occurs (see., e.g. Savolainen 2008, p. 3; Wang 2011, p. 15). Vakkari (2008a) bases his conclusion on human information behavior-related papers submitted to the Information Seeking in Conference (ISIC) biennial gathering: "In 1996 thirteen out of twenty-five studies dealt with use (52%), whereas in 2008 the figure was twelve out of thirty-four (35%). Thus, there is still room for studies with more focus on the use of information." Choo, Detlor, and Turnbull (2000) note that "information use as a concept has been difficult to define satisfactorily." Savolainen (2009) summarily concurs with both Vakkari (2008a) and Choo et al. (2000): "Information use is a generic concept that is frequently referred to but rarely explicated in the research literature" and "tends to remain as an unspecified 'appendix' of information seeking." Fidel (2012, p. 37) concludes that information use remains a difficult information-related behavior to study because use is a context-specific action that, as such, is not generalizable, "a highly-desired attribute of studies," and, additionally, is "work intensive and resource-demanding, which makes it heavily dependent on funding." However, Fidel (2012, p. 37) goes on to note that "Despite these obstacles, the number of LIS researchers who embark on use studies ... is climbing up steadily, if gradually."

Empirical studies in LIS that do focus on information use include those conducted by Bystrom and Jarvelin (1995), who examined whether and how task complexity affects information use; Bartlett and Toms (2005), who applied a task analysis method to explore how information was used to complete a work-related task; and Allard, Levine, and Tenopir (2009), who explored design engineers' and technical professionals' use of information in their workday

responsibilities. Savolainen (2006b) explored the relationship between information use and Dervin's sense-making methodology. Other information-related behavioral- and information use-based studies focus on the use of particular information source and channel types, most notably electronic journals, data sets, Web search engines, the Internet, information and communication technology (ICT), and specific use scenarios (e.g., development of a health system) (see, e.g., Bilal 2000; Mehra, Bishop, & Bazzell 2000; Bilal 2001; Bilal 2002; Bilal & Kirby 2002; Tenopir, King, Boyce, Grayson, Zhang, & Ebuen 2003; Tenopir, King, & Bush 2004; Tenopir, Wang, Pollard, Zhang, & Simmons 2004; Vakkari & Talja 2005; Mehra 2005; Tenopir, Sandusky, & Casado 2007a; Mehra & Papajohn 2007b; Tenopir, Baker, Read, Manoff, McClanahan, Nicholas, & King, 2007b; Vakkari 2008b).

Of particular relevance to the current study is the body of research that explores information use by applying the IUE. For example, Rosenbaum (1993; 1996) expanded the IUE framework in order to clarify the relationship between the IUE and information needs and uses of managers in a public sector organization. Agada (1999) studied the IUE of inner-city information gatekeepers and drew upon his findings to clarify the relationship between the IUE and information needs and uses. Koelker (2002) studied the IUE of academic library directors, while Durrance, Souden, Walker, and Fisher (2006) explored the IUE as a framework for community problem-solving and library best practices. Finally, Berryman (2008) explored how people in an IUE reached the point of satisficing.

Enablers of and Constraints to Health-Related Human Information Behavior

Library and information science (LIS) researchers have conducted a plethora of studies that simultaneously explore enablers of and constraints to human information behavior, particularly

in areas of information seeking and the constraints therein (see, e.g., Julien & Michels, 2004; Zach 2005; McKnight 2006; Slone 2007; Callen, J. L., Buyankhishig, B., & McIntosh J. H. 2008; Thompson, Talley, Caito, & Kreuter 2009; Connaway, Dickey, & Radford (2011). In keeping with the focused nature of locating research gaps that point to the need for this study, this section identifies those studies that focus on enablers and/or constraints that occur either in a health and/or organizational context (e.g., libraries).

With the exception of Khalil (2001), who studied sources of information that enables consumer health behavior; Bruce (2000), who describes information literacy research and those information organizations that enable literacy; Younger (2010), who found that the library typically is not considered by doctors and nurses to be an enabler of online information seeking; and Harris and Dewdney (2004), who explored abused women's access to information, the vast majority of human information behavior studies that occur within a health and/or organizational context focus on *both* enablers and constraints to that behavior. For example, Dervin and Nilan (1986), Walsh and Wilson (1995), and Wilson (1997) focused in part on enablers of and constraints to both information seeking and use. The Cognitive Work Analysis framework developed by Fidel and Pejtersen (2004) found that norms function as both constraints and enablers for information actions. Wathen and Harris (2006) studied enablers of and constraints to rural Canadian's women's access to health information sources, while Urqhart and Rowley (2007) focused on the enablers of and constraints to the use of electronic information services in the development of a toolkit helps academic libraries assess whether their digital library services are becoming more effective. Finally, Taylor (1986) conceptualized enablers and constraints as those elements that comprise "Setting" within an IUE; however, Taylor does not explicitly define general or exact enablers and constraints, thus intentionally or unintentionally providing a rich

opportunity for other researchers to, over time, identify and reflect upon the exact nature of those factors.

Chapter Summary

End-of-life care continues to be realized in the form of hospice care and is increasingly positioned at the forefront of health care as the nation finds itself aging rapidly. Hospice care has a distinct historical grounding founded upon a philosophy of volunteerism that has continuously informed its basic underpinnings, i.e. care and compassion for people who are in the final stages of life. Nevertheless, federal and state laws dictate how hospice care is conducted, which can present factors that both exploit and constrict hospice volunteerism. Moreover, although some research has been conducted on the hospice interdisciplinary team as a collective, little empirical research has been conducted specifically on the overseer of the volunteer in hospice care, other than those that formulate guidelines for volunteer retention, training, and recruitment. Research that does focus on aspects of volunteerism, e.g., training, form a loose collection which, while valuable and insightful, should be not only updated but also expanded to include the role of human information behavior in hospice volunteerism and whether and to what extent that behavior determines volunteer recruitment, training, and retention.

Meanwhile, although a small number of studies have explored the information needs of family caregivers and information sharing among members of the hospice interdisciplinary team, none were found to have explored the information behavior of the overseer of the volunteer, an aspect of the culture of hospice care volunteerism considered by this study to be crucial, given that volunteer recruitment, training, and retention are major outcomes of that behavior, with training identified in particular as how a volunteer is socialized into a hospice program (Seibold, Rossi, Berteotti, Soprych, & McQuillan 1987; NHPCO 2011). Use of information is of

particular concern to this study; as Savolainen (2009a; 2009b) argues, "… the ways in which people make use of information available in sources and channels has remained largely unresearched … the number of studies explicitly focusing on information use has remained fairly low compared to studies on information needs and seeking," an acute observation duly noted by other prominent LIS researchers, as well (e.g., Vakkari 2008a).

CHAPTER THREE: METHODOLOGY

Research Methodology

Many studies that examine health-related information behavior employ a variety of qualitative methods for collecting data (e.g., interviews and focus groups). Qualitative approaches are valuable in that their inductive nature reveals events, situations, and circumstances that could go unnoticed by deductive, quantitative research methods (e.g., surveys), achieving a *verstehen* of the research at hand (Ritzer 2010, p. 36). A qualitative approach to research also allows for flexibility during the research process, by which the researcher can make necessary changes to data collection (McCracken 1988, p. 63). As Wilson (1999) argues, "The general adoption of qualitative methods [in human information behavior] has resulted in work that is in the wider tradition of the investigation of human behaviour [sic] and which, therefore, is more likely to find theories and models in the social sciences that can be applied to the study of information behaviour [sic]."

As such, this study takes a grounded theory approach. Grounded theory calls for an inductive process by which new theory is generated upon exploration of the difference between people's objective realities and their interpretation of it. Accordingly, the grounded theory approach to research involves a "constant" comparison of incidents and their properties, followed by a delimiting of those properties into core categories from which (the grounded) theory is derived (Glaser & Strauss 1967). Grounded theory has been identified as an appropriate tool for studying organizational cultures (Glaser & Strauss 1967; Strauss & Corbin 2008, p. 57) and is found in a handful of health-related LIS studies. For example, Soto (1992) used grounded theory to analyze the information-seeking behavior of dental professionals, while McKnight (2006) used grounded theory to explore on-duty nurses' information behavior. Grounded theory also

has been identified as a major research approach in organizational studies (Locke 2001, pp. 6, 95).

Since its inception, grounded theory has taken one of two trajectories: researchers who collect and analyze data according to pre-defined coding strategies (see, e.g., Strauss & Corbin 2008, p. 160), and those that wait for coding strategies to emerge during data collection and as the analysis takes place (see, e.g., Glaser & Strauss 1967). This distinction is pointed out here if for no other reason than that it should be; however, given that there is support for and criticism of both approaches (see, e.g., Goldthorpe 2000), and since the pedagogical approaches that this researcher has experienced do not emphasize one approach over the other, this study borrows elements of both approaches (e.g., forming and building a rationale for the research based on prior studies while allowing for an open interpretation of the data).

Finally, it is relevant to point out that grounded theory is a particularly applicable (albeit coincidentally so) approach to this study in that Glaser and Strauss, its original developers, first conceptualized the grounded theory during their study of dying patients' awareness of their impending deaths (see Glaser & Strauss, 1965). Therefore, this study involving health-related information behavior as it occurs in end-of-life care is a particularly good fit for a qualitative approach, primarily because it provides what is presumed to be a first *emic* glimpse into the social practices of hospice care volunteerism, and the ways in which human information behavior is shaped and re-shaped by those social practices as they occur in this most intimate and poignant of healthcare settings.

The Participants

This study used a one-to-one, face-to-face, semi-structured, in-depth interview method to examine the information-seeking behavior of trainers of volunteer workers at hospices and the enablers and constraints of that behavior. The interview method permits in-depth discussions with participants and allows for the capturing of the thoughts, reasons, and motives that inform human information behavior (Wang 1999).

Twenty-one participants agreed to participate in this study; in total, forty-nine coordinators were approached and invited to participate. The final number of participants (i.e. twenty-one) was justifiable according to time and budgetary constraints of the research process and to the inductive nature of the research. In many interview studies, the number of interviews is approximately ten to twenty-five (Kvale 1996, p. 102). All participants are employed by a for-profit and state-licensed hospice agency in one of three geographic locations.

Thirteen coordinators (62%) were located in East Tennessee, while five coordinators (24%) were located in northern Georgia and three coordinators (14%) were located in western North Carolina. All participants are paid professionals in a hospice care setting, and all twenty-one (100%) are overseers of volunteers, although four of the twenty-one assume other roles, i.e. two are also their respective agencies' chaplains, and two more are their respective agencies' bereavement counselors. The average length of time spent as a coordinator of volunteers, and external of other positions possibly held by the coordinator, is seven years.

Potential participants were chosen based on three criteria: that they were located in a licensed hospice care organization within the designated geographic area; that they acted in the capacity of an overseer of volunteers (if even they were not officially titled as such); and that they worked for a hospice care organization different from a previously-contacted participant. This last

criterion was particularly necessary, since an interview conducted with more than one participant who worked for the same organization, even if in a different geographic location, would potentially yield answers in interviews that would be so similar as to take away from this researcher's potential to make meaningful comparisons of the nature of human information behaviors amongst the participants.

