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Organization structure and service delivery in hospice organization

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ORGANIZATIONAL STRUCTURE AND SERVICE DELIVERY IN HOSPICE ORGANIZATIONS

by

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DISSERTATION

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Abstract

This research was a qualitative study of organizational structure and service delivery in a sample of three hospices in one California county. Each hospice studied had a different organizational structure and different access to resources. The main aims of this research were to A) describe the organizational structure of each hospice; B) describe the level of service in each hospice; and C) to examine the relationship between organizational structure and service delivery in hospice organizations. Data showed that despite functioning in the same environment, the hospices studied provided very different levels and types of services. Using resource dependency theory and institutional theories of organizations, this study found a relationship between the organizational structure, the values and beliefs underpinning the organization, and the level of service provided in the hospices. In the hospices studied, organizational factors such as vertical integration, profit seeking, and access to foundation funds were primary factors affecting the level of service provided. In addition, data examining the ideas and values within each organization that underpinned the organizational structure revealed evidence of organizational change that may indicate the emergence of one or more new archetypes in the field of hospice care.

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CHAPTER ONE. INTRODUCTION AND BACKGROUND

I. Introduction and Statement of Problem

Since the implementation of the hospice Medicare benefit in 1983, the number of hospice organizations in the United States has increased dramatically, from just over 31 Medicare certified facilities in 1984 to 2,265 facilities in 2001 (CMS, 2002a). Not only has the number increased, but there has emerged a great diversity in organizational forms of hospice care. While pre-Medicare hospices were often free-standing, not for profit organizations, immediately after the implementation of the Medicare benefit there emerged a great number of hospices that are affiliated with or owned by mainstream health organizations (hospitals, home health care agencies, skilled nursing facilities and health systems). Hospices have also emerged in managed care organizations and others have become for-profit endeavors. Currently, some researchers complain that they have no language to describe or categorize the different organizational forms that have emerged in the field of hospice (Lupu, 1996). There is a wide variety in the way that hospice organizational forms are categorized in survey research, making it difficult to synthesize the data collected. To date, little research has been conducted to investigate how different hospice organizational forms differ in terms of their goals, beliefs and values. Less is known about the relationship between these ideas and the services delivered in hospices. While this research will by no means be all-inclusive or necessarily generalizable, this research will be a preliminary step toward understanding the differences and commonalties between the organizational forms that have emerged in the field of hospice care.

A. SPECIFIC AIMS

The **first aim** of this research is to describe the organizational structure of each hospice studied. Qualitative research will be conducted in three different hospices, all with different organizational structures. For each hospice, a description will be provided of the organizational structure, organizational relationships, financial resources and institutional/regulatory pressures. This description and comparison of organizational structure will contribute to future research on hospice care. It may provide a rational for future classifications of hospice organizations in research that seeks to compare across organizational forms.

The **second aim** of this research is also descriptive. The second task is to describe the level of services provided in each hospice organization studied. Very little is known about differences in quality of care, levels of services, and types of services available in different types of hospices. This dissertation will describe the services available in each of the hospices studied. Comparisons will be made across hospices as well as with the Medicare regulations. This description will elucidate differences in the interpretation of the guidelines and differences in ability to meet the guidelines in hospices. It will also compare service delivery across the three hospices studied to show how extensive differences in level and types of services can be in some hospice organizations.

The **third aim** of this research uses resource dependency theory to examine how the hospice organizations are affected by the organizational environment, with a special focus on how access to resources affect organizational behavior. According to resource dependency theor

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dependency theory, an organization's environment is made up of many different factors including other organizations or individuals the focal organization relies on for resources or funding (Pfeffer & Salancik, 1978). One aspect of the organizational environment is an examination of the affects of the outside organizations with which the hospices have dependency relations, such as government funding agencies. The first hypothesis related to this aim was:

HYPOTHESIS #1: The hospices will be heavily dependent on government financing and that dependence will constrain their behavior.

Another aspect of the organizational environment that was examined in this research was access to private funding, i.e. foundation money. Within the non-profit sector, hospices rely on individuals to provide donations to fund their activities. The second hypothesis of this study was:

HYPOTHESIS #2: Access to foundation funds will alleviate the affects of the reliance on government funding.

The **fourth aim** of this research is to examine the relationship between certain organizational structural factors and the service delivery in the three hospices studied. According to resource dependency theory, the way an organization is structured affects its access to resources, mediates its dependency relations and thus, affects its behavior. One major difference in the hospices studied in terms of organizational structure was profit status. The third hypothesis of this study was:

HYPOTHESIS #3: Profit seeking will divert funds from patient care.

Other aspects of organizational structure that were examined were the hospices' relationships with other organizations. One way that organizations can react to uncertainty is to make linkages with other organizations that will help provide more resources or facilitate access to resources. In this study, some hospices were vertically integrated (owned or affiliated with non hospice health care organizations) and horizontally integrated (part of a chain of hospices).

The affects of having affiliations with non-hospice organizations or being part of a chain operation of hospices were examined in this study. Critics have predicted that dependency relationships with non-hospice health care organizations will cause a "spilling over" of rules from mainstream medicine and a subsequent narrowing of hospice goals and services (Abel, 1986). A fourth hypothesis of this research was:

HYPOTHESIS #4: Vertically integrated hospices will have a lower level of care than the freestanding hospice

The **fifth aim** of this research was to examine the relationship between ideas or organizational mission and service delivery. This was a more grounded approach that did not use a hypothesis as a methodological tool. Using the *archetype design method* described later in this proposal, the aim was to provide a description of the interpretive schemes of each of three hospices. The interpretive scheme includes the goals, method of operation, and self-evaluation methods of each hospice. The interpretive scheme of each hospice was described, compared and contrasted. Finally, an evaluation of the level of consensus about these ideas in each hospice was be analyzed to determine if the different hospices represent different design archetypes.

The s*ociology of knowledge approach* was also used to compliment the archetype design method to investigate the mutual production of the social setting (organizational structure) and the ideas (knowledge about hospice care) in each hospice. The sociology of knowledge approach will provide a further analysis of the consensus of goals and values in the hospices and the consequences of different levels of consensus for the delivery of services in hospice.

II. BACKGROUND

The hospice movement emerged in the United States in the early seventies as an anti-medical social movement. The first hospice in the United States, The Connecticut Hospice, began providing services in March 1974 (NAHC, 2002). The early hospice movement has often been likened to other anti-establishment movements born at a similar time in history such as the women's health movement, free schools and food cooperatives (Abel, 1986). Before the Medicare benefit hospices had no formal source of reimbursement and were financed primarily through private pay clients and private donations. They also relied heavily on volunteer workers. A high percentage of early hospices had religious affiliations. Before the hospice benefit, there were no official guidelines or regulations governing the substance of hospice care. Rather, individual hospice organizations were guided by a shared mission: to provide holistic palliative care to dying patients and their families as an alternative to the perceived over-medicalization of death promoted by conventional health care. There was also a strong belief in the benefit of awareness and acceptance of death as opposed to the alleged denial of death prevalent in mainstream medical practice. Hospice care usually consisted of symptom management, psycho-social and spiritual counseling, bereavement counseling, and a variety of other services designed to meet the individual needs of the patients[1].

In the thirty years since the emergence of hospice care, the substance and nature of hospice care has changed dramatically. Many researchers have observed that hospice organizations, which first emerged as anti-medical reformist organizations, have now

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[1] Information about early hospices comes from anecdotal recollections of individuals involved in the early hospice movement. Because early hospices were not regulated, there was very little data collected about their characteristics.

become an institutionalized part of the mainstream health care system in the United States. Some go so far as to argue that hospice organizations represent the institutionalization of "the good death" (McNamara, Waddell, & Colvin, 1994). These critics felt that the major force behind the institutionalization of hospice care was the implementation of the Hospice Medicare benefit in 1983. This act of congress provided for hospice care to be reimbursed under Medicare. In exchange for this reimbursement, hospice organizations became, for the first time, subject to rules and regulations imposed by forces outside of their organizations. Some argue that this institutionalization of hospice care has changed or will potentially change the nature of hospice care significantly (Bradshaw, 1996); (James & Field, 1992).

Institutional theory and Weberian theory of rationalization was used liberally in the early 1980s to make predictions about the affects Medicare regulation might have on hospice care. Institutional theories are commonly used to describe how organizations become more similar to each other. In 1986, Paradis and Cummings used the concept of organizational isomorphism, a term coined by DiMaggio and Powell (1983) to predict how hospice organizations, over time would become increasingly similar to each other as well as to other health care organizations (DiMaggio & Powell, 1983); (Paradis & Cummings, 1986). These predictions about hospice and the affects of the Medicare Hospice Benefit will be discussed further in the last section of this chapter.

Since the implementation of the Medicare hospice benefit, many different types of hospice organizations have emerged. Very little is known about the exact differences between the different organizational structures of hospice and how the each type of organizational structure behaves. This dissertation research is a preliminary step in filling this gap in information.

A. Categorizing Hospice

In research on hospice, hospice organizations are categorized in many different ways. In 2002, the Centers for Medicare and Medicaid Services (CMS) categorized hospices according to their organizational structure/ownership. CMS categorizes hospices as "freestanding," "hospital based," or "home health agency based (CMS, 2002a). Table 1.1 shows that 44.3 percent of Medicare certified hospices in 2002 were independent "freestanding," mostly nonprofit organizations; 30.5 percent were designated "home health agency based," (owned and operated by freestanding proprietary and nonprofit home care agencies.); 24.4 percent of hospices were designated as "hospital based" which means they were operating units or departments of a hospital. And less than one tenth of one percent of hospices (only 20 out of 2,265 in the US) were designated as skilled nursing facilities, meaning they are operating units or departments of a skilled nursing facility or nursing facility (NAHC, 2002).[2]

The problem with these categorizations is that they do not capture many important subtleties of the ownership structure of a hospice and the different ways it can be integrated with other health care organizations. Nor do these simplistic categorizations capture the subsequent consequences of those organizational relationships.

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[2] NHPCO has different estimates about the percentages of different organizational forms of hospice. Their estimates include non-Medicare certified hospices. They estimate that in 2001 there were 3,200 operational hospice programs in the US. Of these, 41% were freestanding, 32% were affiliated with hospitals, 22% were affiliated with home health agencies, 1% with nursing facilities, and 4% unknown. (NHPCO, 2003)

Table 1.1 Number and Percentage of Medicare Certified Hospices, by Auspice, 1984-2001

Year	HHA	Hospital Based	Skilled Nursing facility based	Freestanding	TOTAL
1984 (implementation of Medicare Hospice Benefit)	N/A	N/A	N/A	N/A	31
1985	N/A	N/A	N/A	N/A	158
1986	113 (46.1%)	54 (22%)	10 (.04%)	68 (27.7%)	245
1987	155	101	11	122	389
1988	213	138	11	191	553
1989	286	182	13	220	701
1990	313	221	12	260	806
1991	325	282	10	394	1,011
1992	334	291	10	404	1,039
1993	438	341	10	499	1,288
1994	583	401	12	608	1,604
1995	699	460	19	679	1,857
1996	815	526	22	791	2,154
1997	823	561	22	868	2,274
1998	763	553	21	878	2,215
1999	762	562	22	928	2,274
2000	739	554	22	960	2,273
2001	690 (30.5%)	552 (24.4%)	20 (.01%)	1003 (44.3%)	2,265

***Source: Centers for Medicare and Medicaid Services (CMS), Health Standards and Quality Bureau (CMS, 2002a)** Notes: Home health agency-based (HHA) hospices are owned and operated by freestanding proprietary and nonprofit home care agencies. Hospital-based (HOSP) hospices are operating units or departments of a hospital. Skilled nursing facility-based (SNF) hospices are operating units or departments of a skilled nursing facility or nursing facility. Freestanding (FSTG) hospices are independent, mostly nonprofit organizations.

In other research, especially data that are collected by the NHPCO, hospices are categorized as simply "affiliated" or "not affiliated" (NHPCO, 2003). Greer and Mor (1985) analyzed NHPCO data and categorized hospices as "hospital affiliated" "skilled nursing facility affiliated," "home care agency affiliated," or "not affiliated/freestanding"

(Greer & Mor, 1985)[3]. This categorization of hospices leaves out the multitude of types of relationships that hospices can have with either other hospices or other health care organizations. This categorization does not take into account chain operations, the number of hospices in multi-institutional systems or hospices that are affiliated with more than one type of health care organization, a situation that anecdotal evidence suggests is becoming increasingly common.

The differences in the categorization of hospice organizational forms represents an interesting difference in language used by the hospice industry compared to the language used by organizational researchers from outside the hospice industry. The use of the term "affiliation" to describe organizational relationships would be considered inaccurate by organizational researchers. Affiliation is usually used to describe a more informal contract between organizations as opposed to the way NHPCO uses the term to describe a more formal relationship based on ownership.

There are also other differences in language used to describe hospices coming from inside the hospice industry. NHPCO studies as well as other studies by hospice insiders are more likely to look at profit status as a variable when comparing across organizational structures of hospice (Folliart et al, 2000). To date, no research by the Centers for Medicare and Medicaid Services (CMS) has used use profit status as a variable when looking at organizational structure.

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[3] While some research, especially those who work from inside the hospice industry like the NHPCO, describe hospices as "affiliated" meaning that they share ownership with another organization, for those who study organizations; this is an inaccurate use of the term. In org research, the term "affiliated" means that the organization has a contract with an outside organization as opposed to being affiliated more formally by ownership. In order to be true to the language of organizational researchers, the term "affiliated" will not be used in this dissertation to describe organizations that have the same owner. Instead, terms like "shared ownership" and "integrated" will be used to describe organizations that have the same owner.

Another issue is the identification of hospices and hospice patients. CMS includes only hospices that receive Medicare or Medicaid reimbursement. NHPCO data are more expansive, including hospices that do not fall under the radar of CMS including volunteer hospices that receive no Medicare reimbursement. Since most studies of hospice use CMS data, this means that hospices that do not participate in Medicare are often missing from large data sets causing researchers to greatly underestimate the extent of the expansion of hospice services in recent years. For example, the National Hospice and Palliative Care Organization estimates the number of hospices in the United States to be about 30% greater than does Medicare.[4] NHPCO gets higher estimates because they include hospices in US territories and protectorates, where more non-Medicare certified hospices exist. As a result of this, data on the number of hospices, types of hospices and the number of hospice patients in the United States vary by the source of the data.

B. The Cost of Hospice Care

The Medicare hospice benefit was passed into law with the Tax Equity and Fiscal Responsibility Act in 1982 (Public Law 97-248, &122). Prior to this bill's passing there had been much concern about the high cost of medical care for individuals in their last year of life. Studies showed that 28% of all Medicare reimbursements goes towards the care of people in their last year of life and 50% of those costs are incurred in the last two months of life (Lubitz & Prihoda, 1984); (McCall, 1984); (Hogan, May, 2000). Advocates of Medicare reimbursement for hospice made a strong case that hospice care would prove to be less expensive than conventional care for people with terminal

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[4] NHPCO estimates that there were 1,500 hospice organizations (both Medicare certified and not certified)in 1985; a number which grew to an estimated 3,200 operational hospice programs in 2001, (NHPCO, 2000).

illnesses. The hospice Medicare benefit passed into law rather quickly because data from the earliest studies suggested that it provided a useful service at a lower cost (Hoyer, 1998; Robinson & Pham, 1996).[5] A secondary argument was also made that the Medicare Hospice benefit would afford individuals with a choice in the type of care they received at the end of life with no additional cost to Medicare.

After the first few years of the Hospice Medicare Benefit, the National Hospice Study as well as the Joint Commission on the Accreditation of Health Care Organizations (JCAHO) collected data to determine, among other things, whether hospice care was truly less expensive than conventional medical care at the end of life. Results were mixed. Analysis of these data by the National Hospice Organization (NHO)[6] showed that conventional care expenditures for dying cancer patients are generally lower than the expenditures for hospice care in the period prior to the last three months of life (NHO, 1995). These data showed that the cost of conventional care then escalates dramatically in the last month or two of life because of increased hospital use. In contrast, hospice care expenditures tend to be relatively level in the last year of life, only dipping below the cost of conventional care in the last 3 months of life (NHO, 1995).

Three different studies conducted soon after the implementation of the hospice benefit showed that patients using hospice care received different types of services (usually more home care) but found no differences or only slight differences in costs (Brooks, 1989; Brooks & Smyth-Staruch, 1984; Gray, MacAdam, & Boldy, 1984; Kane, Wales, L., & al., 1984; Oji-McNair, 1985). Other studies showed that the hospice

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[5] The researchers who were contracted by CMS to analyze the earliest data on hospice cost wrote a paper complaining that the Medicare Hospice Benefit was implemented before they had a chance to thoroughly analyze and report on the findings.(Greer, Moore, 1994)

Medicare benefit saved Medicare between $1.22, (Kidder, 1992) and $1.52, (NHO, 1995) for every one dollar spent. Certainly home based hospice charges per day are substantially lower than the hospital and skilled nursing facility charges per day. The National Hospice and Palliative Care Organizations (NHPCO) determined that in 1998, Hospital, SNF and Hospice (routine home care) charges per day were $2,177, $482, and $113 respectively, (NHPCO, 2003). A literature review by Robinson et al. (1996) concluded that the combined research supports the fact that hospice is cost saving only in the last month of life (Robinson & Pham, 1996). Although there is evidence which suggests that hospice care may be less expensive than conventional medical care at the end of life, there is no consensus among experts that electing the hospice benefit results in significant savings to the Medicare program (Austin & Fleisher, 2003). In fact, experts have found that higher quality hospice care may actually cost more than traditional medical care at the end of life (Moon & Boccuti, 2003; Wilkinson, 2003).

Among the different types of hospice organizational structures, research has shown that home care hospice services are less expensive than in-patient hospice care (provided in inpatient hospices or skilled nursing facilities). This is probably because individuals receiving home care hospice are usually required to have a caregiver at home (usually a wife or daughter) who performs most of the patient's personal care services (Banaszak-Holl & Mor, 1996). In a comparison of different hospice organizational structures and their relative costs between the period of 1987-1990, it was determined that freestanding hospices were the least expensive ($77 per day) while skilled nursing

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[6] The National Hospice Organization (NHO) is now called the National Hospice and Palliative Care Organization (NHPCO).

facility based hospices were the most expensive at $93 per day. Hospital-based and home health agency based hospices tied for second at $82 per day (NHPCO, 2000).

The scanty evidence about the cost savings of hospice care have caused some researchers to argue that it is not necessarily the nature of hospice care which has proven less expensive but the result of a selection bias. Robinson & Pham (1996) propose that the people who elect hospice care are people who tend to prefer less aggressive care in general. If this is true, then the argument that hospice is less expensive becomes less persuasive and the argument that hospice provides a much needed choice for patients at the end of life without added cost becomes the salient argument in favor of hospice care.

Nevertheless, the assumption that hospice care is indeed lest costly has expanded its use and change its character in the last 18 years. Since the passage of the hospice Medicare benefit, substantial changes have occurred in the structure, financing and delivery of hospice services in the US. The number of hospice organizations and organizations providing hospice services has increased dramatically from 31 in 1984 to 2,265 in 2001,(NAHC, 2002). In 2001, 2.4 million Americans died and 700,000 of those received hospice care (or one in four of all Americans who died in that year); this figure increased from 540,000 in 1998 (NHPCO, 2003). Of the 700,000 patients who used hospice in 1999, 54.7 percent of these were covered by the Medicare Hospice benefit, (NHPCO, 2000). Among Medicare certified hospices, CMS data show that 70% of patients in these hospices were covered by Medicare (NAHC, 2002).

While the original rational for creating a hospice Medicare benefit was to make end of life care less expensive for Medicare, the research shows that hospice care is not consistently less expensive. The result of this preconception that hospice would be less expensive is that hospice organizations are under great pressure to provide an unprecedented number of services at a low cost. Medicare enforces this expectation of lower costs by setting the per diem reimbursement rate for hospice at a level that is 10 to 20% lower than the average cost of hospice care (MedPAC, May 2002). For the organizational field of hospice, this is a time of exploration and innovation. Hospices seem to be experimenting with different organizational structures and affiliations in an attempt to find organizational models that will allow them to provide quality end of life care at a low cost to Medicare.

C. Hospice Regulations

Another change since the establishment of the hospice Medicare benefit is the increase in institutionalized rules in hospice. Regulations have been written by the Centers for Medicare and Medicaid Services (CMS)[7] and guidelines have been written by the National Hospice and Palliative Care Organization (NHPCO). In addition, accreditation agencies such as the Joint Commission for the Accreditation of Health Care Organizations. (JCAHO) and the Community Healthcare Accreditation Program (CHAP) have also written guidelines for hospice.

Rules written by CMS regulate most aspects of the Hospice Medicare Benefit. In 2001, 90.4% of hospices in the US were certified for Medicare (NHPCO, 2003). CMS has rules about everything from the conditions of participation to hospice eligibility and reimbursement. In Medicare certified/accredited facilities in the year 2000, 70% of hospice patients were covered by Medicare, 9.9% had private insurance coverage, 4.4% were covered by Medicaid (NAHC, 2002). While the CMS criteria officially apply only to Medicare beneficiaries, the regulations, eligibility criteria and reimbursement levels set by CMS are often used by hospice organizations and private insurance companies to set these same criteria for hospice patients who are not Medicare beneficiaries.

CMS eligibility requirements are the most highly contentious aspect of the regulations. According to the CMS requirements, when an individual elects the Hospice Medicare Benefit they waive the right to curative treatment related to their terminal diagnosis (CMS, 1994). To elect hospice, a patient must be eligible for Part A of Medicare and be certified by a physician as being terminally ill. Terminally ill is defined as "having a medical prognosis that his or her life expectancy is six months or less if the illness runs its normal course"(HCFA, 2000). In the original hospice regulation a person could receive hospice services for no more than 210 days. In 1989 the 210 day limit was repealed. Effective with the enactment of the Balanced Budget Act of 1997 (PL 105-33) the Medicare hospice benefit was divided into the following election periods: 1) An initial 90 day period; 2) a subsequent 90 day period; 3) an unlimited number of subsequent 60 day benefit periods as long as the patient continues to meet program eligibility requirements (NAHC, 2002). Before each new election period a patient must be recertified by the hospice medical director as having a terminal illness. The only caveat to this recertification is that the patient must have shown documented "consistent decline" to continue as a hospice patient.

In order to enforce their regulations regarding certified hospice care, CMS makes contracts with state regulatory agencies to oversee the hospice programs in that state. In California, CMS has a contract with the California Department of Health and Human

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[7] The Centers for Medicare and Medicaid Services (CMS) were formerly called the Health Care Financing Administration (HCFA).

Services (DHHS), Division of Licensing and Certification to oversee hospice organizations in three designated regions. CMS requires the DHHS, to conduct a number of different regulatory functions. When a new hospice opens and wishes to receive Medicare reimbursement for their Medicare certified patients, the DHHS conducts an initial survey to determine if the organization meets the conditions of participation (CMS, 1994). The new hospice must be operational and caring for at least one patient at the time of the initial survey. After the new hospice passes this initial survey, they can become officially Medicare certified and can request reimbursement for their Medicare certified patients.

Second, after a hospice becomes certified, the state DHHS then conducts periodic "unannounced" visits where they survey the hospice to make sure the hospice is continuing to meet the requirements for Medicare participation. According to a supervisor at the California DHHS, is not specified in the statutes how often a hospice should be surveyed (personal communication, 2003). DHHS tries to conduct the surveys every 2 to 3 years, but according to a DHHS supervisor, often the DHHS is understaffed and fails to conduct the surveys at this frequency.

In the state survey, the surveyor engages in a number of inspection activities to ensure that the hospice is meeting the conditions of participation. One activity is to review patient's charts to make sure the patient was hospice appropriate. They also examine to see whether there was an appropriate plan of care and whether or not the plan of care was sufficiently executed. The surveyor also interviews patients and family members about the care they received. If the DHHS surveyor finds that the hospice did not meet the conditions of participation, it's referred to as a deficiency. If a hospice is cited with a deficiency, the hospice has a certain number of days to remedy that problem. The surveyor will return after the "grace period" to make sure the problem has been remedied. If it has not been remedied, depending on the seriousness of the problem, the hospice could be made to pay a fine or could be shut down. According to the DHHS, of the top ten survey deficiencies in 2001, eight were for regulations pertaining to improperly documenting the plan of care (see table 1.2). The number and type of deficiencies a hospice accrues during routine inspections is a matter of public record and can be obtained by contacting the DHHS.

Table 1. 2 The most frequently cited deficiencies of US hospices surveyed in 2001.

Citation number	Description of deficiency	% of total deficiencies
L137	Plan fails to state scope, frequency of services	15%
L136	Plan fails to include assessment of needs	12.6%
L135	Plan fails to be reviewed, updated at intervals	12.2%
L134	Plan not established prior to providing care	10.7%
L133	Written plan of care not established	10.6%
L210	RN supervisory visits not made every 2 weeks	9.3%
L200	No plan of care for bereavement services	7.8%
L142	Failure to conduct self assessment of quality	6.5%
L209	Services not available/adequate in frequency	6.3%
L211	No written instructions for patient care	6.2%

Source: A letter responding to questions from the National Hospice and Palliative Care Organization from the Director of the Survey and Certification group, Centers for Medicare and Medicaid. www.hcfa.gov/medicaid/hospice/042401.htm

Third, the DHHS is also responsible for investigating complaints made against hospice organizations. According to an official at CMS regional headquarters, “complaint investigations are the best way to stay on top of hospices” (Personal Communication, 2003). Complaints can come to the attention of DHHS in one of two ways. First, hospices organizations themselves can supply the information for the DHHS to investigate a complaint. Hospices are required to document “adverse events” and these documented adverse events are made available to the surveyor when they come to inspect the hospice. Hospices are also required to conduct self-assessments of quality. This assessment is usually in the form of satisfaction surveys sent to the families of their deceased patients. The results of the satisfaction surveys are made available to the surveyor during their inspection. Second, complaints can come directly to DHHS from concerned individuals. Patients, families, hospice employees or advocacy groups can complain directly to the DHHS about a particular hospice. The fact that a hospice has had a complaint investigated becomes a matter of public record. It is only when that complaint has been substantiated that the content and details of that complaint are made available to the public. If the complaint is not substantiated by the investigation, then the content of the complaint is kept confidential. According to an official at DHHS, the agency is often behind schedule on their scheduled surveys of hospices because investigating complaints is their highest priority (Personal Communication, 2003).

Another source of oversight for hospice organization are the accreditation agencies. 74.6% of all hospices were accredited in 2001 (NHPCO, 2003). The Joint Commission for the Accreditation of Health Care Organizations (JCAHO) and the Community Health Accreditation Program (CHAP) are both accreditation agencies that provide accreditation for home health agencies and hospices.[8] In 2001, 64.9% of hospices were accredited by JCAHO and 6.6% of hospices were accredited by CHAP (NHPCO, 2003). In addition to these agencies, some states also have accrediting agencies. In 2001, 4.2% of hospices were accredited by state agencies (NHPCO, 2003).

A hospice might choose to be accredited for two reasons. First, the accreditation agencies claim that becoming accredited makes a hospice more reputable. Because the survey procedure to become accredited is even more rigorous than the survey procedures for Medicare certification used by CMS and DHHS, accreditation looks good to health care providers and third party payers. According to the JCAHO website, accredited organizations are looked on more favorably by commercial insurance companies, especially by preferred provider organizations (PPOs) and health maintenance organizations (HMOs), and are more likely to be included in their health plan as an eligible agency (www.jcaho.org).

The second reason a hospice might want to be accredited is because both JCAHO and CHAP can provide a hospice with "deemed" status as a substitute for Medicare certification. The Balanced Budget Act of 1997 and the subsequent Balance Budget Refinement act of 1999 gave CMS the authority to allow private, national accreditation organizations to "deem" that a health care organization is compliant with the Medicare conditions of participation. In other words, accreditation by either of these two agencies can be a substitute for the state Medicare certification procedure. If a hospice has deemed status from CHAP or JCAHO, they would not have to undergo the initial state survey procedure for Medicare certification. Although, the state does not give up the right to investigate complaints about the accredited, "deemed" agencies or to conduct unannounced periodic surveys, a "deemed" organization is less likely to receive routine inspection by Medicare state survey agencies (www.jcaho.org).

In order to be accredited, hospices apply directly to the accreditation agency. When the accreditation agency decides that the hospice is eligible, the accreditation agency does an initial site visit and inspection. The hospice must pay the accrediting organization a fee for this inspection. If the hospice wants "deemed" status, that hospice must demonstrate to the reviewer that their program meets or exceeds the Medicare requirements for which they are seeking the authority to deem compliance. In the case of hospices, the hospice must demonstrate compliance with the "conditions of participation" for the Hospice Medicare Benefit as outlined by CMS (CMS, 1994).

When JCAHO accredits a health care organization, depending on the organization's performance during the review, that organization can receive "Accreditation with Full Standards Compliance" or "Accreditation with Requirements for

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[8] Both JCAHO and CHAP consider hospice a "type" of home care agency.

Improvement." If they have requirements for improvement, JCAHO returns within the year to assess whether or not the organization has made the required improvements. Once an organization receives the "Full Standards Compliance" accreditation, JCAHO returns every three years to re-review the organization. While these visits are currently announced to organizations, by the year 2006 JCAHO plans to adopt "unannounced visits" similar to those conducted by the state agencies that survey hospices for Medicare certification. JCAHO also has a complaint hotline where consumers can call either to report a complaint against an accredited organization, or to inquire about whether an organization has received complaints in the past.

Another source of regulation for hospice organizations is the surveillance by the regional Fiscal Intermediary. CMS contracts with fiscal intermediaries, private companies who review Medicare claims from hospices and determine the validity of those claims. One fiscal intermediary will review hospice claims from all the hospices in a certain geographic region. After a Medicare patient dies under the care of hospice, the hospice submits the bill or claim to the fiscal intermediary in hopes of receiving reimbursement for that care. The fiscal intermediary reviews the claim. If a fiscal intermediary receives a claim for hospice care that they find suspect, they will request the patient's chart from the hospice. The fiscal intermediary does not have to inform the hospice about what aspects of the claim they are investigating. The fiscal intermediary looks for: documented evidence of patients' hospice appropriateness, inconsistencies in the charting and any insufficiently documented care. If the fiscal intermediary determines from the chart that the 'hospice appropriateness' of the patient was not sufficiently documented, they can deny payment for that patient. If the patient had been under the hospices care for many months, that hospice can lose thousands of dollars. As a result of these policies, hospices have been forced to become very particular about who they admit as a hospice patient and how they document the care of that patient.

The fiscal intermediary also does routine reviews of claims from hospices. The fiscal intermediary is occasionally instructed by CMS to do routine reviews of all claims of a certain type. For example, they might decide to review every claim from a hospice patient with a certain illness. During the time of research for this study, the regional fiscal intermediary was reviewing all claims for patients with certain non-cancer diagnoses.

A result of all of the regulations and surveying of hospice care is that hospice staff spend a high percentage of their time doing paperwork and documentation. As is shown in table 1.2, the highest percentage of deficiencies comes from errors in documentation of patient care (CMS, 2002b).

D. Hospice Reimbursement

Through the Medicare benefit, payments are made on a prospective, per diem basis. In other words, the hospice is given a daily rate for each qualified patient, but that payment is not made to the hospice until after the patient has received services. The per diem rate is intended to cover all the hospice services including: nursing care, social services, personal care, spiritual and bereavement counseling, durable medical equipment and prescription medication.

The per diem Medicare hospice rate varies according to the level of care furnished to the beneficiary, with four different levels of care. These payment rates are adjusted for each geographic region by that region's hospital market basket index. The current average rates, effective October 1, 2002 are as follows:

Table 1.3 Average per diem Medicare reimbursement rates for hospice in 2002 (NHPCO, 2003)

Level of Service	Per diem rate	Description of level of care
Routine Home Care Day	$114.20	This category is for individuals receiving hospice care at home. The rate does not vary by volume or intensity of services
Continuous Home Care Day	$666.52 for 24-hours or $27.77 per hour	Individuals in this category must need skilled services for a period of at least eight hours within a 24-hour period beginning at midnight. This category is only available for brief periods of crisis and only as necessary to maintain the terminally ill individual at home.
Inpatient Respite Care Day	$118.13	Care can be provided for up to 5 consecutive days in a skilled nursing facility to provide respite for caregiver.
General Inpatient Care Day	$508. 01	Care may be provided in a Medicare certified hospital, skilled nursing facility or inpatient unit of a hospice.

There are four different levels of care reflected by the different per diem rates (see table 1.3). The per diem rate provided to the hospice is different based on the level of care and are adjusted by an area wage index. 94.5% of Medicare hospice patient days in 2001 were covered under routine home care (NHPCO, 2003). These are patients who remain at home with a primary care giver and receive hospice services at home.

Table 1.4. Percentage Medicare expenditures by level of care in 2000 (NHPCO, 2003)

Levels of Care	Percentage
Routine Home care	94.6%
General Inpatient Care	4.3%
Inpatient Respite Care	0.3%
Continuous Care	0.8%

Home based patients can also occasionally be designated at the "continuous care" level of care. 0.8% of Medicare patient days in 2000 were reimbursed as "continuous care" (NHPCO, 2000). A patient is considered continuous when they are having some sort of crisis, for example a pain crisis or a caregiver crisis. When a patient is designated at "continuous care" the hospice must provide them with at least 8 hours a day of nursing care. 51% of this nursing care must be from a registered nurse and 49% can be provided by a certified nursing assistant. Continuous care patients are reimbursed by Medicare at $666.52 per day or $27.77 per hour (NAHC, 2002).

Hospices are also required to provide the families of their home-based patients with respite care. In 2000, 0.3% of Medicare patient days were reimbursed as "inpatient respite care"(NHPCO, 2003). A hospice can admit a home-based patient for up to 5 consecutive days to a skilled nursing facility to provide respite to the patient's family. For "Inpatient respite care", the hospice is reimbursed at $118.13 per day (NAHC, 2002).

Most hospices also provide "general in-patient care" to a percentage of their patients. The hospice facility may have an in patient unit or the hospice may take care of patients who are in another Medicare certified hospital or skilled nursing facilities. 4.3% of Medicare patient days in 2000 were reimbursed as 'general inpatient care"(NHPCO, 2003). As of 2002, the "General in-patient" rate was $508.01 per day (NAHC, 2002).

In addition to the per diem rate for hospice, each patient's reimbursement is capped by Medicare. The Medicare fiscal intermediary calculates the exact amount of each hospice's cap by multiplying the adjusted cap amount by the number of Medicare beneficiaries who elected to receive hospice care from that hospice during a cap period, a 12-month period ending September 30 of each year. For the fiscal year ending October

31, 2001, the average cap amount was $17,390.89 (NAHC, 2002). Each hospice must refund Medicare payments for a patient that exceeds this aggregated cap amount in the designated 12 month period. Hospices are prevented by law from discharging patients whose care exceeds the capitated amount. Set reimbursement rates and yearly capitation on hospice reimbursement provides incentives to admit patients who require less costly care.

Since inpatient care is obviously more expensive than home care, CMS put limitations on the number of total inpatient days that can be offered by any one hospice. Hospices are required to give assurances that no more than 20% of their aggregate patient days are provided on an in-patient basis (Hoyer, 1998). This constraint obviously puts pressure on hospice organizations to admit patients who are more likely to have their needs met by home hospice services and who are less likely to need to be admitted to a nursing facility. A result is that many hospice organizations will not admit a patient unless that patient has a caregiver, which allows the patient to remain at home (Huskamp, 2001).

The fixed Medicare per diem rate that is paid to hospice is often insufficient to cover the daily expenses incurred by hospices caring for dying patients. A 2001 report on the cost of routine home care for Medicare hospice patients conducted by Milliman USA for NHPCO found that the cost of daily care was 10 to 20% more than Medicare reimbursement (NHPCO, 2003). The inadequacy of the per diem reimbursement is particularly salient in the case of patients who have short hospice stays with extraordinary expenses (Miller, February, 2002); (Lynn & O'Mara, 2001). A report by the Robert Wood Johnson Foundation's Changes in Health Care Financing and Organization

Initiative found that the first and last few days in hospice are the most costly (Austin & Fleisher, 2003). Thus, during shorter stays, there are fewer less costly days to offset the more costly ones, resulting in a financial burden for the hospice facility (GAO, 2000).

The capitated, per diem reimbursement rate provided by Medicare for hospice has been shown to be insufficient for many reasons. The rate is based on outdated information about the costs of hospice. In a May 2002 report to Congress, the Medicare Payment Advisory Commission (MedPAC) noted that current per diem rates, although updated for inflation, are based on data from the early1980's and, "probably are not consistent with the costs that efficient hospices incur in furnishing care"(MedPAC, May 2002). The current per diem rates are insufficient mostly because they fail to take into account the increased costs of new pain and symptom management technologies used to alleviate suffering at the end of life (Matherlee, J, 2002).

The per diem rates set by Medicare provide great pressure for hospices to reduce their costs. Furthermore, these rates set by CMS also drive the reimbursement from commercial insurance carriers who rarely if ever meet or exceed the Medicare reimbursement rates.

The financing of hospice has changed in the last decade to include more commercial insurance coverage of hospice services and Medicaid reimbursement of hospice. Currently, 80% of employees in medium and large businesses have hospice coverage through their employer-based insurance plans (NAHC, 2002). In addition, OBRA legislation in 1986 provided for hospice coverage for Medicaid beneficiaries resulting in 46 states currently providing hospice coverage under Medicaid (NAHC, 2002).

Private or commercial insurance companies often negotiate contracts with individual hospices setting their reimbursement rate either equal to the Medicare rate or, if they have a large number of insured patients in the area, they might be able to contract a reimbursement rate lower than the going Medicare rate. Commercial insurance carriers sometimes reimburse hospice on a fee-for-service rate, where they are billed based on the number of visits a patient receives. Often a patient covered by commercial insurance is required to pay a co-pay for each visit, providing an incentive to reduce the number of visits by hospice personnel. When a commercial insurance carrier has a fee-for service rate, they also may not reimburse certain services that hospice customarily provide. In other words, instead of reimbursing comprehensive hospice service, their reimbursement is "unbundled." For example, they may reimburse nursing and social service visits, but may not cover physical therapy or durable medical equipment. This type of situation puts the hospice in a position where they are losing money if they provide the full range of customary hospice services.

Table 1.5 Distribution of Hospice Primary Payment source, 2000 (NAHC, 2002)

Source of Payment	**Percent**
Medicare	70.2
Medicaid/MediCal	4.4
Commercial Insurance	9.9
Out of Pocket	0.2
Other	0.9
Unknown	14.4

While research has not shown that hospice care is substantially less expensive, hospice expansion seems to be driven by this assumption. Due to Medicare reimbursement rates, hospice organizations are feeling greater pressure from the US government to reduce the costs of hospice care. In an acerbic article by the CMS official who participated in the original draft of the Medicare hospice benefit, Thomas Hoyer challenged hospice organizations to "make good" on their promise to provide less costly care (Hoyer, 1998). Furthermore, home care and subsequently hospice care was the target of the Office of the Inspector General's investigation into Medicare fraud in 1994 called "Operation Restore Trust" (ORT). This investigation by the OIG found many hospice programs out of compliance with the Medicare regulations and many hospices were fined or shut down.