Participants were located from individual hospice care agencies by obtaining state government lists of licensed hospice care agencies, as well as state maps that showed county lines, and making lists of each licensed hospice care agency in the designated areas. All potential participants were contacted by telephone. The nature and purpose of the research was briefly but comprehensively explained, as was the estimated time participation would involve (i.e., one hour, which was phrased as "sixty minutes" based on a pilot study of that length of time and in order to encourage participation as much as possible), after which the researcher inquired of the coordinator whether he or she would like to participate. Approximately thirty trainers expressed interest or tentative interest in participating; of those, approximately twenty-five trainers were then mailed a copy of the pilot-study-revised discussion guide (see Appendix A) and a copy of the Institutional Review Board's (IRB) letter of permission to conduct the research. Potential participants who seemed distinctly hesitant to participate were not mailed a discussion guide and letter of permission. A total of twenty-one coordinators agreed to participate, with one of those agreeing to participate prior to seeing the aforementioned documentation (although the documentation was presented to and accepted by that participant prior to the interview).

Of twenty-one participants, four were male and seventeen were female. Although a participant's sex is not part of the final analysis of the data, it is an interesting factor to note, as it

verifies previous studies' findings by the Bureau of Labor Statistics of the U.S. Department of Labor (BLS), which reports that the culture of volunteerism tends to be populated more prevalently by women than by men (2012). In all but three of the twenty-one instances of participation, the participant (n=18/86%) sought permission from his or her supervisor(s) to participate in the study. Permission took anywhere from two weeks to three months to be granted, and sometimes involved the participant asking permission from more than one person, which lengthened the recruitment process. Meanwhile, permission from the IRB, while a requirement for the researcher, was a valuable piece of information in recruiting participants, as it helped demonstrate that the researcher's primary stake in collecting data was for purposes of the dissertation (and not government- or business-related purposes, which, as was noted by a handful of participants, could be viewed with a certain level of guardedness where private hospice care companies are concerned).

Research Instrument

The instrument for data collection adapted the critical incident technique (CIT), which provides a set of procedures for collecting instances of memorable experiences. Traditionally, the CIT is defined as a set of procedures for collecting direct observations of human behavior to facilitate their potential usefulness in solving practical problems (Flanagan 1954). CIT information-seeking behavior studies frequently appear in health-related research (see, e.g., Wood, Palmer & Wright 1996; Davies, Urquhart, & Massiter et al. 1997) and in LIS research that takes place in a medical context (see, e.g., Tenopir, King, & Bush 2004). These studies typically focus on individual users as free agents (Urquhart, Light, & Thomas et al. 2003),

whereas Lamb and Kling (2003) argue for a conceptualization of users as social actors that are influenced by organizational contexts in matters of routine information seeking.

Application of the CIT in this study is based loosely on the time-line approach used in Dervin's sense-making research, in which participants recall the details of an incident in a step-by-step process (1983). Concurrently, to be considered "critical," the incident must be memorable enough to be recalled in as much detail as possible. As such, the CIT is a suitable technique for this study for several reasons. As a qualitative method, it provides a flexible context in which the participant will be able to speak freely and candidly about his or her information-related behavior. Additionally, the CIT provides an underlying structure in which to understand the criticality of circumstances and situations that motivated the participant to seek information by providing a context in which a need for information arises. Moreover, the CIT emphasizes an incident rather than an opinion by asking participants to identify a specific incident they experienced. Finally, and particularly relevant to this study, health-related information behavior studies that contain a service or care quality have increasingly used the CIT to determine positive and negative perceptions of that service or care (Urquhart, Light, Barker & et al. 2003).

Pilot Study

In 2010, a pilot study was conducted to determine whether the critical incident technique was an appropriate method for data collection. The participant who engaged in the pilot study is a hospice volunteer coordinator, chaplain, and team assistant in a licensed hospice care organization in East Tennessee. The pilot study was conducted in the participant's office, and an interview protocol was used to guide the discussion. The interview lasted approximately ninety

minutes; the participant was affable and talkative, and the researcher asked prompting questions when the participant broached points not previously considered by the researcher when the interview guide for the pilot study was under development. The interview was audio-recorded, and the researcher periodically wrote memo notes when a seemingly salient point was made by the participant.

One pilot study was a justifiable number for testing the discussion guide in that interview-based qualitative data collection and analysis is a progressive process and thus makes every interview, by definition, a piloted study (van Teijlingen & Hundley 2001), which, it should be noted, has prompted some researchers to argue that piloted studies are entirely unnecessary in qualitative research (see, e.g., Holloway 1997, p. 17). Despite the variability of opinions within the research community about the usefulness and necessity of pilot studies in qualitative research, the researcher's lack of extensive experience in making "cold" calls to recruit participants; in designing an appropriate discussion guide; in collecting data using the interview technique; and in coding and analyzing qualitative data prompted the researcher to conduct one pilot study, the results of which are included in the final analysis of data.

The pilot study also was used to elicit a consistent framework for the data coding and analysis of subsequent interviews. A notable facet of structuration theory is that it is not intended by Giddens to be a testable theory, but rather, to be a sensitizing device by which researchers can think about research problems and interpret the results (Giddens 1984, pp. 326-327). As Blumer (1954) argues, " . . . A sensitizing concept lacks … specification of attributes or bench marks … it gives the user a general sense of reference and guidance in approaching empirical instances ... [and] merely suggest directions along which to look." Therefore, this study follows Rosenbaum's prescription for binding the IUE to structuration theory by drawing upon

structuration theory as a sensitizing device for data analysis by which to identify the rules (legitimation) and resources (domination) that enable and constrain the information behavior of the overseer of the volunteer in hospice care.

Data collected from the pilot study was coded using the software program QDA Miner version 4.0. The software was chosen because it is designed for analyzing qualitative data (e.g., open-ended interview data) and is available for free from The University of Tennessee, thus meeting the budget constraints of the researcher. The pilot interview was transcribed by hand by the researcher into a Microsoft Word document, which was then imported into the software program (although subsequent interviews were transcribed directly into the program, since, by then, the researcher had become more familiar with the capabilities of the software, e.g., being able to transcribe directly into the program).

Once the pilot study was successfully imported into the program, the researcher began to analyze the pilot study by conducting open-coding of the data so as to reflect upon what the data might indicate, in keeping with the grounded theory approach to qualitative research (Strauss & Corbin 2008, p. 163). Open-coding is the first step of data analysis in grounded theory (Corbin & Strauss 2008, p. 195), in which categories of raw data are created and named; simultaneously, these concepts are qualified by the researcher according to their properties and dimensions, with researcher memos and notes attached to the categories in order to accomplish the qualification process (Corbin & Strauss, 2008, p. 195).

The QDA Miner program provides an entire spectrum of colors to use for coding data and for adding reflective memos. The researcher chose colors that were distinct enough so as to not blend in any way and thus would reveal categories that occurred in the same segment as explicitly as possible. Categories initially emerged according to single words, phrases, and

segments of data that explicitly identified a word or phrase from a research question (e.g., a passage of data that contained the words "need" or "needed" was coded as "Information Need," and placed with all similarly-coded passages in the pilot study under the category name Information Need). An unfortunate drawback of Version 4 of the QDA Miner program is that it does not allow for capturing screen shots of coded data beyond what is highlighted, i.e. of coding as it occurs in the margin of the document, as well as accompanying researcher memos, both of which the researcher had hoped to include here.

Once open-coding of the data was accomplished, the researcher then began axial coding of the data, or comparing categories and identifying relationships among them using memos within the margins of coded text. The results of the pilot study indicated that although none of the questions in the interview protocol needed to be altered or deleted, three questions needed to be added (and were): 1) Can you describe the hospice team?; 2) What steps do you take to recruit volunteers?; and 3) What steps do you take to retain volunteers? These questions were added so as to gain a deeper understanding of the social structure of the hospice care under exploration for this study and to ascertain a basic understanding of the coordinator as a member of a set of professionals, or "People," as called for by the IUE.

Collection of Data

The interview method is aligned with the naturalistic paradigm in qualitative research, which aims to seek understanding and truth about the empirical world as seen by those who navigate within it (Lincoln & Guba 1985, p. 14). Moreover, a qualitative approach to research allows for research to be conducted in the natural setting (e.g., workplace) of the participant, thus enabling the researcher to be involved in the actual experience of the participant (Creswell 2003, p. 181).

As such, qualitative research captures the *emic* view of the participant, i.e. the participant is able to describe a particular setting according to his or her own frame of reference (Punch, 2004 p. 149: Singleton & Straits 2005, p. 307). The researcher gained firsthand access into the environment under exploration (Lincoln & Guba 1985, p. 269) by asking open-ended questions of the participant (Foddy 1993, p. 126).

Twenty-one participants were targeted and successfully accessed for the research at hand. Interviews took place in the participants' offices at their respective hospice care agencies, and all interviews were, by permission of their respective participants, audio-recorded. The offices were private, and the participants kept their office doors closed during their interviews. Prior to each interview, each participant signed an informed consent statement and was made aware of the researcher's copy of relevant HIPAA regulations at hand, although none of the referred to the regulations during their interviews. None of the interviews were interrupted by anyone else who was present at the agencies, although other people (at least some of whom were, presumably, members of the interdisciplinary team) were observed by the researcher within the vicinity of the participant's office. Hand-written notes were taken during each interview, also by permission of each participant.

Each interview was conducted according to an interview protocol. The participant was asked to describe his or her work profile (e.g., length of time spent as overseer of the volunteer); a memorable episode in which he or she recognized a need for information; the way(s) in which he or she sought information; the way(s) in which he or she used information; and the enabler(s) of his or her seeking and use of information. Other than the question "What problems do you encounter when looking for information?", inquiring about constraints to seeking and use was purposely avoided, since it is the unintended consequences of knowledgeable actors that, in part,

constrain and therefore produce and reproduce structure, and thus are not identifiable by those actors (Giddens 1984, pp. 10-11).

The interviews lasted anywhere from forty-five minutes to ninety minutes. Although the majority of participants discussed one critical incident, three participants discussed more than one critical incident. Where deemed necessary and appropriate during the interview, prompting questions were asked by the researcher, none of which any of the participants declined to answer. After the completion of each interview, the participant sent thank-you notes with enclosed bookmarks purchased at a local bookstore. Each interview was transcribed no more than within two days of its occurrence.

Analysis of Data

Data was analyzed according to the framework developed from the pilot study. However, as is the nature of qualitative research, new themes emerged from each interview, with hints of redundancy first noticed by the researcher at the fourteenth interview; redundancy emerged strongly by the eighteenth interview, yet three more interviews were conducted, since those three participants had expressed initial interest in being interviewed. Data was similarly coded and analyzed as it was in the pilot study: open coding followed by axial coding, with memos written in the margins of the transcripts, bearing in mind the sensitizing concepts revealed by the tenets of structuration theory, i.e. rules and resources.

Each participant and the transcript of his or her interview were assigned an ordinal number in order to demarcate each interview. For example, the pilot study participant was designated as "Participant One" by the researcher on the audiotape and the accompanying interview transcript as "P1," since the results of the pilot study are included in the final analysis. The second

participant was designated as "Participant Two" on the audiotape and the accompanying transcript of that interview as "P2," and so on. Additionally, a co-worker of the researcher agreed to code a passage of data from an interview chosen at random by the interviewer (but without the ordinal number of identification) so as to determine how closely aligned the researcher's category labels were to the actual data. A component of Version 4 of the QDA Miner program allows for inter-coder agreement; accordingly, the researcher uploaded her co-worker's analysis into the QDA Miner program, and the result was an eighty-two percent agreement between the researcher and her co-worker.

The researcher also engaged in member-checking as much as possible. Member-checking allows for the participants to provide feedback on the researcher's interpretation of the data; can help in identifying researcher bias; and allows for the collection of additional data if needed (Lincoln & Guba 1985, pp. 314-316). Attempts were made by the researcher to contact all twenty-one participants to verify or suggest changes to the researcher's interpretation of the data. Eighteen participants were successfully located; of the three that could not be reached, one was on a month-long vacation, the other had re-located to another (unidentified) state, and the third did not return the researcher's call. The eighteen participants who were located were in agreement that the data had been correctly analyzed according to their responses in the interviews.

CHAPTER FOUR: FINDINGS AND DISCUSSION

Chapter Overview

The first section of this chapter describes the results for Research Question 1, which identifies the overseer of a volunteer in a hospice care setting, along with the overseer's work profile. The second section provides results for Research Question 2, which identifies the information need(s) of the overseer. The third section describes the results for Research Question 3 and how the overseer seeks information, while section four presents the results of Research Question 4 and the ways in which the overseer uses information. The fifth section describes the results for Research Question 5, which explores those elements which enables the overseer's information seeking and use behavior, and the sixth and final section provides the results for Research Question 6 and the constraints to the overseer's information seeking and use behavior.

Research Question 1: The Overseer of the Volunteer in Hospice Care

The overseer of the volunteer in hospice care is known by more than one title and can fulfill one or more additional roles that are external of responsibility to the volunteer. Moreover, some of those who oversee the volunteers have work roles wherein volunteer oversight is secondary to those roles. Table 1a provides a detailed summary of the titles of each participant, his or her length of employment, the number of patients receiving volunteer services from the participant's respective hospice agency at the time of each interview, and the number of volunteers under the direct supervision of each participant at the time of the interview; averages for length of employment, number of patients, and number of patients also are included in Table 1A.

According to the participants in this study, the overseer of the volunteer in hospice care is known as "chaplain," "bereavement counselor," "volunteer coordinator," "volunteer services

TABLE 1A. THE HOSPICE VOLUNTEER COORDINATOR: ORGANIZATIONAL PROFILE

Participant	Primary Role in the Hospice Agency	Other Role in the Hospice Agency	Length of Employment (in years)	No. of Patients	No. of Volunteers
1	Chaplain	Vol. Coord./Team Assist.	2.5	9	8
2	Volunteer Coordinator		3	67	29
3	Volunteer Services Coordinator		25	250	350
4	Bereavement Counselor	Volunteer Coordinator	6	80	55
5	Volunteer Coordinator		.5	50	38
6	Volunteer Coordinator		5	102	52
7	Volunteer Coordinator		2	55	30
8	Volunteer Coordinator		10	54	27
9	Volunteer Coordinator		7.5	125	100
10	Volunteer Coordinator		1	120	80
11	Chaplain	Volunteer Coordinator	5	62	45
12	Volunteer Coordinator		13	130	110
13	Volunteer Coordinator		4	25	15
14	Volunteer Coordinator		5	64	43
15	Bereavement Counselor	Volunteer Coordinator	5	30	55
16	Volunteer Manager		1	68	44
17	Volunteer Coordinator		17	270	230
18	Volunteer Coordinator		10	200	105
19	Volunteer Coordinator		6	78	60
20	Volunteer Coordinator		2.5	57	32
21	Volunteer Coordinator		19	42	30
Total	--	--	--	1938	1538
--	--	--	7	92	73

coordinator," or "volunteer manager." Sixteen of twenty-one participants identified as "volunteer coordinator"; therefore, for brevity, the overseer of the volunteer hereafter is known as "coordinator" where possible and appropriate. Four of the twenty-one coordinators also fulfill other roles, with two as chaplains and two as bereavement counselors as their primary roles, and the coordinators have fulfilled the role of coordinator for an average of seven years. (The words "coordinator" and "participant" are used interchangeably throughout the remainder of this report, depending on which term is applicable to the topic under discussion).

The average number of patients in a coordinator's hospice care agency at the time of his or her interview for this study was ninety-two, with the most patients numbered at two-hundred seventy and the fewest at nine; ninety-two falls within the range of the average number of patients in thirty percent of all hospice care agencies, but is slightly lower than the current mean number of *daily* patients in all hospice care agencies, which is 117 patients (NHPCO 2011). Meanwhile, the average number of volunteers under the direct supervision of a coordinator at the time of his or her interview for this study was seventy-three, with the most numbering three-hundred fifty and the fewest at eight.

Fourteen of the coordinators expressed the number of patients and volunteers using qualifiers such as "about," "approximately," and "I think we have 'x' number of [patients, volunteers]," but the numbers given were taken to be exact and were recorded and averaged accordingly, as the researcher was trying to obtain merely a basic, general picture of the numbers of patients and volunteers that coordinators, as sets of people in an information use environment, might manage in the typical day-to-day course of his or her responsibilities.

The interviews also revealed that the coordinator employs a variety of methods and venues, hereafter known as "methods," for recruiting and retaining the volunteer. The coordinators in

this study use a combined total of thirteen methods for recruiting a volunteer, with a standard invitation on a hospice agency's website the primary method for recruitment by twelve coordinators (57%), and "nursing school" and "public service announcement" the least used methods (mentioned by two of the coordinators, or 10% of coordinators for both methods). The methods and percentages of the use of each method and venue of recruitment are detailed in Table 1B.

Concomitantly, the coordinator uses at least thirteen methods by which to retain a volunteer, most notably through the hospice agency's training program (mentioned by sixteen coordinators, or 76%), with an Ambassador-of-the-Month program and "help volunteers find 'gladness'" mentioned the least, by one coordinator, or 5%). Table 1C provides a summary of retention methods and the percentage of the use of each.

Finally, the coordinator is part of a hospice care interdisciplinary team (hereafter, "team") that serves the physical, emotional, and spiritual needs of a patient receiving hospice care, as well as the emotional and spiritual needs of a patient's family. Particularly in geriatric populations, an interdisciplinary approach entails members of a team working together to develop and implement goals and a common plan of care while maintaining individual professional roles and responsibilities (USDHHS n.d.). Table 1D details the members of the hospice team.

All twenty-one coordinators in this study mentioned chaplain/spiritual advisor, doctor or medical director, RN/nurse, and social worker as part of their respective teams. These four members of the team are required by Medicare hospice conditions of participation (COP) by hospice care agencies (USDHHS 2005). As one participant confirmed, "Medicare requires four people. Medicare requires a doctor, who is the medical director, it requires a chaplain, it requires

TABLE 1B. VOLUNTEER RECRUITMENT METHODS

Method/Venue	Number of Participants	Percentage of Use of Method/Venue
agency website invitation	12	57
health fair	8	38
general volunteer opportunity website	7	33
church	6	29
bereavement program	4	19
community fundraising	4	19
public interest (telephone calls to agency)	4	19
United Way	4	19
flier	3	14
medical school workshop	3	14
senior center	3	14
nursing school workshop	2	10
public service announcement	2	10
--	--	--

TABLE 1C. VOLUNTEER RETENTION METHODS

Method/Venue	Number of Participants	Percentage of Participants
training program	16	76
support meeting	13	62
continuing education	9	43
monthly in-service meeting	9	43
annual recognition gathering	5	24
annual cost savings report	4	19
good match between patient and volunteer	4	19
help volunteers understand what they're doing	4	19
individual acknowledgement	3	14
one-on-one "pep" talks	2	10
watch for patient overload	2	10
Ambassador-of-the-Month program	1	5
" …help volunteers find 'gladness'"	1	5
--	--	--

TABLE 1D. HOSPICE TEAM

Hospice Team Role	Number of Participants	Percentage of Participants
Chaplain/Spiritual Advisor	21	100
Doctor/Medical Director	21	100
Nurse/Registered Nurse	21	100
Social Worker	21	100
Bereavement Counselor/Coordinator	12	57
Nursing Assistant	12	57
Volunteer	9	43
Team Leader	6	29
Assistant Team Leader	5	24
Case Manager	5	24
Director of Nurses	5	24
Office Manager	5	24
Dietician	4	19
Paramedic Registered Nurse	4	19
Admissions Nurse	3	14
Volunteer Coordinator	3	14
Office Manager Assistant	2	10
Financial Person	1	5
--	--	--

a social worker, and we also have a nurse. Those four people are required for a hospice team. You cannot have a hospice team without those four people."

Various other hospice agency team members also were noted by the participants, e.g. team leader and paramedic registered nurse (PRN), but, apart from the required team members, participants did not necessarily mention the exact same members as part of the coordinators' respective teams. For example, three participants mentioned themselves as part of the team ("coordinator"), while nine participants noted that volunteers were members of the team.

Research Question 2: Information Needs of the Overseer

The coordinator experiences a variety of information needs as part of his or job responsibilities. Seven major categories of need emerged from analysis of the interviews: Death; Disease/Disease-Related; Family; Patient/Patient-Related; Regulations/Standards; Technology; and Volunteer/Volunteer-Related. Analysis of the interviews also revealed twenty-eight total incidents of information need that emerged collectively among the coordinators, with three of the twenty-one coordinators discussing more than one need. Table 2 outlines each category of the coordinator's information need, the information needs from which need categories were derived, and the total number of incidents of need for each category.

The information needs of the coordinator reside primarily under the category "Disease/Disease-Related." Analysis of the interview revealed ten information needs that fell into this category. The category is defined as needs relating to a particular disease or those entities relating to disease in general (e.g., effects, prognosis, and/or trends). Each need was discussed once, and included "dementia," "pain management," "statistics," and "trends." The second primary need was "Volunteer/Volunteer-Related," which is defined as needs relating directly to the volunteers. Six of these types of needs were discussed. They also were mentioned only once each, and included "motives," "orientation," and "skills." The least-discussed categories of need were "Death" and "Family," and included "different religious views" and "general volunteer services needed," respectively.

Research Question 3: Information Seeking by the Overseer

In order to satisfy one or more of twenty-eight information needs, coordinators draw upon three major categories of seeking behavior encompassing fifty-four instances of seeking

TABLE 2. INFORMATION NEEDS

Need Category/Need	Number of Needs	Total
Death		1
Different religious views	1	
Disease/Disease-Related		10
ALS (Lou Gehrig's disease)	1	
Lewy's Bodies	1	
dimentia	1	
unnamed (disease)	1	
diagnosis	1	
effects	1	
pain management	1	
prognosis	1	
statistics	1	
trends	1	
Family		1
general volunteer services needed	1	
Patient/Patient-Related		4
general volunteer services needed	1	
home environment	2	
medications	1	
Regulations		4
new Medicare guidelines	2	
volunteer recruitment	1	
pet therapy	1	
Technology		2
software	2	
Volunteer/Volunteer-Related		6
aspirations	1	
best way to communicate with	1	
motives	1	
orientation	1	
orientation training materials content	1	
requirement	1	
skills		
Total Number of Incidents of Needs	28	28

information: “Consult,” “Explore/Listen in,” and “Monitor.” In keeping with the naturalistic approach to this study, the categories of information seeking were named according to their emic descriptions. Table 3 maps each of the three categories of seeking behavior to their respective need categories.