Since ORT, much has been published on how hospices can be better at following Medicare guidelines. One affect of ORT was to force hospices to increase compliance by paying more attention to eligibility criteria. Hospices are being forced to be much more discerning about who they admit to hospice care. Theoretically, this new attention to compliance produces an incentive for hospices to admit only patients who have very clear prognoses within the six month limit. Hospices are also more likely now to discharge patients for whom they cannot document "consistent decline" as required by CMS. One hospice administrator complained, "HCFA (now called CMS) puts the fear of God in us. We are forced to discharge these patients who are not showing consistent decline...only to see in the obituaries that they died two weeks later."

Since ORT, the length of service (LOS) of the average hospice patient has declined. Length of service, or the number of days a patient is treated by hospice, is a variable that is commonly measured in studies of hospice. Data from both CMS and NHPCO show that average length of service had declined slightly in the last few years (see table 1.6). According to NHPCO, average length of service has gone from 64 days in 1992 to 48 days in 2001. Data collected by CMS shows average length of service in all hospices decreased less dramatically from 58.9 days in 1995 to 49.9 days in 2001(NAHC, 2002).

Table 1.6 Average length of service by year for US hospices participating in Medicare

Year	Length of service
1989	44.8
1990	48.4
1991	44.5
1992	56.1
1994	58.9
1995	58.8
1996	54.5
1997	50.1
1998	47.6
1999	44.5
2000	47.3
2001	49.9

Source: *CMS, Office of the Actuary, Center for Health Plans and Providers (September 2002).*

E. Hospice Patients and Services

Reimbursement provided by Medicare has allowed hospices to increase not only the number of patients they care for, but they have also begun to care for patients with many different diagnoses. While hospice was originally a philosophy of care targeted primarily at people dying of cancer (and in certain regions people dying from AIDS), the universality of the hospice Medicare benefit has attracted patients dying of other diseases such as COPD, CHF, end stage liver disease and Alzheimer's disease. For example, in 1992, 76% of hospice patients had a primary diagnosis of cancer while only 24% had non-cancer diagnoses (MedPAC, May 2002; NAHC, 2002). By the year 2001 (see table 1.7) the number of hospice patients with non-cancer diagnoses increased to 46.4% (NHPCO, 2003).

Table 1.7 Percent of hospice patients by primary diagnosis in 2001 (NHPCO, 2003)

Primary Diagnosis	**% of total hospice patients**
Cancer	53.6
Heart disease	10
Dementia	7
Lung Disease	6
Kidney Disease	3
Liver Disease	2
Other	18.4

The problem faced with non-cancer terminal diseases like COPD and CHF is that, compared to cancer, they are much more difficult to prognosticate within the six month life expectancy required by Medicare.

The NHPCO has developed general guidelines about how to determine six month prognosis for patients with non-cancer diagnoses, but when tested, these criteria have been shown to lack specificity and reliability (Fox et al., 1999; Stuart, 1999; Stuart, Herbst, & Kinsbrunner, 1995). Despite this, patients with non-cancer diagnoses, especially chronic diagnoses, have a significantly longer survival rate after admission to hospice (Christakis, 1998; Christakis & Escarce, 1996). Patients with these diseases are much more risky for hospices because they tend to be more ambiguously "hospice appropriate" and are more likely to result in a denied claim from the fiscal intermediary.

Since the normal course of diseases like end stage COPD and CHF are characterized by peaks and valleys rather than a predictable downward trajectory, it is risky for hospices to admit patients with these diseases. A patient with a non-cancer diagnosis that initially looks hospice appropriate often either improves slightly or fails to show consistent decline. These are the types of cases where the fiscal intermediaries might be able deny payment based on the lack of documentation of hospice appropriateness.

In addition to the tighter Medicare surveillance after ORT, the decreased length of service in hospice has also been linked to the increase in the number of non-cancer hospice patients. Since chronic, non-cancer diseases are more difficult to prognosticate within the hospice eligibility criteria, is likely to be that persons with non cancer diagnoses are referred later to hospice, when the hospice is more certain that they fit the eligibility criteria.

The expansion of hospice care has caused more knowledge to be generated both about the experience of dying and how to manage symptoms clinically (Seale & Kelly, 1997). As more knowledge is accrued, more consensus has arisen in certain areas about how to manage symptoms clinically. Pain management is one of the areas that has made great advances because of the increased clinical attention, research, and subsequent knowledge about how it is best controlled. The incidence of dying in pain or living with uncontrolled chronic pain has decreased substantially due in part to the efforts of hospice advocates (Seale & Kelly, 1997).

On the other hand, increased knowledge about the experience of dying has also created areas of contention about how to best provide end of life care. For example, there is debate over whether it is appropriate to provide intravenous fluids for rehydration to patients who are dying. Other treatments at the end of life have spawned similar debates because they are treatments that can be classified as both palliative and curative. For example, radiation treatments, which are usually considered curative, can also be used in a palliative sense to reduce the size of painful tumors. Other treatments for CHF and COPD (vasodilators and ace inhibitors) are used as palliative treatments to reduce the uncomfortable symptoms of exacerbations, but have also been shown to prolong life.

One result of the expansion of hospice due to the Medicare benefit is the increasing availability of hospice care in skilled nursing facilities (SNF). Hospice care is available to all Medicare or Medicaid certified patients in skilled nursing facilities. In 1989, CMS established certain protocols for Medicare and Medicaid beneficiaries in skilled nursing facilities to elect the hospice Medicare benefit. A nursing home usually makes a contract with a specific hospice agency to provide hospice care to their nursing home residents who elect the benefit (these nursing homes that contract for hospice care are not counted in the earlier cited percentages of nursing home based hospices). That hospice agency will then provide hospice care and case management to the patient while the SNF continues to provide their room and board. In sum, hospice services are expanding to provide care to a greater diversity of patients with different illnesses and in a wide variety of settings.

III. Organizational Structure in Health Care

Organizational structure is a complicated topic in health care. When trying to describe the organizational structure of a health care organization, many factors must be taken into account, including *ownership structure* (who owns the organization and types and numbers of other organizations they own); *organizational relationships* (relationships with organizations also owned by the same parent organization); *profit status* (both the tax status and the symbolic impact of profit status); and *authority* (structure and location of administrative and managerial forces). In this section, different aspects of organizational structure will be discussed. First, an overview of organizational structure and its affects on the behavior of hospital and nursing home industries will be presented. Finally, background on the hospice industry and changes/trends in hospice organizational structure will be reviewed with special attention paid to issues of ownership, profit status, organizational relationships and authority.

A. Profit status and ownership in health care organizations

In the last 40 years, there has been an increase in the number of investor owned (for profit) health care organizations in the United States. The rise of for profit, investor owned healthcare firms has sparked a great debate among policy makers, researchers and consumer advocates. The core of this debate stems from a concern about whether profit seeking is appropriate behavior for health care organizations. Furthermore, there is great interest and speculation about the consequences of profit seeking on the behavior of health care organizations. Does profit seeking actually improve quality of care by providing more impetus for efficiency and innovation or does it divert funds from patient care, thereby decreasing quality? Furthermore, there has been speculation, not limited to one side of the debate, that profit status has little or no affect on the behavior of health care organizations. Some would say that in an environment of increased competition and fewer financial resources, all health care organizations are forces to act similarly, despite profit status (Gray, 1986).

Typically, industries outside of health care are usually characterized by one type of profit status or the other. For example, most insurance companies are for profit while most religious organizations are not for profit. The health care industry is an exception to this rule. In the highly decentralized health care sector of the United States, medical care is provided by a mixture of investor owned for profits, secular and religious not for profit, and public institutions. In all of these categories, some organizations are independent and some are a part of a multi-institutional systems. Historically, different types of ownership typify different types of health care institutions. Nursing homes have long been predominantly for profit institutions while acute care hospitals were historically private, not for profit. Organizations such as psychiatric and tuberculosis hospitals were often government owned because they treated illnesses that were perceived as public health or safety concerns (Gray, 1986:4).

Increasingly, the patterns of ownership are changing in the health care sector of the United States. Many acute care hospitals, for example, are now converting into for profit institutions and nursing homes continue to be predominantly investor owned. Currently 13% of hospitals are for profit (Gray, 1986:27), and two thirds of nursing homes are investor owned (Harrington, 2000).

There is great debate about the appropriateness of profit seeking in the health care sector in the United States. These debates are grounded in certain beliefs about and labels associated with different ownership types. For example, government owned institutions are stereotyped as last resort, inefficient but equitable organizations. Not for profits tend to be labeled as promoting volunteerism, charity, and the overall public good. For profit institutions tend to be seen as efficient and innovative but ultimately self-interested (Gray, 1986). Because of these ownership related stereotypes, the increase in for profit health care has sparked much debate among those who are interested in improving and expanding health care provision in the US.

Some people argue in favor of inserting the values of capitalism into the health care industry. They believe that the promise of profit will promote more efficiency and innovation in health care organizations and that this will improve health care overall. In addition, advocates of for profit health care suggest that the tax-exempt status of not for profits deprives communities of needed tax revenues.

On the other side of the argument, many people believe that health care for a profit will ultimately undermine the quality and access to health care for consumers. Opponents of capitalistic health care would say that profit seeking decreases the quality of care because it diverts funds and focus from clinical care (Harrington, Woolhandler, Mullan, & Carrillo, 2001:3). In addition, opponents would say that in order to be effective, health care providers must be working with the basic ideals of humanitarianism and altruism, and that providing health care for a profit undermines those ideals.

There has been an assumption (not been limited to one side of the argument) that because of their very different financial motivations, for profit and non-profit institutions will behave differently, resulting in significant differences in the costs and outcomes of care. Research pertaining to this will be covered in the next section. On the other hand, some people posit that in an environment of increased competition and financial pressure, all organizations begin acting in a very similar way, despite profit status. They think that financial pressure will force non-profit organizations to act very similarly to for profit organizations and thus, similar outcomes will result.

i. Profit status in Hospitals

In the United States, for profit hospitals are not a new phenomenon. In the early 1900's more than 50% of all hospitals were proprietary. Since then, the number of proprietary hospitals has declined (Steinwald & Neuhauser, 1970). According to Gray, (1986:26) the for profit proportion of hospitals has remained at about 13% since the early 1970s. Despite the stable percentage, the types of proprietary hospitals have been changing. Since the 1970s there has been a drop in the number of independent proprietary hospitals in favor of investor owned and corporate owned hospitals. Within the for profit hospital sector, the number of hospitals organized in chains doubled between 1973 and 1982 (Gray, 1985:10-12). Some non-profit hospitals form themselves into large systems and imitate the new corporate manner (Gray, 1985:13).

ii. Profit, costs and quality in hospitals

Measuring costs in health care organizations can be complicated. Researchers have their choice of many different variables to measure costs. First, they can look at the expenses an organization incurs while providing health care. This would include overhead and capital costs. Another way to measure costs is to look at the price a hospital charges the payer. For example, they might compare Medicare reimbursement at two different organizations for all patients within a certain period of time. The measurement of costs are further complicated by strategies used by hospitals to minimize costs such as patient selection or marking up of prices. Thirdly, researchers sometimes measure profitability when comparing hospitals based on ownership type. The complication of measuring costs makes synthesizing these data difficult.

According to popular belief, for profit organizations are supposed to provide services less expensively. The stereotype of for profit institutions is that they are run more efficiently. In a synthesis of the existing data, Gray et al (1986) showed that increased efficiency and lower costs in for profit hospitals is a myth. They found that though the results were not entirely consistent, the overall weight of the evidence was that not for profit hospitals controlled their expenses more effectively than did for profit hospitals of the same general size (Gray, 1986:77). They attribute this difference to the fact that not for profit hospitals tend to have higher occupancy rates, which effectively reduce costs per patient.

One question that must be asked when looking at cost is: What is the relationship between expenditures and quality of care? Studies have found that though for profit hospitals spend more money overall, they tend not to spend money in the areas that have been associated with better quality outcomes for patients. Sloan et al (2001) found that while payments for Medicare patients admitted to for profit hospitals were higher than for those admitted to either non-profit or government hospitals, they also found that the quality of care at all these types of hospitals were identical (Sloan, Picone, Taylor, & Chou, 2001). One study by Woolhandler & Himmelstein (1997) found that for profit hospitals, while spending more overall, tend to spend less money on clinical staffing than do non-profit hospitals (Woolhandler & Himmelstein, 1997). This is an important finding because nursing staffing level has been shown to affect quality of care in hospitals (Kovner & Gergen, 1998) and in nursing homes (Harrington et al, 2000). In another study that looked at HMOs, researchers showed that while overall costs are identical, for profits have worse quality scores and spend less on care and more on administration than do non- profit HMOs (Himmelstein, Woolhandler, Hellander, & Wolfe, 1999). In answer to the question about the relationship between expenditures and quality, research suggests lower expenditures on patient care (characteristic of for profit hospitals) are related to lower measures of quality.

iii. Profit status, costs and quality in Nursing Homes

Research on the nursing home industry has shown that non-profit and for profit nursing homes tend to behave differently. While the research has sometimes been contradictory, the weight of the evidence has shown that ownership type is a significant predictor of costs and quality in nursing homes. More specifically, non-profit and government owned nursing homes have higher costs than do investor owned nursing homes (Arling, Nordquist, & Capitman, 1987); (Gertler & Waldman, May, 1994). In 1987, Arling, Nordquist, and Capitman (1987) studied 150 Virginia nursing homes and found that chain and independent for profit homes had significantly lower costs than public/nonprofit homes. The conclusion was drawn that ownership type and profit status does have an effect on the patient care costs. These findings suggest that for profit nursing homes may be more efficient and better at controlling costs.

Most research shows that despite lower costs, non-profit nursing homes provide a higher quality of care. A RAND study found that in New York State, for profit nursing homes have approximately 15.9% lower costs, but the non-profit homes score 3.9% higher in quality of care (Gertler & Waldman, May, 1994). Spector et al. (1998) analyzed 1987 data and found approximately 6% higher death and infection rates among private pay clients in for profit homes compared with private pay clients in non-profit nursing homes (Spector, Selden, & Cohen, 1998). Moseley (1994) conducted a study of nursing homes in Virginia which showed that non-profit nursing homes were more likely to provide clinically appropriate care than for profit nursing homes (Moseley, 1994).

One possible explanation of why more costly non-profit nursing homes tend to provide better quality care is because, while they have lower costs, they divert more funds to direct patient care. Aaronson et al (1994) studied nursing homes in Pennsylvania and found higher staffing levels at non-profit nursing homes and fewer incidences of pressure sores (presence of a pressure sore is an indicator of poor quality care) (Aaronson, Zinn, & Rosko, 1994). Elwell (1991) found that non-profit sector nursing homes allocate more money for direct patient care and have higher staff patient ratios than do for profit homes. Higher staffing levels, especially for registered nurses, have been associated with improved quality of care outcomes (Linn, Gurel, & Linn, 1977) and with lower levels of deficiencies (Harrington, Zimmerman, Karon, Robinson, & Beutel, 2000b). Analyzing 1998 data from virtually all Medicare/Medicaid certified US nursing homes, Harrington et al. (2001) found that not only was nursing staffing lower at investor owned nursing homes, but investor ownership predicted increased deficiencies (Harrington et al., 2001). A study by Fottler et al. (1981) showed that the more a nursing home profits per patient, the lower the quality of care they provide (Fottler, Smith, & James, 1981).

These results strongly suggest that investor owned nursing homes deliver lower levels of care and subsequently lower quality of care than do non-profits or public facilities. The evidence from studies of nursing home facilities strongly suggests that non-profit and for profit nursing homes tend to behave differently. While the evidence suggests that non-profit nursing homes have higher expenditures, they tend to spend more on direct patient care and higher staffing levels and subsequently tend to have fewer deficiencies and better quality care than do investor owned facilities.

iv. Ownership structure and organizational relationships in health care

Ownership structure, or whether an organization is independent or part of a multi-institutional system has been shown to be important in affecting behavior in health care organizations. A health care organization that is part of a multi-institutional system can be structured both horizontally with similar type organizations (such as a hospice that is part of a chain of hospices) or they can be structured vertically with other types of health care organizations (such as a hospice that is owned by an organization that also owns hospitals, nursing homes and home health agencies). Mergers and acquisitions in the health care sector are becoming more commonplace. Hospitals are merging and health systems are buying up all types of health care organizations. In an era of increased competition, belonging to a multi-institutional system is increasingly seen as beneficial to health care organizations because it provides more opportunities to streamline costs as well as providing greater bargaining power in negotiating contracts and reimbursement rates with insurance companies.

Research has shown that ownership structure and organizational relationships affect costs in nursing homes. Holmes found that in nursing homes, behavioral differences among nursing home ownership types in respect to patient care costs tended to distinguish multi-institutional facilities (government owned and hospital based) from the freestanding homes rather than a distinction between for profit and not for profit (Holmes, 1996). In 1987, Arling, Nordquist, and Capitman studied 150 Virginia nursing homes and found that chain and independent for profit homes had significantly lower costs than public/non-profit homes (Arling et al., 1987).

B. Hospice Organizational Structure

The number of hospice organizations in the US has increased dramatically since the inception of the hospice Medicare Benefit; from 31 Medicare certified facilities in 1985 to 2,265 facilities in 2001[9] (CMS, 2002a). Along with the increase in the number of organizations, there has also been a diversification of the types of hospices in the US. In fact, the structure of hospice organizations has changed and diversified to such an extent during the period before the Hospice Medicare benefit that one researcher complained that researchers currently do not have the terminology to describe the different structures (Lupu, 1996). While early, pre-Medicare hospices were often non-profit, free-standing organizations (not associated with or owned by organizations from the main stream health care system)[10], hospices are now very often part of chain operations or multi-

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[9] The NHPCO calculates that there are currently 3,200 operational hospices (both certified and non-certified) in the U.S. including the district of Columbia, the commonwealth of Puerto Rico, and the Territory of Guam.(NHPCO, 2000)

[10] There are no formal data on the types of hospice organizational forms that existed before the Hospice Medicare Benefit. Anecdotal information about the typical organizational structure of pre-Medicare hospices comes from personal communication with individuals who worked in hospice organizations in the 1970s.

institutional systems. Hospice organizations are now commonly affiliated with, owned by, or based in home health agencies, hospitals, and skilled nursing facilities, or a combination thereof (see Table 1.1). A related phenomenon is the increase in number of for profit hospice organizations.

i. Profit status in hospice: what does it mean?

It was not until the implementation of Hospice Medicare Benefit in 1983, when Medicare began reimbursing hospice care, that for profit hospices emerged. The idea that hospice care would be a less costly way to care for people at the end of life spurred a new crop hospice care units within for-profit health care organizations (Robinson & Pham, 1996). In 2001, 72% of hospices remained non-profit, while 24% were for profit (up from 18% in 1999), and 4% were government organizations (NHPCO, 2003).

In the hospice industry, the debate about the appropriateness of investor owned, for profit organizations is especially contentious. Profit status is very meaningful to the people working in hospice. The importance of profit status to those working in the hospice industry can be traced from the historical roots of hospice. The hospice industry started as an anti-medical social movement. Not only were early hospices non-profits, but they were often staffed exclusively by volunteers. In fact, there still remain approximately 200 hospices in the United States that are staffed exclusively by volunteers (NAHC, 2002). Because early hospice care was not reimbursed by insurance, most of their funding was made up of charitable donations and profit seeking was rarely a fiscal possibility.

As a result of its origins in idealism and volunteerism, people working in the non-profit hospice sector tend to vilify the new for profit hospices. Anecdotal evidence suggests that individuals who have worked for hospice for a long time have especially negative attitudes toward for profits hospices. Maybe because the despicability of hospice as a for profit institution was a foregone conclusion, there has been very little research actually comparing service delivery and outcomes based on profit status in hospice organizations. One study of hospices in California (conducted by the administration of a non-profit hospice) showed that non-profit hospices tended to have more extensive bereavement programs than for profit hospices (Folliart, Clausen, & Siljestrom, 2001). Despite this one study, there has been little other research comparing hospice service delivery and outcomes based on profit status.

The profit status of hospices is inextricably linked to their ownership. The first for profit hospices emerged when other for profit organizations (usually home health care agencies) began creating hospice care programs within the pre-existing for profit agency. A more recent trend has been the new crop of investor owned organizations that specialize in providing only hospice such as Vitas Corporation. Another trend is that large multi institutional corporations like Beverley Corporation, which owns nursing homes and home health agencies all over the US, has now opened hospice agencies under a different name. As a result, most for profit hospices are affiliated by ownership with other types of health care organizations, and for profit, freestanding hospices are a rare organizational form.

Profit status is very meaningful to individuals who work in the hospice industry. It is a term that is used quite a bit by the people providing hospice care. In the findings chapter, data will be presented about the meaning of hospice status and its role as a symbol/discourse in hospice care.

Despite the importance profit status to hospice workers, the term "profit status" is really a less accurate way of describing the ownership of hospices. For a more accurate description of the organizational structure of a hospice, it is important to look at the ownership structure and organizational relationships.

ii. Ownership structure and organizational relationships in hospice

Just as with any health care organization, hospices can be owned by corporations that are structured vertically or horizontally. No research has been conducted on hospices that investigates the consequences or horizontal integration, or being part of a chain operation. Theoretically, benefits to a hospice that is horizontally integrated might be the sharing of resources and the sharing of information that may improve the quality of care. A negative impact of horizontal integration might be the pressure of uniformity that might inhibit innovation in the individual hospices that are part of a chain operation. In the section on organizational relationships in the Findings chapter, these possible consequences of horizontal integration on the hospices studied will be discussed.

Organizational relationships in the form of vertical integration (relationships with non-hospice health care organizations that have different established patterns of providing care and different types of financial incentives) are likely to affect the type and timing of care provided by hospice organizations. Evidence of this is that different types of hospices have been shown to have significantly different average lengths of service. CMS reported that freestanding hospices have the longest average length of service (53.8 days); while home health agency based hospices have an average lower length of service of 43.9 days (CMS, 2002a). Another study showed that hospice patients in managed care organizations tend to be referred earlier to hospice (resulting in longer lengths of service) than patients using regular Medicare reimbursement (Virnig, Kind, McBean, & Fisher, 2000). It was theorized that physicians working in fee for service practices have a financial incentive not to refer patients to hospice care (they lose their physician's fee) while managed care organizations have no such disincentive and are actually influenced by the promise of cost reduction when referring their patients earlier to hospice care. These research studies suggest that hospices with different organizational relationships feel different pressures and incentives that affect the care they provide.

Survey research studying hospice organizations often do not capture the wide variety of horizontal and vertical integration present in the organizational field. The National Home and Hospice Study survey classifies hospice organizations as: freestanding, hospital based, or home health agency based (CMS, 2002a). This categorization only takes into account vertical integration. It does not take into account: profit status, government ownership, or horizontal integration. Furthermore, it fails to take into account the scope of vertical information by leaving out the number of organizations owned by the parent corporation and does not have a category for hospices that are part of a multi-institutional system or health system where they might have affiliations with more than one type of health care organization. While some surveys such as the National Home and Hospice Study categorize hospices by their ownership (CMS, 2002a), other studies categorize hospices by their affiliations[11] (Greer & Mor, 1985; NHPCO, 2000) or profit status (Folliart et al., 2001). There has been little data collected

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[11] When using the term "affiliations" the NHPCO is really talking about ownership. They describe "affiliated" organizations as being owned by the same parent corporation. They do not use the term "affiliated" in the conventional sense to describe less formal contract relationships between organizations that are owned by different parent corporations.

so far that uses all these dimensions to categorize hospices. Furthermore, surveys studying hospice often ask if the hospice provides in-patient services (Mor, Masterson-Allen, Ruddock, Kaufmann, & Brostrup-Jensen, 1985). Rarely is it ascertained whether the in-patient beds are within the hospice facility or contracted in another type of health care facility (Lupu, 1996). If the beds are contracted, it is rarely clear in what facility the beds are located and whether or not the beds are dedicated.

In sum, the increased tendency of hospice organizations to be owned by or partnered with other non-hospice health care organizations has raised concerns about the integrity of hospice care (Abel, 1986). It has been predicted that providing hospice care within an organization that does not share these priorities and in which core staff, or worse, administration are trained in mainstream health care practices (with a focus on curing instead of comforting) could theoretically produce a "stripped down" effect on hospice care (Robinson & Pham, 1996). To understand the effect of organizational structure and organizational relationships, it is imperative that researchers create a comprehensive system of categorization to take into consideration the wide variety of organizational structures that currently exist.

iii. Location of authority

Another variable that may be important in explaining the behavior of hospice organizations is the geographic location of the authoritative body and its proximity to the hospice branch. There is very little research about geographic location of authority on the behavior of health care organizations, but this dissertation found location of authority to be an important factor. Location of authority refers to the geographic location of the administrative forces in the health care organization. One study by Greene and Monahan,

(1981) found that distantly headquartered chain operations provide lower care levels than locally owned facilities (Greene & Monahan, 1981). Location of authority is becoming more and more relevant for the hospice industry as more hospitals and health systems begin creating or acquiring hospice organizations. When hospice first emerged most hospices were freestanding and thus, the authoritative body, usually a nurse administrator was on site and local. Currently, many hospices are owned by parent corporations that might be headquartered locally in a different office, or distantly in another state. Often when the authority is not local, this is a sign that the authoritative body is likely administering other health care organizations besides hospice. Often you find a distantly located administrator who is responsible for overseeing both hospice branches and home health care organizations. This can be another source of the predicted "contamination" of the hospice mission by mainstream medical models. The location of authority is an important variable to explore for this dissertation because the three hospices studied in this research, one of the main differences is the locally owned versus distant authority variable.

IV. Conclusion to Chapter One

In sum, previous attempts to ascertain the effects of organizational structures on care delivery in hospices have focused mainly on variations in the cost of care and variations on length of stay/length of service (Kane et al., 1984; Mor & Masterson-Allen, 1990; Mor, Schwartz, Laliberte, & Hiris, 1985; NHO, 1995; Oji-McNair, 1985). These studies are not consistent in how they categorize hospice organizational forms. Furthermore, many of these studies are limited to using length of stay as a primary outcome for measuring organizational behavior. Qualitative research is needed to ascertain differences and commonalties in ideas about good end of life care in the different organizational forms of hospice. Once a description of the ideas about quality in hospice organizations is completed, research is needed to understand how all aspects of organizational structure affects the everyday practice of care in hospice organizations. Research into the effects of organizational structures on ideas and work practices in hospice organizations may increase the ability of policy makers and hospice workers to create more cost effective models without reducing the quality of care.

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CHAPTER TWO. THEORETICAL FRAMEWORKS

I. Introduction

This section introduces two theoretical frameworks central to this dissertation: Resource dependency theory and institutional theories of organizations. *Resource dependency theory* (RDT) is applied to examine the relationship between the organizational environment and organizational behavior. According to RDT, an organization's behavior is determined primarily by the outside environment. The organizational environment includes a number of factors such as: other organizations, funding sources, and the way the organization perceives the environment. *Institutional theory of organizations* is also used in this dissertation to examine the relationship between ideas and organizational behavior. Institutional theory of organizations has its roots in Weberian theory of organizations and is an approach which allows for an analysis of the relationship between prevailing ideas, organizational structure, organizational mission and service delivery. The archetype method, which is derived from institutional theory of organizations, is used to examine how sets of widely held ideas and values underpin the organizational structures and systems.

II. Resource Dependency Theory

The resource dependency perspective views organizations as being primarily affected by outside influence. Access to resources through dependency relations are the most important factor determining the way organizations respond to their environment. Resource dependency theory (RDT) is a perspective that is particularly suited to the level of analysis of this study, which focused on focal organizations, and their relations to other organizations that were critical to their functioning and survival.

The most well known theorists of resource dependency theory are Pfeffer and Salancik. In their 1978 book entitled, "*The External Control of Organizations: A Resource Dependency Perspective*," they stressed the importance of examining external, environmental factors and their affect on organizational behavior (Pfeffer & Salancik, 1978). Thus, when using resource dependency theory, the first task is to identify what aspects of the environment are affecting the focal organization. Pfeffer and Salacik (1978) separate the environment into internal and external factors. They describe two different aspects of the external environment that can affect the level of resource dependency an organization feels and thus, its behavior. 1) The entire system of interrelated individuals and organizations who are related to the focal organization; and 2) other non-related organizations who the focal organization comes into direct contact with.

RDT provides a framework for an analysis of inter-organizational relationships, or relationships organizations have through affiliation or ownership. Competition for resources, or an interdependence based on a reliance on another organization for resources causes uncertainty or unpredictability in an organization. In order to control uncertainty, organizations often make linkages with other organization. These linkages can be either informal, such as contracted relationships, or formal such as those formed through mergers or acquisitions. Studies of resource dependency in health care organizations often look at the number and type of affiliations the focal organization has. One RDT study found that in nursing homes, system membership, or an affiliation with a chain operation suggested greater access to resources and greater flexibility in the allocation of resources (Banaszak-Holl, Zinn, & Mor, 1996). In this study of hospices, inter-organizational relationships such as vertical integration (when the hospice is owned by another non-hospice organization) and horizontal integration (when the hospice is part of a chain of hospices) will be looked at in terms of their affect on the focal organization's behavior, especially on the hospice's ability to innovate.

According to resource dependency theory, one of the most important ways that organizations influence each other is through the control of resources. The focal organization is affected by its environment due to competitive or symbiotic interdependence with other organizations in that environment. This interdependence is often described as "dependency relations." Thus, RDT allows for an analysis of the relationships an organization has with other, non-related organizations which the focal organization depends on for resources. Organizational studies using the resource dependency perspective look at inter-organizational cooperation, referral agents, and other outside organizations or individuals on whom the focal organization relies for access to resources such as funding sources (Provan, Sebastian, & Milward, 1996; Alexander & Morrisey, 1989; Banaszak-Holl et al., 1996).

Other studies have shown that the influence of the Medicare program has an affect on the behavior of nursing homes (Zinn, Weech, & Brannon, 1998). In this study of hospice organizations, resource dependency theory highlights the effects of government funding and access to private foundation funds on the behavior of hospice organizations.

RDT allows for an analysis of organizational structure and its affects on organizational behavior. The structure of the focal organization, according to RDT, plays a part in affecting the organizations behavior because the organizational structure mediates the organization's dependency relations. Organizations are more likely to meet the demands of other organizations if they have the capacity to do so. Banaszak-Holl et al (1996) found that in nursing homes, organizational characteristics had an effect on their ability to innovate (Banaszak-Holl et al., 1996). They also found that for profit status was associated with a greater likelihood that specialty care will be provided, suggesting that differences in mission and motivation influence the decision to innovate in SNFs.

A third aspect of the organizational environment that is not external to the organization but which affects organizational behavior is the "enacted environment" (Pfeffer & Salancik, 1978). According to Weick, "The human creates the environment to which the system then adapts. The human actor does not react to an environment, he enacts it" (Weick, 1969:64). Thus, the third level of the organization's environment can be characterized as the level of the organization's perception and representation of the environment. A focal organization responds to the environment that it perceives. As a result, different organizations can respond to the same environment differently. The enacted environment is a useful thing to look at in these hospices because they are in the same environment and may respond to it differently.

The organizational structure also has an effect on the "enacted environment," or the perceived environment that an organization responds to. According to Pfeffer and Salancik (1978), the organizational structure determines and regulates the knowledge or information an organization receives about its environment. The organizational structure acts as a filter through which the environment is perceived. Thus, the structure can alter an organization's perception of their dependency relations, their uncertainty and their resource dependency and subsequently alter their behavior in response to these perceptions.

The structure of an organization constrains the aspects of an environment an organization will take into account or ignore. Different departments control the information being spread within an organization. The level of bureaucracy or the structure of authority can control the flow of knowledge or information through the organization, thus altering the perception of the environment and altering the organization's response to their enacted environment.

RDT also stipulates why organizations change or innovate. The focal organization addresses the uncertainty of resource dependence by making linkages with the environment designed to either make the organization less resource dependent. Thus, changes in organizational structure or behavior may reflect an attempt to secure a stable flow of resources from the environment (Oliver, 1990). While an organization will accommodate the demands of many interest groups, the organization's likelihood of response to any given demand will increase with the importance of the resource provided and the interest group's level of control over that resource. If few alternative sources for a resource exist, compliance becomes more likely (Banaszak-Holl et al., 1996).

Resource dependency theory was used in this dissertation to look at many different aspects of how the hospices studied responded to their environment. It allowed for an analysis of the relationship the hospices had with their affiliated agencies, and with outside organizations with which they had dependency relations. The areas where this was particularly relevant in terms of their behavior were the dependency relations with government funding agencies, their relationships with other affiliated organizations, as well as individual agents responsible for providing donations to their foundations. RDT also allows for an analysis of some structural factors like profit status and vertical integration and the affect these have on the behavior of the organization. Furthermore, it also allows for an analysis of the effect that the organizational structure has on the 'enacted environment,' or the perceptions of the environment that affected organizational behavior.

III. Weberian theory and the rationalization of Hospice Care

Weberian ideas about the rationalization of organizations have been used to understand how the organizational rules of hospice have emerged over time. The rationalization, bureaucratization and institutionalization of hospice care has been predicted, theorized and documented by many social scientists and health services researchers. This section reviews these arguments and seeks to trace the process of the rationalization of hospice as it moved from an anti-medical social movement to an institutionalized part of the mainstream medical system.

A. Weber's theory of rationalization and bureaucratic authority

Many scholars have identified Weber's theory of rationalization and bureaucratic authority as particularly useful for understanding the phenomenon of hospice as it has evolved from a reformist social movement to an institutionalized part of mainstream health care. The social theory of Weber is primarily focused on in the interpretive analysis of social action. Social action, according to Weber, is a term that describes any sort of human conduct that is meaningfully oriented to "the past, present or expected future behavior of others" (Weber, 1968, vol 1:22). Social action takes place most often within the realm of social relationships. Social relationships occur whenever there is reciprocity on the part of two or more individuals, each of whom relates his actions to the action of others. An inevitable consequence of social relationships is that over time, mutually complementary meanings arise among the individuals participating in the social relationships. These mutually complementary meanings define for each individual what is expected of him (Giddens, 1971:152). In Weber's seminal work, *Economy and Society*, (1946) he identified three ideal types of social relationships or organizations, each of which are characterized by a different type of social conduct, shared meanings, and legitimate authority.

Weber argued that the most stable forms of social relationships are those in which the subjective attitudes of the participating individuals are directed towards the belief in a legitimate order (Giddens, 1971:154). Weber defines 'power' as the probability that an actor will be able to realize his own objectives even against opposition from others with whom he is in a social relationship (Weber, 1968; vol 1:61-2). Every sort of social relationship has the potential to be a power relationship. Weber's concept of 'domination' is more specific. It refers only to those cases of the exercise of power where an actor obeys a specific command issued by another. It is only when the participants in a social relationship believe in the legitimacy of the domination, that the social relationship or organization can be stable.

The three ideal types of legitimate domination; traditional, legal-bureaucratic, and charismatic, are methodological tools used in the analysis of real organizations. Organizations held together by traditional authority are often characterized by a belief in the sanctity of established rules and powers.

Organizations which are held together by 'charismatic' domination are usually ruled by "a certain quality of individual personality by virtue of which he is considered extraordinary and treated as endowed with supernatural, or at least specifically exceptional powers or qualities" (Weber, 1968; vol.1:241). Interestingly, for charismatic domination to be effective, it doesn't matter if this individual really has these qualities, it just matters that he and his followers believe that he does. In this type of organization, there is no fixed hierarchy of subordination, the leader simply has a number of intimates who share in his charisma or have charisma of their own. This kind of organization often does not have any stable or systematic means of economic support. In addition, this type of organization has no fixed principles or rules that they live by. Judgments about the actions of the organization are made by the leader in relation to each particular case. A very important element to charismatic authority is that it is revolutionary or reformist in nature. Each new charismatic leader rejects the rules and ideals of the past and creates new ones. One of the greatest challenges faced by a charismatic organization is its ability to survive over time. Weber predicts that charismatic organizations are forced to routinize in order to survive. For example, the new rules and values which are part of the revolutionary mission of charismatic organizations will, over time become institutionalized rules. This means that the rulers of these organizations begin to have less freedom to make free decisions and become more constrained by normative rules. In other words, shared meanings and values in charismatic organizations become more prevalent over time. In the end, charismatic organizations have a tendency to rationalize, loose their revolutionary nature, become more mainstream and begin to be characterized by legal-rational authority.

In *Economy and Society*, Weber (1968:217-220) outlines the characteristics of organizations which are held together by legal-rational authority. This type of organization (often called bureaucracies) have entrenched sets of normative rules and values. In a bureaucratic organization, the rules are written down. The individuals in the established hierarchy follow the rules of the organization. All inferior workers follow the commands of their superiors because they accept the normative rules, not because they owe any personal loyalty to their superior. Individuals who are higher in the established hierarchy of a bureaucratic organization are just as bound by the normative rules of that organization as inferior members of the organization. In bureaucratic organizations, there are often certain established criteria such as credentials or degrees which must be held obtained before being assigned to a certain position. In the ideal type model, an individual is appointed to a position based on achieving the established criteria, not because of sentimental ties. There is an established hierarchy of offices in the bureaucratic organization and an individual's career is based on moving up through the hierarchy.

Weber (1968) asserted that bureaucracy occurs in modern capitalism because it is the only system that is advanced enough to handle the large administrative task of modern capitalism. He also asserts that the advance of bureaucracy in the world is directly associated with the expansion of the division of labor in various spheres of social life. Thus, bureaucracy promotes specialization of labor and vice versa.

B. Early Hospice as Charismatic

Many sociologists such as Emily Abel (1986), and James & Field (1992) have argued that the early hospice organizations were held together by a legitimate authority similar to Weber's charismatic domination. First and foremost, a charismatic organization must have a charismatic leader who promotes the revolutionary mission of the organization. The charismatic leader of the early hospice movement has been identified as Cicely Saunders who opened St. Christopher's Hospice in London, the first modern hospice in 1967, (James & Field, 1992). Saunders was a highly visible hospice advocate who was referred to as the "Mother Superior of the Hospice Movement" by Prince Charles at the National Association of Health Administrators conference in London in 1985.

Early hospice can truly be characterized as a charismatic type organization in that it was founded based on a strong "mission". In charismatic organizations, the "mission" is often spiritually inspired. James & Field (1992) point out that Saunder's vision of providing care to the dying was inspired by her strong faith in Christianity. While hospice was not formally a Christian institution, the emphasis on awareness of spiritual issues and the overt recognition of the spiritual needs of patients was a central theme of the early hospice movement. Bradshaw (1996) discusses the Christian roots of the early hospice movement and notes that Cicely Saunders "was quite clear that the work of caring for the incurable and dying called for a Christian foundation" (Bradshaw, 1996:411).