The most-often cited category of information seeking was “Consult,” with forty-six instances of this type of seeking distributed among the seven categories of information need. This finding confirms Taylor’s (1991) notion of *access* to information within the information use environment (IUE), wherein the belief is held that “… personal dialogue will help to clarify need and response, and … provide more useful information.” Fourteen instances of this seeking category occurred under the need category “Patient/Patient-Related,” followed by ten instances of seeking within the information need category “Disease/Disease-Related,” and eight instances of seeking within the information need category “Volunteer/Volunteer-Related.” “Consult” involved direct verbal communication with or consultation of either people (e.g. doctors and nurses) or objects (e.g., Websites and medical books), although people and objects often were interchangeably used. As one participant noted when she discussed seeking information about a type of dementia known as Lewy’s bodies,

> “Before I went to the Internet, I consulted with the doctor about what good websites would be. Then I went to a [Web]site to see what was here, and then I asked the nurses, since they see disease play out practically. I always try to determine the best information before I hand it to the volunteer like it's gospel.”

Conversely, “Explore/listen in” is defined as information seeking that occurred when the coordinator was uncertain about whether the source of information would satisfy his or her information need. In all, seven instances of information seeking emerged from this category; these included a health fair, a patient’s home environment, and company volunteer training

TABLE 3. INFORMATION-SEEKING ACTIVITY

Information Need	Corresponding Seeking Behavior	Seeking Behavior Category and Total Instances of Each
ALS (Lou Gehrig's disease)	ask doctor; go to nurse; go to website	Consult (Person/Resource) (n=46)
best way to communicate with volunteer	ask former coordinator ; ask volunteer	
different religious views about death	go to Internet	
dementia	go to Alzheimer's website; ask nurse	
disease (effects)	go to doctor; ask nurse	
disease (general)	ask doctor; go to nurse; go to Merck manual; go to websites	
	ask doctor; ask nurse	
Lewy's bodies	ask doctor; go to nurse; consult Merck manual	
medication	call other coordinators; ask hospice team	
new Medicare guidelines	ask doctor; ask nurse; go to nurse's assistant	
pain management	ask doctor; ask nurse; ask director of nursing	
patient diagnosis	call admissions nurse; call activities director	
pet therapy	ask doctor; ask nurse	
prognosis	consult hospice team	
software (record patient information)	go to information systems team	
software (record volunteer hours)	ask volunteer; look at volunteer application	
volunteer aspirations	ask volunteer	
volunteer motives	go to volunteer training manual; go to videos	
volunteer orientation	ask former coordinator	
volunteer orientation training materials content requirement	ask family	
volunteer services (family)	ask patient; ask family; go to social worker	
volunteer services (patient)	ask volunteer; see volunteer application	
home environment	explore home environment	Explore/Listen In (n=7)
home environment	explore home environment	
	explore neighborhood; listen in to team meetings	
new Medicare guidelines	check out church; check out health fair; check out senior	
volunteer recruitment	center	
disease statistics	monitor websites	Monitor (n=2)
disease trends	"keep an eye on" websites	
Total 28	**54**	**3**

videos. Finally, "Monitor" is defined as a routine examination of a particular piece of knowledge or type of information source in trying to resolve an information need. Two instances of information seeking occurred in this category; these were "disease statistics" and "disease trends."

Research Question 4: Information Use by the Overseer

Seven categories of use emerged from the interviews, described emically as follows: "Communicate with Volunteer," "Follow Hospice Agency Standards," "Follow Regulations," "Make Good Match Between Volunteer and Patient," "Satisfy Patient Request," "Satisfy Personal Curiosity," and "Stay Informed." Among these categories, sixty-three instances of use emerged. Table 4A outlines the seven categories of use and their corresponding information needs and information-seeking behavior.

Since the categories of use also describe instances of actual use or closely resemble those descriptions, and since four of the original fifty-five instances of information seeking ("ALS [Lou Gehrig's disease]," "disease effects," "volunteer orientation training materials content requirement," and "volunteer services [family])" resulted in two instance of use (with the remaining needs and their corresponding seeking behavior resulting in one use each), use is described only at the categorical level so as to present a basic framework of use and to make a clear comparison with Taylor's typology of eight categories of information use that occur within the IUE. Taylor's eight categories of use and their descriptions are as follows:

Category 1: Enlightenment (user needs more contextual information)
Category 2: Problem Understanding (user has answerable questions)
Category 3: Instrumental (instructions)
Category 4: Factual (need for and subsequent provision of data)
Category 5: Confirmational (to obtain a second opinion)
Category 6: Projective (future estimates and probabilities)
Category 7: Motivational (getting started)
Category 8: Personal or Political (situations are under control)

TABLE 4A. INFORMATION USE

Information Need	Corresponding Seeking Behavior	Use
ALS (Lou Gehrig's disease)	ask doctor; go to nurse; go to website	Communicate with Volunteer
best way to communicate with volunteer	ask volunteer; ask former coordinator	
disease (effects)	go to doctor; ask nurse	
pain management	ask doctor; ask nurse; go to nurse's assistant	
patient diagnosis	ask doctor; ask nurse; ask director of nursing	
prognosis	ask doctor; ask nurse	
home environment	explore home environment	
home environment	explore home environment	
	explore neighborhood	
new Medicare guidelines	listen in to team meetings	Follow Hospice Agency Standards
software (record patient information)	consult hospice team	
volunteer orientation training materials content requirement	ask former coordinator	
volunteer recruitment	check out church, check out health fair, check out senior center	
new Medicare guidelines	call other coordinators, ask hospice team	Follow Regulations
software (record volunteer hours)	go to information systems team	
volunteer recruitment	check out church; check out health fair; check out senior center	
volunteer services (family)	ask family	Make Good Match Between Volunteer and Patient
volunteer aspirations	ask volunteer; look at volunteer application	
volunteer motives	ask volunteer	
volunteer services (family)	ask family	
volunteer services (patient)	ask patient; ask family; go to social worker	
volunteer skills	ask volunteer; see volunteer application	

TABLE 4A. INFORMATION USE, cont.

Information Need	Corresponding Seeking Behavior	Use
pet therapy	call admissions nurse; call activities director	Satisfy Patient Request
disease statistics disease trends	monitor websites "keep an eye on" websites	Satisfy Personal Curiosity
ALS (Lou Gehrig's disease) different religious beliefs about death dementia disease (general) disease (general) Lewy's bodies medication new Medicare guidelines	ask doctor; go to nurse; go to websites go to Internet ask nurse; go to Alzheimer's website go to doctor; ask nurse ask doctor; go to nurse; go to Merck manual; go to websites ask doctor; ask nurse ask doctor; go to nurse; consult Merck manual call other coordinators; ask hospice team	Stay Informed
volunteer orientation volunteer orientation training materials content requirement	go to volunteer training manual; go to videos ask former coordinator	Train Volunteer
-	63	7

Table 4B compares the categories of use found by this study to Taylor's categories of use. All eight categories of information use that emerged from this study correspond at least once into one of eight categories of use in Taylor's typology, confirming the comprehensive nature of Taylor's categories of use.

Research Question 5: Enabler(s) of the Overseer's Information Behavior

The coordinator draws upon and utilizes a variety of rules and resources by which to seek and use information. According to Giddens, rules and resources are properties of social systems, conjoined and interwoven into the social practices that comprise social systems (Giddens 1976, p 124). Both rules and resources are drawn upon as a means of production and reproduction of a social system; a rule is a social norm that sanctions or disapproves of social interaction, while, concomitantly, a resource is a material object that allows for command, i.e. power over people (Giddens 1976, p. 127).

In this study, information-seeking behavior is undertaken according to rules, which are morally-or procedurally-oriented, as called for by Giddens; however, because of the qualitative nature of this study, the definition of moral and procedural rules are limited to emic descriptions coded in the data (as are allocative and authoritative resources). For example, the phrase "I usually will go to more than one [web]site" did not indicate that the participant was compelled to go to more than one website, whereas procedural rules, for example, did contain compulsory language (e.g., "I have to ask about who in the family lives in the house so I can see if there are multiple caregivers and where the greatest need is in terms of a volunteer").

Accordingly, moral rules inform seeking and use activities that are not required by bureaucratic (i.e. civil law) or corporate law or policy but that nevertheless are undertaken by the

TABLE 4B. INFORMATION USE AND TAYLOR'S TYPOLOGY

Use Categories	Taylor's Typology
Make Good Match Between Volunteer and Patient	1. Enlightenment (user needs more contextual information)
Communicate with Volunteer; Train Volunteer	2. Problem Understanding (user has answerable questions)
Follow Hospice Agency Standards; Follow Regulations	3. Instrumental (to follow instructions)
Make Good Match Between Volunteer and Patient; Satisfy Patient Request	4. Factual (need for and subsequent provision of data)
Satisfy Patient Request	5. Confirmational (to obtain a second opinion)
Make Good Match Between Volunteer and Patient	6. Projective (future estimates and probabilities)
Satisfy Personal Curiosity	7. Motivational (getting started)
Stay Informed	8. Personal or Political (situations are under control)
--	--

coordinator as a matter of doing what he or she feels is ethically correct (e.g., staying informed about disease trends or disease statistics); whereas procedural rules inform seeking and use activities that reflect bureaucratic law or corporate policy (e.g., "We needed accuracy in documenting the volunteers' hours ... because of federal and state regulations"). This study found twenty-one moral rules and thirty-two procedural rules that enable fifty-three of fifty-four instances of information-seeking activity. Table 5A provides details of seeking behavior and its classification as either a moral or procedural rule.

Similarly, allocative and authoritative resources enable the coordinator's information-seeking behavior. This study identified five types of allocative resources and twenty-three types of authoritative resources that enable the coordinator's information-seeking behavior, with "website" the chief allocative resource enabler and "nurse" the primary authoritative resource enabler. Nevertheless, the doctor and the nurse are not necessarily considered best source of information. As one participant stated, "I try to get information from the nurses or a medical director … But sometimes the information from the nurse or the medical director isn't as specific as what I need, which the Internet can be good for." Table 5B outlines allocative and authoritative resources according to their corresponding seeking behaviors.

Meanwhile, rules and resources also enable information use. Of the eight categories of use in this study, four categories of use (Communicate with Volunteer, Make Good Match between Volunteer and Patient, Satisfy Personal Curiosity, and Stay Informed) are enabled by moral rules, while five categories of use (Communicate with Volunteer, Follow Hospice Agency Standards, Follow Regulations, Satisfy Patient Request, and Train Volunteer) are enabled by

TABLE 5A. INFORMATION-SEEKING ENABLERS: MORAL RULES AND PROCEDURAL RULES

Information Need	Corresponding Seeking Behavior	Moral Rule	Procedural Rule
ALS (Lou Gehrig's disease)	go to website; ask doctor; go to nurse	✓	✓✓
best way to communicate with volunteer	ask former coordinator; ask volunteer	✓	✓
different religious beliefs about death	go to Internet	✓	
dementia	go to Alzheimer's website; ask nurse	✓	✓
disease (effects)	go to doctor; ask nurse		✓✓
disease (general)	go to Merck manual; go to websites; ask doctor; go to nurse	✓✓	✓✓
disease statistics	monitor websites	✓	
disease trends	"keep an eye on" websites	✓	
home environment	explore home environment		✓
home environment	explore neighborhood; explore home environment		✓✓
Lewy's bodies	ask doctor; ask nurse	✓	
medication	consult Merck manual; ask doctor; go to nurse	✓✓	
new Medicare guidelines	listen in to team meetings	✓	✓✓
new Medicare guidelines	call other coordinators; ask hospice team		✓
pain management	go to nurse's assistant; ask doctor; ask nurse	✓	✓
patient diagnosis	ask director of nursing; ask doctor; ask nurse	✓	✓✓
pet therapy	call activities director	✓	✓✓
prognosis	ask doctor; ask nurse		✓
software (record patient information)	consult hospice team		✓✓
software (record volunteer hours)	go to information systems team		✓
volunteer aspirations	ask volunteer; look at volunteer application		✓
volunteer motives	ask volunteer	✓	✓
volunteer orientation	go to volunteer training manual; go to videos		✓
volunteer orientation training materials content requirement	ask former coordinator		✓
volunteer recruitment	check out church; check out health fair; check out senior center	✓	
volunteer services (family)	ask family	✓✓✓	
volunteer services (patient)	ask patient; ask family; go to social worker		✓
volunteer skills	ask volunteer; see volunteer application		✓✓✓
		✓	✓
Total 28	53	21	32

TABLE 5B. INFORMATION-SEEKING ENABLERS: ALLOCATIVE RESOURCES AND AUTHORITATIVE RESOURCES

Information Need	Corresponding Seeking Behavior	Allocative Resource	Authoritative Resource
ALS (Lou Gehrig's disease)	go to website; ask doctor; go to nurse		doctor, nurse, website
best way to communicate with volunteer	ask former coordinator; ask volunteer		coordinator, vol.
different religious beliefs about death	go to Internet	Internet	
dementia	go to Alzheimer's website; ask nurse		nurse, website
disease (effects)	go to doctor; ask nurse		doctor, nurse
disease (general)	go to Merck manual; go to websites; ask doctor; go to nurse	Merck manual	doctor, nurse, website, Merck manual
disease statistics	monitor websites		website
disease trends	"keep an eye on" websites		website
home environment	explore home environment		home environment
home environment	explore neighborhood; explore home environment		neighborhood, home environment
Lewy's bodies	ask doctor; ask nurse		doctor, nurse
medication	ask doctor; go to nurse; consult Merck manual	Merck manual	doctor; nurse, Merck manual
new Medicare guidelines	listen in to team meetings		team meetings

TABLE 5B. INFORMATION-SEEKING ENABLERS: ALLOCATIVE RESOURCES AND AUTHORITATIVE RESOURCES, cont.

Information Need	Corresponding Seeking Behavior	Allocative Resource	Authoritative Resource
pain management	call other coordinators; ask hospice team		coordinators, team
patient diagnosis	go to nurse's assistant; ask doctor; ask nurse		nurse's assistant, doctor, nurse
pet therapy	ask director of nursing; ask doctor; ask nurse		director of nursing; doctor; nurse
prognosis	call activities director		activities director
software (record patient information)	ask doctor; ask nurse		doctor, nurse
software (record volunteer hours)	consult hospice team		team
volunteer aspirations	go to information systems team		i.s. team
volunteer motives	look at volunteer application; ask volunteer	application	volunteer, application
volunteer orientation	ask volunteer		volunteer
volunteer orientation training materials content requirement	go to volunteer training manual; go to videos ask former coordinator	training manual, videos	training manual, videos, coordinator
volunteer recruitment	check out church; check out health fair; check out senior center		church, health fair, senior center
volunteer services (family)	ask family		family
volunteer services (patient)	ask patient; ask family; go to social worker		patient, family, social worker
volunteer skills	see volunteer application; ask volunteer	application	volunteer, application
Total 28	54	5	40

procedural rules. Communicate with Volunteer is the only category of information use in this study that was found to be enabled by both moral and procedural rules. Table 5C provides the details of information use categories and their classification as a moral rule, procedural rule, or both.

Finally, allocative and authoritative resources enable the coordinator's use of information. Three categories of use involved allocative resources, while six categories of use involved authoritative resources; one category, Training the Volunteer, involved using both allocative and authoritative resource. The use of an allocative resource as an enabler for information use occurs most often in the use categories "Training the Volunteer" and "Make Good Match between Volunteer and Patient." The most-used allocative resources are the volunteer training manual and the volunteer training videos. The volunteer training manual and volunteer training videos also are used the most by the coordinator in his or efforts to ensure that a volunteer and a patient are well-suited to one another. One participant noted, "I need a clear definition of what the patient needs, what the patient's family needs, so that I can choose a good volunteer fit. A good match is crucial. Volunteers won't last if there is not a good match with a patient."

In comparison, a wide variety of authoritative resources enable information use. Most notably, the use category "Communicate with Volunteer" contains nine types of authoritative resources, followed by the use categories "Make Good Match between Volunteer and Patient" and "Stay Informed," with eight and seven types of authoritative resources contained therein, respectively. Table 5D provides details about information use categories and the types of allocative and authoritative resources that enable information use by the coordinator.

TABLE 5C. INFORMATION USE ENABLERS: MORAL RULES AND PROCEDURAL RULES

Information Need	Use	Moral Rule	Procedural Rule
ALS (Lou Gehrig's disease) best way to communicate with volunteer disease (effects) pain management patient diagnosis prognosis home environment home environment	Communicate with Volunteer	✓	✓
new Medicare guidelines software (record patient information) volunteer orientation training materials content requirement	Follow Hospice Agency Standards		✓
volunteer recruitment			✓
new Medicare guidelines software (record volunteer hours) volunteer recruitment volunteer services (family)	Follow Regulations	✓	
volunteer aspirations volunteer motives volunteer services (family) volunteer services (patient) volunteer skills	Make Good Match Between Volunteer and Patient		✓
pet therapy	Satisfy Patient Request	✓	
disease statistics disease trends	Satisfy Personal Curiosity	✓	
ALS (Lou Gehrig's disease) different religious beliefs about death dementia disease (effects) disease (general) Lewy's bodies medication new Medicare guidelines	Stay Informed		✓
volunteer orientation volunteer orientation training materials content requirement	Train Volunteer		
--	**8**	**4**	**5**

TABLE 5D. INFORMATION USE ENABLERS: ALLOCATIVE RESOURCES AND AUTHORITATIVE RESOURCES

Information Need	Use Category	Allocative Resource	Authoritative Resource
ALS (Lou Gehrig's disease) best way to communicate with volunteer disease (effects) pain management patient diagnosis prognosis home environment home environment + neighborhood	Communicate with Volunteer		doctor, nurse, director of nursing , nurse's assistant, former/other coordinator, volunteer, home environment, neighborhood, website
new Medicare guidelines software (record patient information) volunteer orientation training materials content requirement volunteer recruitment	Follow Hospice Agency Standards		information systems team
new Medicare guidelines software (record volunteer hours) volunteer recruitment volunteer services (family)	Follow Regulations/Standards		hospice team, church, health fair, senior center
volunteer aspirations volunteer motives volunteer services (family) volunteer services (patient) volunteer skills	Make Good Match Between Volunteer and Patient	volunteer application, training manual, training videos	family, former/other coordinator, patient, volunteer, volunteer application, social worker training manual, training videos

TABLE 5D. INFORMATION USE ENABLERS: ALLOCATIVE RESOURCES AND AUTHORITATIVE RESOURCES, cont.

Information Need	Use Category	Allocative Resource	Authoritative Resource
pet therapy	Satisfy Patient Request		activities director
disease statistics disease trends	Satisfy Personal Curiosity		websites
ALS (Lou Gehrig's disease) different religious beliefs about death dementia disease (effects)	Stay Informed	Internet, Merck manual	doctor, nurse, coordinator, team, website, Alzheimer's website, Merck manual
--	8	5	23

Research Question 6: Constraint(s) to the Overseer's Information Behavior

The coordinator has constraints imposed upon his or her information behavior. With one exception, which is discussed further in this section, some of those rules and resources that enable the coordinator's information seeking and use also constrain also constrain his or her information seeking and use. Table 6A outlines information needs, corresponding seeking behavior, and whether that behavior is a moral or procedural rule constraint.

The seeking behavior of the coordinator is constrained by eight moral rules and eighteen procedural rules. "Ask former coordinator," mentioned twice, is the chief moral rule that constrains the information behavior of the coordinator. This constraint is found in the information needs "best way to communicate with volunteer" and "volunteer orientation training materials content requirement." One of the participants, who had been with her agency for less than six months, and who consulted with the person who is the former volunteer coordinator of the participant's agency stated,

> "When I first came here, I wasn't sure, and sometimes I'm still not sure, if the training materials for the volunteers are accurate …There are no guidelines telling me what I have to have and what I don't have to have, and I'm friends with the person who used to be the coordinator here, so I know I can call her if I need to, but she isn't always around, so there are those times when I just have to swing it."

Procedural rules also constrain the coordinator's information-seeking behavior. Asking or going to the doctor, and asking or going to the nurse, are the primary procedural rule constraints, mentioned four and three times, respectively. According to two participants, although they are required to be part of the hospice team, doctors and nurses might work only part-time at a hospice agency, and therefore aren't always available for consultation.

TABLLE 6A. INFORMATION-SEEKING ACTIVITY CONSTRAINTS: MORAL RULES AND PROCEDURAL RULES

Information Need	Corresponding Seeking Behavior	Moral Rule	Procedural Rule
ALS (Lou Gehrig's disease)			
best way to communicate with volunteer	ask former coordinator; ask volunteer	✓	✓
different religious beliefs about death			
dementia			
disease (effects)	go to doctor; ask nurse		✓✓
disease (general)	ask doctor		✓
disease statistics			
disease trends			
home environment	explore home environment		✓
home environment	explore neighborhood; explore home environment		✓✓
Lewy's bodies	ask doctor; go to nurse	✓✓	
medication			
new Medicare guidelines	listen in to team meetings		✓
new Medicare guidelines			
pain management	ask doctor; ask nurse		✓✓
patient diagnosis			
pet therapy	call admissions nurse		✓
prognosis			
software (record patient information)			
software (record volunteer hours)			
volunteer aspirations	ask volunteer; look at volunteer application	✓	✓
volunteer motives	ask volunteer		✓
volunteer orientation	go to volunteer training manual; go to videos		✓✓
volunteer orientation training materials	ask former coordinator	✓	
content requirement	check out church; check out health fair;		
volunteer recruitment	check out senior center	✓✓✓	
	ask family		✓
volunteer services (family)	ask patient; ask family		✓✓
volunteer services (patient)			
Total 28	26	8	18

Meanwhile, allocative and authoritative resources also play a role in constraining the information-seeking behavior of the coordinator. Three allocative resources - the volunteer's initial application, the volunteer training manual, and the volunteer training videos - were the only three such resources. Most notable is how the volunteer's application can be a constraint in determining the volunteer's aspirations, since, as one participant stated,

> "… we get volunteers who don't get right away that the people they help [i.e. patients] could die at any time. It usually doesn't sink in with that volunteer until their first patient passes. What they want to accomplish sometimes doesn't work out because the patient dies before the volunteer has had a chance to have the effect they want to have."

As for authoritative resources that constrain the coordinator's information-seeking behavior, the doctor and the nurse take primacy; the doctor and the nurse were implicated three times apiece. The doctor and the nurse typically constrain the coordinator's information-seeking behavior either when the doctor and nurse are temporarily unavailable or inaccessible or if the coordinator has a question about a disease with which he or she is unfamiliar (e.g., Lewy's bodies, which, according to one participant, is a form of dementia). Table 6B provides in detail the allocative and authoritative resources that constrain the information-seeking behavior of the coordinator.