Just as charismatic organizations are usually revolutionary in nature, early hospice has been characterized as a reformist social movement. Abel (1986) compared the early hospice movement to other reformist movements in the United States such as the free schools, food cooperatives, communes and other counter-institutions of the 1960s and early 1970s (Abel, 1986:71). Early hospice, both in Britain and in the United States was revolutionary in nature (Abel, 1986; James & Field, 1992). Hospice leaders argued that the modern medical system had failed to provide adequate care for dying individuals. The aim of the early hospice leaders was specifically stated as an effort "to revolutionize the American health care system from the inside out" (Fulton & Owen, 1977:17).

One way that the reformist stance of hospice was made possible was that hospice organizations originally developed outside of the established structures of modern medicine. Taylor (1983), in an analysis of the hospice movement in Britain pointed out how important it was that the modern hospices developed outside of the National Health System (NHS). Taylor (1983) quotes Cicely Saunders in saying that hospice intentionally stayed out of the NHS "so that attitudes and knowledge could move back in" (Taylor, 1983:4). Hospices in the United States also were developed outside of the mainstream medical structure. In the US, Abel shows that the reason for this was two-fold. Not only did hospices feel it was important to their reformist mission to be established outside of mainstream medicine, but also the organizations of mainstream medicine such as hospitals or home health agencies were "skeptical of the hospice movement and wary of associating with it" (Abel, 1986:76).

Another aspect of the revolutionary nature of early hospice was that they challenged the institutionalized rules of modern medical care. Instead of following the traditional rules of practice for patients with a particular disease (otherwise known as "standards of care"), they emphasized the importance of individually oriented care for the dying. An early hospice leader was quoted as saying, "The primary message that must be conveyed to the dying patient is that he is unique and that his needs are special and will be met in an individual way" (Buckingham, 1983:6). Thus, hospice organizations displayed another characteristic of charismatic organizations in that they attempted to avoid set rules and procedures about how to care for dying people. They replaced those with an individualistic approach whereby each patient's case was considered and choices about their care were determined within the context of that patient's particular needs.

Hospice was similar to many of the counter-institutions of the 60s and 70s in its emphasis on promoting an acceptance of the "natural" (Abel, 1986:73). Hospice leaders viewed medical technology as over-used for terminally ill patients and as a major contributing factor to the prolonged agony of dying. They sought to change the views of society to promote the idea that death was a natural event and to promote a widespread acceptance of dying. Central to this was an emphasis on the decreased use of technology and an increased use of palliative and holistic treatments that included psycho-social and spiritual care.

Early hospice was similar to charismatic organizations in that the structure of hospice care challenged the traditional hierarchy established by modern medicine. In the medical model of care, the physician is seen as the utmost authority, dominating over the other health professionals and non-professionals. The original hospice movement minimized control by physicians over the experience of dying by placing equal weight on the skills of diverse professionals. They established a model of care that used interdisciplinary teams made up of professionals and non-professionals who ideally held equal authority over the care of the dying patient. Another aspect of hospice care which challenged the hierarchy of medical model care was hospices attempt to bridge the gap between expert and non-expert. Hospice incorporated non-professional hospice volunteers as an essential element of hospice care. In addition to this, the patient (a non-expert) was expected to be honestly informed about all aspects of their care in order for them to participate actively in all decision making.

Abel (1986) and James & Field (1992) note that the early hospice eschewed stable forms of financial reimbursement. This is characteristic of organizations legitimated by charismatic authority. In order to remain separate from the modern medical establishment, early hospices rarely sought reimbursement from the health care establishment and relied primarily on charitable contributions. They often relied on a cadre of professional and non-professional volunteer workers. To further fuel their financial instability, hospice increased the type of services and the scope of care. They transgressed the traditional boundaries of medical concern and expanded the unit of care to include not only the dying patient, but their entire family. They also expanded services by providing psycho-social and spiritual care in addition to palliative health care. In addition, care to the family did not end when the patient died. Hospice care provided bereavement counseling to families, which continued to be provided to family members for up to a year after the patients' death.

In the 30 years since its inception, hospice has become a well-regarded model for providing quality care to terminal patients. As argued in earlier sections, the number of hospices has grown and expanded all over the world. They have also become more accepted and integrated into the mainstream health care system. The following section will discuss how hospice has become more rational and bureaucratic as it has become more a part of the mainstream health system.

Descriptions of early hospice described above will be used in this research to describe the traditional hospice archetype and to ascertain whether or not the hospices studied deviate substantially from this form.

C. Modern Hospice as Bureaucratic

A central problem identified by Weber for most organizations held together by charismatic authority is the problem of sustained legitimacy. Weber predicts that charismatic organizations are often short lived unless they undergo some routinization. This routinization allows them to be managed more efficiently and to become more financially stable. Routinization (resulting in more bureaucratic organizations) allows institutions to grow, reproduce and persevere over time. Bureaucratic administrations are a more efficient way of managing organizations as they grow. It has been noted by many scholars that hospice organizations in the United States and Britain have moved away from charismatic authority toward rationalization, institutionalization and bureaucratization.

One of the main differences between charismatic organizations and bureaucratic organizations is that the former have as their foundation a mission or spiritual ideal upon which they are founded, often reformist in nature. The later is based on normative rules that are usually not obeyed out of passion, but out of a sense of duty to the normative order. Seale (1991) expressed concern that the expansion and widespread acceptance and utilization of hospice has resulted in a diffusion of the initial ideals and high standards of hospice in some organizations (Seale, 1991). Field (1989) and James & Field (1992) have suggested that when the original dedicated idealists left the organization, the hospice movement became susceptible to the forces of bureaucratization (Field, 1989; James & Field, 1992). They conclude that the rationalization of hospice results in the loss of spontaneity, flexibility and individuality. Bradshaw (1996) followed up on these assertions and also used Weberian theory to specifically discuss the "secularization" of the hospice ideal. Bradshaw (1996) agrees that there had been a marginalization of the original "Christian consciousness" in the hospice movement. She showed how the original spiritual/Christian values of hospice have diminished due to a change in our culture that marginalizes religion and promotes medical technology, aesthetic creativity, and efficient management.

One of the main hallmarks of the early hospice philosophy was its emphasis on holistic care for the dying patient, including emotional and spiritual support. This was a revolutionary concept for mainstream medicine that had always emphasized maintaining professional distance from the emotional responses of patients. What this meant for the hospice professionals was that, instead of maintaining a professional distance from the emotions experienced by dying patients, the staff must engage those emotional responses. Olesen and Bone (1997) wrote about the emotional work of professional nurses in the increasingly bureaucratized organizations of mainstream medicine (Olesen & Bone, 1997). They stated "changes in organizational structures, poses the issue of how emotions and emotional behaviors fare in altering contexts" (1997:311). They argued that efforts to become more cost-efficient are causing increased rationalization of all health care organizations including hospitals, clinics, HMOs and hospices. They suggested that all of the changes posed by rationalization of organizations inhibit the emotional work of nurses and may cause what they call an "emotional lag" whereby health professionals are not able to express the emotions that they would otherwise find appropriate (Olesen & Bone, 1997). Their conclusions are important for this discussion of the rationalization of hospice in that they suggest that the emotional support, so central to the hospice philosophy of care, may be hampered by the increased need for cost-efficiency resulting in the increased rationalization of hospice organizations.

Diversification of services is another characteristic of bureaucratic organizations. James & Field (1992) note that while the philosophy of early hospice was general, the targets of early hospice were relatively specific with a specialization on people dying of cancer. They go so far as to say that hospices "have become synonymous with 'dying of cancer'" (James & Field, 1992:1366). Because of the expansion of hospice services made possible in part by the passing of the Medicare benefit, the traditional specialization of hospice on cancer or AIDS may no longer be possible. The hospice Medicare benefit provides hospice coverage to any person eligible for Medicare Part A who has been given a prognosis of six months or less to live. In addition to acute diseases like cancer, older adults tend to suffer and die of chronic diseases such as chronic obstructive pulmonary disease (COPD) or congestive heart failure (CHF). Even though COPD and CHF are notoriously difficult diseases for predicting death and thus more difficult to fit into the 6 month prognosis required by hospice, they are becoming more commonly seen in hospices (Stuart, 1999). James & Field (1992:1373) go so far as to suggest that the diversification to inclusion of other types of diseases "may pose a potential threat to the identity and practice of hospice care."

Hospice is not only undergoing a diversification in the type of diseases they treat, but also in the location of treatment. Anecdotal evidence suggests that early hospice services were ideally provided in hospice inpatient facilities or provided in the patient's home. Many studies have documented the recent proliferation of hospice services being provided in skilled nursing facilities, palliative care hospital units, and even symptom control or palliative care consulting teams in hospitals and out patient medical practices. The diversification of the location of hospice services is another example of the rationalization of hospices from charismatic/reformist organizations to legitimated members of the mainstream health care system.

One of the main characteristics of the routinization of organizations is when the rules of the organization become established or, as Weber says, "written down." The original hospice philosophy emphasized the importance of meeting the individual needs of patients and having the freedom to respond spontaneously to the needs of patients. Early hospices accomplished this by having very few "written rules," a circumstance made possible by the fact that they existed outside of the mainstream medical establishment. As hospice has become a more accepted part of the mainstream medical establishment it has been continually undergoing a process of establishing their own rules, adopting rules from mainstream medicine, and being forced to adopt rules from the State.

D. Critique of Weber's theory of rationalization

Weber's theory of rationalization is particularly applicable when looking at current end of life care as a product of a socio-historical process. It is effective for understanding the evolution of hospice as an institution. But at the same time, this theory is over-deterministic and does not allow for some diversions from the outlined course of rationalization. Also, this theory does not provide for an analysis of end of life care from the perspective of human agency or experience. Within the policies of hospice, there are still opportunities for individual choice. While the policies regulating the provision of hospice under Medicare may be the same for all individuals, they do not result in the same experience of dying under those regulations. Hospice care is still being provided in a multitude of settings with equally diverse approaches to care. Weber's theory of rationalization does not allow for analysis at the inter-organizational level.

Seale (1998) critiques what he calls the "bureaucratization thesis" and asserts that this thesis depends largely on the "insinuation about what actually happens in hospices" (Seale, 1998:116). He also turns the argument inward and suggests that this thesis is an attempt to fuel a flagging revivalism, by giving the hospice movement a new cause to fight against… the bureaucratization of an ideal. Seale quotes Giddens on the limitations of Weber's theory of bureaucracy, "it can be argued that rather than tending toward rigidity, (such) organizations produce areas of autonomy and spontaneity which are actually often less easy to achieve in smaller groups" (Giddens, 1990:138). In sum, the bureaucratization thesis is just that, a prediction; and there has been little empirical evidence to back up these predictions about the changes in hospice and the consequences of those changes.

Theorists and researchers have predicted that the changes in modern hospice represent the emergence of a substantially different organizational form or archetype. They describe changes in the structures and systems of hospice and predict that these changes are somehow related to differences in the philosophy of care. What they are really worried about is not simply changes in hospice structure, but they are worried about changes in the hospice philosophy that will promote a different or lower level of care in hospice. Weberian theory is useful for making predictions about the changes in the structure of hospice, but it is less capable of understanding the relationship between the structure and the underlying values or philosophy. In the next section, the archetype method (derived from institutional theory of organizations) will be described which is a way of looking at the underlying beliefs and values in an organizational field and how those underpin the organizational structure. The archetype method is used in this dissertation to determine whether the critics of hospice were correct in predicting a substantial change in both the structures and philosophy of hospice care.

IV. Institutional Theories of Organizations

Institutional theory is an appropriate framework to use when studying hospice organizational structure and behavior for two reasons. First, using institutional theory is historically appropriate because most of the early analysis of hospice organizations was based on concepts from Weberian theory, or institutional theory. Second, using institutional theory is also appropriate because institutional theory of organization privileges the study of shared ideas or values and the hospice field is particularly known as an organization that was founded on a philosophy or ideal. In this chapter, a discussion of institutional theory will be presented followed by a description of the archetype method, and how both were used to design this study and to analyze the data from this study.

While resource dependency theory provides a framework for looking primarily at how an organization is affected by the outside environment, institutional theory of organizations provides a framework for understanding how the ideas and beliefs that exist within an organizational field come to affect organizational behavior. Institutional theory of organizations addresses the idea that, over time, shared beliefs and norms that exist within organizational fields become institutional rules. The term "institutionalization" is defined by Scott (1987) as "a process by which beliefs and norms come to be more formalized as rules and regulations which constrain and shape organizational behavior and structure."

Institutional theories of organizations have their roots in interpretive social theory. Until the introduction of institutional concepts, organizations were viewed as being shaped largely by their technologies, their transactions, or the power-dependency relations growing out of such interdependencies. Institutional theorists have not dismissed the view that environment influences organizational structure, but they have expanded these theories to acknowledge the symbolic aspects of beliefs and culture, which act to shape organizational forms. Most institutional theories privilege the effects of normative belief systems and shared socially constructed views of reality on the structure of organizational forms. Institutional theories of organizations, while all look at how organizational fields are held together by shared definitions of social reality, vary to the extent that they view institutionalization as a process or an outcome. Meyer and Rowan see institutionalized rules and norms in organizations as created mostly by forces outside the organization (Meyer & Rowan, 1977). DiMaggio & Powell (1991) share this belief that societal norms influence the institutionalization of organizations (DiMaggio & Powell, 1991). Zucker, on the other hand, was more interested in studying how institutionalized elements of organizations commonly arise from within the organization (Zucker, 1987). She considered that institutionalized elements of organizations are highly stable and actually create new institutional elements, or rules. In addition, Zucker thinks of institutionalization of organizations as a process and thus, emphasizes the importance of an historical approach to the analysis of organizations. In the study of the institutionalized ideas of hospice organizations, this study seeks to understand both how shared beliefs and rules emerge from within the organization; as well as taking into account how these institutionalized elements are shaped by forces outside the organizational field.

Institutional theory of organizations is clearly a descendent of Weber's (1968) theories pertaining to the inevitable rationalization of organizations, discussed in the background section. Institutional theorists, for instance, believe that the institutionalization of organizations leads to stability. DiMaggio & Powell (1983) have theorized that institutionalization is not limited to individual organizations, but that, as members of an organizational field seek greater stability, institutional isomorphism occurs. They define isomorphism as "a constraining process that forces one unit in a population to resemble other units that face the same set of environmental conditions"

(DiMaggio & Powell, 1983). This idea explains the process by which different organizations within an organizational field come to share institutionalized rules.

In their article entitled "The Institutionalization of the Good Death" McNamara et al. (1994) argue that what we see is not just the bureaucratization of the rules of hospice, but actually the institutionalization of what it means to have a "good death" (McNamara, Waddell, & Colvin, 1994). They trace the concept of a "good death" and show how it's meaning has been informed at different historical periods of time. They show how, in earlier historical periods, the event of death had been seen as one fixed event in time. In the 1965, just before the time when the hospice movement came into being, scholars began creating models of dying which involved stages. Glaser & Strauss (1965) studied the behavior of dying patients and developed models of the stages of death awareness . In 1969, Kulber-Ross created her psychological model of the "stages of dying," further transforming the meaning of "good death" from a that of a fixed period of time, to a meaning that may be viewed as "a complex set of relations and preparations" (Kubler-Ross, 1979; McNamara et al., 1994). Through interviews with registered nurses who care for dying patients, McNamara et al., show that there is a certain level of agreement on the characteristics of a "good death." These characteristics include: open communication, open awareness and patient autonomy; holistic care and symptom control. McNamara et al. argue that it is not necessarily hospice, but the ideas about what it means to have a "good death" that have been institutionalized. They further suggest that this institutionalization itself poses a contradiction and conflicts with the creativity and flexibility inherent to the ideal of a good death.

Institutional theory of organizations was particularly useful in designing this research and for looking at the relationship between the ideas or organizational mission, and the structures and systems of the hospices studied. In this study, the archetype method of classification, which is derived from institutional theory of organizations, was used to examine in detail this relationship.

A. Archetype Method of Classification

The archetype method was created by Greenwood and Hinings, two organizational theorists concerned with practical methods of measuring change or difference in organizational forms within a particular organizational field (Greenwood & Hinings, 1988; Greenwood & Hinings, 1993) This method of classification is used to determine whether or not there has been a transformation in organizational form within a particular organizational field. It was used in this research, not to look at change over time in a particular organization, but to determine the extent of the differences between different hospice organizational forms.

The archetype method has its roots in institutional theory of organizations. According to Greenwood & Hinings, organizational structures should be seen as "embodiments of ideas, beliefs and values which constitute an overarching and prevailing interpretive scheme" (1988: 294). The archetype method stems from institutional theories of organizations that look at organizational structure as a product of the ideas, values and goals within an organization. Thus, an archetype is a coherent set of structures and systems that is underpinned by a set of values or norms called an "interpretive scheme" (Greenwood and Hinings, 1988:282). They argue that structures and systems do not constitute a disembodied organizational frame, but rather are infused with meanings, intentions, preferences and values. Therefore, when trying to understand organizational structure, it is important to also look at the underpinning ideas and values (or interpretive scheme) that inform and bind those structures.

While some people might measure organizational change by looking at level of rationalization, aspects of authority, or financing mechanisms, Greenwood and Hinings (1993) developed a method of determining whether or not transformation had occurred in an organizational field by measuring the shared beliefs, ideas, and values of individual organizations within an organizational field. They call these shared ideas, beliefs and values the organization's "interpretive scheme" (Greenwood & Hinings, 1993). More particularly, the interpretive scheme constitutes three different aspects of an organizations beliefs and values. The *first* aspect of the interpretive scheme are beliefs about the appropriate domain of operations or "raison d'etre." In other words, they look at the ideas within an organization about **why** this organization exists and **what** is its purpose. *Second*, they look at the beliefs and values about appropriate principles of organization. These are ideas about **how** the organization should be organized and what is the appropriate structure and method of operation for the organization. *Third*, this method looks at beliefs about the appropriate criteria that should be used for evaluating the organization's performance. In other words, ideas about factors that determine whether or not this organization is a success or achieving its goals. True change in an organizational form is called a new "archetype." According to Greenwood and Hinings, "An archetype is thus a set of ideas, beliefs, and values that shape prevailing conceptions of what an organization should be doing, of how it should be doing it and how it should be judged, *combined with* structures and processes that serve to implement and reinforce those ideas" (1988:295).

Greenwood and Hinings combine the notion of archetypes with the concept of tracks of change to help compare the process of organizational change over time (1993:1055). They distinguish between organizational fields that experience no change (inertia), fields that begin changing but then do not complete the transformation (unresolved excursions), and those organizational fields in which new archetypes emerge (transformations). It is only when there is a distinct change in all three elements of an interpretive scheme combined with a change in structures and processes, that it can be determined that a "transformation" in organizational form has occurred. If a transformation has occurred, it can then be said that a new archetype exists within the organizational field.

Most organizational fields encompass just one archetype. DiMaggio and Powell for example, use the term "institutional isomorphism" to refer to the tendency for organizations within fields to develop similar norms, structures and systems (1983:148). For example, most insurance companies are the same archetype. Kitchener (1998) refuted this presumption that organizational fields are always characterized by one archetype by conducting research in hospitals in the UK. Using the archetype method, he showed that, especially in the modern health care industry, change can occur in the interpretive scheme, structures and systems within organizational fields that is distinct enough to be characterized as an archetype transformation. According to Kitchener, the organizational fields within the health care industry are particularly susceptible to encompassing competing archetypes.

While institutional theory of organizations looks at norms and values in organizations that have been institutionalized, it does not account for a lack of consensus about norms and values within any particular organization. The archetype method expands on the institutional theory of organizations to account for change in the ideas of an organization. Because the interpretive scheme of an organization often serves the function of justifying the uneven distribution of power and resources, once in place, they are extremely difficult to change (Ranson, Hinings, & Greenwood, 1980). But change in interpretive scheme does happen. One way to identify change in the interpretive scheme of an organization is to identify a lack of consensus in the interpretive scheme. Although archetypes are seen to comprise a set of structures and systems, it is not suggested that any organization within a field, exactly resembles any one archetype.

If an interpretive scheme lacks consensus within a field, organizations may be between archetypes or a 'hybrid' archetype. For example, in the beginning stages of organizational change, there may only be consensus in some of the elements of the interpretive scheme, or there may be a wide variety of ideas. A "hybrid" archetype can be considered to be a very unstable form. It often is characterized by not one solid interpretive scheme, but with two or more contradictory interpretive schemes that compete for legitimacy and resources (Kitchener & Harrington, 2002). A hybrid archetype can exist for a period of time, but may eventually evolve into a different archetype all together. The archetype method requires a measure of the level of consensus in order to describe the extent of organizational change. Classifications are made by using the interpretive scheme of the original archetype of the organizational field as a baseline against which the interpretive schemes of potentially new archetypes are measured. In this way, archetypes are similar to Weber's ideal types. It is only when there is a new interpretive scheme, with a relatively stable level of coherence in all three elements that it can be determined that a new archetype or organizational form exists.

While archetypes are often deeply institutionalized and difficult to change, they can be subject to both internal and external challenges (Brock, Powell, & Hinings, 1999). This research raises the issue of whether one or more new archetypes have emerged in the organizational field of hospice care. In this research, the archetypes and interpretive schemes of the hospices studied will be compared to the classic or traditional model of the hospice archetypes. The traditional model of the hospice archetype was ascertained through the research on early hospice described in the Weberian theory section of this dissertation. The interpretive schemes, structures and systems of each of the three hospice organizations in this study were described and the coherence of those schemes were measured. Through a comparison with the traditional hospice archetype, it was ascertained whether new archetype have emerged in the field of hospice organizations. The identification of a possible new archetype among the three hospices studied would not necessarily be enough to prove that transformation has occurred. But it would strongly suggest that a larger research study should be conducted to identify new archetypes in the field of hospice care

B. Sociology of Knowledge Approach

The institutional theory of organizations provides an analysis of how ideas and normative beliefs produce the structures and systems of an organization. Institutional theory and the archetype method also allow for an analysis of how ideas and beliefs within an organization produce the structures and systems. This theoretical framework falls short though, when trying to understand the opposite direction of the relationship: how the structures of an organizational field produce the ideas. RDT views this relationship in terms of the "enacted environment" or how an organization's structure mediates and filters the knowledge of the environment, thus changing how an organization responds to that perceived environment (Pfeffer & Salancik, 1978). The sociology of knowledge approach can contribute to both of these theories by examining the opposite direction of the relationship. The sociology of knowledge approach goes farther than RDT by promoting the notion that structures don't just modify ideas or knowledge, they produce knowledge. The sociology of knowledge was used in this dissertation to understand how social structure produces the ideas in an organization. Data about the ideas of an organization using the sociology of knowledge approach enhanced the descriptions of the interpretive schemes of each organization providing for a fuller understanding of the differences between the hospices. In this research, the sociology of knowledge also helped to understand the mutual production of organizational structures and ideas in hospice organizations.

The sociology of knowledge is not a theory per se, but rather an approach common to many sociologists working within a social constructionist perspective. The classic premise of the sociology of knowledge is that ideas are shaped by the social settings in which they take place (Mannheim, 1936). While approaches differ slightly, there are three themes common to all sociology of knowledge approaches: (1) ideas about the world are relative to particular times, places, and social groups; (2) ideas are viewed as socially derived from the practical interests of these groups; and (3) the interests of a social group arise out of its position in a larger social structure (Anspach, 1993).

Renee Anspach (1987) used the sociology of knowledge approach to study how organizational structure, societal structure and social relations influence the ideas and the practices of the different health care professionals working in the neo-natal intensive care unit (NICU). She conceptualizes the organization as an, “ecology of knowledge” (Anspach, 1987). Anspach shows that medical knowledge about neo-natal intensive care is not an objective truth, but a set of socially constructed ideas. For example, in her research she found that as a result of the way a hospital is structured, different types of staff accrue different types of knowledge about their patients which result in different prognoses. She showed how doctors and nurses have very different kinds of interactions with patients. In the NICU, a nurse’s interaction with the patient involves long periods of time where the nurse is very physically intimate with the child. The data the nurse collects about the child are based on knowing the child over time, getting to know the child’s temperament, their family and support network. Anspach calls the knowledge or data that the nurse accrues from these experiences with the child “interpretive cues.”

The resident physicians, on the other hand experience the child in very different ways. The physicians rotate through the hospital in month long blocks, so they only work in the NICU for a month every year. Thus, their experience with a particular child never spans longer than one month. The data they collect in order to make decisions about the child’s care come predominantly from short physical exams, laboratory values, and other quantitative measurements of the child’s condition. Anspach calls this quantifiable data collected by the physicians, “technological cues.” The way that both nurses and doctors interact with the child and the kind of data or knowledge accrued by these interactions are thus influenced or produced by the structure of the organization and the individual's position in that structure.

Anspach then problematizes the constructed medical knowledge by showing how these different kinds of knowledge have consequences for the child's prognosis. Because of their different locations in the social structure of the hospital, physicians and nurses accrued different kinds of knowledge about the child's condition, thus, they tend to arrive at different prognoses for the same child. Anspach observed case conferences were nurses and physicians met to discuss whether or not to continue treating particular children. Because of their different kinds of knowledge about and prognosis for the child, Anspach found that nurses and physicians often disagreed about whether or not to continue supporting the child's life.

Just as nurses and physicians have different levels of power and are at different places in the hierarchy of the hospital, Anspach found that the kinds of knowledge they accrue about neo-natal care, resulting from the type of work they do, are afforded different values. Anspach showed how technologically based information about the newborn are the only data that can be entered into the chart. She found that "technological data" have the power of biomedical "truth" to legitimize them. The knowledges, or "interpretive cues" obtained by the nurses through long term interaction are considered to be "gut feelings" and have little scientific value. Anspach found that the social organization of the NICU makes it so information and ideas that are based on biomedicine and technology have dominance over intuitive kinds of knowledge that comes from interacting with a patient. The hierarchical nature of the social organization thus creates hierarchies of knowledge. These knowledges are enacted in practice relative to the power ascribed to them by the hierarchy of the organization. In the end she found that the opinion of the physician predominated over the opinion of the nurse in these decisions, not only because of their higher place in the hierarchy of the hospital, but because of the hierarchy of their different types of knowledges.

Anspach (1987) looked at a particular kind of idea: how decisions are made about premature babies' prognoses. She looked at the relationship of these ideas to one type of social setting: the neo-natal unit in a hospital. The research presented in this dissertation investigated a more complex set of relationships. Instead of looking at how ideas are constructed in one organization, this research looked at different types of organizations within the field of hospice care. This research looked at one kind of knowledge: ideas about what constitutes appropriate end of life care, and the relationship of these ideas to many aspects of the social setting: organizational structure, organizational relationships, and access to resources. It is possible that different organizational forms of hospice care will produce different categories of knowledge about end of life care. Thus, this dissertation seeks to understand how ideas about end of life care may be constructed differently because of the social setting particular to each organizational form within the field of hospice.

Sociology of knowledge is a good approach to use for studying organizations and the knowledge that is produced within them. It does not look at organizations and their relationship with the outside society in a dichotomous way. It also does not create false dichotomies between organizational structure and the individual agents who work within the organizations. It takes into account all of these levels of analysis: micro (individual), meso (organizational), and macro (societal), the relationships between these different levels, and the subsequent knowledge that is produced by these relationships. Finally it takes into account the mutual construction of (all three levels) the social setting and the knowledge that is produced.

In conclusion, the three theoretical frameworks used in this dissertation compliment each other in addressing different aspects of the relationship between social structure, ideas, and service delivery in hospice organizations. The age old debate among sociologists about privileging structure or agency in the analysis of the social world is often resolved by an analytical stance with looks at the mutual construction of micro and macro aspects of the social world. The sociology of knowledge, as used by Anspach, attempts to look at the construction of ideas and structure as a mutual and ongoing process. In this research, the sociology of knowledge approach will be used to supplement the archetype method and resource dependency theory in understanding the relationship between ideas and organizational structure in hospice.

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CHAPTER THREE. METHODOLOGY

I. Sample

This research is a qualitative descriptive study of organizational forms within the organizational field of hospice care in one county of California. For the purposes of this study, the organizational field is defined to include hospices only in one county. All the hospices studied were Medicare certified. In-depth case studies were conducted with three different hospice organizations, each with a different organizational structure. The organizational structures selected for this research are based on information derived from informational interviews conducted with a number of hospice administrators and hospice medical directors from the selected geographic region. They also reflect the classifications of organizational forms used by previous survey research on hospice organizations. The main constructs used to classify hospice organizations for the purposes of this study were: for-profit vs. non-profit and freestanding vs. affiliated (see table 3.1).

Table 3.1 Hospices studied based on organizational structure.

	Free-standing	Affiliated
Non-profit	*	*
For profit		*

* *indicates hospices that were recruited for this study.*

The term "freestanding" includes hospice organizations that are a single institutions and are not affiliated through ownership with any other health care organization. The term "affiliated" reflects a term used by the National Hospice and Palliative Care Organization to classify hospices. A hospice is "affiliated," when it is owned by a parent corporation that also owns other health care organizations. Thus, it is affiliated through ownership. Hospices can be affiliated either with other hospice organizations such as those that are part of a chain operation (horizontal integration) or they can be affiliated with other types of health care organizations such as a hospice that is affiliated with a nursing home, hospital or home care agency (vertical integration). In addition, hospices can be affiliated with a combination of organizations.

The main categories of hospices as defined by the Centers for Medicare and Medicaid Services (CMS) include: freestanding (30.5%), home health agency based (24.4%), hospital based, (44.3%), and SNF based (.01%) (NAHC, 2002). This research included case studies of three hospices: one not for profit, freestanding hospice; one for profit hospice owned by a large national corporation (affiliated with both SNFs and home health agencies); and one non-profit hospice owned by a regional health system (affiliated with home health agencies and hospitals).

While the first section of chapter four will discuss in detail the exact organizational structure of the hospices studied, it is important to note that the hospices studied in this research represented the diversity of organizational forms in the county studied, but they are not exactly representative of the organizational forms of hospice as classified by CMS. Most notably this study does not include a hospice that could be categorized definitively as "hospital based." One hospice studied did have affiliations with hospitals, but it does not exactly meet the criteria of being an operating unit or division of a hospital as set forth by CMS (see chapter one, categorizing hospice). In the county studied, no hospital based existed.

It was important to include hospices that are affiliated with or owned by non-hospice organizations in order to look at how these affiliations may affect ideas and service delivery in hospices. Because more than 90% of hospice days of care are provided in patients' homes (NHPCO, 2003), in-patient hospice facilities were eliminated from this sample. While the organizations studied did not have in-patient units, all of the hospices did provide care to patients in skilled nursing facilities and residential care facilities. Missing from this sample was a for-profit, freestanding hospice. Hospices of this particular structure are very rare in the United States and did not exist in the county where this research was conducted. In fact, in the CMS category for "freestanding" hospices they indicate that most of these freestanding hospices in the United States are also non-profit (CMS, 2002a).

Hospices in managed care organizations were also not included in this study because of resource constraint. In addition, most managed care organizations typically contract out with other hospice organizations for their patients' care. While there was at least one managed care organization in the region that provides hospice services directly, this is unusual.

All of the hospices studied were Medicare certified, consistent with the fact that almost all of the hospices in the US are currently Medicare certified (NHPCO 2003). Volunteer hospices and hospices that are not Medicare certified have rarely been looked at by researchers. Because they are not certified by Medicare and are not included in the

National Home and Hospice Care Survey, it is unclear how many volunteer hospices exist in the United States today. There were no volunteer hospices in the region covered by this research.

In sum, the hospices selected for this research reflect the organizational diversity in the county that was studied. There are some prevalent types of hospices that were not included in this study, the most notable is a hospital based hospice.

II. Data Collection

Data were collected in each of the research sites using the general principle of triangulation. Triangulation refers to collecting information from a diverse range of individuals and settings using a variety of methods, (Denzin, 1978). Three different qualitative data collection methods have been employed: semi-structured interviews, participant-observation, and collection of archival/textual data. Each of these methods will allow for the collection of different kinds of information.

Table 3.2 Data collected in each hospice studied

	Semi-structured interviews	**Observations in staff mtgs/training**	**Observations in case conferences**	**Shadowing staff**
Hospice A	8	5	10	3
Hospice B	8	5	8	4
Hospice C	8	4	5	2

A. Semi-Structured Interviewing

Interview data can be a valuable means of gaining descriptions of actions and events that are not observable. This is especially important for this study because this research studied organizations that serve an especially vulnerable population: the dying. For both reasons of privacy and ethics, there were some aspects of the hospice work practices that the researcher did not have access to, such as the personal care of patients, or during times of bereavement counseling when it would not have been appropriate to have a researcher in the room observing. Often, a phenomenon of interest would be alluded to during an observation. Subsequent interviews provided an opportunity to have a subject expand further regarding that phenomenon. Interviewing participants provided opportunities to check the accuracy of information or test conclusions.

Semi-structured interviews were conducted with selected staff members of each hospice organization under study. Eight interviews were conducted in each of the organizations. A staff member was eligible for an interview if they had been actively working for the hospice organization for at least six months. In each organization, an initial structured interview was first conducted with the hospice administrator/director to ascertain initial descriptive aspects of the organizational structure, financing, and service delivery (see appendix A). In the initial interview, the administrator was asked for an organizational chart and a list of employees and their contact information. This was also an opportunity to obtain a calendar of upcoming meetings and events, and to obtain permission to sit in on particular meetings. The administrator interview was followed by semi-structured interviews with other members of the hospice clinical staff including: medical directors, CFOs, nursing staff, social work staff, bereavement counselors, chaplains and volunteer coordinators. Interviews with the clinical staff members revealed how the structure of the organizational, relationships with outside organizations, the structure of services and the structure of authority were related to the staff's views on end of life care (see appendix B). After the interviews with the clinical staff members were completed, follow up, or exit-interviews with the hospice administrators were conducted.

This was a useful means of determining the consensus in ideas about end of life care and level of consensus about the goals, operations and evaluation methods (elements of the design archetype) among the clinical staff and administration of each hospice organizations. Interviews with all staff members were tape recorded and transcribed verbatim.

B. Participant Observation

Observation often enables researchers to draw inferences about someone's meaning and perspective that couldn't be obtained by relying exclusively on interview data. For example, individuals often say one thing and do another, or do something that sheds light on a phenomenon that was not described clearly in an interview.

Participant observation research was conducted for approximately 6 to 10 weeks in each of the three hospice organizations. For this study, observations were made: in case conference meetings, in other staff meetings/training sessions, while shadowing staff, and during informal conversations.

The purpose of participant observation in this study was twofold. First, observing in staff meetings and events served the function of providing an opportunity for the researcher and hospice staff to get to know each other. Seeing the researcher in meetings week after week helped to establish a rapport between the hospice staff and researcher and probably made the staff members more agreeable to being interviewed. Furthermore, it allowed the researcher to meet the staff and identify subjects to be interviewed.

The second purpose of participant observation was to help understand the structure of the organization and the services provided. Observing in meetings allowed me to identify who was a part of the hospice team, what services they provided to patients. It also allowed me to ascertain the hierarchies in the organization and the structure of authority. Participant observation was often the first method through which I came to understand important phenomena in the hospice. Subsequent interviews were then used for member checks to confirm the threads of understanding gleaned from participant observation.

While naturalistic observation describes observation with no interaction with subjects, participant observation stipulates that the researcher may observe as well as interact with participants (Maxwell & Miller, 1996). The extent of researcher participation can vary widely. In this study, the type of participant observation was used whereby the researcher gathered data from the subjects while observing and interacting with them.

During the fieldwork, observations were made while the researcher sat in on staff meetings and staff training sessions where methods of operations, organizational issues, and hospice philosophy were discussed. These observations helped answer questions about organizational structure, and shared values, norms and goals within the organization.

The researcher also sat in on patient case conference meetings where decisions regarding care of individual patients were discussed. Each hospice held case conferences once or twice a week. These meeting usually include every member of the inter-disciplinary team. The team would sit in a conference room for up to 4 hours discussing particular patients, what made them appropriate for hospice and their plan of care. These observations helped to reveal each organization's level of service delivery and their ideas about appropriate or "best" care for patients at the end of life.

In this research, certain hospice staff were occasionally "shadowed" by the researcher, which allowed for documentation of the hospice staffs' everyday work practices, patient interactions and decisions about patient care. In order to do this, consent from the patient or family was always obtained before accompanying staff to a patient's home. Because obtaining consent from families was difficult, there was only an average of 2 - 4 patient visits documented in each hospice. Despite the paucity of these observations, observing the hospice staff in their interactions with patients was helpful in revealing how ideas about end of life care were enacted in actual work practices. It also provided an opportunity for informal conversation with staff members on the car rides to and from the patient's house.

Data collected during participant observation research were recorded through note taking, either during the observation (as in case conferences) or immediately following observations (as with patient visits). These notes were transformed into descriptive field notes after exiting the field. Often, threads of understanding gleaned from participant observation would be incorporated into subsequent interviews in order to clarify the researcher's understanding of these phenomena. In other words, information gleaned from observations was almost always confirmed in interviews before it was considered a finding in this research. Rarely did observational data alone provide confirmation of phenomena.

C. Collection of textual/financial data

A third method of data collection was the collection of textual data from each hospice organizations. One aspect of an institutionalized rule, according to Max Weber, is that they are "written down." Texts, such as hospice pamphlets and advertisements describing hospice philosophy and services available were collected and coded. Textual information collected included, training materials, marketing materials, and historical information about the hospices. Data was collected both in hard copy and from the hospices' websites. These data provided information about how each hospice organization defined end of life care and the services they provided and how they portrayed that understanding to potential clients.

Texts pertaining to organizational relationships such as contracts with other health care organizations and financial records describing hospice financing and donations and the extent of endowments were also collected. These data provided information about certain aspects of the structure of the organization, patient mix, the financing of the organization and organizational relationships. Financial records from each hospice were particularly useful for comparing access to financial resources across hospices.

Training material for hospice staff, research articles used for training purposes, and "handbooks" describing methods of operation were also collected. These data provided descriptions of how the organization defined hospice work practices. Any other texts produced by the hospice organization that gave insight into institutionalized rules, financial constraints/incentives or hospice philosophy were also collected and coded.

In sum, triangulation of data allowed for comparisons across sites while also reducing the risk that study conclusions will reflect the systematic biases or limitations of one specific method. Triangulation of observation, interview and textual data, which was used for this study, provided a more complete and accurate account than any of the single data sources could have achieved alone.

D. Informed Consent

Informed consent was obtained, both from the hospice administration and from the individual staff members who were interviewed. At the initial meeting with the administrator, they were asked to read and sign a consent form, providing consent for the researcher to conduct observations and interviews within the hospice (See appendix C). At that interview, the researcher made an arrangement with the administrator to attend a staff meeting where she would be introduced to the staff.

At the first staff meeting, the researcher was introduced to the staff by the administrator. The researcher then described her research to the staff in a verbal presentation and passed out research information sheets which described the nature of the research and confidentiality issues (see appendix D). The staff were encouraged to take this information sheet home with them. During this presentation the researcher told the staff that in addition to sitting in on staff meetings, she might occasionally approach certain staff members and ask them to be interviewed. The staff were informed that their interviews would be confidential and that they could refuse to be interviewed. When a staff member was asked to be interviewed and consented, they were asked to read and sign a consent form (see appendix E). All consent forms and processes of informed consent were reviewed and approved by the UCSF, Committee for Human Research.

III. Data Analysis

Analysis of collected data, including transcribed interviews, written field notes and archival materials, occurred simultaneously with data collection. Beginning analysis immediately allowed the researcher to progressively focus interviews and observations according to the categories that were revealed in the data. Glaser refers to the insights gathered while coding data as "theoretical sensitivity" (Glaser, 1978). Theoretical sensitivity gained through ongoing coding allows the researcher to modify the queries of the research as important categories and insights emerge. It is an analytical tool that is especially suited to an exploratory study like this one, where constant comparison (between the data from the three different collection methods) was central to the analysis.

Maxwell and Miller identify two main tasks of data analysis: categorization strategies and contextualizing strategies (Maxwell & Miller, 1996). While categorization techniques are useful for making comparisons and identifying similar phenomenon across research sites, contextual strategies provide in depth descriptions of phenomena occurring within particular organizational structures. Because the research questions required that analysis were conducted within the context of individual hospice organizations while also conducting comparisons across research sites, it is important to describe and distinguish between these two strategies.

A. Categorization Strategies

The main goal of *categorization strategies* is to "fracture" the data and rearrange it into categories that facilitate the comparison of data within and between these categories and that aid in the development of theoretical concepts (Strauss, 1987).

Categorizing analysis, then involves sorting the data into broader themes and issues. The main categorizing strategy in qualitative research is coding. In this research, analysis was conducted both deductively with pre-established coding categories, and inductively, allowing for new categories and themes to emerge from the data. The first wave of data analysis was conducted using some pre-established coding categories that were drawn from existing research and which were evident in the research questions (see Appendix F).

Other coding categories were developed inductively during the analysis using the general principles of grounded theory (Strauss & Corbin, 1990). As coding continued, the pre-established categories were expanded and merged, resulting in the final coding categories listed in Appendix G. Strauss calls the inductive process of ongoing coding, "systematic coding." The main goal of this systematic coding is to reveal categories and themes that are grounded in the data, categories that may not have emerged in prior research. Systematic analysis begins as data is collected and proceeds in a sequence starting with open coding, where concepts are labeled and grouped into categories, and those categories are developed in terms of its properties and dimensions. Analysis then moves to "axial coding" where connections between categories are noted and labeled, eventually forming the basis for constructing major categories and determining the conditions and the contexts within which phenomena unfold (Strauss & Corbin, 1990).

All coding of data was carried out using ATLAS.ti, a computer program designed for qualitative data analysis. After entering the transcribed interviews and fieldnotes from each hospice into Atlas.ti. Every piece of data was read through several times and the computer program was used to code pieces of data based on categories that emerged (see Appendix G for the final list of coding categories). The computer program allowed the researcher to write descriptions of each code and write memos about the codes. Once coding of the data was completed, I could generate lists of quotations for each code. These lists of data assisted in the writing up of the research. In this way, Atlas.ti allowed for systematic coding of the data.

Atlas.ti also allowed for axial coding to take place. When lists of quotations for each code were generated, the computer program also listed, for each quotation, any other code that had been attached to that piece of data. In this way, Atlas.ti helped the researcher to establish some links between coding categories. In general, Atlas.ti was found to be a very useful tool for managing, coding and retrieving data for this research study.

B. Contextual Strategies

While systematic coding focuses primarily on the relationships of similarity that can be used to sort data into categories independently of the context, *contextual strategies* focus the analysis and look for relationships that connect statements and events within a context into a coherent whole. To execute contextual analysis, a case-oriented approach, where data collected within each research site was analyzed independently of the others, was used. This strategy allowed the researcher to identify the relationships between organizational structure and ideas about end of life care that emerge in each individual hospice setting. Contextualizing analysis on its own is limited to understanding a particular individual or case cannot be used to understand a larger theory about what is taking place on a grand scale. Categorization and contextualizing strategies worked well together in this research to provide an analysis of both the organizational structure and ideas about end of life care in the individual hospices and then a comparison across hospices (Maxwell & Miller, 1996).

The computer program ATLAS.ti was also helpful in completing this aspect of the analysis. After the data were coded and memoed, ATLAS.ti then generated lists of data and memos for each code and category from each hospice. Thus, data on certain subjects could be compared across hospices.

C. Memoing

Memoing is another important aspect of qualitative data analysis. Memoing refers to any writing that a researcher does in relation to the research other than transcribing, coding or writing field notes (Maxwell, 1996). Probably the most detailed treatment of memoing comes from Glaser and Strauss's description of grounded theory (Glaser & Strauss, 1967). Analytic and theoretical memos were written throughout this research process. Memos were used for a variety of purposes: to summarize data, to identify new themes or concepts emerging in the data, and to document new relationships that emerged from the data which warranted new paths of inquiry. Most importantly, writing memos was a way to synthesize conclusions and new theories grounded in the data. In this study, memos were written during the entire phase of data collection. ATLAS.ti allowed for memos to be inserted into the data. Memos could then be printed with the codes, searched, and analyzed. Memos generated throughout the data analysis process were used in the final writing of the findings and conclusion chapters of this dissertation manuscript.

D. Validity

Many different strategies were employed in this research study in an attempt to ensure the validity of the data. The term "validity" is used here in the same sense as it is used by Maxwell, "a fairly straightforward, commonsense way to refer to the correctness or credibility of a description, conclusion, explanation, interpretation, or other sort of account" (1996:87). In this research, the term "validity" does not imply the existence of some essential truth to which the data can be compared. The term validity is used here to distinguish accounts that are credible from those that are not.

The main task in establishing validity was not to compare the researcher's accounts to an observer-independent "gold standard," but to systematically test conclusions, executing a fair attempt to prove these conclusions wrong. There are many different methods that were used in this dissertation to establish validity including: collecting "rich" data, triangulation of data, member checks, and searching for discrepant data/negative cases.

"Rich" data refers to data that are detailed and complete enough to provide a full and revealing picture of what is going on (Maxwell, 1996). Techniques for achieving this kind of data require a high level of rigorousness in data collection. During participant observation research, notes or "jottings" were written whenever possible to facilitate a clear memory of the observations. Descriptive field notes were written immediately after exiting the field so as to avoid loss of detail due to memory loss. Interviews were tape recorded and were transcribed verbatim by the researcher using a transcribing machine. The collection of textual data, especially financial records and patient care records, was also a means to supplement the richness of the data, thereby ensuring the validity of the conclusions. Denzin suggests that the analysis of textual data to supplement interviews and observation results in richer data in which subtler interpretations of phenomena can be made (Denzin, 1989). Becker (1970) argues that such "rich" data helps the researcher avoid "the twin dangers of respondent duplicity and observer bias" by making it "difficult for the observer to restrict his observations so that he sees only what supports his prejudices and expectations" (Becker, 1970:53, cited in Maxwell, 1996). In this research, collecting "rich data" provided a test of the developing theories by revealing both negative cases and incidents of respondent duplicity. For example, in one hospice there was a question about how many hours of care patients were provided. While the administrator responded to this question in one way, observations, textual data and "member checks" revealed that the administrator's responses were misleading and were not representing the true level of care provided.

The method of triangulating data was discussed earlier in the methods section of this proposal. Collecting data from a variety of sources and using a variety of methods (here using interviews, observations and textual data) in this research reduced the risk that the data were biased by the inherent flaws of any one data collection method. It also supplied more sources for testing nascent theories.

Guba & Lincoln (1989) articulated an important technique for testing the validity of qualitative data (Guba & Lincoln, 1989). They coined the term, "member checks" to describe the process by which a researcher articulates their theories to their subjects, soliciting the subject's opinion of their accuracy. According to Maxwell (1996) this is the single most effective way of ruling out the possibility of misinterpretation of the meaning of what they say. While member checks are a good way to get a clear idea of the subject's perspective about what is going on in the organization, they are not however the final word on the validity of the data or accuracy of the conclusions, they are simply another opinion about what is going on. Member checks were used in this research project in an attempt to validate conclusions. As a result, many of the data that were presented in the final draft of this research were the result of member checks. Data from member checks tend to produce good data to cite in research reports because member checks pertain specifically to the conclusions being drawn by the researcher.

One of the most important tasks for establishing validity, inherent in all the methods described above, is an attempt by the researcher to prove her theories wrong. Searching for discrepant data and negative cases must be an ongoing process in data analysis. While sometimes discrepant data may not be enough to discredit a conclusion, it is often important to report these data and allow readers to evaluate the importance of these data for themselves (Wolcott, 1990).

Finally, one of the greatest threats to validity is researcher bias. Every researcher enters the field with preconceived notions of what they believe is really "going on." Most people would agree that it is impossible to deal with this problem by eliminating the researcher's theories, preconceptions, or values. Researcher bias was dealt with in this research by taking stock of my own ideas about hospice care and being wary of ideas that were not well grounded in the data. End of life care is not a new topic for this researcher. The hypotheses presented in chapter four represent ideas the researcher had developed after many years of participating in research, reading and writing about end of life care. The pre-established coding categories and theories will be subject to the same validity testing as will the categories and theories produced inductively. In the writing up of this research, I have tried to take account of my personal values that may have influenced my perception of the data.

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CHAPTER FOUR. FINDINGS

I. Introduction to chapter four

This dissertation research was designed as a preliminary step in understanding the relationship between organizational structure and service delivery in hospice organizations. There were many different tasks involved in addressing this question. The first step was to describe the organizational structure and service delivery of the three hospices studied. As outlined in the first chapter, ways to describe and categorize the organizational structure of hospice have been so diverse that it has caused difficulty in comparing across research studies. The confusion about ways to categorize hospice organizations makes an in-depth description of their organizational structure particularly important.

The first section of this chapter will address the first aim of this research, which was to describe and compare the organizational structures of the three different hospices: hospice A, a non-profit freestanding hospice; hospice B a for profit, chain affiliated, corporation owned hospice; and hospice C, a non-profit, chain affiliated, corporation owned hospice. The description of the organizational structure of three different hospices provided in the first section is an important finding in itself, because it outlines the complexity of organizational structure and will be a tool for future researchers to understand what dimensions are important when categorizing hospices for research.

The second section of this chapter addresses the second aim of this research, which is to describe and compare the level of service provided at the three different hospices. It is a major finding of this research that despite the fact that these hospices were located in the same market and were caring for the same community, there are significant differences in the level of services they provided. These three hospices all provided primarily out-patient care, were located within a mile and a half of each other, and served the same market; which means they were competing for patients and referrals. They were also experiencing the same external environment such as being reviewed by the same fiscal intermediary and were subject to identical ebbs and flows of the market. As will be shown, despite their similar geographic locations, they did differ in the type and level of care they provide. The main areas where level of service differed were: staff to patient ratio, home health hours available, volunteer hours, bereavement services and social work services. Providing an in-depth description of the differences in service delivery in hospices is particularly important because to date, no studies have documented significant differences in level of service in this level of detail.

The third section of this chapter addresses the third and fourth aims of this research. This section moves from description into analysis. The third aim of this research was to examine the relationship between resources and organizational behavior. The fourth aim of this research was to examine the relationship between organizational structure and service delivery. The third section of this chapter is organized around four main hypotheses that were informed by the theoretical frameworks as well as past research on health care delivery. The two main approaches used to design this research were resource dependency theory and institutional theory of organizations.

In the fourth section of this findings chapter addresses the fifth aim of this research, which was to use organizational theory to understand the relationship between the social setting (organizational structure of the hospice), the ideas (organizational mission) and how those underpin the structures and systems of the hospice organization's studied. The main theoretical approaches used to design this research were the archetype design method and the sociology of knowledge approach.

Section 1. COMPARISON OF ORGANIZATIONAL STRUCTURE

This comparison examined three very different hospice organizations. In the next sections, descriptions of the three hospices studied will be provided, including descriptions of organizational structure, organizational relationships, the structure of services and authority. In section two a more in depth comparison of level of service will be presented.

Table 4.1 Organizational structure of hospices studied

	Hospice A	**Hospice B**	**Hospice C**
Profit Status	Not for profit	For profit	Not for profit
Ownership	freestanding	Corporation owned, multi-institutional	Corporation owned, multi-institutional
Other organizations owned by parent corporation	N/A	300 skilled nursing facilities, 90 other hospice/home health agencies	10 hospitals, 6 other hospice/home health agencies
Foundation	Yes, dedicated	No	Yes, dedicated and shared with other hospice/home health agencies in chain
Authority	Local, on site	Out of state	In state but off site
Administration	One RN administrator on site, an assistant administrator, an RN nursing administrator and an administrator of social services with an MSW, all on site	One MBA branch manager on site who answers to a Hospice Director and CEO/CFO at corporate headquarters out of state.	One RN branch manager on site who answers to a higher administration off site including a hospice director and CFO and CEO at the corporate headquarters.
Scope of organization	Community	National	Regional
Certification and Accreditation	Medicare Certified and JCAHO accredited	Medicare Certified, CHAP accreditation pending	Medicare Certified and JCAHO accredited

II. Hospice A: a freestanding, not for profit.

A. Parent Corporation

Hospice A was a not for profit, freestanding hospice that claimed to have been one of the first hospices in the region. They were first established as a hospice in the early 1970s. Hospice A is its own corporation, and is the single organization in that corporation. Operating as a single organization, hospice A accrued gross revenues of approximately 3.5 million dollars in 2000.

B. Foundation

One of the most extraordinary aspects of hospice A was its large foundation. According to both interview and financial data, in the year 2000, Hospice A was raise one and a half a million dollars in donations through a thrift store and direct charitable donations (see table 4.8). The hospice A foundation was a separate corporation with a separate staff and board of directors. Financial reports show that this foundation exists exclusively to provide funds for the care of the patients at hospice A and salaries for staffing non-reimbursed programs described below.

Due to the foundation, as well as other factors such as management style, staff at hospice A did not feel the financial constraints that were felt at the other hospices. During an interview, one hospice A nurse who had worked at another for profit hospice said:

"I: So what did you feel was the main difference between the place you worked before and this place? R: Um, the place I worked before was all about the numbers. It was about how fast could you get a patient admitted. Even now one of the nurses came over this week and she said that they are still doing admissions that way. They have one nurse to cover X amount of people. The bottom line is that, I wouldn't say that they don't care, but the numbers are more important to them than the patients. I: They have higher case loads? R: Yes they do."

Thus, the non-profit status was seen as a positive feature that contributed to staff satisfaction.

C. Structure of Authority

The authority in hospice A rested with an administrator who had worked for hospice A for over a decade. She had an office on site and was involved in the everyday operations of the hospice staff. In an interview, administrator at hospice A reported that she had been a hospice nurse since the "early days of hospice." She shared authority over the organization with the hospice's local board of directors, most of the members of which she chose herself.

There were also many other administrative and managerial posts at hospice A. There was an assistant administrator, a director of clinical services, and an administrative head of the social services department. So the most salient features of the authority at hospice A were: First, that there was more administrative personnel at hospice A than at the other two hospice. Second, the authority at hospice A was local. The administrator had worked in the hospice industry in this particular region for many years. In addition, the members of the board of directors were all local people who were familiar with the medical industry in the region. Thus, the administration were familiar with the needs of the particular community served by the hospice.

A third salient aspect of the authority at hospice A was that the administration at hospice A was on site, meaning that the administration was in the same building as the clinical staff. This was very different than at the other hospices. Their location on site caused the administration to be very in touch with the everyday workings of the organization. The administrative staff provided training, consulted directly on patient care issues, and were even there for emotional support of the clinical staff. The majority of the efforts of the administration were executed in a supportive nature toward the clinical staff. The result was that the staff and administration had a shared experience of the hospice, a shared experience of the community and subsequent shared goals for the hospice.

Fourth, because hospice A was first and foremost a hospice, and not a hospital or home health care agency, even the higher echelons of the administration had end of life care as their foremost priority. The higher levels, meaning the main administrator had many years of experience in hospice and had a personal commitment to providing excellent hospice care. She worked as nurse in hospice care for many years and was a great resource for information about the history of hospice care in the region.

According to both interview data and participant observation, the clinical staff at hospice A felt very supported by the administration. Repeatedly in interviews nurses and social workers talked about their wonderful administrator who "lets us do the work we know how to do." The staff at hospice A did not feel constrained by the authority of the administration. The clinical staff saw the administrator on a daily basis and felt that she supported them.

"(Administrator) is a great leader. She is really good. She has foresight too. It's really nice. So this is my place."

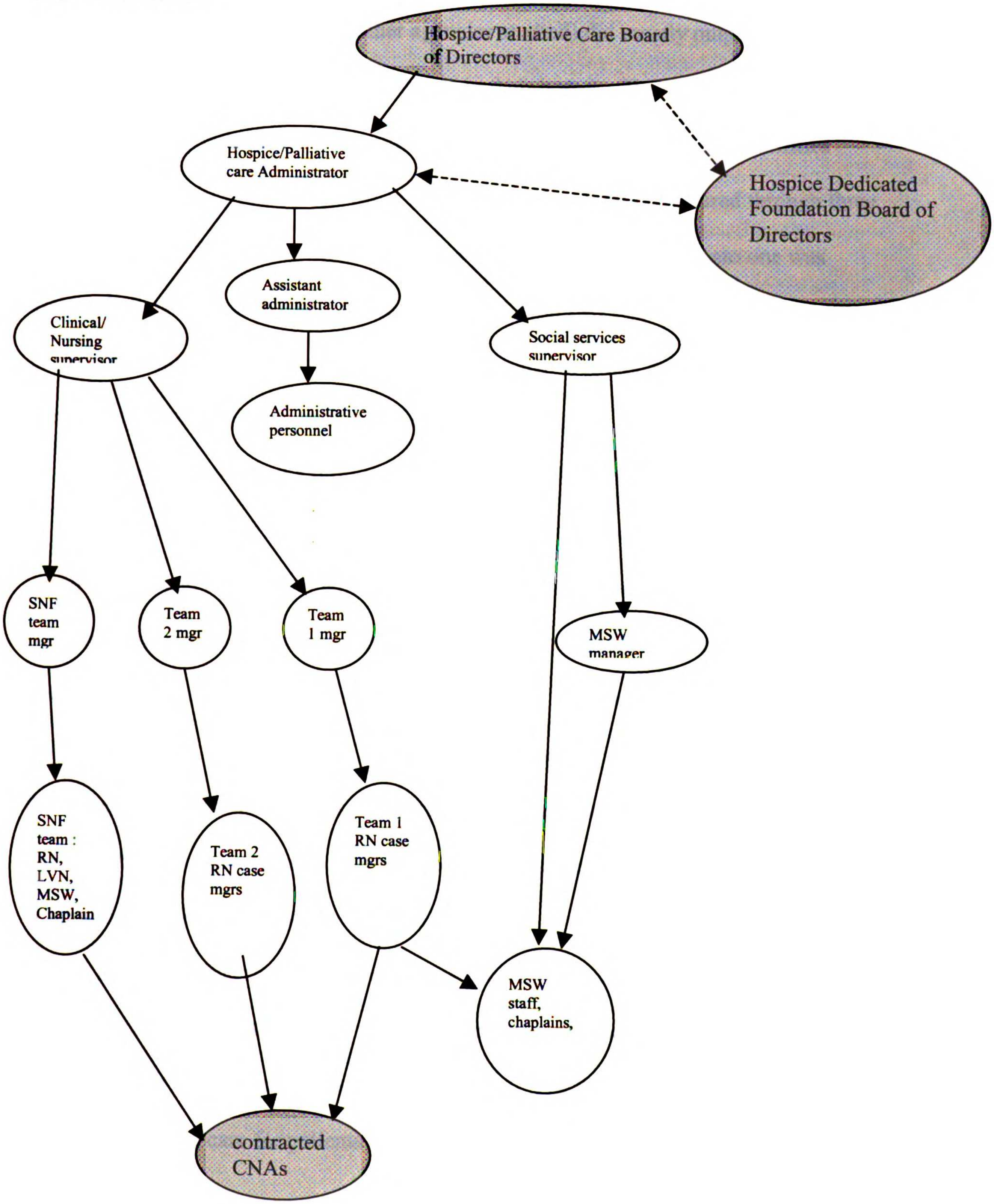
"I think the leadership chain follows the formal leadership structure. It seems like a very personally driven organization. I think because this is a small agency. (Administrator) is a great hospice advocate. And (Administrator's) philosophy and management style seems to filter through the whole agency."

" (The administration) is very accommodating toward the staff. Not just with the work but with our personal lives. (Staff member) is taking time off due to chronic fatigue syndrome. Employees are offered a standard 12 week package of disability time off and then (this employee) was offered a lot of extra disability coverage. I don't think (this employee) will ever come back to work, and I'm pretty sure (the administration) knows that, but they're saving her job for her anyway since she asked for that option. Most social workers here work 4 days a week, but working 5 days makes more sense for me financially. The administration was happy for me to work 5 days. I think they offer the 4 day week just to avoid staff burnout"

As these quotes show, the administrator is well liked and is perceived to share the same goals for the organization as the clinical staff. This contributes to a sense of appreciation and job satisfaction on the part of the clinical staff at hospice A.

FIGURE 4.1 ORGANIZATIONAL CHART FOR HOSPICE A

<u>KEY</u>
white= located on site;
gray = located off site



D. The Structure of Services

Hospice A (similar to the other agencies studied) did mostly outpatient care (90%), meaning they care for dying patients in their homes. The other 10% of patients were cared for in either skilled nursing facilities (SNF) or residential care facilities (RCF). Because they had a large census, care at hospice A was structured through three different teams. Two of the teams were structured geographically. Team one was assigned all patients in one part of the county and team two was responsible for patients in the other half of the county. Most nurses and social workers worked for one team exclusively, although a few staff members worked for both.

Hospice A also had a third team (called the SNF team) which was responsible for all patients who were in skilled nursing facilities. The SNF team had specific nurses, a social worker and a physician who specialized in care for patients in SNFs. In an interview, the clinical supervisor explained that having specific staff members focused on SNF patients lends itself to better communication and thus, better relationships with the SNFs in the area. A specific SNF team makes it so the SNF staff are always dealing with the same hospice nurses and thus, can forge better relationships. The administration reported that this approach was designed to improve patient care by improving communication between hospice and SNF staff.

Hospice A had two types of reimbursed care: one was called "hospice" and the other was called "palliative care." While the services were basically identical, the reimbursement and patient eligibility was different. The "hospice" service was traditional hospice care for patients who fall under the CMS requirements for reimbursement under the hospice Medicare benefit. The "hospice" designation was for people who have a terminal prognosis and are expected to live for less than 6 months. People who were on the hospice service were required to give up all treatments considered curative as required by Medicare. Only people who were on the "hospice" service could be reimbursed by the hospice Medicare benefit or a hospice benefit provided by commercial insurance.

The other main service provided by hospice A was called "palliative care". Patients were put on this service if they had a terminal diagnosis but for some other reason did not qualify for hospice reimbursement under Medicare. For example, if a patient's condition was not deteriorating quickly enough to be considered hospice appropriate by the Medicare guidelines, this patient would be put on the palliative care service. Other types of people who would be accepted into the palliative care program were patients with a terminal diagnosis who were not willing to give up all treatments considered curative. For example, a person with AIDS who was taking ace inhibitor drugs or a person with cancer who wished to continue with chemotherapy or radiation would be admitted under the "palliative care" designation. Financial records showed that patients in the palliative care program at hospice A usually had less reimbursement available. Some were covered by home health care insurance or by Medicare insurance for home health care. Many did not have insurance coverage or only limited number of days and these patients would end up paying out of pocket, or if they were indigent, they would be covered by hospice A's foundation money. While Hospice A received less money for the average palliative care patient than the average hospice patient, the clinical supervisor reported that no patient at Hospice A was ever turned away because of inability to pay.

One of the most important distinctions between hospice patients and palliative care patients at hospice A was that only patients on the hospice program had prescription drug coverage paid by Medicare. The Medicare hospice benefit covers the cost of prescription drugs used for palliation for hospice patients. When patients are in the palliative care program at hospice A, they were usually covered by some sort of home health care benefit that did not cover prescription drugs. Patients on the palliative care program at hospice A were thus required to pay for their own medications.

While the care provided to the patients on both programs was identical, with nursing, social work, chaplain services, personal care, volunteers and bereavement support, palliative care patients often had home health care reimbursement that did not provide reimbursement for all the services. In other words, many of the palliative care patients had "unbundled" coverage which only paid for the nursing and personal care visits. Despite this, all the patients were provided all the services at hospice A despite their program designation. Thus, palliative care patients were often getting services that the hospice was not paid for.

To both hospice staff and patients at hospice A, the difference between the hospice and palliative care services was negligible. Occasionally a patient would be switched from one program to another due to regulatory reasons. This might happen if a hospice patient was not deteriorating quickly enough to be eligible for the Medicare hospice benefit, instead of being discharged, they would be switched to the palliative care service. Data from observations at case conferences showed that when a patient was

switched from one program to another, there was no change in services or staff. The nursing staff at hospice A saw the distinction between the programs as purely administrative and did not alter the care they provide based on the service the patient is signed up for. In an interview, a team manager said, "*No matter if you are hospice or palliative care, you are getting the whole team.*"

By providing both 'palliative care' and 'hospice' services, hospice A was consciously trying to provide care for patients who might fall through the cracks in the Medicare hospice benefit. Both interview data and observational data showed that hospice staff and administration were aware that they were better able to serve the community due to their two end of life care programs.

Hospice A also provided other "extra-hospice" programs for terminally ill patients. They provided both pre-hospice and post hospice programs. They had two pre-hospice programs, one for patients with breast cancer and one for patients with AIDS. Patients in these programs were usually not sick enough to qualify for the Medicare Hospice benefit and did not yet require intensive medical monitoring. Patients in the pre-hospice program were provided by hospice A with social worker support, volunteers and chaplain services.[1]

Hospice A also had a post-hospice program. This program was for individuals who had to be discharged from the hospice or palliative care service and at the time of research, they had just inducted their first patient. The only reason a patient would be

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[1] The breast cancer program had up to 30 participants all with different levels of participation. The AIDS program had about 10 participants. The number of participants in the pre-hospice programs at hospice A was not documented on any financial records because the hospice was not reimbursed for their care. The hospice provided the salaries for the staff who worked in these programs, usually as a small percentage of their overall work.

discharged from both programs was if their condition was considered no longer considered to be terminal.[2] This program provided the same social services and volunteer services as did the pre-hospice program. It was a way for hospice A to continue to care for patients who had to be discharged. Hospice A received no reimbursement for any of the extra-hospice programs other than funding raised through their foundation. One staff member described how the post-hospice program worked to reduce the trauma a patient might feel when they are discharged from hospice:

> *"You know we have this (post-hospice) program? So I think that addresses somewhat those people who don't fit into hospice care and Branch don't fit into palliative care either. We all know, we all say this, but the minute we discharge somebody, they crash and then they wind up going to a hospital and dying. So if we have this kind of holding group where social workers and chaplains can go, that the patient and the family too can continue to feel that there is some connect there. There is just such a psychological and emotional piece to all of this. You know, you provide them with so much, and then they are left with such a hole there when you take it away. You know, families, you just see them go pale when they know that we are pulling out."*

The pre and post hospice programs are seemingly altruistic endeavors, but they did have strategic marketing value. When a patient was in the pre- hospice program, their condition was monitored and they would be switched to the full hospice or palliative care program when they became increasingly sick. Thus, this program provided hospice A with a sort of marketing tool, giving them a better chance of acquiring these people as patients when they did become ready for hospice care. The post hospice program had similar benefits. Many people feel alienated by a hospice organization after they are discharged. This alienation can lead to bad feelings on the part of ex-patients. By continuing to provide services after the patient was discharged, hospice A ensures that the discharged patient will come back to Hospice A at a later date when they may again need

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[2] Even patients on the 'palliative care' service still had to have a diagnosis of a terminal illness. Unlike 'hospice' patients, they did not have to have a prognosis of 6 months to live. So if a patient on the 'palliative care' service no longer had a terminal illness, they would have to be discharged to the post-hospice program.

full hospice care. Providing care to discharged patients also prevents the deterioration of the hospice's reputation in the community.

Table 4.2 Description of services provided at hospice A

	Eligibility requirements	Services provided	Reimbursement	Medicare Licensing	Prescription coverage	# of patients FY 2000	Ave LOS
Hospice Care	Must meet the hospice eligibility requirements of Medicare including a terminal prognosis with an expected 6 month life expectancy.	Full hospice team including nursing, social services, spiritual care, personal care and bereavement for family. Palliative care.	Hospice Medicare Benefit; Medicaid hospice benefit; Commercial insurance coverage for hospice, Foundation insurance; private pay	Hospice	Yes	288	42 days
Palliative Care	Must have a terminal diagnosis but not required to have a 6 month life expectancy	Full hospice team including nursing, social services, spiritual care, personal care, volunteer support and bereavement for family. Palliative and curative treatments	Medicare home health care benefit; Medicaid home health care benefit, commercial insurance coverage for home care, foundation insurance; and private pay	Home Health Care	No	102	73 days
Pre hospice AIDS	Anyone with a diagnosis of HIV	Social services, spiritual care, volunteer support, and support groups	Foundation funds	N/A	No	Not reported	N/A
Pre-Hospice Breast Cancer	Anyone with a diagnosis of breast cancer	Social services, spiritual care, volunteer support, and support groups	Foundation funds	N/A	No	Not reported	N/A
Post-Hospice	Anyone discharged from the hospice or palliative care program.[3]	Social services, spiritual care, volunteer support, and support groups	Foundation funds	N/A	No	1	

Hospice A was able to provide services to people who fall through the cracks of the Medicare requirements such as people who do not obviously meet the criteria of having a prognosis of 6 months to live. Hospice A manipulated their services so that the

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were able to provide hospice type care to patients who other hospices would have had to discharge, such as patients who are not deteriorating quickly enough or patients who want to continue with certain treatments considered curative by CMS. Having two hospice type programs as well as the two pre-hospice and one post hospice program allowed hospice A to have more flexibility in caring for patients and theoretically allowed them to better meet patient's needs. In addition, the pre-hospice programs especially worked as a marketing strategy. If a patient was in one of their pre-hospice programs, they believed it was more likely that that patient would choose hospice A when they began actively dying. Thus, these programs allowed hospice A to admit and keep patients who would not be admitted by other hospices.

E. Licensing and reimbursement

Hospice A was licensed as both a hospice and a home health agency[4]. Being licensed for home care allowed them to use home care reimbursement for some of their palliative care patients. The "hospice" care was usually reimbursed by the Medicare hospice benefit (81%); by Medicaid coverage for hospice (5%); or by commercial insurance that covered hospice care (11%). Only 2 percent of hospice patients were not covered by these sources were thus covered by foundation funds.

For the "palliative care" patients at hospice A, 19% were covered by Medicare reimbursement for home care services (this only lasts 100 days). 48% were covered by commercial insurance. Only 7% were covered by Medicaid home care reimbursement

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[3] The only way a person can be discharged from the hospice or palliative care program at hospice A is if their condition becomes no longer terminal.

and 26% were covered by the foundation funds. The reason for this is that Medicare reimbursement for home care is limited to 100 days. After their Medicare reimbursement is used up, many palliative care patients are then covered by the foundation insurance.

Patients were admitted to hospice A despite their ability to pay. Once admitted, the administrative staff would try to get an indigent patient signed up for Medicaid. If they were not eligible for Medicaid, then the patient's care would be covered by foundation funds.

Table 4.3 Percent reimbursement by payer at hospice A

	Medicare Hospice Benefit	Medicare Home health care benefit	Medicaid for Hospice	Medicaid for Home health	Commercial Insurance	Foundation Insurance
Hospice	81.2%	N/A	5%	N/A	11%	2%
Palliative care	N/A	19%	N/A	7%	48%	26%

F. Certification, accreditation, and quality

Hospice A was certified by Medicare. According to the state agency that conducts Medicare certification surveys, hospice A had 4 deficiencies found in their most recent unannounced survey. All 4 deficiencies were for incomplete or incorrect documentation of care in the patient's chart. Hospice A also had two patient complaints on file. Both of these complaints were investigated. For one complaint, the department was unable to substantiate a violation of regulations. For the second complaint, the violation was substantiated and the hospice was required to provide a plan of correction.

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[4] Many older hospices who were licensed before the hospice Medicare benefit are licensed at home care because early on there was no separate licensure for hospice. Hospice A is licensed as home care also because their palliative care service is reimbursed as home care.

Hospice A was accredited by JCAHO. In their most recent accreditation review they were designated as "Accredited with Requirements for Improvement." When JCAHO returned a few months later to review the requirements for improvement, hospice A was then found to have sufficiently addressed the requirements for improvement and were designated as, "Accredited with Full Standards Compliance." Officials at the complaint JCAHO reported no complaints against hospice A.

III. Hospice B: a for profit, corporate owned hospice in a multi-institutional system

A. Parent Corporation

Hospice B was owned by a for profit parent organization that is one of the top 5 nursing home chains in the United States. In addition to nursing homes, this corporation also owned about 100 other hospice/home health care agencies across the United States. According to their annual report to stock holders, this corporation generated 283 million dollars in net revenues in 2001. The headquarters of the parent corporation is located in another state.

One of the main profit seeking strategies of this corporation has been one of vertical integration. Their acquisition of an investor owned chain of hospice/home health agencies in the last few years caused an increase in their revenues of over 25 percent. It was as part of this recent acquisition of the hospice/home care chain that the parent corporation acquired Hospice B in addition to almost 100 other hospice/home care agencies in that chain operation. At the time it was studied, it was one of almost one hundred of hospice/home care agencies with the same name all over the nation. Thus, though the ownership of their new parent corporation, hospice B was vertically integrated with other types of health care organizations (SNFs); and horizontally integrated with other hospice/home care organizations.

While hospice B could be described as being officially part of a chain operation, they had very little contact with the other organizations in that chain. One consequence of horizontal integration (being part of a chain operation) is that the organization is subject to the uniformity required by the parent corporation. All of the hospices owned by the

parent corporation had the same name and were subject to the same rules and paperwork. One benefit of horizontal integration is that members of a chain operation can engage in resource sharing and information sharing to improve the care they provide. The researcher, during field work did not collect data that revealed any information sharing between the hospice branches. For example, there were no occasions where all the social workers or volunteer coordinators from all the branches met to offer support or exchange ideas.

B. Foundation

Hospice B did not have a foundation, but one staff member did report that hospice B had a non-profit fund where people could contribute money that would be used to help cover patients who could not afford to pay for hospice care.

"*(Hospice B) has a fund, a non-profit fund that they can go to if they have to. I: And what do they use that for? R: For people who have no money to cover their costs. But we can never turn anyone down, and neither can the non-profits.*

When the branch manager was asked about this non-profit fund, she denied its existence.

C. Structure of Authority

When fieldwork at Hospice B began, there was no branch manager. The former branch manager had left the organization a few months before and the RN Clinical Supervisor was carrying out the duties of the branch manager as acting administrator. Half way through the period of data collection, a new branch manager was hired. The new branch manager had an MBA and had a past history of working with durable medical equipment companies in addition to some experience working in hospice management. But she did not have a clinical degree.

In terms of the location of authority, the new branch manager had formerly lived in a different part of the state, and moved to the area to assume her new position. She did

not have a history of living in the community. Because the branch manager was new to the area and because her job was to fulfill mandates sent down from the corporate headquarters located in another state, for the purposes of this research it was determined that the authority at hospice B was not local.

After the new branch manager had been in her position for a few weeks, the RN Clinical Supervisor (who had been doing all the administration before the arrival of the new branch manager) was terminated for reasons that were not disclosed. At this point, the manager was managing both the nursing staff and the social work staff. There was no separate social work manager.

The branch manager at hospice B was not considered part of the clinical hospice team. This may have been because she was new, or because she did not have clinical experience doing hospice care. She occasionally attended case conferences where she provided moral support to the team. According to the branch manager, her main task was to make sure the Medicare rules and the rules of the parent corporation were followed by the hospice staff. She accomplished this through reviewing the charts of patients and then contacting the RN case managers to suggest things like cost cutting measures (remind them to use the generic brand of the drug) or efficiency measures (questioning whether the patient really needs so much home health aide visits). Here, the branch manager described her interactions with the staff:

" I: So you are relying on your team a lot to watch these costs. Do you do any sort of training with them about...R: Yes. We give them constant reminders, from inservices, from voice mail. I will say, 'hey you guys make sure that you use generic brands.' Or, questioning them when they come in. I will say, 'You know, I noticed this patient's chart has a morphine pump. Could they use (something else).' just to get some creative thinking going. So the next time they have a patient in that situation they will think, 'What else can I use?' And sometimes we discuss it at our meetings."