The coordinator also experiences constraints to his or her information use behavior. There were no moral rule constraints on use found by this study. In contrast, four procedural rules constrain use of information, i.e. "Follow Hospice Agency Standards," "Follow Hospice Regulations," "Satisfy Patient Request," and "Train Volunteer". In the first category, information was used to try to recruit volunteers from a church, a health fair, and a senior center. However, all three locations pose constraints in that they do not exist solely for the purpose of

TABLE 6B. INFORMATION-SEEKING ACTIVITY CONSTRAINTS: ALLOCATIVE RESOURCES AND AUTHORITATIVE RESOURCES

Information Need	Corresponding Seeking Behavior	Allocative Resource	Authoritative Resource
best way to communicate with volunteer	ask former coordinator; ask volunteer		former coordinator, volunteer
disease (effects)	go to doctor; ask nurse		doctor, nurse
disease (general)	ask doctor		doctor
home environment	explore home environment		home environment
home environment	explore neighborhood; explore home environment		neighborhood; home environment
Lewy's bodies	ask doctor; go to nurse		doctor, nurse
new Medicare guidelines	listen in to team meetings		team meetings
pain management	ask doctor; ask nurse		doctor, nurse
pet therapy	call admissions nurse		admissions nurse
volunteer aspirations	ask volunteer; look at volunteer application	volunteer application	volunteer; vol. application
volunteer motives	ask volunteer		volunteer
volunteer orientation	go to training manual; go to videos	training manual, videos	training manual, videos
volunteer orientation training materials content requirement	ask former coordinator		former coordinator
volunteer recruitment	check out church; check out health fair; check out senior center		church, health fair, senior center
volunteer services (family)	ask family		family
			family
Total 28	26	3	8

hospice volunteer recruitment; the coordinator simply attends with the intention to recruit, but lacks specific information about whether other attendees are there to be recruited. In the second category of use, "Follow Regulations," a participant discussed a critical incident in which a family sought volunteer services for a patient but were not forthcoming about certain details of the home environment that the coordinator otherwise would have passed along to the volunteer selected to care for the patient in question. In the third category of use, "Satisfy Patient Request," a coordinator attempted to but was unable to use information to obtain pet therapy for a patient. In the fourth category, "Train Volunteer," a coordinator discovered what she considered to be outdated information about the five stages of death that she ordinarily would have used to train the volunteers. Table 6C outlines the (procedural rule) constraints to information use.

Similarly, allocative and authoritative resources also constrain the coordinator's information use. In terms of allocative resources, two types - the volunteer application and the volunteer training manual - constrain information use, while twelve types of authoritative resources constrain information use. The doctor was discussed most often as the authoritative resource that constrains use. "Communicate With the Volunteer" was the category of use that contained not only the most number of instances of authoritative resource constraints, but also the most number of types of authoritative resource constraints. The fewest number of authoritative resource use constraints occurred in the category "Satisfy Patient Request," and involved the admissions nurse. Table 6D provides details of allocative and authoritative information use constraints.

TABLE 6C. INFORMATION USE CONSTRAINTS: MORAL RULES AND PROCEDURAL RULES

Information Need	Use Category	Moral Rule	Procedural Rule
ALS (Lou Gehrig's disease)	Communicate with Volunteer		
best way to communicate with volunteer			
disease (effects)			
pain management			
patient diagnosis			
prognosis			
home environment			
home environment; neighborhood			
new Medicare guidelines	Follow Hospice Agency Standards		✓
software (record patient information)			
volunteer orientation training materials content requirement			
volunteer recruitment			✓
new Medicare guidelines	Follow Regulations		
software (record volunteer hours)			
volunteer recruitment			
volunteer services (family)			
volunteer aspirations	Make Good Match Between Volunteer and Patient		
volunteer motives			
volunteer services (family)			
volunteer services (patient)			
volunteer skills			✓
pet therapy	Satisfy Patient Request		

TABLE 6C. INFORMATION USE CONSTRAINTS: MORAL RULES AND PROCEDURAL RULES, cont.

Information Need	Use Category	Moral Rule	Procedural Rule
disease statistics disease trends	Satisfy Personal Curiosity		
ALS (Lou Gehrig's disease) different religious beliefs about death dementia disease (effects) disease (general)	Stay Informed		
			✓
volunteer orientation volunteer orientation training materials content requirement	Train Volunteer		
28	8		4

TABLE 6D. INFORMATION USE CONSTRAINTS: ALLOCATIVE RESOURCES AND AUTHORITATIVE RESOURCES

Information Need	Allocative Resource Constraint	Authoritative Resource Constraint	Use Category
best way to communicate with volunteer		former coordinator, volunteer	Communicate with Volunteer
disease (effects)		doctor, nurse	
pain management		doctor, nurse	
home environment, neighborhood		home environment, neighborhood	
volunteer orientation training materials content requirement		former coordinator	Follow Hospice Agency Standards
volunteer recruitment		church, health fair, senior center	Follow Regulations
volunteer services (family)		family	
volunteer aspirations		volunteer	Make Good Match Between Volunteer and Patient
volunteer motives		volunteer	
volunteer services (family)		family	
volunteer services (patient)		patient, family	

TABLE 6D. INFORMATION USE CONSTRAINTS: ALLOCATIVE RESOURCES AND AUTHORITATIVE RESOURCES, cont.

Information Need	Allocative Resource Constraint	Authoritative Resource Constraint	Use Category
pet therapy		admissions nurse	Satisfy Patient Request
Total --	--	12	7

General Discussion

The overseer of the volunteer in hospice care typically is known as "volunteer coordinator" (interchangeably referred to as "coordinator"), and he or she might simultaneously fulfill more than one paid, professional role (e.g., bereavement counselor). The coordinator oversees an average of ninety-two patients and seventy-three volunteers, and has fulfilled the role of coordinator for an average of seven years. The coordinator uses as many as thirteen methods for recruiting a volunteer, and as many as thirteen methods for retaining a volunteer.

The coordinator is considered to be a formal but legally unrequired member of the hospice care team, in contrast to the doctor, nurse, social worker, and chaplain, who are legally required, by Medicare, to be present on the team. In contrast, Medicare regulations do not require a volunteer coordinator per se. However, hospice agencies that receive payment from Medicare are required by that agency to document their efforts to recruit, train, and retain volunteers, although Medicare regulations do not stipulate who or whom within a hospice agency is responsible for meeting that requirement; nor do those regulations *prevent* an agency from employing a person who only fulfills the role and who only assumes the responsibilities of volunteer coordinator. Medicare regulations also require at least five percent of the total hours devoted to patient care to be fulfilled by a volunteer, which casts the volunteer as an integral and, by derivation, required member of the hospice care team, albeit the only unpaid member of the team.

Interestingly, however, there was some discrepancy among the participants' responses in whether volunteers are considered as members of the team in terms of their inclusion in team meetings. One participant commented that "… the volunteers don't go to team meetings, because in the meetings I hear about different patients … There isn't a need for them [the volunteers] to hear about everybody else. So they're not allowed to be in those meetings. Any

information that comes up in the meetings can be communicated to them, but only the information that pertains to their patient." The same sentiment, to some extent or other, was mentioned by several other participants.

Conversely, other participants were adamant that the volunteer is part of the team and thus is present at team meetings as part of their overall involvement in patient care. As one participant insisted, when asked about the purposive presence or absence of volunteers at team meetings, "Oh, yes, they go to team meetings. They need to know firsthand about what's going on …" That the researcher could determine, there are no Medicare guidelines for volunteers' presence at patient-oriented team meetings; it appears that volunteer involvement in those meetings are at the discretion of an individual hospice agency.

The participants in this study experienced one or more information needs, with a total of twenty-eight needs distributed among twenty-one participants and subsumed under seven major categories of need. Information needs most often occurred within a disease or disease-related context, whereas information needs related to death occurred the least often. Information needs emerged from critical incidents that were discussed by each participant. Although during each interview the researcher inquired about only one critical incident of need, data analysis revealed that other (recent) incidents involving an information need emerged during the interviews; these incidents also had concurrent seeking and use behavior, as well as enablers and/or constraints imposed during information seeking or the use of information, and thus fit the parameters of the critical incident as a concept. Accordingly, since those incidents were expressed in enough detail so that they could be fully analyzed as a distinct incident, they were included in the final analysis.

By that same token, conversation that had the potential for being an expressed information need, typically in the transcripts in the form of a think-aloud, rapid-fire series of questions pertaining to a broader need, was not coded as a need. For example, one participant identified assessing a patient's home environment as a critical incident (which subsequently was coded as the need "home environment" under the category "Patient/Patient-Related"). She then explained that as she conducts a home assessment, she asks herself certain questions, which she expressed in the following manner during her interview:

> "What is the neighborhood like? Are there safety issues? Is there something [about a home environment] that stands out that I want to be sure to tell the volunteer? Those are some of the questions I remind myself of when I go out to the patient's home for the first time."

All three of these questions represent an information need in that they explicitly indicate a knowledge gap; however, all three of these needs can be subsumed under the information need "home environment" because they can be traced to the general seeking and use behavior associated with the experience of assessing a patient's home environment. These and other similar types of conversation were thus considered as part of an overall critical incident, but not as separate critical incidents in and of themselves.

In order to resolve one or more of the twenty-eight information needs, the coordinator engaged in a one or more of a total of fifty-four instances of information seeking activities. The type of information seeking activity most often engaged in by the coordinator is "Consult," which involves consulting a person or, to a lesser extent, an object in an effort to satisfy an information need. The coordinator's seeking behavior is implicated most explicitly in the information seeking model developed by Leckie, Pettigrew [Fisher], and Sylvain (1996), who formulated a model of human information behavior based on their analysis of empirical studies of three groups of professionals, including health care professionals found in health care systems.

The authors describe health care systems as comprised of three elements, the most relevant of which for this study includes "... personal health care services available to individuals and families through hospitals, clinics ... and similar agencies, and in ... the clients' own homes ..." (Leckie, Pettigrew [Fisher], & Sylvain 1996). Health care systems, as described by the authors, are located in a variety of settings, including "hospitals" and "public health units" and in which can be found "physicians [and] nurses," with some holding "joint positions" within the community (Leckie, Pettigrew [Fisher], & Sylvain 1996). Nurses comprise the largest group of professionals in health care systems, and are typically concerned with patient care. In describing nurses' interaction with information in their efforts to care for patients, the authors' own characterization of nurses' information-seeking activities, as well as the research they cite to support their assertions, bear a stark resemblance to the information-seeking activities of the participants in this study:

> "For routine questions, nurses usually sought information from a single source, including both interpersonal (for example, other nurses, [or] a physician) and print (for example, patients' records ...). But for non-routine questions, they would often use multiple sources. Blythe and Royle [1993] explained that nurses sought 'clear directions from knowledgeable oral sources or quick reference material because the information-seeking was either routine and task-oriented or was triggered by patient needs that required quick decision making' [25, p. 434]. Further, because nurses must remain near their patients, they require information sources that are accessible from the unit. Other studies confirm Blythe and Royle's finding that nurses primarily seek patient care from knowledgeable colleagues" (Leckie, Pettigrew [Fisher], & Sylvain 1996).