A nurse described getting a voice mail from the branch manager:

> *"Usually we get calls (from the branch manager) about medications or DME equipment. Durable medical equipment. You know, "Why did you order from this company when this one is going to be cheaper?" I: Who says that? R: Well, (branch manager) is the one who tells us. Yeah, she is the one. Or if you need the meds on the weekend and then they have to be taxied out. We hear about that because that is so expensive. "*

At hospice B, the authority of the parent corporation was issued through mandates sent from corporate headquarters. There was a regional manager who would sometimes visit the branch and attend interdisciplinary team meetings. It was the responsibility of this regional manager to relay the wishes of the parent corporation to the hospice staff working at the branches. He would make suggestions for cost cutting and put pressure on the staff to provide care that would bring in more money to the organization. At one meeting the regional manager pressured the staff to more readily provide the "continuous care" level of care to patients.[1] The clinical supervisor described how the parent corporation pushed for the hospice employees to provide "continuous care" because it not only meets the needs of the patients, but it brings in more money to the organization:

> *"So that is another example of continuous care. I: So what is the ownership saying?...you said there was a push for this? R: Yeah. It's a push because if people are in their last stages of life, there are more needs and we should be there is the philosophy. Its financially adventitious. Especially if you can send out a nurse for that 51% and send out an aide for that 49%. I: 49 (laughs) R: Yeah, for the 49% for the, you know, much less money per hour for the employee. That's the business sense of it. I: And this was something that is emphasized by (parent corporation)? R: Yeah, there's a push for continuous care."*

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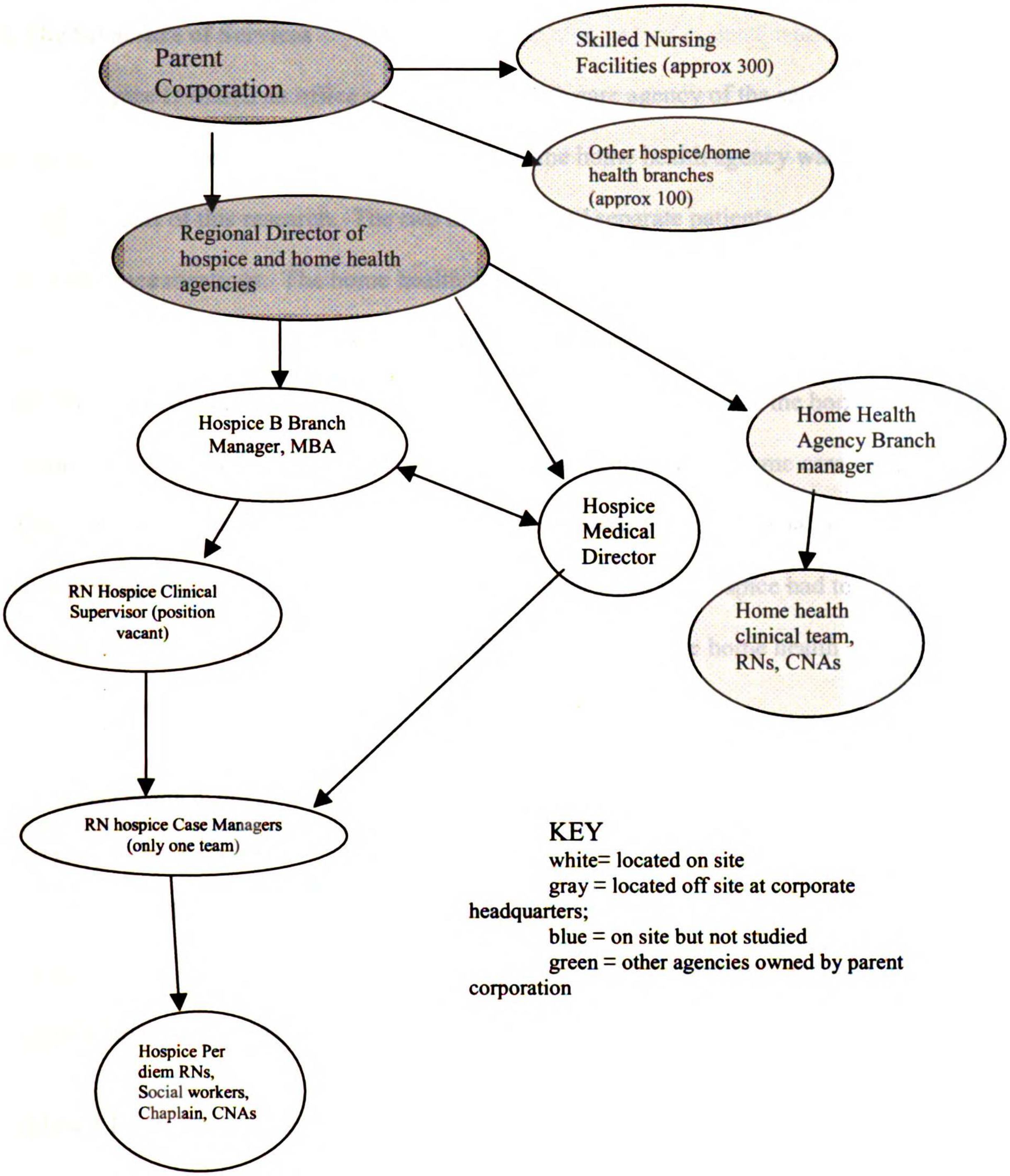
[1] . "Continuous care" is a higher level of care for hospice patients that provides a much higher reimbursement rate from Medicare. It is appropriate for patients who have recently had a "crisis" and who need more hours of hands on care. The stipulation is that the hospice must be provided 8 hours of care a day, with at least 51% of that care from an RN. The other 49% of the care can be provided by a home health aide.

The Medical Director at hospice B was the only other figure of authority on site at hospice B besides the branch manager. The Medical Director was a full time employee of the parent corporation who worked full time as a medical director for a few of the other hospice organizations in the same chain located around the state. He provided expertise and guidance to the nursing staff and social work staff. He was available to the clinical team at the weekly case conference meetings as well as by pager most other days of the week.

FIGURE 4.2 ORGANIZATIONAL CHART FOR HOSPICE B



KEY

white= located on site

gray = located off site at corporate headquarters;

blue = on site but not studied

green = other agencies owned by parent corporation

D. The Structure of Services

Hospice B shared an office with a home health care agency of the same name, but the two services were not closely integrated. Thus, the home health agency was not studied as a part of this research. The two divisions had separate patients and separate case conference meetings. The home health nursing division was a tradition home care agency that provided mostly care to individuals who need post surgery or post natal care. While the hospice division was administered out of the same building as the home health division, there was a strict division between the hospice team and the home care team. For instance, the home care division had its own administrator, nurses, social worker, etc. The only integration between the two divisions was that when the hospice had to discharge someone, the hospice staff tried to discharge them to the home health care division at their hospice.

"So we had to discharge the patient. Turn him over to home health. I: Then you switch them over to home health in this organization? R: Most of the time. I: well that's good. R: Yeah, so they are still getting something and that will be short term and they are informed of this. That this is going to be short term."

Because their census was smaller than hospice A's, at hospice B there was only one hospice team that cared for all the patients (they weren't divided into teams based on geographic location, or whether or not they were in skilled nursing facilities).

Table 4.4 Percent reimbursement by payer at hospice B

	Medicare Hospice Benefit	Medicaid hospice reimbursement	Commercial Insurance
Hospice Care	65%	22%	13%

E. Licensing and reimbursement

While the home health division at hospice B took care of patients who had insurance of some sort for home care; the hospice division cared for individuals who qualify under the CMS requirements for hospice eligibility. They admitted patients who were eligible for the Hospice Medicare Benefit, MediCal or who have a hospice benefit as part of their commercial insurance. Hospice B claimed that they would admit anyone, despite their ability to pay. The RN Clinical Supervisor discussed the company's policy toward the uninsured:

> *"I: Is there anybody within the organization who is overseeing that kind of thing (who you admit) or is it really just up to you guys what kind of care you provide. R: It's a matter of, you know, some patients that might be quote, unquote controversial. We will discuss what we anticipate for costs. And you know then you know we can say yes or no to the patient. But theoretically the philosophy for (parent corporation) is to take on most anyone. We don't turn anybody down because of a lack of insurance. We do take on the indigent. But here in California that is few and far between because everybody seems to get MediCal real quick and easy."*

While the branch manager and other staff members claimed that the hospice took patients who did not have the ability to pay, the data on reimbursement they provided did not reflect any such cases.

F. Certification, accreditation and quality

Hospice B was Medicare certified. According to DHH records, hospice B cited for 4 deficiencies. Two of these deficiencies were for improperly documenting care. But the other two deficiencies were for providing a lower level of care than was appropriate for the patient. The DHH has in their records that hospice B has had 5 complaints filed against them from patients or families. All of these complaints were investigated by the DHH. In three of these complaints, the department was unable to substantiate a violation

of regulations. In two cases however, the complaint was investigated and substantiated and the hospice was required to provide a plan of correction.

IV. Hospice C: A non-profit, corporate owned hospice in a multi-institutional system

"When we went to (parent corporation) we took a warp speed leap into another health care system." **Hospice Medical Director**

A. Parent corporation/ownership

Hospice C was owned by a non-profit parent corporation or "health system" that owned a number of hospitals, private medical practices, home health care agencies and hospice organizations throughout the northern part of one state. The parent corporation grossed over 52 million dollars in revenues in 2001.

Hospice C had previously been a part of a chain of 5 hospice/home health care agencies that had functioned as a non-profit chain operation for many years. That chain operation was acquired by the new parent corporation a few years prior to this research. The parent corporation also acquired a number of hospices and home health care organizations around the same time. At the time of this research the parent corporation owned approximately 7 hospice branches dispersed around the northern part of the state, all with the same name. During the time of data collection, the parent corporation was still undergoing efforts to promote uniformity among the now affiliated hospice branches.

Hospice C was integrated both vertically and horizontally. In terms of vertical integration, the hospice had a relationship with all of the hospitals, outpatient medical practices and home health agencies owned by the parent corporation. Many of the hospice staff at hospice C worked for this hospice before it was acquired by the current parent organization. The acquisition was met with mixed feelings, both positive and

negative. One staff member described the financial situation before they were acquired by the parent organization:

"(Parent corporation) brought in much more financial stability. There were situations before (with past owners) when you would take your paycheck to the bank and have it bounce. We don't have to worry about that anymore."

Another staff member described her mixed feelings about the acquisition:

"(Parent Corporation) does provide us with a large corporate structure which has been both good and bad. They immediately came in, looked at our salaries and raised them. Which was very nice of them. We all appreciated that. They gave us a better benefits package. But then we had to deal with the suits from (corporate headquarters) who really had no sense of what hospice meant here. So it's getting used to new management styles. It is nice to have the overall coverage of a big outfit. But also they have people who wear green eyeshades that are looking to see whether we make a profit or at least can hold our own. And we didn't have as much of a sense of that before we were (acquired by parent corporation). And that is OK too. We have to have that kind of management in order to survive."

Thus, staff describes how vertical integration provided more stability to their organization, but the payoff for that security is a sense of increased surveillance by the parent corporation.

Hospice C was also integrated horizontally with the other 6 hospices owned by the parent corporation. One positive effect of horizontal integration at Hospice C was the resource and information sharing with the other members of the chain operation. Hospice C had relatively close ties to the other hospices in the chain. All seven hospices in the chain were within driving distance to each other. The branch managers of each hospice in the chain met regularly. Other disciplines, like the bereavement coordinator and volunteer coordinators from all the branches also met occasionally. In addition to having a common higher administration, the hospice branches also shared services and shared their foundation funds.

B. Foundation

Before hospice C was acquired by the parent corporation, they and the other hospices in the chain had a dedicated foundation that they shared. After they were acquired, their foundation remained dedicated to the hospice/home health division of the parent corporation.

Hospice C did not use foundation funds for extra services like the pre-hospice program at hospice A. The foundation money was used in part for a "patient assistance fund." This fund was used primarily in crisis situations, usually when the patient needed something in the home that was not covered by their particular insurance. According to the foundations director:

> *"They (branch managers) write an application to get money from the patient assistance fund. This fund provides money on a one-time basis for a special need for a patient. It could be for respite for the caregiver. It could be for a lift chair or an emergency like no food in the home. I have never heard of them refuse a request from the patient assistance fund. Nobody is turned down."*

The branch manager confirmed that she had never been turned down when she asked for foundations funds for a patient. Hospice C also used foundation money to supplement funds available for the bereavement program or spiritual care program. The foundations funds were also used by the parent corporation for uncompensated care. In 2001 these funds were used to cover uncompensated care for 2 patients.

Table 4.5 The use of foundation funds at hospice C chain operation in 2001

Uncompensated care	Spiritual care	Children's bereavement	Patient assistance fund	Volunteer program
$190,000	$40,000	$25,000	$25,000	$20,000

C. Structure of Authority

At hospice C there was a branch manager on sight whose job it was to oversee all the hospice staff including nursing, social services and administrative assistant. The branch manager answered to the hospice director who was located at the corporate headquarters approximately 30 miles away. This hospice director was in charge of overseeing all the branch managers of all 7 hospices. The hospice director oversaw the hospices primarily by talking to each branch's manager by telephone in daily conference calls. There were also monthly management meetings with the director and all the hospice branch managers.

The hospice director answered to the CEO and CFO of the hospice/home health division who were also located at corporate headquarters. The CEO and CFO oversaw the hospice and home care division of the health system. The CEO and CFO of the hospice/home health care division answered to the CEO of the health system.

Despite the feelings among the staff about the increased stability of the organization since the acquisition by the new parent corporation, there was some animosity toward the higher administration[5]. The CEO and CFO particularly were not perceived by the staff of hospice C as having either expertise in or a commitment to hospice care. The rift between the hospice higher administration and the on site staff at hospice C mimicked their geographic separation. The staff felt that the higher management enforced rules that were not in the best interest of promoting high quality hospice care. The branch staff felt that the higher management's main priority was cutting costs as opposed to promoting high quality end of life care. In addition, they did

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[5] The term "upper administration" in this section is used to describe the CEO, CFO, and hospice director

not feel supported or understood by the higher management. One staff member described the difference since the parent corporation took over:

"R: It doesn't feel like a family at all anymore. It feels like a corporate job is what it feels like. It doesn't feel like health care. It feels like working for corporate. And it feels awful. It feels awful. And I have not worked for any other hospices, but there is so little regard for the nurses and what they are doing and what it costs. So it is still always about productivity and having everything done perfectly. But there is no understanding about the emotional, spiritual and psychological issues that nurses go through. We do it by choice and we have to find our ways to take care of ourselves. But there are times when I have just felt rage at how insensitive and inhuman it feels like the corporation is."

The hospice C branch manager was the middleman in the tension between the higher administration and the staff. The branch managers attended management meetings where they were lectured by the CFO about the need for increased productivity of the branch staff (see above example). Part of the branch manager's job was to try to diffuse the tension between her staff and the higher administration. The branch manager had the difficult job of both enforcing the rules of the higher administration and being supportive to the hospice staff. In an effort to enforce the productivity standards, she required each RN case manager leave her a voice mail message every evening informing her of their billable hours for that day. But observational data showed that when an exigency occurred that makes it look like a nurse was not meeting productivity standards despite their hard work, she would manipulate the reports in an effort to reflect the staff member's hard work.

One of the most interesting aspects of the authority at hospice C was that it was much more hands on than at either of the two other hospices. There was a great deal of surveillance of the staff at hospice C. The hospice staff, through the productivity standards and the restrictions on medications and durable medical equipment, were much more tightly regulated than at the other hospices. As has been shown, this management

style, imposed by the higher administration was probably effective in cutting costs, but also resulted lower moral on the part of the hospice staff.

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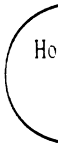
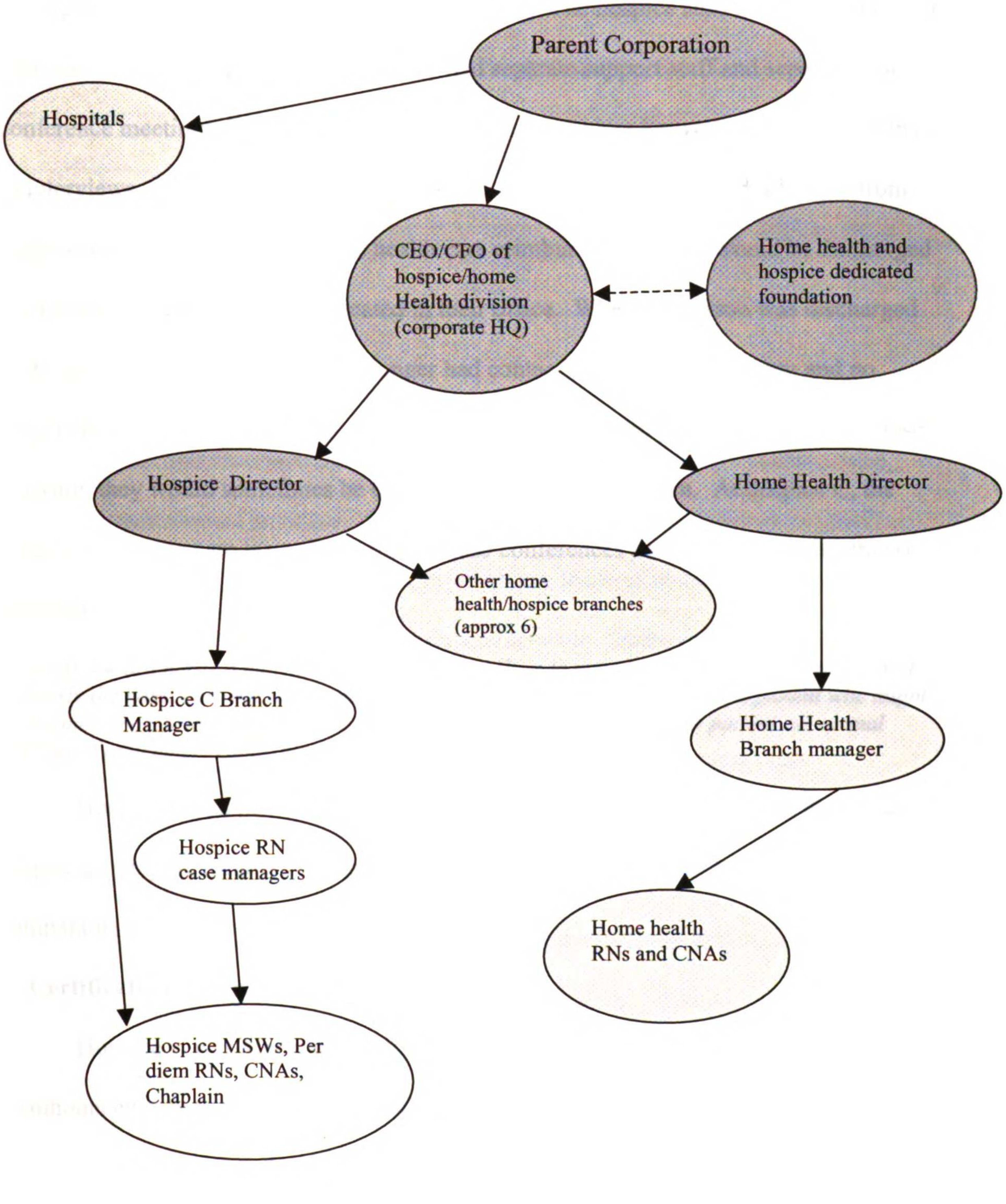


FIGURE 4.3 ORGANIZATIONAL CHART FOR HOSPICE C

white= located on site;
gray = located off site at corporate headquarters;
blue = on site but not studied;
green = other agencies owned by parent corporation not studied



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D. Structure of Services

Hospice C was located in an office building that they shared with a home health care agency owned by the same parent corporation. The hospice staff had their desks in a designated corner of the building and they had separate support staff and separate case conference meetings. There was some integration of services between the two programs. In interviews, clinical staff reported that occasionally, if someone was discharged from hospice and were eligible for home health care reimbursement, they would be discharged to the home health care service located in their office. When the person was discharged to the home health agency, they no longer had contact with the hospice team and no longer received hospice services. Conversely, if a home health patient began to get close to dying, they would sometimes be transferred to the hospice team. At hospice C, the hospice and home care teams had separate case conferences and separate administrative personnel.

"I: So if you discharge a patient can you discharge them to your home care? R: Oh yeah. And similarly the home care nurses are good about referring to us when they see a patient who might be hospice appropriate. It does get a little hard because then you lose the patient, so normal feelings of attachment come into play."

Hospice C had just one hospice team that cared for all the patients in the county, despite geographic location. Hospice C did not provide any "extra" hospice services comparable to those at hospice A.

E. Certification, accreditation, and quality

Hospice C was Medicare certified, and accredited by JCAHO. In their last unannounced survey they received 7 of deficiencies. When the DHHS returned to follow up on these deficiencies, they found three more deficiencies. There was one complaint on file wi

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on file with the DHHS about hospice C that was investigated and found "unsubstantiated."

Hospice C was accredited by JCAHO with "full standards compliance." JCAHO has received no complaints about hospice C.

Table 4.6 Measures of quality and deficiencies across hospices

	Deficiencies	Investigated Complaints	Substantiated complaints	Accreditation
Hospice A	4	5	2	JCAHO "Full Standards Compliance"
Hospice B	4	2	1	None, CHAP pending
Hospice C	10	1	0	JCAHO "Full Standards Compliance"

V. Conclusion to section one

This section described how each of the three hospices that were studied had a different organizational structure. Many of the most important differences included: ownership, organizational relationships, profit status, location of authority, access to resources through a foundation, and structure of services. These data show that organizational structural variables such as organizational relationships for example which are often described as dichotomous in other research, are actually much more multifaceted and should be measured as such.

This section showed that there were differences in how the hospice staff and services were structured in each hospice. In hospice A there were different teams that provided care to people in different geographic locations and different settings. In both hospice B and C there was only one hospice team. Hospice A had almost double the census of the other two hospices.

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There were also differences in the types of services provided by the three hospices.

Table 4.7 Comparison of types of services across hospices studied

	HOSPICE A	HOPSICE B	HOSPICE C
End of life Care	Hospice and palliative care available	Hospice care	Hospice care
Home health care	No traditional home care available for non-terminal patients	Non terminal home care available through the same organization. Occasional referrals between two services.	Non terminal home care available through same organization. Occasional referrals between two services.
Pre hospice care	Pre hospice support services available for people with AIDS and breast cancer.	No pre hospice services available.	No pre hospice services available
Care for discharged patients	Post-hospice program for discharged patients available	Occasional referral to home care. No specific program for discharged patients	Occasional referral to home care. No specific program for discharged patients
Bereavement	Support groups, individual counseling, and volunteer support for up to one year.	Telephone call or card from bereavement coordinator. Referrals to counseling. No support groups or counseling provided by hospice B.	SW bereavement assessment. Letter from team. Package of materials on grief from corporate HQ. Telephone call from bereavement coordinator offering support groups run by local branch or other organizations.

Hospice A had many different types of programs including hospice care, quasi-hospice care for people who were not eligible under Medicare rules, pre-hospice programs and post-hospice programs. Both hospice B and C provided only hospice care for those who meet the requirements of eligibility under the Medicare guidelines.

One of the main differences between the three hospices was the amount of foundation money that was available.

Table 4.8 Description of Foundation revenue in each hospice

	Foundation revenue	Foundation expenses*	Net foundation,
Hospice A	1.5 million	501,963	928,392
Hospice B	N/A	N/A	N/A
Hospice C (all branches)	2.9 million	1.88 million	756,056

*Includes expenses associated with foundation staff salaries and fund raising activities.
**Other uses for foundation funds include staff salaries, supplies, extra programs.

Hospice A had the most foundation funds available and they used these funds to provide the extra hospice services. Hospice B had a much smaller amount of foundation money available and that money was much more tightly regulated than the foundation money at hospice A. Hospice C was for profit and did not have a foundation per se. Hospice C's parent corporation had a non-profit fund that was available for people to contribute to, but these funds were not readily available for the hospice staff.

The data presented in this section showed that the social settings of the three hospices studied were different. The clinical staff in each hospice were working in three distinct environments as created by the different organizational structures. At hospice A the staff were working in an environment where they had a great deal of freedom and autonomy to provide the care to patients that they wanted to. They were not hampered by Medicare restrictions because there were so many programs available to patients. They were also not restricted financially because they had foundation money available. At hospice B and C there were a lot more restrictions on the care the staff could provide. Staff had to stay within the boundaries of the Medicare regulations in the care they

provided because there were no extra-hospice programs. In sum, the three organizations reflect three very distinct social settings within which hospice care was being provided. In the next section, data will be presented which describe and compare the different levels of service being provided in each of the three hospices.

Section 2. COMPARISION OF LEVEL OF SERVICE

This section will address the second aim of this research which is to describe and compare the level of service at each of the three hospices studied. For each aspect of care, the regulations pertaining to that discipline will be described and then the level of care provided by each hospice will be compared to the regulations. The Center for Medicare and Medicaid Services (CMS) has certain minimum requirements for the services a hospice must provide its patients. All the hospice organizations in this study were certified by CMS to provide hospice care, meaning they were surveyed and showed they met the criteria set by CMS. Section 418.50(b) of the State Operations Manual Interpretive Guidelines states that *"As required by 418.202, hospice services include, but are not limited to, the following: nursing services, physical therapy, occupational therapy, speech-language pathology services; Medical social services; home health aide and homemaker services; physician services; counseling services (dietary, pastoral and other); short term inpatient care; and Medical appliances and supplies including drugs and biologicals. In addition, the hospice must provide bereavement counseling to the patient's family/caregiver after the patient's death. Nursing services, physician services and drugs and biological must be made routinely available on a 24 hour basis; and these services must be provided in a manner consistent with accepted standards and practice."* (CMS, 1994)

In addition to the Medicare guidelines, there are also guidelines/recommendations concerning level of service and content of care that are put out by the National Hospice

and Palliative Care Organization (NHPCO)[6]. While these are not legal requirements, state surveyors who are assessing Medicare compliance take them into consideration. The NHCPO guidelines are also often cited by hospice personnel as a measurement of whether they are meeting standards of care.

Other regulations that govern hospice care are the accepted standards of practice that are typically developed by the professional associations of nurses, therapists, and social workers. The accepted professional standards and principles that the hospice and its staff must comply with include, but are not limited to: State practice acts, commonly accepted health standards established by national organizations, boards, and councils (i.e. American Nurses' Association, Centers for Disease Control and Prevention); and the parent corporation's own policies and procedures.

Although the regulations and guidelines for hospice care may seem rather extensive, this study found significant differences in the level of care provided by the three hospices studied indicating that there may have been different interpretations of these guidelines. The next section will provide a more thorough description of CMS regulations and NHCPO guidelines regarding for each aspect of hospice care. This section will then look at the level of service actually provided by each hospice, or each hospice's interpretation of those regulations and guidelines. Finally, a comparison will be made of the level of service across study sites.

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[6] Also known as the National Hospice Organization (NHO).

Table 4.9 Comparison of level of staffing and services across hospice studied

	HOSPICE A	HOSPICE B	HOSPICE C
Census	40 to 60 patient census	40 to 60 patient census	27 to 31 patient census
Administration	Administrator of over a decade on site, local board of directors, large administrative staff.	New branch manager answers to CEO located at headquarters out of state.	Branch manager oversees entire team. Answers to a hospice administrator and CEO located at corp HQ off site. One admin asst.
Nursing	Director of clinical services, two team managers, # RN case managers, 1 LVN	Director of nursing fired, 5 RN case managers, 2 RN per diem,	5 RN case managers, 2 night nurses, 1 administrative RN to assist with charting.
Personal care	Contracts out with home health agencies for certified nursing assistants	Trains and utilizes its own certified nursing assistants. Currently 4 HHAs.	Trains and utilizes its own home health aides. Currently 3 HHAs
Social work	1 social work manager, 1 social work coordinator, one full time MSW and four 75% time MSWs	One full time MSW and one part time LCSW	3 part time MSWs
Physician	Two medical directors for out patient care and one additional medical director for SNF patients	One medical director for all patients . Also the medical director for another branch.	One medical director who is also medical director of another branch. Patients keep their own physician.
Pharmacist	One pharmacist available at all IDT meetings and for consultations in patient's homes	One pharmacist available for telephone consultation.	One pharmacist available who attends occasional IDT.
Chaplain	Two full time chaplains representing both Christian and Jewish traditions	One full time chaplain works only with this branch.	One ½ time chaplain who splits time with one other branch.
Bereavement	One full time bereavement coordinator, one part time bereavement assistant, and 30 bereavement volunteers. Several ongoing support groups.	One part time bereavement coordinator. No support groups.	One ½ time MSW (also does ½ time as a social worker). Several support groups run by other branches. Referral to outside support groups.
Volunteer	One volunteer coordinator with over one hundred volunteers	One volunteer coordinator with eleven volunteers.	One volunteer coordinator with approximately 45 volunteers.
Medications	Few restrictions on medications perceived by clinical staff.	Restrictions on certain medication and DME enforced by director of operations and Medical director.	Adherence by all clinical staff to a written medication formulary. Restrictions on certain DME enforced by higher administration.

I. Nursing Services

In terms of nursing services, CMS regulations state that hospices *"must provide nursing care and services by or under the supervision of a registered nurse. Nursing services must be directed and staffed to assure that the nursing needs of patients are met."(418.82(a))* (CMS, 1994). While there is no specific regulation on the part of CMS restricting the case load of hospice nurses, *the NHCPO guidelines state that a full time nurse should have no more than 8 to 12 patients at one time* (NHPCO, 2003). In a survey by the Hospital and Healthcare Compensation Service (HCS, 2002) collected information from 258 hospices, measuring the productivity of hospice staff. They found that, in an 8-hour day, hospice nurses made an average of 4.48 visits.

Table 4.10 Nursing case loads at the hospices studied

	Average nursing case loads	**Criteria for determination of case load**
Hospice A	5 to 14 patients	Number and patient acuity
Hospice B	12 to 16 patients	Census
Hospice C	10 to 12 patients	NHPCO guidelines

Each hospice studied for this dissertation was experiencing a significant rise in census at the time of data collection. At **hospice A**, each full time nurse typically had between 5 and 14 patients. Despite the rise in census at hospice A, the nurses who were interviewed did not seem particularly overwhelmed by their work. When one nurse was asked what her case load was like, she replied:

"R: At the moment I have eleven. There is no normal case load. There are times you have four or five when the census is really low. And the other thing is acuity (how sick people are). They (team managers who assign patients) pay a lot of attention to that here. Sometimes you can have four or five patients who take up your entire day. Right now I have a lot of patients who I only see once a week."

This nurse described how, rather than paying attention to the number of patients, they were assigned patients based on the level of acuity of the patient and the varying level of time required to care for certain patients. The management paid attention to how much time they were working rather than how many patients they "should" be caring for. This was different than the approach at the other hospices where staff had productivity requirements that did not take into account acuity. A supervisor at hospice A compared their staffing to that of other hospices in the community:

"R: Our staffing is so much better. We have better staffing. Our patient to nurse ratio. I: What is that ratio? R: For a full time person, which would be 40 hours a week it would be 10 to 14 patients. If you look out in the community they would be bumping up to close to 18 or 20. And the expectations in many of the other agencies is that the nurses are only with a patient for an hour. Its like home care when the nurse is usually there for one hour. But if our patients need us for 2 hours, 3 hours, (the nurses) have the flexibility to do that."

Staff at hospice A perceived a philosophy among the management not to overwork staff, even if it means turning patients down. One nurse told this story:

"One thing that happened when I came to work here (from another hospice). One of the physicians I used to work with, I had to call in some orders for one of my patients and the nurse said, 'You know I am not sure I like (hospice A).' and I asked her to tell me why and she said, 'I referred a patient and they told me they couldn't do it for a couple of days. With (the for profit) you said you would get a nurse there within 24 hours. And that's what they did.' Well, I immediately came into the office and went to the intake person and asked them about it and asked, 'Why is this happening?' And she said, 'I am not going to work my nurses so that people are working overtime. And if I don't have the staff I am not going to take on the patient.' And that is the way it is here. Whereas, you know at the other place, they would work the nurses to whatever lengths to get patients."

"We just hired 4 nurses from another hospice. I: what happened. R: Well, they love being here which is a good sign. They didn't have a lot of flexibility in terms of their clinician to patient ratio. As we do here. So they couldn't coordinate as much care together like going out to see the patient. And also I think that there isn't the pressure, the productivity pressure here that you see in other agency. I: People seem pretty relaxed. R: There is no productivity here. (laughs) I used to kid them when I first came here, I said to another nurse, 'I have been in nursing for 27 years and now I feel like I am back to the old days when there was better staffing and you could give better care and you had the time to sit down and comfort somebody'."

At hospice A, interview and observational data showed that though the staff were working very hard to meet the rise in census, they were not assigned a case load that prevented them from providing as much care to a patient that they needed. While the nursing case loads were not significantly lower than those at the other hospices, managers assigned patients taking into account the acuity of the patients in a case load. This attention to acuity in assigning patients relieved some of the stress of high case loads. As a result, staff at hospice A did not report that they were forced to cut back on care in order to provide care to all their patients.

At **hospice B**, each full time nurse had up to 16 patients. While the branch manager indicated verbally that the nurses have a caseload no greater than the NHCPO guidelines (8-12), observations of case conferences showed that the hospice B nurses had caseloads exceeding this standard[7]. In both interviews with and observations of nurses, data showed that hospice B nurses were very concerned with their increased caseload. They felt overwhelmed by the work and felt a decreased ability to provide good quality care. Here are some quotes from interviews with RNs at Hospice B confirming this point:

"Well, our case loads are so heavy that we cannot see all of our patients all of the time. So we get the per diem nurses to see them."

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[7] This discrepancy between the case loads that were reported by the administrator and what was observed during participant observation is an example of the importance of observational data to supplement interview data. In a study that was based on primarily interview data or in a survey research study, researchers would have found inaccurate data about the nurse case loads at this hospice.

"I: What is your case load like here? R: It varies. Right now it is kind of heavy. I think my case load is 15 right now. NHO says that hospice case loads should be from 8 to 12. Because of my experience I have carried many, many more than that in times of crises. I can carry 15. But I don't like carrying that many because I don't feel like I can see them all...Sometimes I only get to see people once a week. And when you have 15 it is really difficult to, because of the paperwork involved, to do a lot of visits as well as keeping up on the paperwork. One of the other nurses had 15 and that was too many for her. But she is not been in hospice as long as some of us. And she felt a little overwhelmed. And so we reduced her case load a little."

"There are constraints of time. It is not as bad as in the hospital. But some (patients) take a lot of time, like an hour or two. Some (patients) take two or three hours. Not very many but sometimes. And then you know you've got a whole schedule of people and so you are feeling pressured. You are feeling overwhelmed. Because you can't give everybody the time that they need. So time is a big factor especially when our census is up. We have never had a census of 60. (current census)."

These statements by nurses show that at hospice B, the nurses were feeling like they did not have enough time to spend with their patients because of their large case loads. Observations of case conferences indicated that patients were assigned to nurses without regard to the acuity of the illness or the level of care required. RN case managers at hospice B were having to send out other nurse to see their patient's for them. Part of the reason for the high case loads was an unprecedented rise in their census mixed with a local nursing shortage.

At **hospice C**, interviews and observations of case conferences showed that each full time nurse had between 10-12 patients. Hospice C was unique in that their organization had firm productivity standards for the staff that were imposed by the higher administration. The productivity standards set by the higher administration required each RN to make 4 billable visits to patients per day. Unlike hospice A, the productivity standards imposed at hospice C did not take a patient's acuity into account. While some staff felt pressed for time and annoyed by the productivity standards, most staff did not feel

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feel that their caseload inhibited their ability to provide good care. They knew that if they got overwhelmed, they could ask a per diem nurse to go out and visit a patient for them. An RN at hospice C described their case loads:

"I: How many patients does a case manager usually have? R: Ten to twelve. Sometimes a little more if we are short staffed. But the average is 10 to 12. Sometimes you have your patients and generally if you are seeing them one to three times a week you can pretty much see them all but sometimes if things start to escalate with your patients then you are doing a lot more visits, so you can't see everybody and you need a revisit nurse to go out and check on some of your patients.

Each hospice in this study was experiencing a rise in census at the time of study. This provided a unique opportunity to observe all three organizations at a time of relative crisis. The nurses at hospice A and hospice C, while they felt they were operating at their maximum capacity, did not feel that their ability to care for patients was compromised by the increased census. At hospice A, patients were turned down if the nurses were too busy. At hospice C, while administration was strict about imposing productivity standards, they were also adherent to the NHPCO standards which limited case loads to 10-12. Nurses at hospice B had a generally heavier case loads than did the nurses at hospice A and C (15 compared to 12). Observational data showed that the hospice B administrator continued to admit more patients despite the high case loads and in interviews many nurses reported frustration about this practice. Unlike hospice A and C, nurses at hospice B felt that they were forced to cut back on care for some of their patients in order to provide a minimum amount of care to all of their patients.

II. Personal Care

According to CMS, *" home health aide and homemaker services must be available and adequate in frequency to meet the needs of the patients." Home health aides must also meet certain standards of training.* (CMS, 1994:418.94) The actual

frequency and duration of visits by home health aides is left up to the individual hospice to determine. In their research on hospice productivity, HCS found that home care aides made an average of 5.09 visits in an 8 hour day (HCS, 2002). There were significant differences in the number of home health aide hours generally provided by the three hospices in this study.

Table 4.11 Comparison of personal care in hospices studied

	HOSPICE A	HOSPICE B	HOSPICE C
Personal care hours under routine home care	Up to 25 hours per week (5 hours , 5 times a week)	Up to 6 hours a week (2 hours, 3 times/ week) but usually 1 hour 3 times/week.	Up to 7 hours a week, (1 hour, 7 times a week) but can DO up to 14 hours a week in a crisis situation)
HHA training	Contract out with other agencies, on the job training by nurses	Trained by organization	Trained by organization
Use of Continuous care	Common	Rare	Occasional

At **hospice A**, when a patient was admitted, they were offered up to 5 hours of personal care a day, five days a week. The social worker would attend the admission meeting and assess the patient to determine how much of that available time the patient needed. At one admission, the social worker simply asked the patient's daughter how much personal care time she needed and the daughter requested all 25 hours of the personal care available. The social worker immediately arranged for the patient to receive that care. Observational data of case conferences suggest that there was no pressure by the part of the administration to limit or reduce the personal care hours provided to patients at hospice A. Data from interviews with case managers and social workers confirmed that they did not feel pressure to reduce personal care hours.

Hospice A did not train their own home health aides, but contracted out with a few different home care agencies to provide this personal care. They had developed relationships with certain agencies and knew most of the home health aides who came to work

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work with their patients. One nurse reported that they occasionally had a problem because the home health aide did not understand the hospice model of care:

"We know most of the home health aides at (agency), but there is some turn over. Sometimes you get an aide who doesn't understand that eating and drinking makes a person who is dying more uncomfortable. Sometimes you go in and see a patient who is all swollen and you know their aide gave them water."

Despite the fact that the home health aides were not trained by their agency, the staff at hospice A did not see this as a detriment to quality of care. Because the home health aides were not part of the organization, observational data showed that it was rare for a HHA to attend a case conference meeting. At hospice B and C, where home health aides are hired and trained by the organization, it was more common to see home health aides attend case conferences.

Hospice A commonly used the "continuous care" level of care for patients who needed between 8 and 24 hours of care during crisis situations. When a patient was is crisis and needs more care, typically during the final days of life, a hospice can increase the level of care from "routine care" to "continuous care." They are reimbursed by Medicare at a higher level in return for providing at least 8 hours a day of care to the patient. The requirement is that eight hours of care must be provided to the patient. 51% has to be RN care and 49% can be HHA care. Because they contracted out for HHAs and because the RN case loads were not totally overwhelming, hospice A had the flexibility to provide "continuous care" when the patient needed it.

At **Hospice B**, there were 4-5 home health aides who are employees of the organization and trained by the organization. Observations of case conference meetings revealed that it was common for the HHAs to attend the meetings and to contribute information about patients. Many informants at hospice B reported that hospice B offe

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offered personal care at a maximum of 1-2 hours, three days a week. This is an informal policy that was denied by the administrator of hospice B. The administrator reported that the hospice provided *"as much personal care as the patient needs."* Despite the fact that they tended to provided fewer hours of personal care than hospice A, most of the staff were not conscious of the fact that other hospices provide more care. In fact, one nurse at hospice B thought that they provided **more** home health aide time than other hospices in the area.

"How is this hospice different from other hospices around? R: I think one way that I am really acutely aware of is the home health aides. We do provide a lot of home health aide services where some of the other hospices provide next to none."

I think we do better quality care from what I have seen and heard, than some of the others. And that's not all of them. I: Quality in what way? R: We give a little better care. We are a little more on top of things from what I have heard. Like I said, that's not all of them...but this is feedback I have gotten. So that's what I am basing that on. I: So this is feedback from patients? R: Yes, from people who have had both. And why patients would drop one hospice and come to another. Because we get a lot of that. I: Like which hospice would they drop to come here? R: Like (hospice C), but often its just because they can't get along with whoever or because their expectation is so high.

This is an example of a staff member who had very little awareness of the level of care at other hospices. When the staff at hospice B were asked in interviews if there were any services they wished they could provide but were unable to, a common answer was, "I wish we could give these people more personal care." There was a common believe among hospice B staff that the public had been given the wrong idea about the realities of hospice care. Staff thought the public was somehow under the misconception that when they signed up for hospice, that they would have someone with them 24 hours a day.

"R: Yeah. And then some people do, because of misinformation. Well, patients get the impression from somewhere that hospice is 24 hours. So they are expecting a physical body 24 hours a day. And then you walk in there and you say, 'Well see you in a few days.' And they are dumbfounded. You know, its...they have only heard what they have wanted to hear, from the beginning of the start of care, even for a few days."

"I mean, families think that we are going to come in and be there 24 hours and do the housekeeping and the respite care and whatever. And that is just not what we do. So we have those kinds of issues and I think everybody has those kinds of issues. And sometimes the clients come in a little unrealistic."

Hospice B rarely if ever utilized the "continuous care" level of care where patients could receive 8 hours a day of care. The administration and regional director at hospice B put pressure on the nurses to provide "continuous care" to patients. (see earlier section) While the nurses at hospice B are under pressure to provide continuous level care for patients, according to one of the nurses, they rarely do provide this level of care because they have no incentive to do so:

I: Under what circumstances can you put them in that continuous care category? R: That is the biggest confusion. We have no incentive to do that. I: I think they have to have some sort of documented crisis, not just that they need the care but...R: Yeah, its got to be some sort of pain crisis or something. And (clinical supervisor) has said that if you go out there and pain isn't under control and you are looking at your watch and you see that you are there for already 2 hours and you see that you are going to be there, then you have to ...then you start continuous care, but it has to be after 12 midnight. I: I wonder if I could get some sort of copy of any written copy of continuous care. R: And they brag about...well I shouldn't say brag, but you know,...that guy who comes to case conferences some times (regional director). Anyway, he stood up one time and said, "You have to do continuous care. This means a lot of bucks. Blah, blah, blah, blah." I: Bucks? Like dollars that you have to spend or dollars you get. R: dollars we get. I mean, we don't get it but the company does. But that means we have to stay up all night. And what incentive have we got. I mean, they don't pay us more for anything. So..."

At hospice B, the nurses felt that they would simply be forced to work overtime to provide continuous care to patients and they are already working overtime with very high caseloads. The result was that hospice B was rarely able to provide the continuous level of care to their patients.

At **hospice C** they had 3 HHAs trained by their organization. Staff took pride in the fact that their HHAs were trained by their hospice and felt that this ensured a higher quality of care for patients than if they contracted out with other home health agencies. They did not contract outside the agency for home health aides. The productivity standards set by the higher administration required home health aides to make at least 5 visi

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visits to patients per day. Since the aides worked 8 hour days, this means that the aide had up to 1.6 hours including driving time for each patient.

Observational data and interview data revealed that patients at hospice C commonly received HHA visits 3 to 5 times per week. Visits usually lasted about one hour. If it was documented that the patient needed more care, hospice C would occasionally provide up to one hour of care, 7 days a week. One staff member described how she felt the personal care they provided at hospice C was less than what was promised by both Medicare and the literature produced by the parent corporation:

"In some ways you can read both our purple book that is published in house as well as the Medicare book and it will make you believe that you are entitled to 4 or 8 hours a day of custodial hands on care. When in fact that is not what we are able to provide. Both because the staffing and because we couldn't afford it. So that we are only giving patients an hour a day seven days a week. Although in crisis situations we can stretch and really take a hit."

More home health aide time is something most staff members feel needs to be increased. One nurse at hospice C complained:

"I wish we could do more. We could help more if lets say we had a home health aide going in twice a day and we could improve some of these situations, the ones on the fringe. Like where they are near neglect but everybody is doing the best they can and they don't have money for a nursing home. Even just being able to have an aide go in twice a day for that empty space before family gets home to make sure they are OK. I: And the reason why you can't is? R: Its finances. I: And so if the patient needs more care, if they can afford it they end up hiring outside help? R: Yeah, they end up hiring outside or they go into a nursing home or if they are poor enough they get Medical and they can hire a worker."

"I have about 20 years with hospice in many different settings. I did night call with hospice when I worked with the (other agency). I did discharge planning and then I worked hospice per diem on the side. So I saw a lot of different things and I worked with a hospice in (another state) that had home care and hospice together so I have seen a lot of different models. And what I notice here is they are very skimpy with the home health aides. In (other state) you could order up to, I think the benefit provides something like 20 hours a week. And you could get 2 hours seven days a week if you needed to. Or you could get 3 hours, five days a week or you could get 4 hours, 5 days a week. For respite, one hour is nothing. You can just about make it out to the drug store and back. Or maybe. Or if somebody like the caregiver is older and needs to get to the doctor or something like that, the volunteers do help with respite, but however, its not enough. I am just really shocked. I: What happens if someone wants, if someone needs more than 1 hour 7 days a week. R: Then we send out the SW and we see if they can afford to have private care."

At hospice C they do provide care to patients occasionally at the "continuous care" level. But because they do not contract out for home health aides, availability of staff is often an impediment to providing this level of care.

The amount of home health aide (or personal care) hours that were provided to patients varied significantly in each of the three hospices studied. This is one of the greatest differences in level of care at the three hospices.

III. After hours care

The CMS regulations require that nursing services, physician services and pharmaceuticals must be available to hospice patients 7 days a week, 24 hours a day (CMS, 1994). To make sure patients have access to staff on a 24 hour basis, every hospice has to work out a system of after hours care. The three hospices studied had very different systems for providing after hours care. At **hospice A** there was a nurse whose job it was to be on call every evening and night. She took calls, provided telephone support to patients and families and would call in other hospice A nurses to visit the patients at night when necessary. At **hospice C** they also had night nurses. There were

two nurses who switched off every week taking calls and making visits at night. These nurses did not usually work during the day when they were going to be on call at night. At **hospice B**, they had the nurses who had been working all day take calls and do visits at night. There was only one nurse on call at a time, so if there were two crises at the same time, chaos ensued. There were a few meetings at hospice B where they tried to change around the call schedules for night and weekend call, but the options available always consisted of nurses taking call who had been working all day.

IV. Social Services

The main requirement by CMS for social services is that *medical social services must be provided by a qualified social worker under the direction of a physician.(418.84)* (CMS, 1994). The NHCPO guidelines specify that the social worker must see a new hospice patient and perform an assessment within 72 hours of admission (NHPCO, 2000). They are also required to see the patient at least once a month. In the study of hospice staff productivity by HCS, they found that licensed social workers made an average of 3.44 visits in an 8 hour day (HCS, 2002). In this study, there were significant differences in the amount of social work care provided by the three hospices studied.

Table 4.12 Comparison of social worker case loads in hospices studied

	Full time social worker case loads	**Social worker duties**
Hospice A	10 to 15 patients	Financial matters, counseling for patient and family, funeral arrangements
Hospice B	Up to 45 patients	reimbursement for hospice; funeral arrangements
Hospice C	Approximately 13	Financial matters, counseling for patient and family, funeral arrangements

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At **hospice A**, they had both a social work manager (the counterpart to the clinical supervisor for the nurses) and a social work coordinator, each working 100% time. The SW manager's job was administrative and the SW coordinator did both clinical and administrative work. Hospice A also had four other social workers all holding Master's degrees. Three of these other social workers worked 75% time and one worked 100% time. The social workers' job at hospice A was to attend the admission and then continue to see the patient about once a week. Observations of some patient admissions showed that social workers accompanied the nurse to the admission and worked with the nurse to address the patient's needs. The social worker often became very involved in the lives of the patient and family. They would help with financial matters, provide counseling, help with funeral arrangements, and work to solve any family issues that might arise. Social workers at hospice A had 10 to 15 patients each.

At **hospice B,** observational data and interview data showed that there was significantly less social work time available to patients. With a census of up to 60, there was one full time social worker with an MSW and one part time assistant who holds a LCSW. In an interview with the social worker at hospice B she described her typical interactions with patients. The social worker at hospice B tried to telephone each new patient within 72 hours of their admission, but she did not attend the admission like the social workers at hospice A. She said that she would like to attend admissions but does not have the time. She visited patients in person occasionally. Her main work with patients was to make sure their financial situation was stable and especially to make sure that the patients were tapping into any insurance coverage they are eligible for. For example, whenever they were eligible, the social worker would sign patients up for In

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Home Support Services, a benefit that pays family members for the care they provide to their ill relative. By her own admission, the MSW at hospice B did not engage in family counseling.

I: Do you ever find yourself doing like counseling, like family counseling or mediations or that kind of thing? What percentage of your time do you spend on that kind of stuff? R: Not a lot. I would really say not a lot. I: So that's not one of the main things you do? R: Yeah, if it is really glaringly obvious. There was one where we had the kids and the parents and we had (Chaplain) and I. And we sat together and went over everything. I: I just wanted to know if most of what you are doing is going out and just dealing with the family issues, counseling and all that stuff. Or is it really more the concrete, like getting the finances in order? R: Most of what I do is more concrete. And my guess would be that if you talked to every other social worker that is doing hospice in (this area) you would probably find that more of them are doing counseling than concrete. (laughs). I: Oh really? You think so? R: Well I just am a concrete person. I didn't take therapy classes. I don't have a license. I'm not going through the procedure to get a license. I do case management and I do it very well".

The social worker at hospice B knew that CMS required her to see patients at least once a month, but she rarely has time to meet that requirement.

I: How often would you say you see most patients? R: Again the requirement is supposedly once a month, but (sighs) maybe once every two months if they are lucky... Because of the huge census."

The SW at hospice B felt very pressed for time and wished she could spend more time with patients. She described how the high census and subsequent large case load created time pressure that reduced the quality of care she felt she could provide:

"R: Medicare has a requirement that the social worker be in touch with every patient within 72 hours. So I at least have to call everybody. And they really want me to be out there and to be doing assessments. And for the most part that happens. I: Are there ever times when you say to yourself, "I wish we could provide this patient with this service but for some reason we can't?" R: More than anything in that instance its time. I mean, the guidelines are somewhere around 20 to 25 patients and with the two full counties, 20 would be fine. At this rate.... the census is 60. And (other part time SW), she travels a lot and has a lot of other little things. So, of the 60 she may have 10. I: So you are taking care of quite a few patients right now. R: yeah. That is the biggest thing. Is the time. If I just had...cause there are several patients right now that I felt like if I spent more time sitting there with them going over the things or just being there, then they wouldn't be so nervous or whatever and wouldn't need to call the nurse as much. It would just be a more calm period for them."

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The data from hospice B show that the hospice was cutting back on social services care in order to admit more patients. The social worker at hospice B felt that it would be useful if she could participate in the patient's admission but felt she did not have the time to do so. As was the case with the nurses, the social worker at hospice B felt pressed for time and felt she could provide better care if she had more time to spend with patients.

In **hospice C**, with a census of around 30 to 37 there were three MSWs who each work part time, the equivalent of one and a half social workers. At the time of data collection, when the census was at 37, each social worker had 13 patients, give or take a few. Each social worker was responsible for all the patients in a certain geographic, so sometimes the patients were not split up exactly equally. The productivity requirements set by the higher administration at hospice C required social workers to make a minimum of 3 billable visits to patients per day. This did not include telephone calls. Furthermore, social workers at hospice C were expected to see patient 4 times a month, usually on a once a week schedule. Like hospice B, the social workers at hospice C did not attend the patient's admission.

At hospice C, the branch manager and administrative assistant were responsible for making sure the patient was insured and that the hospice was being reimbursed. This freed up the social worker so that she was able to primarily provide psychosocial support to the patient and family. The social worker occasionally attended the admission of new patients and commonly did the "death visit" immediately after the patient had died. The social workers at hospice C were more like those at hospice A, in that they were involved

with the psycho-social aspects of the patient more than the financial side of things. One MSW at hospice C described her role:

"A medical social worker here has multiple duties. We go in and do an evaluation. What we are looking for is the patient and family coping abilities. We are looking at the kinds of support systems that are in place. We are looking at what kind of spiritual resources they have. So it's the concrete as well as the non concrete supports that are present. The patient's and family's understanding of the disease. Their understanding of what hospice is all about. We sometimes go in and do the consents to try to make life a little easier for the nurses because they have so much going on. If we can go in early and explain more about hospice and kind of diffuse some of the anxieties and the questions and whatever else, then we do. I: You go to the open? R: Right. There is a special open packet that the social workers go in and they go in first and then the nurse has to follow. That same day."

Social worker services at the two non-profit hospices were very similar. The MSWs had lower case loads than at the for-profit and were able to get out to see patients on the same day as they were admitted to the hospice. At hospice B, the MSWs were so overloaded that they took much longer to get to see the patients for the initial visit. Also, the MSWs at A and C were more involved in psycho social aspects of the patients care whereas at hospice B, the MSW described her work as more focused on the financial aspects of the patient's care. The main difference between the social work services at the two non-profit hospices was that, at hospice A, social workers participated in the admission, which meant that they conducted an average of one extra visit. Furthermore, MSWs at hospice A were free to spend as much time with patients as they felt necessary while at hospice C, the MSWs were limited to shorter visits due to productivity requirements. One social worker at hospice A was interviewed on the way to an admission. Here is an excerpt from fieldnotes where she describes why she came to work for hospice A rather than hospice C:

"SW had interviewed for a job at (Hospice C) and she told me that she didn't want the job because the SWs there only get one hour to visit patients and 2 hours for an assessment. That includes driving time and patients are located all over the county. If a social worker (at hospice C) takes longer to get to the appointment or spends longer with the patient than the designated time, then that is considered their own time and they are not paid for the extra time. (Hospice A SW) feels fortunate to be working at Hospice A where she is given a lot of leeway to spend as much time as she needs for a visit or assessment. SW works full time and has a case load of 28 patients. Overall, (SW) said she feels that the (hospice A) administration is exceptionally supportive of its employees."

In sum, the data confirm that social workers at hospice B are much more pressed for time and much more likely to be forced to cut back on care than the social workers at the two non-profit hospices. They also focus their energies more on financial matters at hospice B while MSWs at the non-profit hospices focus their energy more on counseling and psycho-social matters.

V. Chaplain Services

*CMS requires that hospice provide spiritual care and counseling to patients. The hospice must make reasonable efforts to arrange for visits of clergy and other members of religious organizations in the community to patients who request such visits and must advise patients of this opportunity. (CMS, 1994:*418.70(f))

At **hospice A** there were two full time chaplains. One was a female rabbi and the other was a female who described her religious orientation as, "Christian with a splash of Buddhism." Officially the chaplains were non-denominational in their work for the hospice. Both chaplains were assigned to cases by the RN case manager. One chaplain was officially assigned to each team (Team 1 and Team 2) but these were not strict boundaries. For example, if a family was Jewish, they would probably be assigned the

rabbi as their chaplain irrespective of the team they were assigned to. Also, if a patient or family did not like one chaplain they could request the other. They both also participated in the pre and post hospice programs. There was a chaplain present at every case conference observed during this research.

In a conversation with a hospice A chaplain, she described her typical interactions with patients. Upon admission, the patient and family were asked by the social worker if they would like spiritual care. If a family agreed, they were assigned a chaplain who would call or usually visit soon after admission. If the patient or family refused spiritual care they were not assigned a chaplain. For the families who refused, throughout the course of care, both the RN and case manager and the social worker would continue to look for signs that a chaplain might be needed. Sometimes the case manager RN would take a chaplain along to visit the patient (even when the chaplain was not requested) if they thought the patient really could use some spiritual care. The spiritual care provided to the patient depended on the patients needs, but proselytizing was specifically banned. After a patient died, the chaplain sometimes conducted the funeral services. The chaplains often saw patients and families on a weekly basis or even more often. Their services included praying with patients and providing family counseling. Their interactions were not limited to issues of religious nature.

At hospice A, the chaplains were considered an integral part of the patient's care by the rest of the team. The nurses and social workers often talked about how important the chaplain's work was and how it complimented the work that they do. Many nurses at hospice A talked about how they work very closely with the chaplains:

"So we are very tightly connected between all of the services. We work very closely together. That might be the difference between us and some other hospices. In that we work on a daily basis with each other, nursing and social workers and chaplains and volunteers and home health aides and doctors."

Another staff member described the experience of nurses who came to hospice A from other hospices in the area and differences in their access to chaplain services.

"(At hospice A) we have more access to the interdisciplinary team. I: More access? R: They (when they worked for other hospices) didn't have people on board, like physically here, and have access to them the same way we do. Like a chaplain and social workers. And here we do a lot more joint visits."

In addition to their work with patients, chaplains at hospice A also provided leadership in the bereavement of the staff. They opened case conference meetings with a moment of silence and maybe a poem or inspirational story. They also coordinated what is called, "the peace room" which was a conference room set aside for a few hours, once a week for staff to have quiet time and to reflect on their lives and work. Finally, it was part of the chaplain's job to coordinate a monthly remembrance ceremony where the names of those patients who died under the care of the hospice were read and where members of the team were able to share memories of their interactions with those patients.

At **hospice B** there was one full time chaplain for up to 60 patients. In an interview with the chaplain, she described the spiritual care services provided by hospice B. At the admission, the case managers asked new patients if they wanted the chaplain to come and visit them. If the patient requested a chaplain, the case manager would either leave a message for the chaplain or report to the chaplain at the next case conference meeting. Even if the patient said no initially, sometimes the patient was reassessed and

would change their mind later on in their course of care. The chaplain at hospice B had a Christian background. She made phone calls and visited patients regularly. Her job was to address many aspects of a patient's life, not just their religion. At one meeting she described her job:

"The chaplain said that her job is spirituality, not religion and she went on by describing the difference between spirituality and religion., 'Spirituality is the care of what we are. Everything that gives meaning to our lives. It does not exclude religion. Can include walks, doing dishes, praying, meditating. Some people would say that everything we do is spiritual'."

Another aspect of the chaplain's job that was different from the chaplains at the other two hospices was that she works closely with the volunteer coordinator in helping to recruit volunteers. She would sometimes go out to local organizations, usually churches, where she gave presentations about hospice followed by a description of the volunteer program.

The chaplain at hospice B was much less an integral part of the team than the chaplains at hospice A. During an inservice on spiritual care she expressed feelings of frustration that her role was not well understood by the rest of the team. At the inservice she tried to convey to the rest of the staff about the nature of her work so that they would incorporate her more into the team process. Here is an excerpt from that inservice:

"The chaplain said that to have an effective multi-disciplinary team we must understand each other's disciplines. She said that at each admission a person should be asked whether they want or need to see the chaplain and also what their religion is. Currently, this is not happening. The regional director, who was observing the inservice said that a chaplain must call every patient regardless of whether or not they indicate they want the services of a chaplain".

At **hospice C** there is one part time chaplain. He divides his time between hospice C and another of the parent corporation's hospice branches in a nearby town. The chaplain was expected to attend case conference meetings at hospice C every other week. Indeed, he was present at about half of the case conference meetings observed

during data collection. There was some confusion among the staff about how to get in touch with the chaplain when a patient needed him. During one case conference a nurse complained that she had left a voice mail for the chaplain to go see a patient but found that he never went to see the patient. The branch manager told the nurses that when that happened, she needed to know about it. Nurses and social workers at hospice C conducted an assessment of the patient's need for spiritual care and offered the services of the chaplain to all of their patients. If the patient agreed, the case manager RN or SW would leave a message with the chaplain to call or visit a particular patient. There was some annoyance among the hospice staff that the chaplain often did not have the time to follow through. In addition to patient care, the chaplain also participated in community inservices and would do memorial services for the staff in nursing facilities where hospice patient's had died. When the chaplain attended the case conference, he ran the 'remembrance' portion where the staff would go around and remember patients who had died that week. When he was not there, the bereavement coordinator MSW would run that portion of the meeting.

In conclusion, hospice A had the most chaplain time available. They had chaplains at every case conference, and their chaplains were more integrated into the interdisciplinary process than at either of the two other hospices. Hospice B had a chaplain at every case conference but there was some evidence that she was not well integrated her into the interdisciplinary team as much as she would like. Hospice C by far had the lowest level of care by a chaplain with only a part time chaplain who only attended case conferences half the time and who sometimes failed to see patients, even

when the patient had requested a chaplain. Chaplain services are an area where data show great differences between the two non-profit hospices.

VI. Bereavement services

The CMS State Operations Manual for hospice specifies that there *must be an organized program for the provision of bereavement services under the supervision of a qualified professional. The supervisor of bereavement services may be the IDG social worker or other professional with documented evidence of training and experience in dealing with grief. The plan of care for these services should reflect family needs, as well as a clear delineation of services to be provided and the frequency of service delivery (up to one year following the death of the patient).* (CMS, 1994:418.88(a). The bereavement programs at the three hospices in this study varied significantly: in the services provided to patients, in the training of the bereavement staff, and in the number of bereavement service hours available to patients.

At **hospice A** there was a full time bereavement coordinator. She had an RN and an MFA and a certification in bereavement counseling. At the time of data collection, the bereavement coordinator had just hired a part time assistant who had also completed a certificate in bereavement counseling. Observations of case conferences showed that the bereavement coordinator attended all the team meetings. In an interview with the bereavement coordinator she described her work. She was often forewarned about patients who were close to dying and families that would soon need her help. She usually made telephone contact with family members immediately after the patient had died. Occasionally though, she would go out with the nurse and attend the death of the patient

so that she could make immediate contact with the surviving family members. If she had not attended the death, she would telephone the family members a day or so after the patient died. She would often call many different surviving family members and offer them a number of support services to help them move through their time of grief. First, she offered one on one support from either herself or her assistant. Next, she coordinated and facilitated many support groups available for surviving family members[8]. The support groups had different emphases in order to cover the needs of as many grieving family members as possible. Survivors were encouraged to come to these support groups for at least a year after their family member had died. Next, the bereavement coordinator had trained a special group of about 30 volunteers who worked specifically as bereavement volunteers. They worked one on one with survivors who needed support as they move through their grieving period. After participating in an intensive training program, the bereavement volunteers met together with the bereavement coordinator once a month to report on their work with their assigned survivor. An observation of a monthly bereavement volunteer meeting showed that the volunteers shared their experiences and received guidance from the bereavement coordinator about how to best support the survivor in their grieving process.

The support groups at hospice A were not limited to patients/survivors of hospice A. Other hospices sometimes refer their patients to hospice A to join a support group that might fit their needs, especially if that hospice does not have such a highly developed bereavement program.

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[8] For reasons of confidentiality, it was not possible to observe any of the support groups offered by any of the hospices.

One of the most unique aspects of the bereavement coordinator's job at hospice A was that occasionally she would go out with the nurses to be there, not only for the family, but also for the patient before they die. The bereavement coordinator at hospice A tries to address the anticipatory grief that patients may be experiencing. Addressing anticipatory grief, the grief a patient feels when they know they are dying and they are mourning their own imminent death, was part of her job. This demonstrates a fundamental difference in terms of the idea about what hospice is and what problems hospice A was there to solve.

At **hospice B** there was one part time bereavement coordinator. Observations of case conference meetings showed that the bereavement coordinator did not attend these team meetings. It was difficult to find out about her job because she did not attend meetings or in-services. According to the director of clinical services, the bereavement coordinator sent out a card to patient's families after the patient had died. These cards were not signed by the rest of the staff. On this card it suggests to the family that they call the bereavement coordinator if they felt they need some support. In a case where the family did call the bereavement coordinator, the family was usually referred to counseling. There were no support groups or services run by hospice B that were available to patients. As you can see, bereavement services at hospice B were much less available than at hospice A. At hospice B, there was a very "stripped down" version of hospices role in bereavement and grief.

At **hospice C** there was a part time bereavement coordinator who also worked part time as a social worker at hospice C. During an interview the bereavement coordinator reported that she truly felt that these two jobs were very complimentary and

liked the fact that, as a social worker she could don her "bereavement hat" when appropriate. She said:

> *"Doing SW and bereavement together has worked out well. They are really complimentary jobs because when I go to meet someone or call them for bereavement after their family member has died, often I know them because I have worked with them as a social worker. Often I will do a death visit and when I get there will put on the bereavement hat."*

The bereavement coordinator gave an example of how these two jobs were complimentary. She said that if she attended a death as a social worker, she could also do a bereavement assessment and offer bereavement services right away. Though she only worked as a bereavement coordinator part time, the fact that she does social work for hospice C the rest of the time means she was more available to the team and to patients for bereavement services than the part time bereavement coordinator at hospice B.

Observations at case conference meetings showed that at hospice C, when a patient died, a card was sent around in the meeting and signed by everyone on the team. This card was sent to the family to offer condolences. During an interview the bereavement coordinator described the details of the bereavement program at hospice C. After a patient died, a surviving family member was sent a packet of information. This packet was sent from the corporate headquarters but signed by the bereavement coordinator and included a book on bereavement and a letter encouraging them to call the bereavement coordinator. It was the job of the social worker to conduct a bereavement assessment either in person or by telephone for each family immediately following a patient's death. During this assessment the social worker would describe the bereavement services available to the family. Each family was then labeled as "normal contact" or "early contact." Then based on whether the family was designated as early or normal contact, the bereavement coordinator would personally telephone every family between

one and two months from the time that their family member died. In this phone call she would mention the names of the nurses and social workers that had worked with them so that they won't feel she is a stranger. According to the bereavement coordinator, one of the main purposes of this call was to let the survivor know that their loved one is not forgotten. The bereavement coordinator explained that, "*people get a lot of meaning from that…knowing that we remember their spouse or parent.*" The other main goal of this phone call was to offer survivors the bereavement services that were available. The bereavement coordinator would assess them to see what they might want in terms of bereavement support. She reported that she would often do "one on one" visits with family members in addition to trying to get them hooked up to a support group. Hospice C patients and families had access to any of the support groups offered by any of the hospice branches that hospice C was affiliated with. The bereavement coordinator at hospice C ran one support group but there were many others offered by other branches. The bereavement coordinator also felt free to refer people to community based support groups. For instance, if Hospice A offered a support group with a theme she believed would benefit one of her families she would refer people there. The bereavement coordinator at hospice C also helped conduct memorial services in facilities where one of their patients had died.

The bereavement services at the three hospices were very different. Probably because there are not specific requirements by CMS or NHPCO, the different hospices had very different bereavement programs. Hospice A by far had the most involved bereavement program with 1.5 staff members, a large number of specially trained bereavement volunteers, and many support groups offered through the organization. At

hospice A, bereavement services were provided not only to the family members of their deceased patients, but also to members of the community. In addition, at hospice A, patients and families were sometimes provided bereavement support before the death of the patient in order to address "anticipatory grief. The inclusion of "anticipatory grief" as a part of the responsibilities of the bereavement coordinator at Hospice A constituted a major variation from the other two hospices in what was considered to be appropriate bereavement care.

Hospice C, the other non-profit hospice had the second highest level of bereavement services. They had a part-time bereavement coordinator/social worker who facilitated some support programs, did follow up with all survivors and conducted memorial services. Like the other non-profit hospice, bereavement services at hospice C to both family members of their deceased patients and to members of the community. Unlike the other non-profit, hospice C did not provide bereavement services for anticipatory grief.

Observational data showed that hospice B had the most "stripped down" bereavement program with a part time bereavement coordinator who did not attend case conferences, who merely sent a letter to survivors, and who ran no actual groups or counseling services for survivors. The bereavement services are one of the greatest disparity in level of service seen between the three hospices studied for this dissertation.

VII. Volunteer services

The CMS regulations stipulate that *a certified hospice must document and maintain a volunteer staff sufficient to provide administrative or direct patient care in an*

amount that, at minimum, equals 5 percent of the total patient care hours of all paid hospice employees and contract staff (CMS, 1994). This emphasis on volunteer work stems from the fact that many early hospices consisted of all volunteer workers. When the CMS regulations were written, there was an effort made to be true to the early philosophy of hospice care that relied heavily on volunteer workers. In addition and more realistically, it has been recognized that one of the main reasons why hospice care can be less expensive is because of the use of unpaid volunteers. The volunteer services are one of the areas most directly affected by the organization's profit status.

Volunteer services were very different at the three hospices. At **hospice A** there was a full time volunteer coordinator. In an interview, she described her work. She coordinated over one hundred hospice volunteers. At a new patient's admission meeting and throughout the course of a patient's care the patient was continually asked by the case manager if they wanted a volunteer. When a patient agreed, the volunteer coordinator was contacted and would send a volunteer to the patient. The volunteers provided a variety of services to their patient. They provided companionship, transportation, light housekeeping, etc. There was one situation where a volunteer provided house painting and light construction for a patient. There were no restrictions about how many hours a volunteer could work or what kind of service they could provide.[9] In addition, there were some volunteers with special skills. Some had massage certification or spoke foreign languages. The volunteer coordinator tried to find the volunteer who would best meet the needs of the patient. For example, Spanish-speaking volunteers were assigned to Spanish speaking patients. Observations of case conferences

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[9] There were no restrictions by the hospice on volunteer activities except for the obvious things such as not performing nursing services.

showed that the volunteer coordinator at hospice A also attended all the team meetings. The volunteer coordinator listened to the stories of the patients presented at the case conference and tried to identify situations where she could assign volunteers. In sum, the volunteer coordinator was very involved in the interdisciplinary team process at hospice A.

The volunteer coordinator held monthly meetings for the volunteers at hospice A. Observations of these meetings showed that the volunteers would give a presentation about the patient were working with and were subsequently given guidance and support by the volunteer coordinator. The coordinator also used this opportunity to provide some training. Once a year hospice A had a volunteer appreciation dinner attended by all the staff. In addition, the coordinator reported that once a year the she conducts a training program for new volunteers. All potential volunteers were interviewed by the volunteer coordinator so that she could assess their appropriateness as volunteers. The volunteer coordinator reported that she was actually very selective in who she agreed to accept as a volunteer. She does not hesitate to reject potential volunteers if she feels they are inappropriate.

The volunteer program at hospice A was quite developed, with many volunteers, an ongoing training program, and a volunteer coordinator who was actively participating in the interdisciplinary team process.

At **hospice B** there was one full time volunteer coordinator. At the time of data collection the volunteer coordinator had only worked for hospice B for a few months. Observations indicated that she attended all case conference meetings and tried to identify patients who might need a volunteer. At the time of data collection the volunteer

coordinator reported that hospice B had eleven volunteers signed up, but not all of them were active. In an interview, the volunteer coordinator described her job. The main thrust of her job was to make contact with the volunteers who were already signed up and to recruit new volunteers. After being on the job for a few months, the volunteer coordinator at hospice B had made contact with approximately 9 new potential volunteers who she was planning to train. The volunteer coordinator at hospice B knew she was supposed to make sure that volunteer hours made up 5% of the total hours, and she said that some months she made that percentage and some months she didn't.

Often times when a patient was being presented at the team meeting, the nurse case manager would say that the patient declined a volunteer. The data do not reveal one instance during observations where a patient requested a volunteer at hospice B. RN case managers reported that they were required to document in the chart that the patient had been offered a volunteer and declined.

The volunteer coordinator reported feeling very frustrated in her efforts to recruit volunteers for hospice B. She often went to give presentations at local organizations, mostly churches asking for people to volunteer. She also put an ad in a local newspaper to attract volunteers. She also attended a local conference of local volunteer coordinators. She said that she felt "humiliated" because some of the other hospices had over 200 volunteers and she had eleven. She said that the profit status of the hospice was an impediment to her recruitment efforts. She said there were times when people would be interested in volunteering only to recant when they heard the hospice was for profit. She thinks that there are misconceptions out there about what it means to be for profit, or

really what it means to be not for profit. She thinks that people are wrong to think that non-profits are more deserving of their volunteer hours.

At **Hospice C**, they had one full time volunteer coordinator who had approximately 45 volunteers. All patients and families at hospice C were offered a volunteer. There were some restrictions at hospice C about what a volunteer was allowed to do and how many hours they were allowed to work. These restrictions were not regulations or guidelines from outside sources, but restrictions imposed by the hospice C administration. For example, a volunteer is only allowed or asked to work for 4 hours a week for a patient.

"I: are there enough volunteers for patients? I: Yeah, well I think, I don't know what the standard is for other hospices are, but our volunteers just have 4 hours a week. And (patients) can't even be assigned two volunteers... I think it would be incredible if they could be assigned two volunteers. I: So one patient gets a maximum of 4 hours a week? R: Four hours a week maximum. And that may be great for some families but for some other families, oh God, even double that would make all the difference in the world."

In an interview, the volunteer coordinator reported that the volunteers at hospice C were allowed to do primarily respite care, and were restricted from providing other types of care like housekeeping or shopping. Usually volunteers came to the patient's house so the caregiver could get a few hours away. They were not normally required to do personal care or housekeeping. This is very different than at hospice A where volunteers regularly performed a wider variety of chores for patients including laundry, carpentry, house painting, and providing transportation.

The volunteer coordinator at hospice C reported that she was very supportive and protective of "her" volunteers. She organized many volunteer appreciation events attended by the staff. She often managed to get gifts and prizes donated from community businesses for the volunteers. She did a lot of community relationship building by

attending community forums, chamber of commerce meetings, etc. In this way, she recruited people to be volunteers as well as soliciting donations of various kinds. She also reported that the higher administration was actively trying to get her to do more public relations work for the parent corporation by attending community functions and getting their name out in the community.

In conclusion, once again the data show a disparity in the level of care provided by the three hospices. Hospice A provided the most well developed volunteer program with the highest number of volunteers who performed the widest variety of services for patients. Hospice C had volunteers, but the volunteers were more limited in their hours and more restricted in their activities than were the volunteers at hospice A. At hospice B, despite an effort on the part of the volunteer coordinator, they basically did not provide volunteers. Volunteer services is an area where profit status, and the meaning that represents to the community, have a direct impact on the level of care provided.

VIII. Pharmacy Services and Medications

According to CMS, "*Medical supplies and appliances including drugs and biologicals, must be provided as needed for the palliation and management of the terminal illness and related condition*" (CMS, 1994:418.96). All the hospices in this study had access to pharmacists who they used as consultants. All the hospices also provided durable medical equipment and pharmaceuticals to patients for symptom control related to the terminal illness.

Hospice A had a pharmacist who attended all case conferences. He worked for the hospice part time and reviewed all charts for medications. He was considered by the

staff to be an expert in pain control and symptom management and was often consulted by the medical director about different approaches or dosing. During fieldwork, the researcher never observed a situation where a medication was changed for financial reasons. Patients commonly had duragesic patches for pain control, something that was often resisted at the other hospices.

One nurse who had worked at other hospices where they had to be more cost conscious about medications was surprised at how free she felt to order medications that would have been discouraged at her former place of employment. In this excerpt, we see that she is free to order a drug that, as will be shown later, the nurse from hospice B could not order because of cost:

"I: Do you ever have to pay attention to the financing of hospice care? R: No. I: So it doesn't ever change the care you provide? R: No. I did when I worked for the for-profit. It was like you couldn't order that because it cost too much money. And sometimes I'd get into that. I have a patient now and the son wants something to improve his appetite. So I started with some steroids and it didn't help. And the son called and he really wanted Megase, is that OK? My first response was, no, it costs $240 a bottle. And then I thought to myself, you know what? That is not my concern. So I told them order it for a week and lets see what happens. And I thought to myself, its not about the money. Here, if you need something you get it. Its not like they don't care about the cost. But they trust and respect that the nurses in the field are the ones that know the patients and if we say this is something the patient needs, then nobody is questioning us. I think that other nurses who haven't come from somewhere else don't realize how great it is here. But sometimes when I think, could we order this or could we order that, and it goes through so easily...its like, you know. Its always been like that for everybody here so they think its like that all over. (At the for profit) it was like, do everything else first, then maybe we could go that way."

At hospice A, there was very little consciousness among the staff about how much things cost. And cutting costs on medications was not a part of their shared mission.

Hospice B had a pharmacist available for consultation who did not normally attend case conferences. Observations at case conferences found that it was the Medical director's job to determine what medications the patients would have. In an interview, the Medical director reported that he did have pressure from the parent corporation to cut

back on duragesic patches for pain medication because they are so expensive. He said that there was an employee from the parent corporation who came out to review things and who made a big stink about trying to decrease the number of duragesic patches used to help with pain. These patches are a very expensive way to provide pain control and the administration thought that the staff at hospice B was using them too often. The Medical Director did not think this was an unreasonable assessment. He said that there are very good alternatives to using patches and that the administration at hospice B had good reasons for discouraging their use. At hospice B there were also restriction on expensive medications, especially if they were seen as not promoting the hospice philosophy of not providing curative measures. One nurse described the situation:

> *I: How much do you have to think about how much stuff costs? R: That is always a part of the picture. There are some medications that we just don't provide because we don't feel, number one that they are beneficial in a hospice sense; and that are very expensive. Like Megase, we don't provide Megase for patients. I: What is Megase? R: Well it was originally developed for breast cancer, but one of the main side effects and what they are now prescribing it for is its an appetite stimulant. These people are losing weight and they are not eating so they, the families, want something to make them eat better. Well OK, but that kind of goes against the hospice criteria. So and Megase is very expensive. If it were dirt-cheap we would probably say, "Sure go ahead."*

This quote shows how the nurse at hospice B was not able to order the drug Megase, the same drug that was shown to be ordered at hospice A in an earlier section. The restrictions discouraging the use of expensive medications at hospice B were not institutionalized rules. These restrictions were not written down, but it was understood by the staff they should always look for an alternative to expensive medications.

At **Hospice C** there was a pharmacist who attended one out of 5 case conference meetings observed for this research. He also worked at other hospice branches and switched off each week where he attended case conferences. According to interview data, he worked as an intermediary between the hospice and the local pharmacies to

negotiate contracts and facilitate access to the narcotics that the hospice needed. He helped the hospice obtain these narcotics with the minimum of paperwork.

The prescription of medication to patients at hospice C was highly regulated through a medication formulary which was a list of "approved" medications that could be prescribed to patients by hospice C nurses. Medications were "approved" for the medication formulary based on their appropriateness for hospice patients and their cost effectiveness. This medication formulary was created by the medical directors at hospice C with input by the branch managers. It was used by all the hospice branches owned by the parent corporation. Each hospice nurse carried with her a card with a written list of all the medications that were acceptable to order for patients. Staff always tried less expensive drugs and generic versions of drugs in an effort to cut medication costs. According to the branch manager in an interview, she said:

"*Why use a more expensive medication and give extra money to the pharmaceutical drug companies when you can use a less costly medication that is just as effective.*"

Observations showed that cutting drug costs was an overt team effort at hospice C. It was discussed openly during case conference meetings. As a result, observations showed that the nurses at hospice C were very aware of what substitutions they should make in medications in order to cut costs. For example, all the nurses knew that they should not start someone on a duragesic patch for pain control without trying less costly alternatives beforehand.