This study confirms the authors' comment, partly from which their model of information seeking was developed: the information-seeking activity of the participants in this study typically is based either on routinized tasks that generate information needs for which people (e.g., the social worker) or objects (e,g, a volunteer training video) are consulted, while non-routinized tasks

germane to unexpected, real-time urgency of patient care typically involve immediate consultation of other members of the hospice care team (e.g., the nurse).

On a different note, (Leckie, Pettigrew [Fisher], & Sylvain 1996) conclude that the healthcare professionals they profile, i.e. nurses, physicians, and dentists, "seek information from informal and formal sources, both from inside and outside their organizations, and their choices are largely determined by ease of access, past success, time constraints, and the format and quality of the information." While the participants in this study do engage in information-seeking activity based on, for example, accessibility of an information source, that activity also is governed and monitored by internal (established corporate policy) and external (bureaucratic law) forces that play a substantial role in shaping the participants' information seeking choices. One participant tells of the time when a hospice care patient requested pet therapy:

> "She [the patient] was receiving [hospice] care from us in a nursing home ... I called the [nursing home's] admissions nurse, but she wasn't returning my calls, and I had to see if they [the nursing home] would accept a dog being there, and if they could help me find a certified pet therapist that could be there, because the dog can't be there without the therapist. I talked about it with the social worker - we were just talking - and she said, 'Oh, you have to call the activities director [at the nursing home]. She'll talk to you about it.' So, that's what I did, and we got the therapy in about a week."

The participant's information seeking, while generated by a routinized task, i.e. not an urgent matter of life or death, nevertheless was bound by bureaucratic law ("help me find a *certified* pet therapist") and corporate policy ("the dog *can't be* there without the therapist"; "you *have to* call the activities director"), two power structures that fall outside Leckie et al.'s scope of "... choices ... largely determined by ease of access, past success, time constraints, and the format and quality of the information."

More broadly, Leckie et al. (1996) found that the information behavior of all the three groups of professionals profiled in their model, including healthcare professionals, is primarily dependent upon source and awareness [of the changeable nature of information] (Leckie, Pettigrew [Fisher], & Sylvain 1996). While that may hold true in some healthcare settings, the participants in this study are subject to bureaucratic laws and corporate policies that often transcend any one individual participant's selection of an information source or his or her awareness of the mutable nature of information. It should be re-iterated, however, that the Leckie et al. model is germane to the findings of past studies and thus is limited to empirical research not of the authors' undertaking. In terms of bureaucratic or corporate power structures as discovered by this study, Leckie et al. only note that "... in [the professional's] search for relevant and necessary information... factors such as the corporate culture ... converge to affect the outcome."

As such, the participants in this study use information according to the same bureaucratic and corporate provisions that support and monitor that use. Sixty-three instances of use emerged and were directly associated with twenty-eight information needs and fifty-four instances of information seeking activity generated by those needs. While information was used most often by the participants to communicate with the volunteers, other uses of information by the participants included following their respective agency's standards; following (Medicare) regulations; and satisfying a personal curiosity related to disease trends and statistics. For this study, information use was analyzed at a categorical level similar to Taylor's typology of information use. Although not empirically-derived, Taylor's typology is worthy of comparison so as to meet one of the major goals of this study, which is to explore the possibility of adding one or more new dimensions to the IUE.

This study confirmed all eight categories of use according to the IUE; however, as is the case with the participants' information seeking activities, use is often determined by bureaucratic law and corporate procedures and standards unaccounted for by Taylor. While Taylor does mention the bureaucracy as a facet of "Setting" within the IUE, he does so in a way that seemingly discounts the potentiality of the role of the large bureaucracy (e.g., Medicare) therein: "The rise of the service sector is epitomized by the small organization ... in many cases these services are closer to information ... than are larger and more formal organizations ...Within limits, information behavior essentially transcends the bureaucratic organization." While it is the case that hospice care agencies can be small organizations, the majority of participants in this study were employed by mid-range (i.e., regional) to large (i.e., nationwide) corporations, all of which receive Medicare payments, and thus are bound by state and federal laws that, in large part, do not allow for the participants' use of information to extend beyond those laws. As one participant pointed out, "... each state has its own set of requirements ... they can be stricter than Medicare, but they cannot be more lenient than Medicare." Information use by the participants is subsumed under these sets of requirements; therefore, the setting of the IUE should account for large-scale power structures (e.g. those of a bureaucratic or corporate nature), since Taylor does not stipulate that an organization be of a certain size or scope in order to qualify as an IUE.

Concurrently, the information seeking and use activity of the participants in this study are enabled and constrained both by moral and procedural rules, as well as by allocative and authoritative resources. Specifically, information seeking and use activities undertaken by the participants are enabled mostly by procedural rules and authoritative resources. Information seeking and use activities also are constrained, mostly by procedural rules; yet information seeking is constrained mostly by allocative resources, while the use of information is constrained

more by authoritative resources. In other words, although bureaucratic law, corporate policy, and people in the hospice care agency do facilitate the participants' information seeking and use activities, those activities also are constrained by those very same factors, with the addition of allocative resources as a constraint on the participants' ability to seek information.

CHAPTER FIVE: CONCLUSIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH

Information Behavior of the Overseer of the Volunteer

This study was undertaken to explicitly identify the overseer of the volunteer in hospice care and his or her information behavior; to explore whether and how that behavior affects volunteer retention; to potentially discover one or more new dimensions of the information use environment (IUE); and to contribute to the growing body of human information behavior and its theoretical underpinnings, and particularly those that exist within a social context. To achieve those goals, this study adopted a naturalistic approach in order to qualitatively capture critical incidents in in-depth, emic terms, a necessary approach given the absence of research in this vein.

The overseer of the volunteer in hospice care, typically known as the volunteer coordinator, experiences a variety of information needs, most notably those having to do with disease, followed closely by information needs relating to the volunteer. The coordinator, although a member of a set of professionals in his or her own right, is not a medical professional and thus must seek information about disease and its particulars from those professionals on the hospice care team (i.e. the doctor and the nurse) during the course of his or her efforts to train and retain the volunteer.

Consequently, the information-seeking activity of the coordinator is overwhelmingly grounded in consulting a particular person or resource, usually the doctor and the nurse. Information also is sought vis-à-vis the exploration of particular environments (e.g., a hospice patient's home environment) and the monitoring of disease statistics and trends. While the coordinator's seeking behavior partially can be located in the Leckie model of the information

behavior of professionals, the model does not account for power structures (i.e., bureaucratic law or corporate policy) that could determine the extent to or the conditions under which information seeking and use occur. The coordinator's information-seeking activity is enabled and constrained mostly by procedural rules and authoritative resources which implicate the coordinator's tendency to consult with other members of the hospice team (e.g., the doctor and the nurse) as a routine habit when seeking information.

Accordingly, the coordinator uses information chiefly to communicate with the volunteer about a patient's home environment; disease or disease-related; and how the coordinator effectively can interact with the volunteer. As with the coordinator' seeking activity, the coordinator's use of information is both enabled and constrained mostly by procedural rules and authoritative resources, which suggests that the coordinator's (seeking and) use of information is closely scrutinized. The eight categories of the coordinator's information use behavior found by this study can be entirely located in Taylor's (1991) typology of information use as it occurs in the IUE, which lends definite credibility to Taylor's categories, given that they are not derived empirically. However, as with the aforementioned Leckie et al. model, Taylor's concept of the IUE does not include a power structure as a factor in its makeup. Thus, the participants' information seeking and use activity is overwhelmingly shaped and formed by a well-calibrated system of power that has remained largely unexplored in human information behavior research.

The Power Structure in Hospice Care

A power structure typically is defined as a distribution of power among individuals, social categories, or entire social systems, the latter of which is encompassed by a power elite that holds a consensus by which to promote its self-interest (Johnson 1995, p. 211). A social system

is complex, and, as such, power is used in part to make decisions in order to "... coordinate activities" within that system (Turner 1986, p. 117). However, power is not merely held; rather, by virtue of its unequal distribution, power flows through social interaction and networked relationships and is exercised accordingly (Foucault 1998, p. 93).

A key component of the exercise of power is the acceptance of domination among leaders and followers and, more specifically, the belief by subordinates in the legitimacy of their subordination (Giddens 1971, p. 156). The classic sociologist Max Weber referred to legitimate forms of domination as "authority," and recognized three bases upon which authority is considered legitimate by subordinates; chief among these is legal authority, or, in its structural form, the bureaucracy (Ritzer 2007, pp. 240-241). Following Weber, Giddens notes, "[In the bureaucracy] ... those who are subject to authority obey their superordinate ... because of their acceptance of the impersonal norms which define that authority ... and follow commands [of the superordinate] only within the restricted sphere in which [the superordinate's] jurisdiction is clearly specified" (1976, pp. 157-158).

According to Weber, the bureaucracy is the "purest type of exercise of legal authority," wherein it is "... capable of attaining the highest degree of efficiency, and is in this sense ... the most rational known means of exercising authority over human beings" (Ritzer 2007, p. 241). Giddens points out that for Weber, within the bureaucracy, the "... spheres of competence of the officials are clearly demarcated; ... rules governing ... authority and responsibilities [are] recorded in written form; ... office property is not owned; ... routinized tasks are performed; ... [and] ... a separation is maintained by the office and the official" (1971, p. 158). Despite these seeming advantages, Weber also cautioned against the so-called "red tape" (i.e., barriers to

efficiency) famously characteristic of the bureaucracy, cynically describing the bureaucracy as "escape-proof" and an ominous threat to individual liberty (Ritzer 2007, p. 242).

Given hospice care's own relationship with bureaucratization, a clear and present power structure within hospice care volunteerism emerged as the major finding of this study and as this study's unique contribution to the corpus of LIS research concerned with human information behavior. Hospice care is ostensibly bound by the legal authority of the Medicare program, the nation's largest payer of hospice care. While hospice care agencies, as corporations, represent a power structure of their own accord, in that they exercise power to promote their capitalist, entrepreneurial self-interests, it is Medicare that is the dominant force over the nation's entire hospice care system and thus, by derivation, the arbiter of power in the hospice volunteer coordinator/hospice volunteer (social) relationship. This power is legitimized vis-à-vis the volunteer coordinator's acceptance of his or her position of subordination to Medicare, in that the coordinator willingly, for example, documents his or her efforts to recruit, train, and retain the volunteer, as required by Medicare if it is to pay for a patient's hospice care services. Meanwhile, the volunteer accepts subordination to the volunteer coordinator and, by derivation, to Medicare, in that he or she willingly abides by the direction of the coordinator (and without material compensation).

While the coordinator and the volunteer are knowledgeable actors, and thus cognizant of the *intended* consequences of their information seeking and use behavior, the unequal distribution and exertion of power within the relationship between Medicare and the hospice care agency limits that behavior, thus producing *unintended* consequences of that behavior which, in turn, produce and reproduce the social system that is hospice care, and determine the nature and type of social practices that occur between the coordinator and the volunteer. A troubling aspect of

this finding is that although hospice care volunteerism continues to be under threat of extinction, Medicare produces and reproduces a (social) system of hospice care volunteerism that has a reportedly deleterious effect on the volunteer (e.g., lack of explicitly-known overseer of the volunteer; information gatekeeping), the very subordinate whom Medicare relies upon as a cost-savings measure (and thus potentially its own survival). However, as Weber argued, the bureaucracy is virtually indestructible once it is formed (Ritzer 2007, p. 242). Dahms (2010, p. 90) provides insight into why this is so:

> "At its core, the social world, along with most of its members and forms of organizations, does not 'want' to achieve ... the kind of enlightenment, including especially self-enlightenment ... that would lead to expectations of ... lasting improvements of self and of social forms ... Instead, many forms of social life continue to be characterized by a strong impetus to avoid improvements, to stay exactly as they are, and to continue to survive in their present condition, while continuously growing in size ... even if this pattern in the end will undercut the continuity of growth [and] threaten the forms' very existence."

The Volunteer in Hospice Care

The volunteer in hospice care is crucial to patient care. This study found that the volunteer coordinator engages in information-seeking and use behavior that is primarily geared toward passing information to the volunteer, although that is not always the case. Those who choose to volunteer in hospice care do so for a variety of reasons (e.g., coming to terms with the death of a loved one); those who theorize about volunteerism in general surmise that volunteer work is, in part, a "collective behavior that requires social capital" (Wilson & Musick 1997). By that token, the volunteers in this study presumably are able to communicate fairly openly with their respective coordinators, although they are not necessarily recognized as part of the hospice team, which could impede not only their access to information, but also their willingness to remain in

hospice care. Volunteer training has been found to play a role in volunteer retention, and that training is wholly dependent upon the ways in which the coordinator is able to seek and use the information that is intended for the volunteer according to the purview of Medicare and its authority. Moreover, volunteer training, as an antecedent to retention, is the initial introduction by which a volunteer might gauge whether and how he or she is to provide care to a patient. Leete (1994) describes her experience as a hospice care volunteer-in-training as follows:

> "In the first class of the ten-week program, we learn about hospice, its operation, and its philosophy of helping the dying to die with dignity and in as little pain as possible...The nurses, the social workers, the doctors are caring and compassionate, but they are doing a job. It is we, the volunteers, who will be the companions."

Since Medicare does not explicitly stipulate beyond HIPAA guidelines the information with which a volunteer might engage, it is vital to the survival of hospice care volunteerism and to hospice care itself that hospice care agencies take a closer look at the extent which the volunteer is included in the flow of information amongst the hospice team and, by that inclusion, might help unblock the information gatekeeping that occurs in hospice care so as to be the companion that the dying and their families deeply hold so dear.

Implications for Library and Information Science and Recommendations for Future Research

A second contribution of this study is that it joins the handful of LIS studies that have introduced Gidden's theory of structuration into LIS research (see, e.g., Solomon, 2000; Savolainen 2007). This study draws upon structuration theory in order to illuminate unforeseen dimensions within the IUE, using hospice care volunteerism as the impetus for the study; accordingly, a power structure emerged as a major component of hospice care volunteerism as an IUE. Structuration theory posits that the human information behavior in hospice volunteerism is

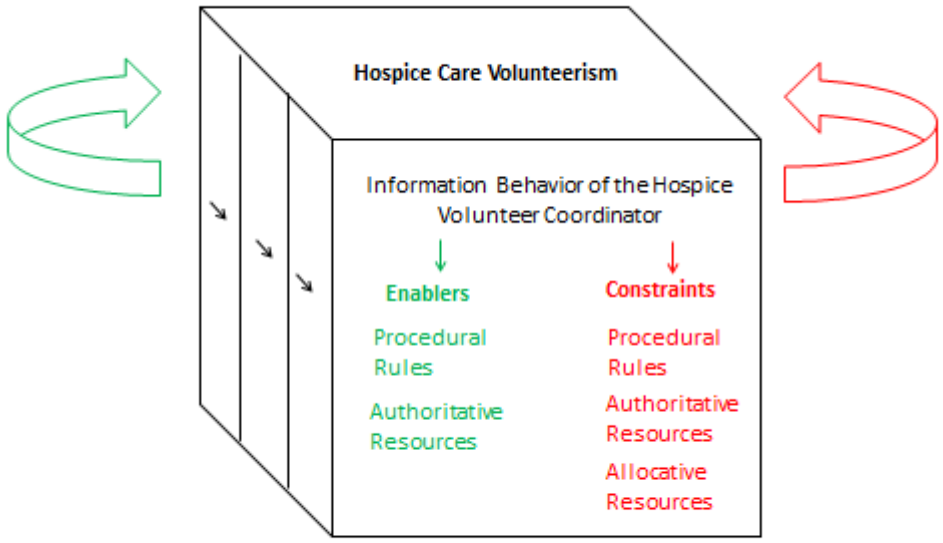

FIGURE 3. STRUCTURATION THEORY APPLIED TO HOSPICE CARE VOLUNTEERISM AS AN INFORMATION USE ENVIRONMENT

produced and reproduced according to rules and resources that both enable and constrain that behavior (see Figure 3). Rules and resources, a given component of the IUE in that Taylor focused on organizational (i.e. workplace) structure as an IUE of type, allow for power to flow among the social relationships that occur within an IUE (considered in this study as the information behavior of the hospice volunteer coordinator). While subordinates to the power structure are knowledgeable actors aware of the intended consequences of their information behavior as it occurs within the IUE, the exploitation of that behavior by the power structure produces unintended consequences of which those knowledgeable actors are unaware, further ensuring the production and reproduction of the power structure itself. This revelation presents rich opportunities for LIS research involving human information behavior and the IUE.

For example, on a practical level, the findings of this study could be presented to either the participants involved in this study or to a new set of participants in order to conduct a plan of action research as a means of determining new rules and resources that could further enable the volunteer coordinator's seeking and use of information and thus his or her opportunity to leverage power within hospice care on behalf of the volunteer (see, e.g., Mehra 2006; Stringer 2007).

In terms of further developing theoretical frameworks for studying human information behavior as it occurs within the IUE, the Kuhlthau model of the information search process could be applied to capture the uncertainties that generate information needs (see, e.g., Kuhlthau 2004). According to Kuhlthau, the information search process is grounded in three dimensions (2004; p. 41), including the affective, in which uncertainty is grounded (2004; p. 44). Future research could align Taylor's concept of "problem" (conceptualized in this study as an information need but that is defined by Taylor as an *uncertainty* that generates a need) and Kuhlthau's affective state in the search process (in which *uncertainty* is implicated) and thus could allow for the discovery of possibly still-obscure dimensions of the IUE, thereby further explicating theoretical underpinnings of the IUE.

A second theoretical approach could involve Pierre Bourdieu's theory of habitus and field (see, e.g., Bourdieu 1977), which characterizes power according to the social practices agents undertake that are sustainable (although not necessarily permanent) and transferable amongst contexts. Unlike Giddens, who developed structuration theory as a means of examining social practices in an effort to bridge what he considered to be a wide gap between the subjective and the objective within social structures, Bourdieu sought to close that same gap by focusing on actors' mental structures and schemata as they occur contextually. However, Giddens and

Bourdieu similarly conceptualize structures in terms of unintended consequences (Giddens) or, as is the case with Bourdieu, the subconscious.

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APPENDICES

APPENDIX A - INTERVIEW GUIDE

All questions for this interview are designed so as to *not reveal specific patient information or to violate the Health Insurance Portability and Accountability Act (HIPAA) of 1996.* However, the participant may choose to not answer a question if he or she feels that it will reveal specific patient information, and may choose to withdraw from the interview at any time.

Interview Guide

Part I: Demographic Information

1. What is your role in the hospice?
2. How long have you been employed as a hospice volunteer coordinator?
3. How many patients does the hospice serve?
4. Can you describe the hospice team?
5. How many volunteers participate in serving the patients?
6. How do you recruit volunteers?
7. How do you retain volunteers?

Part II: Critical Incidents

1. Can you tell me of a recent time in your role as hospital volunteer coordinator when you needed information to help train the volunteers?
2. How and when did you know you needed this information?
3. What did you do first?
4. What did you do next?
5. How long did you spend looking for information?
6. Did you get what you needed when you stopped looking for information?
7. What *general type(s)* of information were you hoping to get during this experience?

Part III: Information Needs

1. Can you tell me about the kind kinds of information you need in your work as a hospice volunteer coordinator?
2. Can you tell me about the kind of information you use the most?
3. Can you tell me about information you need but can't find?
4. For what *general* purpose do you use the information you find?

Part IV: Information Use Environment

1. Where do you go to find information? *[setting]*
2. Who on the hospice team do you consult when looking for information? *[people]*
3. What problems do you encounter when looking for information? *[problems]*
4. How do you solve these problems? *[problem resolution]*

Part V: Enablers of Information Seeking

1. Where/what sources do you go to for help when you are looking for information?
2. What helps you get the information you need?

APPENDIX B - INFORMED CONSENT STATEMENT

Re-conceptualizing the Information Use Environment: Enablers of and constraints to human information behavior in hospice care volunteerism in southeastern Appalachia

INTRODUCTION

You are invited to participate in a research study that explores the information-seeking behavior of hospice volunteer coordinators and the factors that both enable and constrain that behavior. Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed your data will be returned to you or destroyed. By signing this form, you confirm that you are at least eighteen years of age.

INFORMATION ABOUT PARTICIPANTS' INVOLVEMENT IN THE STUDY

You will be interviewed by a Ph.D. student enrolled in the University of Tennessee's College of Communication and Information. The student will guide the conversation, and, with your permission (expressed by initialing this document), will audio-record the interview. However, if you do not wish to be audio-recorded, the student will take notes by hand. The interviews will be conducted in a place and at a time you choose. The interview will take approximately sixty minutes. The purpose of the interview will be to explore the information needs of hospice volunteer coordinators, the ways in which hospice volunteer coordinators find information, how that information is used, and the factors that enable and constrain hospice volunteer coordinators' information need, seeking, and use. You will be asked to describe a recent information-seeking behavior experience. *The reports based on this interview will not include information that will reveal your or any other individual's identity to the readers of the reports.*

RISKS

All questions for this interview are designed so as to *not reveal specific patient information or to violate the* Health Insurance Portability and Accountability Act of 1996 (HIPAA) (see researcher's copy if you prefer). However, you may choose at any time not to respond to a particular question or to terminate the interview. You are also asked to choose a location for the interview that is comfortable and convenient for you.

BENEFITS

The results of the project will be written as a Ph.D. dissertation. Additionally, articles based on the dissertation will be written with the intent of publication in scholarly journals and at scholarly conferences. The research will reveal the ways in which hospice volunteer coordinators can have improved access to the information needed for volunteer training and retention, and, thus, sufficient rates of volunteer retention. In this way, hospice volunteer coordinators can play a direct role in twenty-first century hospice care, as healthcare itself continues to play out on the national stage.

_____Participant's signature _____Researcher's signature

VITA

Sheri Edwards is a doctoral candidate at the College of Communication and Information, School of Information Sciences (SIS), at The University of Tennessee, Knoxville. She is a graduate student library assistant at the University's John C. Hodges Library and a librarian at a local community college, as well as a former interim Social Sciences Librarian at the University. Edwards has taught several for-credit undergraduate courses for the SIS, as well as numerous graduate- and undergraduate library instructional courses, and is a former public-school teacher of English. She holds a Master of Science degree in Library and Information Science; a Master of Education degree in English; and a Bachelor of Arts degree in history. Her grandmother's recent passing while in hospice care made this research particularly meaningful.