While cutting medication costs was an important part of the work of the staff at hospice B, the medication formulary was used as a guideline for medication choices and did not forbid the use of more costly drugs if they were needed. The branch manager explained:

" The formulary is not in stone. There are other medications that we order all the time that are not on those formularies. I: It just has to go through the doctor? R: Well the doctor orders it and then it needs to go through the supervisor to talk about if its needed. Sometimes we get orders from physicians for Oxycontin when someone has never even tried MS Contin and that is a third of the price. So why wouldn't we use MS Contin if it works for the patient. And the doctors have the drug companies come to them trying to sell them Oxycontin. But its not necessarily something we need to provide. Or before anything else, doctors will order a patch. A $150 patch when a patient can swallow easily and has no problem with MS Contin. So those are the kind of conversations that we need to have to survive as far as keeping our costs down. "

According to interview data, if a patient or doctor insisted that a patient stay on a non-formulary medication, refusing to switch to an equally effective lower cost drug, then hospice C would refuse to pay for that medication. In that situation, the patient would have to pay for the non-formulary drug out of pocket. Hospice C would pay for a non-formulary drug only after the lower cost alternative had been ruled out. The medical director at hospice C explained:

"There are medications we aren't paying for because they're not on our formulary but there is a substitution that we can afford. We have to determine why a patient is not on a formulary drug. Have they been tried on a lot of different drugs for nausea and that is why they are on this more expensive drug? Because if you have gone through all the other measures, you DO approve the more expensive drug. "

If non-formulary medication was needed for some reason, then that medication could be ordered with the approval of the medical director. Observations at a case conference revealed one such case where a patient who had a history of addition to prescription pain pills needed pain medication. The staff worried that taking a pill would set off addictive behavior, so the duragesic patch (which was a non-formulary pain medication) was approved by the hospice C Medical Director because the patch was less

likely to instigate addictive behavior. This reasoning was documented in the chart and a duragesic patch was ordered for the patient.

At hospice C, the rules about prescribing medications were highly institutionalized through the medication formulary, much more institutionalized than at the other hospices studied. The goals of this medication formulary was to cut medication costs while still providing appropriate medications to patients. While it was beyond the scope of this research to determine if they were prescribing appropriate medications to patients, there was data collected which showed that the use of the medication formulary had been effective in cutting medication costs at hospice C. Here is an excerpt from fieldnotes describing a case conference meeting:

"(Branch manager) announced that she had tallied their pharmacy bills. She thinks she got all the bills and unless something else comes in that she doesn't know about. It looks like the spend $7.02 per day per patient on medication which is well under the national average of $12 per day. She congratulated the staff. Their efforts to keep costs down has been really wonderful. They spent a total of $5,251 for the month. Patients still get good care but you guys have to have those hard conversations with patients b/c nobody likes to change medications. I talked to (branch manager) about this after the meeting. She said that doctors often use a certain drug just because the drug company gave them samples. The hospice needs to use the equivalent but cheaper versions and that is difficult to get across to patients. Hospice staff has to work together on this. It does not involve compromising care at all, it's a good thing b/c why should they give extra money to the drug companies. Branch manager said she would be announcing to the (Director, CEO and CFO) about their low drug costs. She also told them that she left (the Director) a message about how great they had been is in responding to crisis this week. Thanked staff for all their hard work."

As this excerpt shows, reducing medications costs was a team effort at hospice C. The pressure to cut medication cost was not an unwritten rule. It was an explicitly written rule. It was something the staff were made to feel proud of and was equated with providing high quality care to patients.

In sum, hospice A had the most well developed set of pharmacy services. Every case conference had a pharmacist present and advising the medical director on drug dosing. In addition, there were fewer restrictions on medications because hospice A had

no established restrictions on medications. At hospice B there was a pharmacist available for consultation, but the medical director did most of the medication dosing. At hospice B there was a non-written, underlying policy to restrict expensive medication like duragesic patches or morphine pumps for patients whose pain could be controlled by other measures. Hospice C had the most well developed, institutionalized restrictions on medications (the medication formulary). The goal of these policies were to rationally cut medication costs without lowering the quality of care to patients.

IX. Physician Services

According to CMS regulations, *a physician must be a part of the interdisciplinary team caring for a hospice patient. The responsibilities of the medical director include, but are not limited to: certifying that the patient is terminally ill*[10] *and recertifying eligibility for hospice care for subsequent election periods. In addition to palliation and management of terminal illness and related conditions, physician employees of the hospice, including the physician member(s) of the interdisciplinary group, must also meet the general medical needs of the patients to the extent that these needs are not met by the attending physician* (CMS, 1994:418.86). The medical director can be a full time or part time employee of the hospice, or a volunteer.

At **hospice A**, there were three part time medical directors, one each for team 1, team 2, and one for the SNF team. Though the hospice A medical directors were not interviewed, other staff reported that each medical director had their own practice separate from the hospice. The medical directors were available to the hospice staff on

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[10] Terminally ill is defined by the statute to mean that the medical prognosis of life expectancy is 6 months or less if the terminal illness runs its normal course.

the day of the case conference and then available by page the rest of the week. The medical director for each team participated in the case conference, reviewed charts and commonly took the hospice patients on as their own patient. For patients they did take on, they visit that patient a minimum of once a month.

At **hospice B**, there was a medical director who was also the medical director for another branch of the same parent corporation. She was a full time employee of the parent corporation. Observations showed that she attended all case conference meetings and reviewed charts. She was available to hospice B on the day of the case conference. On other days she could be paged to consult about a patient. Observations of case conference meetings showed that she would occasionally take a patient on as her patient, especially if the person's own physician was not familiar with hospice. During a casual conversation riding in a car to visit a hospice patient the medical director reported that because she was the one who was responsible for establishing hospice appropriateness, she would commonly visit patients at their home, especially if they were due for recertification. She would make these visits even to patients who had another community doctor as their primary physician.

At **Hospice C**, there was a medical director who was also a medical director at another hospice branch of the same parent corporation. She was a full time employee of the parent corporation. She attended all case conference meetings and reviewed all patients' charts. She was available during the week by pager for the nursing staff if they had questions. In an interview she reported that she did not normally take patient's on as her own. At hospice C, all patients had a primary care physician who wrote the orders for the patient's medications. This lead to a lot of interaction with the community

physicians on the part of the nurses at hospice C. Nurses reported spending a lot of time making telephone calls to primary care physicians trying to make changes in medications. A lot of these changes had to do with the medication formulary. The nurses had to get written orders delivered or faxed in order to change a patient's medications, which required a great deal of exchanging of paperwork with physicians in the community. This time interacting with community physicians was a big part of the nurses' job that did not count toward their billable hours. Occasionally when a physician was particularly difficult to deal with, the hospice C medical director would step in to assist the nurse in communicating with that community physician.

At all three hospices, it was the job of the medical directors, with the help of the nurses to establish hospice appropriateness. The medical directors were the ones who took legal responsibility for meeting the eligibility requirements set by Medicare. The involvement and role of the physician at all three hospices was very similar.

The most significant difference between the three hospices was that the medical director at hospice C did not normally become the primary physician for the patients. This meant that the nurses at hospice C always had to consult with the patient's primary care physician when any changes in orders were needed. When a medical director does become the primary physician for a patient, the hospice nurses then only need to deal with the hospice medical director when patient's medications need to be changed and it reduces the work load for the nurses quite a bit.

X. Conclusion to section two

The second aim of this research, to describe and compare the level of service in each of the three hospices, was accomplished in this section. In summary, there were many differences in the types of services and the level of services provided by these three hospices. In general, hospice A, the non-profit freestanding hospice usually provided the highest level of service, with lower case loads and less pressure on the staff. Hospice B, the for profit, corporate owned hospice usually provided the lowest level of service with the highest case loads. At hospice C, the non-profit corporate owned hospice, the level of service usually fell somewhere in the middle (except for chaplain services which fell below hospice B). While hospice C usually provided a higher level of care to patients than hospice B, the staff at hospice C were more tightly regulated by their administration and had a lower moral than the staff at either of the two other hospices.

Section 3. RESOURCES, ORGANIZATIONAL STRUCTURE AND SERVICE DELIVERY IN HOSPICE: A RESOURCE DEPENDENCY PERSPECTIVE

I. Introduction

In the first two sections of this chapter, the organizational structure and the level of service delivery in each of the three hospices were described and compared. This third section addresses the third aim of this research, which is to examine the relationship between the organizational environment (resource dependence) and organizational behavior (service delivery) in the three hospices studied. It also addresses the fourth aim of this research, which is to look at the relationship between organizational structure and service delivery.

Despite functioning in identical market environments, the three hospices provided different types of services and levels of services. This section will explore how organizational factors and access to resources were related to the difference in level of service. In the background chapter, the literature on ownership, profit status, organizational relationships and location of authority in other health care industries like hospitals and nursing homes was reviewed. In this section, hypotheses relating to these factors will be presented and these four dimensions will be discussed with particular attention to their "meaning" in each hospice and how they are related to the level of service provided in an organization.

In this section, resource dependency theory is used to examine the relationship between access to resources, organizational structure and service delivery. Resource dependency theory (RDT) conceptualizes organizational behavior as a direct consequence of A) access to resources; and B) the influence from outside organizations

with which the focal organizations has dependency relations, (i.e. the organizational environment) (Pfeffer & Salancik, 1978). In the case of this particular hospice market, the resources that would determine organizational behavior would be mostly financial resources like the added revenues from the foundation. Another resource that will be discussed is access to the most financially desirable patients or "cream skimming."

Hospices are not only competing for financially desirable patients, but they are also competing for contributions. The two non-profit hospices (Hospice A and C) both relied on foundation funds to meet the needs of their patients. In this section, a discussion will also be provided of the competition for charitable donations to supplement reimbursement.

The organization environment as stipulated by RDT includes any outside organization that influences the behavior of the organization in question. In the case of the hospices studied, the organizational environment would include: 1) the inter-organizational relationships, (vertical and horizontal integrations); 2) other hospices that are competing for patients; 3) hospital and physician practices who provide referrals; 4) authoritative bodies like parent organizations or board of directors; and 5) regulatory agencies that influence behavior through actual monitoring or the threat of monitoring.

This next section will look at the affects of dependence on outside entities (like government funding agencies) and competition with other hospice agencies for resources.

II. Resource dependency and hospice behavior

Proponents of resource dependency theory would say that the reason why the hospices studied behaved differently was probably because they had different access to resources and were responding differently to those resources and relationships. In this section, two different types of access to resources will be examined in the hospices studied, including: access to financially desirable patients and access to foundation funds

According to resource dependency theory, an organization will behave in a way that ensures a greater access to resources. For hospice, government funding is the primary entity that provides financial resources. The first hypothesis to be explored regarding the hospices access to financial resources pertains to the source of funding:

Hypothesis #1: Hospices are heavily dependent on government funding, which affects the way they behave

As was described in the background chapter, hospices are reimbursed on a per diem basis. Table 4.13 shows the reimbursement rates from both Medicare and MediCal that each hospice received for routine home care patients.

Table 4.13 Per diem payment rates by payer

	Medicare	**MediCal**	**Commercial Insurance**
Hospice A (year 2000)	139.82	131.38	Not reported
Hospice B (year 2001)	156.30	107.28	Not reported
Hospice C (year 2001)	163.57	155.73	Usually Medicare rate

**The rates for hospice A are lower because they reflect an earlier year than the rates from hospice B and C.

Hospice A, B and C all received higher reimbursement from their Medicare patients than from their MediCal patients. The disparity was the greatest though, in the

for profit hospice B, where they received almost fifty dollars less per day for MediCal patients. Commercial insurance rates are usually driven by the Medicare rates. As was described in the background section, commercial insurance carriers often match the Medicare rates but never exceed those rates.

Nationally, approximately 70 percent of all hospice patients are covered by Medicare while just under 5 percent are covered by Medicaid (NAHC, 2002). Table 4.14 shows the percentage of patients in each hospice that were reimbursed through each type of payer during the year that hospice was studied.

Table 4.14 Percentage of patients by payer in each hospice studied

	Medicare	MediCal	Commercial Insurance	Private pay	Foundation insurance/ charity care
Hospice A (2000)	(63.2%)	(5.9%)	(21.5%)	0	(9.1%)
Hospice B (2001)	(65.1%)	(22%)	(12.9%)	0	0
Hospice C (2001)	(79.3%)	(4%)	(15.6%)	(0.3%)	(0.6%)

In each hospice, a high percentage of patients are reimbursed through the government programs, making each hospice highly dependent on government funding, but this is especially true for hospice B and C. In hospice A, 69.1% of their patients receive government funding through Medicare or MediCal. In hospice B, 87% of their patients are funded through these government sources. And in hospice C, 83.3% of their patients rely on government funding. Thus, hospice A is less reliant on government funding than hospice B or C.

According to resource dependency theory, due to their greater reliance on government funding sources, hospice B and C have a higher level of dependency relation with the government than does hospice A. Hypothesis one contends that hospice B and C might act in a way that is more accommodating toward the Medicare regulations, in an attempt to insure continued access to that primary resource. In interviews, hospice staff members were asked about their perceptions of the constraints of the Medicare regulations. Interview data reveals that hospice B and C staff were more likely than hospice A staff to find the Medicare regulations constraining: Here are some excerpts from interviews with hospice B staff about how they find the Medicare regulations constraining:

"I: What about Medicare regulations? Do you ever have to think about Medicare regulations when you are doing work? R: Yes. Like when we do an open we have to make sure that they are hospice appropriate. Meaning that they have a prognosis of less than six months but that also....I mean a doctor can say that the prognosis is less than six months but if somebody is up and walking around and going shopping and blah, blah, blah. Then we have to think about it, depending on the diagnosis we have to think about it because it could be not necessarily hospice appropriate. I: You could get in trouble? R: Yes. I: So what kind of things do you have to look for to make sure they are hospice appropriate? R: Well, each disease has their own factors. They have to have certain lab work results of whatever.

"You have to think about everything. State regulations are very important. If you don't follow the guidelines they can shut you down. (interrupted) R: I would say that you really gotta know your regs. You've got to know your guidelines. You gotta know what you have to do. But the problem is that the state is so...they have so many gray areas. Where every time they come in to do a survey, it's a different rule than it was last time. Or they have a different definition they use for the regulation. And the rules are not consistent."

These staff member's comments reflected an attitude at hospice B that was very negative toward the Medicare regulations. They felt that the regulations were constraining and they expressed fear of being surveyed by the Medicare contracted surveyors. In hospice C there were similar negative feelings toward the Medicare regulations in general:

"I: what about other constraints from Medicare? R: Mostly they have those requirements about when and how quickly a patient should die. The six month criteria is difficult. We have to do constant documentation about how a patient is declining and if we can't document it then we have to discharge them. It doesn't make any sense. Just because a person is experiencing a period of relative stability, it doesn't mean that they still don't need the support. It doesn't make sense."

"When I knew Medicare was going to be funding (hospice) I knew it was going to be awful because Medicare just regulates things to death. And it is awful. I: And you feel that here? You feel regulated to death? R: Yes, I do. And it impedes my ability to provide the care I want to provide. But you know more than anything, I mean I feel like we provide excellent care. But more than anything it takes away our energy, it takes away our focus. It takes away the time we could be giving our skills and our energy to the families. To constantly be having to do audits and paperwork and you didn't write this and you didn't write that. To constantly have to be doing all of that stuff. It takes a lot of time and a lot of energy. If I had my fantasy somebody would call and say, we have this person who is dying, can you do anything? And we would just run out there we would call the doctor and get them what we need. We would do what we needed. But no, here we have to make sure we have the 2 page history, we have to make sure we have some kind of history from the doctor, we have to make sure they meet the criteria even if they are on their last leg. There are all kinds of hoops that (branch manager) has to go through and admissions has to go through. And then this person might be dead in 4 hours or the next day. And in order to be reimbursed we have to write it up. If we didn't have to do all that documenting and all following all those rules, we could be doing so much more."

"I: Do you feel constraints from the Medicare regulations. R: Yeah like when we get an ADR, a request for additional information. Medicare has everyone scared that they are going to deny a claim. You feel it more in social work. There is more pressure there."

As the interview data shows, staff at hospice C felt that the Medicare regulations were overly strict and sometimes unreasonable. Staff at hospice B and C both find the Medicare regulations very constraining. They thought about the regulations during their daily work and felt negatively about the affect that the Medicare regulations and paperwork had on the care they provide patients.

Hospice A, while it is also reliant on government funding, has a higher percentage of patients with commercial insurance in addition to a large foundation that covers patients who do not have access to any form of insurance. Thus, they are less reliant on government funding for resources than the other two hospices. According to resource

dependency, a lower level of dependency relations with the government would affect hospice A's behavior, making them less likely to feel constrained by the Medicare regulations.

From interview data, staff at hospice A revealed that they did not feel that the Medicare regulations were a constraint on their behavior. Here are some excerpts from interviews where hospice A staff talk about how the Medicare regulations are a nuisance but not a constraint:

"R: So we are hassled about Medicare but that's no big deal. I: You guys know how to deal with it pretty well. R: We keep learning because they keep changing the rules for how to do it."

"I: You said something interesting earlier, you were talking about ways the regulations help things. I wanted to ask you about that. R: I think that this is the way the government works. They use the purse string to ensure that the philosophy is adhered to. It would be very easy to go around and just do what you want to do. But if there is someone around saying, well, that doesn't cut it. I don't see anything in here where a person has ever talked to a social worker about anything. And that is not what hospice is supposed to be about. I: So you think in some ways the regulations help. R: Yes, I think in that way it does. I: Because you hear people say that well, hospice has become so regulated and its not what hospice used to be. R: And I think that is true. I think all of this is a trade off. And probably some things could be...a lot of the regulation could be thrown out. The extent of regulations is so time consuming, its insane.

"I: You know all the Medicare fraud investigations and the State audits that they do. How much do you have to think about that? How much does that come into your everyday consciousness in terms of what you do? R: It doesn't, unless there is a patient that's questionable."

"I: What are the guidelines for Medicare in terms of somebody....R: It has to be six months or less. But you know, I took of one patient for 2 years. But as long as you document...Like with this woman, we needed to adjust her pain medication all the time. We were doing something. As long as you are doing something, you feel OK. If something is needed."

"I: One other question about Medicare. Are there any other positive effects of the Medicare regulations? R: Sure. I think it keeps people on their toes. It makes you reassess and sit back and say does this person really need this and does this person really need that. Yeah. I think any kind of regulation is a way of thinking things through. Just like when you come to the end of a recertification period and they give you this piece of paper to fill out. The paperwork is a pain in the neck but what it actually does is it gets you to go through the chart and say, I didn't realize this medication was expired or that I didn't do this charting. So there is actually a little silver lining, not a big one, but some."

"I know in nursing there are probably certain things that aren't allowed by hospice Medicare benefit. But in spiritual care, it seems like there are not really those kind of problems."

"I: Do you have to think about the Medicare regulations very much? R: Not too much. Its just really a nuisance. It's a nuisance, its not a constraint."

"Because the regulations are difficult they also help you deliver quality care. No one wants to admit that the regulations do that but they really do. Also I think guidelines allow you, enforce you to think, so that you don't do things by rote. Even though a patient may not meet the guidelines, guidelines are not always to be met. They are guidelines. Then it says to you, my patient doesn't need these guidelines, then I have to think and asses why is this patient appropriate and document it. I think guidelines I see them from a very positive standpoint. They are a pain in the neck. Yes I agree. And I hate to see more. But also you can look at them as a challenge. As a professional challenge."

The data presented above from Hospice A show a considerable difference in terms of their attitude toward the Medicare regulations. These staff members at hospice A think that the paperwork and documentation imposed by Medicare are a nuisance. Though some staff members think that some of the regulations are too much, overall there is not a sense that the Medicare regulations are a constraint to the care they provide. Many of the staff members at hospice A also recognize that the Medicare regulations drive higher quality of care, and enforce an adherence to the hospice philosophy, both positive affects of the Medicare regulations, both in other hospices that might otherwise skimp on care, and in their own work. This more positive attitude toward Medicare regulations at hospice A is probably partially affected by the fact that hospice A is not as reliant on government funding as the other hospices due to their higher number of commercial insurance patients and their foundation funds that cover patients. When the hospice A administrator was asked about government regulations and the staff's relaxed attitude about them, she replied:

"I'll tell you. If it weren't for Medicare, hospice would not be what it is today. Medicare is the primary reason for the expansion of hospice services in this country. I have pounded that into people's heads here. But on the other hand, it's a little disconcerting that the staff is not a little more wary of the hospice regulations."

This quote shows that the more positive attitude at hospice A toward Medicare is something that was originally encouraged by the administration and had subsequently trickled down to members of the clinical staff.

In sum, hypothesis one appeared to be supported. Hospices that were more reliant on government funding behaved differently than the one that was less dependent on government funding. Staff in the agencies that were most dependent on government funding perceived the Medicare regulations to be a constraint on the amount and type of care they could provide. Observational data collected during case conference meetings revealed that staff at hospice B and C appeared to spend more time and energy documenting that patients were hospice appropriate. In a later section of this chapter, more data will be presented showing that staff at hospice B and C were more focused on measuring hospice appropriateness in order to appease regulators.

A. Access to the "right" patients

Resource dependency theory stipulates that an organization's behavior is driven by their need to increase their access to resources. In hospice care, patients can be seen as a resource that hospices may be competing for. Different types of hospice patients are more or less financially attractive to a hospice based on many different factors. Factors that play into this attractiveness are type of illness, acuity of illness, level personal care/nursing care required, type of insurance, level of insurance reimbursement, and length of service. Since hospices are reimbursed for the most part on a per diem basis, they have a financial incentive to admit patients who, among other things, do not require

as much nursing care, durable medical equipment or expensive medications. They also ideally want patients who are easily proven to be hospice appropriate (so their claim doesn't get denied) and who will stay in hospice long enough for the hospice to break even financially. Data from this study were not complete enough to provide an analysis of the patient mix based on all of these factors, but there is some evidence to suggest that the for profit hospice was not able to attract the most financially desirable patients.

Looking at reimbursement type in order to determine the financial desirability of patients across hospices is complicated because different hospices received different per diem rates from Medicare, MediCal, and commercial insurance payers. As is shown in table 4.13 (per diem rates from payers), the different hospices had different per diem rates from Medicare and MediCal. Table 4.14 shows that they also had different percentages of patients based on payer. Hospice B had the greatest disparity between their per diem Medicare and MediCal rates, ($156.30 and $107.28 respectively). They also had the highest percentage of MediCal patients at 22% (compared to 5.9% and 4 % in the nonprofits). These figures further suggest that hospice B was at a financial disadvantage because of the patients they admitted. It is significant though, that despite their tendency to admit financially undesirable patients, they still managed to make a profit without access to foundation funds.

Because of the higher Medicare reimbursement rates, the hospices studied were likely to have been competing against each other for the better-reimbursed Medicare patients in the community they served. While most staff members who were asked about competition for patients denied that payer source was taken into consideration, this may have been a practice that staff members were unaware of. According to table 4.14 we see

that hospice C was the most successful in attracting Medicare patients, with 79.3% of their total census reimbursed by Medicare.

Different hospices also negotiate different reimbursement rates with commercial insurance companies. In other words, the same commercial insurance company might reimburse one hospice at a higher rate than another hospice. All of the different payers and the reimbursement rate they provide play a part in the financial attractiveness of a certain patient. Unfortunately, data on commercial insurance reimbursement specific to each hospice were considered confidential in two of the hospices studied so analyzing commercial insurance rates across hospices was not possible.

Another area where differences in access to financial resources could be measured across the three hospices studied was the number of "uncompensated care" patients admitted by each hospice. The term "uncompensated care" is a confusing one because hospice A and C did receive compensation for the patients who were designated as uncompensated; the compensation came from their own foundation. Table 4.14 shows that in the year they were studied, hospice A had 48 patients who were not eligible for any form of insurance and whose expenses were subsequently covered by foundation funds. Hospice B reported no cases of uncompensated care in 2001. If they had had an 'uncompensated care' patient they would not have had foundation resources to cover that care and that care would have come out of the profits accrued by the parent corporation. Hospice C reported 2 cases of uncompensated care in 2001 whose care was subsequently covered by foundation funds. The number of patients who were classified as "uncompensated care" was significantly different at the three hospices, and was directly comparable to the amount of foundation funds they had access to. This indicates that

some "selection" of patients on the part of the hospices was occurring. Differences in the number of uncompensated care patients is an interesting finding because the administration of every hospice studied claimed to take all patients regardless of their ability to pay. But despite this, they took "uncompensated" patients based on their ability to cover the costs of those patients with foundation funds. Another possible explanation is that there was some selective referral taking place on the part of referring physicians and discharge planners who might know to send a patient without insurance to a hospice with a large foundation.

One type of patient that is generally attractive to hospices are cancer patients. Cancer patients fit with the hospice model of care. Hospice was originally founded through care of primarily cancer patients and, as has been described, the course of end stage cancer has a downward trajectory that fits with hospice eligibility criteria. In other words, cancer patients are less risky than patients with non-cancer diagnoses who might be more likely to have a claim denied due to lack of evidence of hospice appropriateness. In this study, table 4.15 shows that the different hospices had different types of patients by primary diagnosis.

Table 4.15 Percent of Patients by primary terminal diagnosis in hospices studied

	Hospice A (non profit)	Hospice B (for profit)	Hospice C (non profit)
Cancer	58.2%	20.9%	61%
Heart Disease	5.9%	22.5%	5%
COPD	4.3%	24.7%	3.1%
ALS	0.6%	20.4%	0.3%
Liver Disease	0.6%	3.2%	1.6%
Debility & Decline	0.8%	0.8%	24.7%
Renal Failure	1.1%	0	2.2%
HIV	1.3%	0	0.3%
Alzheimer's/Dementia	3.4%	0	1.3%
Other non cancer	23.5%	0	0

In this study, the nonprofit hospices had significantly higher percentages of cancer patients (58% and 61%), both higher than the national average of 51% cancer patients in hospice (NAHC, 2002). The for profit hospice, on the other had less than 30% cancer patients, resulting in over 70% of their patients having more risky non-cancer diagnoses.

Another type of patient that is inherently "risky" for a hospice to admit are patients whose primary diagnosis is "debility and decline" or D&D. Depending on the hospice, D&D can also be called "general debility" or "terminal debility." This diagnostic category is used in hospices for patients whose primary disease process (usually non-cancer, CHF, COPD, Alzheimer's/dementia, or a combination of diseases) do not fit the eligibility criteria for hospice appropriateness. Guidelines for hospice appropriateness for D&D have been adopted by the NHPCO and include mostly a focus on weight loss and decreased mobility as criteria for being hospice appropriate. Often patients who are designated as "debility and decline" have a number of diseases that have the combined

effect of causing a terminal prognosis, but no one single disease fits the criteria for hospice appropriateness. Another type of patient who tends to be designated as D&D are patients who are very old and have a history of both good health, and avoidance of doctors. These are very old patients who do not have enough of a medical record to determine conclusively a diagnosis or the terminal nature of that diagnosis. In other words, these are patients who might be described as dying of "old age." According to interviews with staff and administration at all three hospices, D&D patients are inherently risky for a hospice. While a D&D diagnosis might allow a hospice to admit a patient who would otherwise not be eligible, theoretically, D&D patients are more risky for a hospice because they are more likely to have their cases reviewed by the fiscal intermediary.

Interestingly, hospice C had a far greater percentage of D&D patients than the other two hospices (24.7% compared to 0.8% at the other two hospices). The reason for this difference in unclear. Possibly hospice C had a different understanding of the risk of a D&D diagnosis and felt that it was more risky to give patients another diagnosis that was more difficult to establish hospice appropriateness. This may be a difference in the "enacted environment" or the perceived environment of hospice C. Most of the non-cancer patients at hospice C were designated as D&D. Furthermore, hospice C had a much lower percentage of COPD and CHF patients than the other two hospices. It could be that hospice C was designating most of their COPD and CHF patients as D&D because they felt it was somehow more appropriate. In other words, the difference in percentages could represent a difference in the organization's standards of practice in determining diagnosis. On the other hand, there may have been some selection bias of

some sort whereby hospice C ended up with the debility and decline patients in that market. More research would need to be gathered to understand why hospice C had such a greater percentage of these seemingly financially risky patients.

The length of time a patient stays under the care of a hospice, or their length of service, is an important determinate of that patient's financial desirability. As was covered in the background chapter, research has shown that the first and last few days in hospice are the most costly (Austin & Fleisher, 2003). There is a high output on the part of a hospice during the patient's admission and also around the time of their death. Thus, during shorter stays, there are fewer less costly days to offset the more costly ones, resulting in a financial burden for the hospice facility (Testimony of William J. Scanlon before the Special Committee on Aging, September 18, 2000). Data from this study suggests that because of the increased costs of care both at the beginning of care and at the patients death, a hospice does not break even financially unless a patient is under their care for more then two weeks. One branch manager said:

"And we have the horrendous issue of this length of stay issue. We take a financial beating if we can't keep a patient for more than 2 weeks. The opens and the initial here are always the most labor intensive when you are talking about a per diem rate. Talk about a per visit rate, that is a whole different kettle of fish. We can be getting killed, yet we have this obligation to provide services because that's what is expected of us as decent human beings as well as hospice providers. So there's always knowing that we are obligated to provide but we may not be provided for. How long can we go on doing this or end up going out of business as many hospices have?"

Table 4.16 Average length of service by hospice and program

	Average length of stay
Hospice A (hospice patients)	42.2
Hospice A (palliative care patients)	72.6
Hospice B	24
Hospice C	34

Table 4.16 shows the average length of service at each of the hospices studied. Maybe due to their high percentage of non-cancer patients, the for profit hospice also had the lowest average length of service of any of the hospices studied. While there is no data from this study to support this assertion conclusively, theoretically, a lower average length of service could indicate a larger number of patients who stay in hospice for shorter than 14 days, the threshold for breaking even financially. The lower length of service in the for profit hospice is another piece of evidence that might suggest that they did not have access to the most financially desirable hospice patients, though further research is needed to determine conclusively if this is the case. It might also explain why hospice B had to cut costs by providing a lower level of service to make up for their less financially desirable patients.

The differences in types of patients at the for profit hospices might indicate that "cream skimming" or "patient dumping" may have been taking place either purposely or inadvertently on the part of some of the hospices in the region. To determine this, more data would need to be collected about discharges of patients at hospices in the region and whether or not those patients were subsequently admitted by other hospices. Also, more data would be needed to be collected about what types of patients were refused admission by the hospices and whether or not they ended up receiving hospice care from another source. Tracking patients and their hospice care in a certain region would be useful information to understand more about "cream skimming," would be an important area for future inquiry

In sum, the fact that differences existed in access to financially desirable patients was an important finding in this study, but one that would require further research to

understand. This study found that that the for profit hospice was more likely to care for non-cancer patients and for MediCal patients, a practice that is directly contrary to the stereotype of for profits hospices and their alleged "cream skimming." On the other hand, the for profit hospice admitted fewer uncompensated" patients. Furthermore hospice C, one of the non-profit hospices, was more likely to have patients with "debility and decline" as their primary diagnosis and much less likely to have COPD or CHF patients, indicating either a bias in patient selection or a bias in diagnostic practices. Finally, data show that hospice A was much more likely than either of the other two hospices to admit patients who were uncompensated. While the data suggest that there are forces at work selecting patients based on the organizational structure and access to resources at the different hospices, more detailed data on these factors, such as exact reimbursement levels, discharge and admitting practices of the hospices, and community reputation are needed to unravel this quandary.

B. Access to foundation funds

Non-profit hospices are allowed to solicit charitable donations to supplement the reimbursement they get for patient care. Both hospice A and C had dedicated foundations while Hospice B, being for profit was not allowed to have a foundation and did not thus, have access to extra funds for patient care. The second hypothesis addresses the affects of access to foundation funds.

Hypothesis #2: Increased access to foundation funds will be related to a higher level of care at the hospices studied.

Table 4.17 describes the foundation revenue and expenses in each of the hospices.

Table 4.17 Description of Foundation revenue and expenses in each hospice

	Foundation revenue	Foundation expenses*	Net foundation,	Uncompensated care expenses	Patient care and services expenses	Other uses of foundation funds
Hospice A	1.5 million	501,963	928,392	231,722	696,670	
Hospice B	N/A	N/A	N/A	N/A	N/A	
Hospice C (all branches)	2.9 million	1.88 million	756,056	190,000	210,000****	456,056***

*Includes expenses associated with foundation staff salaries and fund raising activities.
**Other uses for foundation funds include staff salaries, supplies, extra programs.
***This figure was calculated by subtracting uncompensated care and patient care funding from the net foundation revenue. Uses for these funds were not specified by the hospice
****This figure includes foundation funds that were used for the "patient assistance fund".

It is an important finding of this research that the amount of money each hospice had access to through foundation funds was directly correlated with their level of service. Data from financial records obtained from each hospice show that Hospice A had access to $928,392 from foundation funds in 2000 (this is equivalent to over $1,500 per patient). Hospice C and all their affiliated branches together had access to $756,056 in 2001, covering all patients in all of the hospice branches in that chain operation (this is equivalent to approximately $316 per patient). Hospice B, being for profit, was not eligible to receive financial donations. NHPCO (2000) data showed that hospice care in the US costs an average of 10% to 20% above what is reimbursed by Medicare (MedPAC, 2002). The additional funds that hospice A had access to helped them to meet costs of care incurred above and beyond the reimbursement of Medicare. Hospice C, though they had a foundation, had a significantly lower amount of money to spend on patient care, explaining the lower level of service they provided.

Not only were there differences in the amount of money available at the two non-profit hospices, but there were differences in access to those funds that made a difference

in terms of level of service. Hospice C staff access to foundation funds was more limited than it was at hospice A. While hospice A staff had the authority to use foundation money for exigencies in patient care, Hospice C's foundation was distributed based on strict rules. Hospice C staff could petition the parent corporation for access to the funds in certain circumstances where patients had a one time crisis. For example, one staff member explained that if a patient was having a financial crisis and was not able to buy food that month, the hospice C staff would petition the parent corporation for funds to buy the patient food. It was understood by staff that the foundation money could only be accessed one time per patient. At hospice A, foundation money was used to cover expenses in patient care, it was actually referred to as an insurance source (see table on revenue). At hospice C, foundation money was not directly available for patient care reimbursement, only for emergency assistance. Hospice C did provide care to patients who did not have insurance. This was called "charity care." In 2001, the hospice C branch provided "charity care" to two patients.

Not only did access to increased foundation funds affects the level of care, but also less rigid rules governing access to foundation funds had a positive effect on the level of care. Staff at hospice A had more freedom to use foundation funds. They did not have to obtain administrative approval in most cases to use foundation funds. The use of foundation funds only needed to be approved by the interdisciplinary team. In addition, at hospice A there were no rules about the types of ways foundation funds could be used, resulting in hospice A staff being able to use foundation funds in innovative ways to assist patients. At hospice C there was a procedure of administrative approval or petitioning that had to be executed before using foundation funds. In addition, there were

rules about specific ways foundation funds could be used at hospice C resulting in less innovate use of foundation funds.

It has been established that hospice A and C, both non profit, relied on charitable contributions. In fact, each of these organizations would have been operating at a loss if it were not for contributions to their foundations. Because they were operating in the same community, it is likely that these two hospices were competing for foundation contributions within a finite pool of potential contributors. One way that hospices obtain contributions is through targeting wealthy patients. Both non-profit hospices described how a portion of their foundation support is donated from patient's families who were happy with their care or patients who endowed a certain portion of their estate to the hospice while they were under their care.[10] While there is no data from this study to support this assumption, it is likely that the two non-profit hospices were competing for wealthy patients who could potentially contribute to their hospices.

Having commercial insurance could be considered a proxy for higher income patients. Patients who have worked in jobs that afford them with commercial insurance coverage might be patients who have had a steady income through their lives and may indicate that they are more likely to have the means to provide contributions to the hospice that cares for them. Table 4.14 shows the percentage of patients by payer in each hospice. According to this data, hospice A has the highest percentage of commercial insurance (probably wealthier) patients. At hospice A, 21.3% of their patients had commercial insurance, while only 12.9% of hospice B patients and 15.6% of hospice C

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[10] In addition to contributions from patients and family members who were treated by the hospice, foundation money is also accrued through community fund raising events like dinners, walks and other campaigns. They also solicit donations from local corporations. In addition, both hospices operate thrift stores whose profits go to directly into their dedicated foundation.

patients were well off enough to have commercial insurance. The higher percentage of commercial insurance patients and the high level of foundation contributions suggest that hospice A was more successful at attracting the wealthy patients who were capable of providing donations to the hospice.

In conclusion, the second hypothesis posed in this section appeared to be supported in that greater access to resources resulted in higher levels of care in the hospices studied. Data from financial records show that there were significant differences in the amount and flexibility of financial resources available to the three hospices. Access to foundation funds also helped to alleviate their reliance on government funding and probably was related to their feelings of less constraint due to Medicare regulations. Most important, the level of care provided in each hospice appeared to be related to the amount of foundation money each hospice had access to per patient. Hospice A had the highest level of foundation money per patient and provided the highest level of care. Hospice C is an example of a non-profit organization that was forced to provide a lower level of care because they only had limited foundation money and had to conserve resources for financial solvency. Differences in amount and access to foundation money appear to explain the disparity in level of care between the two non profit hospices. Furthermore, flexibility in access to foundation funds was also a factor in promoting more innovative services at hospice A than at hospice C. Finally, data showed that the for profit hospice provided the lowest level of care which is consistent with its lack of access to extra funds through a foundation in addition to their tendency to admit patients who were less financially desirable. In conclusion, this research has shown that access

to increased financial resources through foundation funds appeared to be related to an increased level of service delivery in the three hospices studied.

III. Organizational Structure and Service Delivery

The fourth aim of this research is to look at the relationship between organizational structure and organizational behavior. Both resource dependency theory (RDT) and Weberian theory provide frameworks for looking at this relationship. RDT posits that organizations will behave in ways to reduce uncertainty, but only to the extent that they have the capacity to do so. Organizational structure mediates dependency relations because it can have an effect on the resources an organization has access to. An organization's structure can affect its behavior in two ways. First, the organizational structure can affect the dependency relations it has with other organizations. For example, an organization that is affiliated with a health system may not have to rely on other organizations for referrals or other resources. Second, the organization's structure can affect its "enacted environment' or the perceived environment of the organization. The type of organizational structure can affect the way that information about resource dependence is filtered into the organization, thus affecting its behavior. Aspects of the organizational structure such as profit status and affiliations in the hospices studied will be looked at in this next section.

Weberian theory describes how organizations that are increasingly bureaucratized (as with highly affiliated organizations) have a harder time innovating or changing their services. Both of these theories will be utilized in this section to ascertain the affects of

organizational structural variables such as profit status, vertical integration and horizontal integration on the services delivered in hospice.

A. Profit status and Profit seeking in hospice

The first dimension of organizational structure to be examined in this chapter is *profit seeking*. The third hypothesis of this research pertains to the effect of profit status on service delivery at the hospices studied.

Hypothesis #3: Profit seeking diverts funds from patient care

This hypothesis was derived from the research and evidence in other health care sectors, most importantly the nursing home sector, that profit seeking in health care diverts funds from patient care.

The first part of this discussion describes the "meaning" of profit status in each of the three hospices and the effects that profit status had on the behavior of the hospices studied for this dissertation. Finally this section discusses the consequences of the profit seeking in the one for profit hospice studied and the relationship between profit seeking and level of service delivery in hospice B.

i. Profit Status in hospice

Data from this study showed that profit status was very meaningful to people who work in the hospice industry, especially those who work in non-profit agencies. This research found that each organization's "profit status" was referenced repeatedly by the workers in the non-profit organizations studied. Data showed that the meaning of profit status was different at the different hospices. The term profit status was often used as a proxy for describing other aspects of the organization besides just the tax status. This

section concludes that while profit seeking did have an impact on the services delivered in the hospices studied, the profit status itself was more of a symbol that did affect the hospice, but in more subtle ways.

It was particularly important to examine the variable of profit status in depth because there is speculation, and not much valid research on the affects of this variable on quality of care in hospices. For example, an assumption about hospice care that occurs *within* the hospice industry is that people who work with non-profit hospices tend to think that only non-profits provide high quality care to patients. A staff member at a non-profit hospice said:

> "R: *And of course, we are a non-profit. We don't have shareholders and our sense is that we cover a much larger territory than hospices who are for profit. I: In what sense do you cover a larger territory? R: In terms of the kinds of patients we are willing to take on.*"

This hospice worker assumed that for profit hospices refuse to admit patients who are particularly expensive or unable to pay. There is an assumption among hospice workers that for profit hospices provide lower quality of care, a lower level of care, and that they are less likely to provide uncompensated care. So far, there has very little valid research to back up these assumptions.

In this study, data showed that the "meaning" of profit status in each hospice was different (see table 4.18).

Table 4.18 The meaning of profit status in each hospice

	The meaning of profit status	The affect of profit status
Hospice A	Equated with: altruistic intentions; the freestanding, independent structure of the hospice; and access to foundation funds to provide extra care	Higher moral on the part of the staff, greater access to financial resources through the foundation, a symbol to the community of their altruistic intentions.
Hospice B	Tax status	Stigmatized by outside agencies. Lower number of volunteers.
Hospice C	Equated with: intentions to serve the entire community as opposed to just their patients, and access to foundations funds	Access to some extra financial resources through the foundation; providing some bereavement services to non-patients in the community, a symbol to the community of their altruistic intentions

At **hospice A**, the staff often brought up the non-profit status of the organization when attempting to describe why they liked working for the organizations. In interviews, when asked to describe why they liked working for a non-profit organization, their profit status was usually talked about as a proxy for or in conjunction with, other factors. For example, when staff at hospice A talked about the profit status, they also talked about the fact that they were freestanding (not part of a corporation) and the benefits of this independence.

"And I have got to tell you that the difference between us as a non-profit and them as a profit whatever. They are usually part of a big corporate structure. They have to think about things about money that we don't have to think about. I: Like what? R: We are frugal. You can't throw your money around but we don't have...you know if someone needs oxygen and we will get it for them. What they need is what we give them. We don't have to check with anybody."

This hospice worker felt that their profit status was related to their independent organizational structure and that that was related to fewer financial constraints.

When employees in hospice A were asked about their profit status, they also often equated their non-profit status with the existence of their large foundation. Staff reported that they were able to provide a higher level of care because of their access to foundation

money and that this was linked to their profit status. Here are some excerpts from interviews with both clinical staff and administrative staff at hospice A:

"I: Is what this hospice does different than other hospices? R: Yes, and I think the difference is, which allows the difference. Is that we are non-profit and we have a foundation that supports us. We could not deliver the level of care that we deliver based on our reimbursement from Medicare, MediCal and any of the commercial payers. Our foundation, bottom line last year was 1.4 million dollars. And that pays for salaries to deliver care"

" As a non-profit, our goal is to give the best possible care to the greatest amount of people we can. From your heart... not worrying about your pocketbook. Because we have a wonderful foundation that raises money for us. Because we never turn away patients. We never have. And that is a wonderful thing. We can treat people who don't have insurance at all or who don't have anything."

"We are very lucky here because we have money available when people do not have money available. Because of the foundation. So that is probably something that is very different than for profit hospices. That we are very lucky here that we can tap into some funding to set up things for families that they don't already have."

Due to the foundation, as well as other factors such as management style, staff at hospice A did not feel the financial constraints that were felt at the other hospices. One nurse who had worked at another for profit hospice said:

"I: So what did you feel was the main difference between the place you worked before and this place? R: Um, the place I worked before was all about the numbers. It was about how fast could you get a patient admitted. Even now one of the nurses came over this week and she said that they are still doing admissions that way. They have one nurse to cover X amount of people. The bottom line is that, I wouldn't say that they don't care, but the numbers are more important to them than the patients. I: They have higher case loads? R: Yes they do."

Hospice C was owned by a parent corporation that was non-profit. The staff at hospice C were very aware of their profit status, brought it up often, and tended to be proud of the fact that they work for a non-profit. But once again, when staff members talked about the profit status, they did not talk about their tax status. At hospice C, many staff members felt their non-profit status was a proxy for allowing them to serve the entire community instead of just the well-insured patients. Here are some excerpts from interviews with staff at hospice C discussing what their profit status meant to them:

" I feel that (being non profit) gives us the ability to...I always equate it with being able to care for anybody who lives in the community. Whereas if I worked for a for profit organization there might be some limitations about who we could care for and who we couldn't care for."

"We do a lot of clinics and things that are not hospice but clinics in the community that are nice to be able to do because we are non-profit. I: It sounds like you will also provide like bereavement services to people even if they aren't patients. R: Right. We are a community- based organization that provides support to anybody in the community. For instance when we went through nine eleven. We provided support to anybody in the community who wanted support as far as going through that trauma."

Hospice C's profit status was also equated with being able to take uninsured patients. One nurse describes this as the reason why she wanted to work for a non-profit.

"I like working for a non-profit because I can always care for somebody. I can. I know that if somebody calls me...of course we try to deal with insurance and stuff. But the bottom line is, whether they have it or not, I can take them. So an example of that is that if we get a referral on the weekend from some hospital somewhere where they say that this person has such and such insurance but we don't have time to check it. Some places would say you know we can't take the patients until we check their insurance. What I would say is bring them on and then we will check it on Monday. If they don't have it then we will still take them anyway. I: So you feel totally free to take whoever. R: Well yeah. Of course we have to look...we have to do this as frugally as possible. But I do feel free to take whoever."

Staff at hospice C also equated their non-profit status with having a foundation. The presence of extra resources from a foundation was believed, among the staff at hospice C, to allow the hospice to provide a higher level of care to patients. One staff member described her work at a past job when she used to refer patients to hospice and her belief that the non-profits offered an higher level of care than did the for profit (proprietary) hospices:

"We had our choices between proprietary and non-profit and my observation was that the for profits could not offer as much because they could not raise funds. And so they had no foundation and if somebody was very needy and needed extra care, needed equipment that wasn't covered by the benefits, they were stuck. They wouldn't get it, it was just that simple. Which is why I would never go with the proprietary. Because I like to be able to do the embellishments when it is indicated and to not be restrained."

While non-profit status was associated with a vague sense of being able to provide a higher level of care by the staff at hospice C, there was a sense among some of the staff that their organization was not a "true" non-profit.

"This is a large, not traditional model for a not for profit. (she smirks). Sometimes you can't believe it's a not for profit. There is tension between what must be done and what you do because its good for the Community. I: Where does the tension come from? R: Its just something you feel. Like I just know that there is no money for (service). I haven't run into this problem yet but if there is something you want to do something that might cost money you know you will run into trouble trying to get the money. I have not butted heads with the administration over this but they let us know in round about ways that this is the case. But because (service) is not a money making endeavor, you can see that it is not a priority of the organization...but you can't let that deter you because there is such a need for it."

This staff member reported that hospice C was not typical of a non-profit because of the managerial focus on cost saving at hospice C. In her mind, a non-profit organization should have been more like hospice A, and should have been able to provide many extra services without regard to cost. She also reported feeling that the managerial style (a corporate style), which exerted tight regulation over the finances at hospice C, was not a style she typically associated with a non-profit organization.

While their level of service to patients was a little lower than at hospice A (especially lower in personal care and extra hospice programs), hospice C was able to meet the minimum requirements of Medicare. In addition, hospice C was able to provide a few extra services to the community (usually bereavement) and a small amount of uncompensated care (2 patients in 2001).

At **hospice B**, being for profit was not considered a detriment to the care they provided. As I have shown, many staff at hospice B were unaware that they were providing a level of care that was lower than that provided at the non-profit hospices. At hospice B, profit status was equated with tax status, and hospice staff felt that this tax status had very little affect on the care they provided. In comparison, staff at hospice B

were a lot less inclined than staff at the non-profits to talk about their profit status without prompting.

In interviews, when they were asked about their profit status, hospice B staff reported being aware of the stigma associated with for profit status and were frustrated by what they felt was the inaccuracy of the negative stereotype. Staff members at hospice B insisted that their services were no different than those provided by non-profit hospices. Some staff members summed up their attitudes toward the organization's profit status:

"When people ask me, 'What is the difference between our hospice and the non-profit hospices?' I always tell them...we pay taxes. That's the only difference."

"I: Are there really differences between the different types of hospices out there? R: Like us being for profit? People look at us differently in what they will and won't do for us, in helping us. I: So people really notice your profit status? R: Yes. Versus non-profit. And so what I did was, I looked into seeing what the actual difference is. The non–profit puts everything back into their program. We do not, we do it for profit. Even though we know non-profit makes money. I mean, they do make money. And what I have learned about it is that that's the only difference... It's a whole tax status that makes it different. And they do more fund raising that we do. But when it comes right down to the treatment and care of our hospice patients, we have to do exactly the same. We do not ever turn anyone down whether they have money or don't have money. So we are no different than they are."

These two hospice workers thought that profit status was simply a tax status and did not think it should be equated with any other aspects of service delivery or access to financial resources.

The main area where the stigma associated with for profit status was a direct detriment to service delivery at hospice B was in the volunteer program. Sometimes the volunteer coordinator ran into resistance in her attempts to recruit volunteers because of the organization's profit status:

I: Have people actually said to you, 'no I am not going to volunteer for you because you are for profit?' R: No, that I haven't got but I went to the Senior Center over in (nearby town) and they asked, 'Are you profit or non-profit?' That was her first question. I wanted to do a presentation there so I had to go through her. But being for profit, she said no. She said that I could leave my flier, she'll put it before the board, but I thought, how weird. She was one of them I took the time and said, the difference between the profit and non profit, it's just a tax status. That's all it really is. It's a tax status. I've been around too many non-profits. It has nothing to do with anything else. We all have the same requirements; no hospice will turn anyone down. No hospice anywhere will turn anyone down. We can't. Its illegal. If you are a true hospice you cannot refuse anyone because of no money. You can refuse them if they don't need hospice, but you can't because of no money. And I don't care if you're profit or non-profit, you can't do that. And I make sure people understand that because, I don't know what they think non-profit Is? Their staff gets paid the same as our staff, maybe not as much. But they pay everybody."

Hospice B had fewer active volunteers than the other hospices, resulting in a very limited number of volunteers available for their patients. In an interview, the volunteer coordinator reported that she believed hospice B was stigmatized by their for profit status to the extent that it was an impediment to her recruitment efforts. She thought that there were misconceptions out in the community about what it means to be for profit, or really, what it means to be non-profit. She thought that people were wrong to think that non-profits were more deserving or altruistic organizations and she saw no difference between hospice B and the non-profit hospices.

Another stigmatizing affect of profit status was revealed by the types of patients who were referred to the for profit hospice. While all three hospices had very high censes, indicating no lack of hospice patients for the for profit hospice, data do suggest that the for profit hospice tended to admit the less financially desirable patients as noted above. This may have been a result of a stigmatizing affect of their for profit status with referring members of the community. The possibility of "cream skimming" will be discussed in more detail in the next section.

In reality, an organization's profit status is a determinant of its tax status. Non-profit organizations are exempt from certain taxes. In addition, these organizations are able to solicit charitable donations from the community, a practice that for profit organizations are forbidden. Also, for profit health care organizations are often investor owned, meaning that the administration would be responsible to outside investors who expect to make a profit from their investment.

Besides being an indicator of the tax status of an organization, in this study profit status also acted as a symbol, both to the people who work in hospice and to the general public. Among the non-profit hospices, non-profit status appeared to be more of a symbol of the supposed altruistic intentions of the organization than an indicator of tax status. At the two non-profit hospices, non-profit status was used as a proxy for describing the existence of extra foundation money, or the organizational mission of serving the whole community. No staff member at hospice A or C ever mentioned that their profit status made them exempt from certain taxes or the benefits of that exemption. Profit status also can have a strong stigmatizing affect. The for profit hospice in this study suffered from the negative stigma of its for profit status. More research needs to be conducted to understand the meaning of profit status in hospice organizations before the affect of profit status on service delivery can be clearly understood.

ii. Profit seeking in hospice

Hypothesis three, asserts that for profit (profit seeking) hospices will provide a lower level of care to patients based on the fact that profit seeking diverts funds away from patient care and toward investors and highly paid administrators.

Financial data from this study (Table 4.19) showed that both nonprofit hospices A and C would have been operating at a loss without the subsidy from foundation funds, funds they had access to because of their nonprofit status. Hospice B, as a for profit did not have foundation funds, but it did not operate at a loss, indicating that they were more effective at cutting costs than the non-profit hospices. While the organization was not willing to provide specific data on the net revenues of the hospice B branch, their parent corporation did report an annual profit of $283 million for that fiscal year (see table 4.19).

Table 4.19 Revenue and expenses for hospices studied in US Dollars

	Gross Revenue	Expenses	Net Revenue/Profit
Hospice A	3,674,949***	3,646,081	28,868
Hospice B	1,506,639*	1,981,339	(see note)**
Hospice B parent #	2.7 billion	2.4 billion	283.4 million
Hospice C parent @	52,836,000***	52, 363,000	473,000

*This figure does not include revenue from commercial insurance at hospice B.

@ These figures reflect all of the revenue and expenditures for the entire hospice C chain of hospices and home health care agencies. Individual figures for hospice C were unavailable.

These figures reflect all of the revenue and expenditures for the hospice B parent corporation including their SNFs and other health care endeavors.

**Figures on the exact amount of profit gained by hospice B in 2001 were not available, but verbal assurance was given from the branch manager that hospice B was not operating at a loss.

***includes revenues from foundation funds

To determine if profit seeking diverted funds from patient care in hospice B, the amount that each hospice spent on patient care as a percentage of their total expenditures was examined.

@

Table 4.20 Expenditures for hospices studied

	Hospice A **(621 patients)**	**Hospice B** **(186 patients)**	**Hospice C$^{@}$** **(2,393 patients total including all 7 branches, at hospice C there were 320 patients)**
Administration (Salaries)	340,533 (9.3%)	563,514 (28.4%)	Not reported
Direct/Nursing care (salaries)	1,392169	626,145	Not reported
Social Services (salaries)	293,534	250,441	Not reported
Total Salaries	2,026,236	1,440,100	28,826,000
Taxes/Benefits	409,395	Reported as part of salaries	6,886,000
Total Salaries/Benefits	2,435,631 (67%)	1,440,100 (73%)	35,712,000 (68%)
Physical plant	14,878	Not reported*	1,868,000
Drugs/DME	680,575 (19%)	347,917 (18%)	$8 per day per patient
Other	514,997		
Total expenditures	3,646,081	1,981,339	52,536,000

In hospices, patient care expenditures can be determined by examining clinical staff salaries (see table 4.20). In this study, Hospice B, the for profit hospice spent the highest percentage of their total expenditures on staff salaries (73% as compared to 67 and 68 percent at the nonprofit hospices). But this percentage includes administrative salaries. If you look at the salaries of nursing staff and social work staff, hospice A spent 55% of total expenditures on salaries for clinical staff went toward direct patient care. In comparison, hospice B, spent just 44% of total expenditures on clinical staff salaries.[1] This figure becomes more significant when you take into consideration that interview data reveal that hospice B staff are actually paid more than hospice A staff. These different percentages on expenditures for patient care show that hospice A diverted a higher percentage of funds to staff direct patient care. Furthermore, the financial data are substantiated by observational data on level of service delivery which show that the

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[@] Reflects all 7 hospices owned by hospice C parent corporation., Individual figures for hospice C not available.

[1] Data on clinical staff salaries for hospice C were unavailable.

for profit hospice did provide a significantly lower level of care to patients than the nonprofit hospices. In sum, data from this study strongly suggest that profit seeking and higher administrative salaries at hospice B were responsible for diverting funds away from patient care.

In conclusion, the findings appeared to support the third hypothesis that profit seeking would divert funds from patient care in hospice B. Data from this study do suggest that in hospice B, there appeared to be a link between their lower percentage of expenditures on clinical staff and their lower level of care to patients.

B. Organizational relationships in hospice

The second main aspect that determines organizational behavior according to resource dependency theory is the organization's relationship with the **organizational environment**. The organization environment as stipulated by RDT includes any outside organization that influences the behavior of the organization in question. In the case of these hospices, the organizational environment would include: 1) the inter-organizational relationships, (vertical and horizontal integrations); 2) other hospices that are competing for patients, 3) hospital and physician practices who provide referrals; 4) authoritative bodies like parent organizations or board of directors; and 5) regulatory agencies that influence behavior through actual monitoring or the threat of monitoring.

The first aspect of the organizational environment that was explored in this study were hospice *inter-organizational relationships*. Mergers and acquisitions in the health care sector are becoming more commonplace. Hospitals are merging and health systems are buying up all types of health care organizations. In an era of increased competition,

integrating is often seen as beneficial to health care organizations because partnerships provide more opportunities to streamline costs as well as providing greater bargaining power in negotiating contracts and reimbursement rates with insurance companies.

Hospices can have a variety of different organizational relationships. An organization can be vertically integrated with other types of organizations such as a hospice that is owned by a parent corporation that also owns a hospital, health system, or nursing home chain. An organization can also be horizontally integrated such as a hospice owned by a parent corporation that also owns other hospices, in other words, part of a chain operation. Within these two types of integration, there are variations in terms of the scope and size of the organization. The fourth hypothesis of this study pertained to the effects of vertical affiliation in hospice organizations.

Hypothesis #4: Organizational relationships, especially vertical integration with non-hospice health care organizations will affect service delivery in the hospices studied.

In the next paragraphs the different types of ownership structures, vertical and horizontal integration, will be discussed. In addition, this section will show that there are variations within those categories of integrations that had an affect on the hospices studied.

i. Vertically structured organizational relationships

Within the category of *vertical integration*, there are differences in the number and type of organization within the multi-institutional system. For example, a hospice may be owned by a parent corporation that also owns a single hospital, a health system, or with other health care organizations like a large chain of nursing homes or a small chain of home health agencies.

Both hospice B and hospice C were integrated vertically with other non-hospice health care organizations (see organizational structure section). Theoretically, vertical integration can be helpful to a hospice by increasing the number of referrals. For example, if a hospice is owned by an organization that also owns hospitals or nursing homes, that hospice might receive more referrals from those agencies. While vertical integration can be helpful to a hospice, there has been concern about the negative affects produced when hospices have relationships with non-hospice health care organizations. Researchers speculating about the future of hospice were often skeptical about the outcome of hospices that were integrated vertically with other health care organizations. The concern was that integration into a mainstream health care organization would stifle the hospice model of care (Abel, 1986) (James & Field, 1992; Seale, 1991) (Field, 1989). Organizational isomorphism could occur, causing hospices to become more like non-hospice organizations and would result in a lower level of hospice care (DiMaggio & Powell, 1983) (Paradis & Cummings, 1986).

This research revealed some evidence of organizational isomorphism at **hospice** C due to its ownership by a largely non-hospice health system. The higher administration at hospice C (the CEO and CFO) was responsible for administering both hospice and home health care agencies for the parent corporation. One example of the infiltration of the home care model onto the hospice model due to vertical integration at hospice C were the productivity requirements imposed by the higher administration at hospice C.

The higher administration of hospice C had productivity requirements for their hospice workers similar to those that exist in the organization's home health agency.

Each full time hospice nurse was required to conduct 4 billable visits per day. The 4 billable visits were required without regard for the acuity of the patient's condition. A visit was only considered "billable" when the hospice staff member went out to see the patient. The constant telephone calls and paperwork that were also a required part of the job were not considered "billable." Every member of the hospice staff was required to come into the office by 10am to fill out a record of their billable hours from the previous day. The staff was not allowed to submit their "productivity" over the telephone or by fax. This record was then sent to the CFO of the health system, and the administrator of the hospice division at corporate headquarters through an electronic system. This electronic system produced data which made it possible for the administration to quickly ascertain which hospice staff members were meeting productivity standards and which staff members were not. Periodically the branch manager would receive a report back from corporate headquarters with a list of each staff member's productivity.

The productivity requirements caused a great deal of tension between staff and the higher administration (including the hospice Director, CEO and CFO). In an already time constrained system, the staff felt that reporting productivity in this way was a time consuming task that was not perceived as being beneficial to the patients. Staff reported in interviews that the paperwork and documentation involved in reporting their productivity to the higher administration was taking time away from patient care. In addition, staff stated that they felt it was a flawed system that did not take into account the exigencies that occur when providing care to the dying.

One example of how the parent corporation's push for increased productivity did not fit in with the hospice model of care was revealed while observing at a "management

meeting". A management meeting is when all the branch managers of all the hospices in the chain come together to meet with the higher administration including the CEO and CFO of the health system and the hospice director. Fieldnotes taken at one management meeting and at a later branch meeting where the same issue of productivity was discussed:

> *"All the branch managers had assembled in a conference room and were being addressed by the CFO of the corporation. He was displaying statistics about the productivity of each hospice branch. These were numbers produced by the daily productivity reports submitted by staff. These statistics showed that hospice productivity was much lower than it was supposed to be at many of the branches. He went through each chart, pointing out to the whole group what hospice branches were not "making their numbers." The CFO gave some suggestions for improving productivity. He suggested that hospice staff do their charting and paperwork during the weekly case conference meetings. He went on to compare the driving time of the home health branches with the driving time of the hospice branches. The hospice driving time was much higher. He suggested that the hospice nurses were spending too much time driving and could be more efficient in scheduling their visits geographically to reduce driving time. He said that he could not understand why hospice nurses spent a significantly higher amount of time in their cars than the home health nurses and even suggested that the branch managers should be on the lookout for hospice nurses "padding" or falsifying their driving time."*

> *"Later, back at the branch at a case conference meeting the branch manager brought up driving time. A hospice nurse addressed the driving time issue specifically. She said that she had scheduled her appointments yesterday in order to reduce driving time. But in hospice care, there are so many unforeseen crises that it often disrupts your efficient plan. She was seeing a patient in one part of the county when she got a page from another one of her patients 30 miles away who she was planning to see later that evening. When she returned the page she found that the patient had an increase in pain that was not being met by the current medications. Uncontrolled pain is considered a top priority of hospice care, so she immediately disrupted her schedule by going to see the patient who was in pain and increasing his medication. This added an extra hour to her driving time that day."*

The productivity requirements at hospice C are an example of how management models borrowed from mainstream medical practice tend to clash with the goals of hospice care. The way that productivity is counted by the higher administration at hospice C did not allow for the many exigencies that commonly occurred when providing care to people at the end of life. Data showed that meeting these kinds of standards of productivity was very difficult when working under conditions of constant crisis. In

hospice C, staff reported that these productivity requirements and they way they were measured were contradictory to their goals of meeting the ever-changing needs of dying patients. One staff member explained:

> *"Hospice patients, they are always changing. To be eligible for hospice thy have to be in a state of consistent downward decline. That means they have new needs all the time and what they need is never really predictable. Every change in condition is a new crisis that has to be dealt with now, not later after you see your other patients who live in (nearby neighborhood). You have to respond to patients based on whose in crisis, not who lives close by."*

As a result of the productivity requirements and the high level of surveillance, the morale of the staff at hospice C tended to be low.

> *"What is that like working for a health system? R: (pause) I hate it. I have to be honest. And I hate that truly the only reason I am here is because I have been here so long. I was here when (hospice) was just (hospice). When I started with this particular branch we were just one little branch and it was home care. I: So what changed? R: Well (parent corporation) got involved and everything became so much about productivity. And that is all its about, productivity, productivity, productivity."*

In sum, vertical integration at hospice C was associated with institutional isomorphism, whereby rules from mainstream medicine (home care) were imposed on the hospice staff and were seen by the staff as contrary to the goals of the hospice staff. These rules from the health system included productivity requirements that restricted the freedom of the hospice staff and reduced their ability to innovate. Subsequently, this affected the morale of the staff.

Hospice B was also vertically integrated. It was owned by a corporation that also owned home health agencies and nursing homes all over the country. While some vertically integrated hospices might benefit from referrals from affiliated nursing homes, this was not the case for hospice B. According to the branch manager, although their parent corporation owns hundreds of nursing homes all over the country, there were no

nursing homes owned by the parent corporation located close enough to refer patient to this particular branch.

Hospice A did not share ownership with any outside organizations. There were no non-hospice organizations that had authority over their actions. This allowed hospice A to engage in more innovation, resulting in the extra hospice programs they were able to provide. Hospice A was able to innovate based on the perceived needs of their community. Many of their extra hospice programs were created following a suggestion by a nurse or other hospice staff. Their innovation and changes were driven from below, from a community level where the changes and innovation of hospice B and C were driven from above, from the higher, non- hospice administration.

"(Hospice A) is an organization that, I do think is a really great one to work for. I think that generally they are open to new learning and suggestions and recommendations about the organization."

In hospice A, if the staff wanted to create a new program or change the way things worked, the staff member would present the idea to the administrator. If the administrator agreed, she would simply take that request to the board of directors. In an interview, the administrator described how the flexibility of the board of directors has allowed their organization to innovate.

"We were discussing why they have so many programs that fill in the gaps of hospice care. (Administrator) said that she thinks it is mostly due to the flexibility of the board of directors. She said that she or someone else on the staff come up with a proposal to expand or change services in some way and she will take it to the board of directors. They are very flexible and open minded to changing things. She said that she has a great board of directors and she won't let any of them leave once they have signed on."

In contrast, hospice C had a much more difficult time innovating or changing the way they provided health care. The management style, including a high level of

bureaucracy and the resulting high level of surveillance over the everyday workings of the branch staff made it difficult for changes to be made that resulted from staff suggestions. One hospice C staff member explained:

> *"Someone has an idea for an innovative... something. A new form that they want to use for reporting pain or something. Usually what you have to do...you can do a little pilot but, in order to get it implemented, up the chain, down the chain. Sometimes that is slower. But you also get to know that it has been looked at by a lot of people. It takes a lot of energy though if you feel strongly about something you have to really push it through. The sheer inertia that can happen just because of multiple layers of authority. That can slow things down. So you have to learn to live with that. On the other side of it though is that there is such potential for changing health care. I mean, (Hospice C) can be a model for what you can do for advanced illness and end of life care that other organizations can emulate if we can show something here."*

In addressing hypothesis four, vertical integration was found to effect the behavior of the hospices in this study. According to resource dependency theory, the structure of an organization affects the extent to which an organization can respond to its environment. Vertical organized health systems can impose a greater level of bureaucracy on hospices which can prevent innovative responses to environmental pressures. Hospice C, had the most highly restrictive relationship with the organizations it was associated with. The vertical integration at hospice C also clearly resulted in a great deal of organizational isomorphism that imposed rules, which were contrary to the hospice staff's goals and impeded innovation. Hospice A on the other hand was freestanding and was the most innovative of all three hospices. There was also the highest level of job satisfaction among the staff at hospice A. While both hospice A and C were non-profit, their organizational relationships had different effects on the experience of working for these organizations. The effects of vertical integration is another factor associated with differences in service delivery between the two non profit hospices.

ii. Horizontally Structured organizational relationships

A health care organization can also be *horizontally* integrated with similar type organizations (such as a multi-hospice chain operation). Within the category horizontal integration, or "chain operation" there can be further differences in the extent or closeness of that integration. For example, it makes a difference how many hospices are in the chain, how close they are geographically, and whether the chain hospice actually engages in information or resource sharing with the other hospices in the chain. In this study, the two horizontally integrated hospices that were studied had important differences in the care that was provided. The data from this study show that terms like "hospital affiliated" "chain affiliated" or "multi-institutional system" are inadequate to describe the subtleties of horizontal integration that need to be studied to understand the affects of organizational structure on service delivery in hospice organizations.

Horizontal integration can have both positive and negative effects for a hospice. The positive effects include information and resource sharing among affiliated hospices. The negative effects can include enforced uniformity that might decrease a hospice's ability to innovate and serve its particular community. The term "chain operation" can be misleading because while hospice B and C would both be categorized as being chain operations, they were part of different types of "chains" and had very different relationships with the other members of their chain.

Hospice B was part of a chain that encompassed hundreds of hospice organizations around the nation. There was one other hospice in the region within driving distance that was part of the chain. Hospice B had very little interaction with the other hospice organizations in the chain. As a result, they did not benefit from the

information sharing they might have had as a part of a chain. The only area where there was sharing at hospice B was among the volunteer coordinators, who reported that the hospices would share names of potential volunteers who might not be in their area but were in the area of another hospice in the chain.

The hospice C chain included 7 different hospices, all within driving distance. Thus, they were more geographically close than the hospices in the hospice B chain. There were benefits and constraints that resulted from the close integration that hospice C had with other branches. One benefit was information and resource sharing. Hospice C engaged in quite a bit of information sharing and resource sharing with the other affiliated hospices. Observations of these meetings showed that the branch managers would regularly meet and share information on topics like managing relationships with nursing facilities and strategies for providing after hours care. Other disciplines, such as the bereavement coordinators and the volunteer coordinators from every branch would also meet to exchange information and support.

One staff member discussed the benefits of being integrated with other branches including continuity of care for patients as well as for staff:

"I: What is the benefit of being a branch in a system of hospices? R: Well the benefit is that if (a patient) moves from place to place that can happen... and its really a smooth transition. And that has happened when someone has moved from here to (another branch). For staff members they can transfer from place to place without loosing their seniority within a system. The other thing is that there are more people to get ideas from and interact with about ways to do things and so forth... so you are bringing a lot of expertise together from people from a lot of different places to give us ideas on how to do things. And that is a plus."

Sharing a foundation was beneficial for hospice C because, as a branch, hospice C was able to raise less money than some other branches, yet it got to share in the use of this money through the patient assistance fund.

On the down side, certain aspects of the chain integrations and the uniformity imposed on each branch acted as a constraint. For example, hospice C shared an intake RN with its other branches in the form of a central referral line. The central referral line was the number anyone, a nurse, physician, discharge planner or family member would call when they want to refer a patient to hospice C. One staff member describes how sharing a referral line with many different branches becomes a constraint:

"One of the big things is the central referral thing. It used to be that we used to do that on a branch level. But currently, pretty much every branch goes through (central referral line at HQ). I: And how is that working out? R: It's got its pros and cons. I think it makes it more consistent for how its done throughout the organization. But, it takes away from the people that are taking the referrals knowing the physicians who they're taking the referrals from. So you create relationships with physicians and their office staff. And it creates a barrier when you don't have that relationship. So centralizing takes some of that away. Currently there are a bunch of different people taking calls from central intake. Um, I felt that it worked better when we had a specific person doing intake just doing hospice because they really knew about hospice and they also knew a lot of physicians in this area because she just happened to have been a nurse in this area before. And I felt like that added some quality to the referral process."

Imposition of uniformity was another affect of chain integration for both hospice B and C. In both chain affiliated hospices, the higher administration was making efforts to make the paperwork and protocols of each hospice uniform. One problem that arises with the imposition of uniformity is that hospices serve a particular community or neighborhood and often there are methods that work better in one community than another. Sometimes hospices were forced to use protocols such as central referral lines that did not work smoothly with their particular community because that was the model that the higher administration had chosen. On the other hand, they often found that the model or uniform paperwork worked better than what they were using:

I: Do you feel like the (hospice C) administration is adding anything to make your work better?
R: Well they have done a lot and I really think it is because they have had some great people who they have recruited from (another branch) and other places who have had a lot of hospice experience who have helped them figure a model that we can live with. And so much of the paperwork is as streamlined as possible. And they put all this stuff in there that all you have to do is just check boxes and just put in little things if you need them you know.

The medical director at hospice C, who was active in creating the standards of practice for all the branches, had more positive things to say about the uniformity that was imposed on the branches in the chain. This staff member believed that the organization could come up with standards that would be appropriate for all the branches to follow and that would ensure high quality care at every branch. She was speaking about standardizing care, as opposed to standardizing paperwork or other administrative practices:

"When we went to (parent corporation) we took a warp speed leap into another health care system. So I immediately, we started to see a lot more impact from being part of an agency where what you are trying to do is standardize care at multiple sites. Which is not a bad thing. It is not a bad thing. I think what it is is that people do not like change. And so it gets hard sometimes to implement that. And if our model is the best possible care in the most cost efficient way, that is the thing that you can apply standards to and it should apply all over. You may have constraints at different branches where maybe physicians would have their patients using duragesic patches or something that you have to work within. And that makes more challenges for that branch and they may be more grouchy about having to do some formulary or something. But all in all, in terms of best medical care, best medical practice, that is wonderful. That is how it should be. So there are some advantages to being part of a health system. I believe that having us be part of a larger agency offers incredible potential."

In sum, organizational relationships had an effect on the service delivery and staff moral at Hospice C. While they received some positive benefits from the information sharing, resource sharing, and support from other hospices in the chain (horizontal integration), the effects of being closely tied to a predominantly non-hospice health system (vertical integration) had a negative affect on both the level of innovation in the services provided and the moral of the staff. While the vertical integration helped hospice C to be more financially stable than they had been before the integration, the

imposition of non-hospice management styles and rules from the higher administration did appear to have detrimental affects. It is an important finding that the one independent hospice in this study, hospice A, had the highest level of service delivery of all the hospices in addition to a culture which allowed and encouraged innovation to meet the needs of the community.

iii. Relationships with outside organizations

Another aspect of the **organizational environment** that is capable of affecting the behavior of an organization according to resource dependency theory is the influence from other organizations with which they have exchange relations. This is applicable in the case of the hospices studied. There are many different organizations that each hospice had to associate with. First, each hospice had to forge relationships with the organizations and individuals who provided referrals to hospice. It is a rare case that a potential patient calls hospice on their own. Usually, the patient is referred to hospice either by their physician, or more usually by the social worker or discharge planner at the hospital. This means that the individual hospice has dependency relationships with outside organizations like hospitals and doctors' offices. To successfully negotiate these relationships, hospices must engage in information sharing and other forms of communications. They also have to engage in marketing in order to get their name out to physicians, discharge planners, and members of the community who might have a need for hospice. All the hospices studied engaged in marketing to a certain extent, but some were more successfully than others.

Hospice A had a grass roots marketing strategy. A main aspect of their marketing strategy was to provide services to the community above and beyond hospice care. They

provided the extra hospice programs described in the second section of this chapter. These extra hospice programs had a double effect of both providing a much needed service to their community, while also situating potential patients on track to be admitted to their hospice. For example, a person who participated in one of the pre-hospice programs at hospice A would be more likely to choose hospice A when they become hospice appropriate. So the extra hospice programs had marketing value for hospice A. In addition, pre-hospice programs at Hospice A provided opportunities to promote informal integration with some local agencies. The pre-hospice program that they provided was a shared endeavor with a clinic at a local hospital. Observations of case conferences showed that nurses from the hospital who cared for those patients would come to the case conference at hospice A, thus promoting a positive relationship with this other institution. Hospice A also engaged in marketing through many other activities including but not limited to: conducting inservices for physicians at local hospital, attending hospital grand rounds[2], sponsoring charitable thrift stores, participating in conferences, and sponsoring tree lighting and other fundraising events.

The success of their marketing strategies was evident in the high number of referrals to their agency, the high number of individuals volunteering for their patients, and the high level of contributions their hospice received from the community. In addition, hospice A had good working relationships with many other types of agencies in the community.

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[2] According to one nurse at hospice A, the local hospitals only allow representatives from hospice A to attend grand rounds. Representatives from the other hospices in the area are prohibited from attending these meetings. This nurse described a situation where a representative from one of the for profit hospices in the area attempted to solicit business at a local hospital and was escorted out by security. Attending rounds is a very effective way of soliciting new patients for a hospice.

Hospice B did not have as strong relationships with the local environment as hospice A. One marketing strategy was to send the chaplain and volunteer coordinator to give presentations at local churches. According to hospice staff, the parent corporation of hospice B had regional representatives who acted as sales people whose job it was to get the name of the organization out in the community and to solicit business, probably similar in scope to a pharmaceutical sales representative. These representatives were not present in the office of hospice B and no data was collected about the scope of their activities. Hospice B did have relationships with nursing homes that were owned by the same parent corporation and who were probably encouraged to refer patients to hospice B, but according to the director of operations, there were very few of these affiliated nursing homes in the region around hospice B.

The nurses at hospice B had established relationships with some physicians' offices in the area, especially when the physicians had been impressed by their work. According to a nurse at hospice B, there are many physicians in the community who only refer patients to hospice B. As a result of their weaker integrations with the local environment, hospice B was not as well known in the community as was hospice A. While their high census showed that they did not have trouble attracting patients, other data showed that they tended to attract less "desirable" patients. The low percentages of cancer patients, high percentage of Medical patients and low average length of service at hospice B may be an indicator of the for profit hospice's lack of ability to attract the financially desirable patients and might be an indicator of the stigma of their profit status with discharge planners and physicians in the community. The most obvious result of

their weaker relationships with the local community was their trouble attracting volunteers.

Hospice C had affiliations with hospitals in the area owned by the same parent corporation that eased their marketing requirements. That is to say, instead of having to forge relationships through positive interactions, these relationships were pre-arranged. Staff reported that there were employees of the parent corporation stationed in the affiliated hospitals whose job it was to direct dying patients to hospice C.

Hospice C also marketed by offering continuing medical education (CME) courses on palliative care for physicians in the community. They also sponsored fundraising events in the community like tree lightings and event dinners which served to get their name known in the community. The volunteer coordinator also did marketing in a sense when she went to community events like the local chamber of commerce dinner. Hospice C also provided services to the community like support groups that were offered to any member of the community, whether or not they were a patient. The bereavement coordinator and chaplain sometimes provided memorial services in skilled nursing facilities where they have had a patient who died. In addition, the nursing staff sometimes did inservices for the staff at SNFs. The higher administration at hospice C was actively encouraging branch staff to more aggressively target skilled nursing facilities as a potential client pool to increase their censes at many of the branches. Unlike at hospice A, observations showed that staff at hospice C rarely had time to attend funerals or conduct post-death visits to families.

If success in marketing can be measured by the level of contributions and volunteers, hospice C is between the two other hospices. Its foundation funds were lower

than hospice A but higher than hospice B. Also they had a thriving volunteer program that was more active than the one at hospice B, but had fewer volunteers than hospice A.

iv. The Enacted Environment

RDT allows for an analysis of the "enacted environment" or how the organization perceives the environment. One of the major factors affecting the enacted environment is the organizational structure. Organization's respond the information or knowledge they receive about the environment. The organization's structure can mediate or filter the information that certain actors receive, thus affecting their perception of the environment and their response to that environment.

The location and structure of authority is a structural aspect that can effect the way information is filtered through an organization. In hospice A, the higher administration was located on site, while at hospice B the higher administration was in another state. In hospice C, the higher administration was approximately 30 miles away at corporate headquarters. A study by Greene and Monahan, (1981) found that distantly headquartered chain operations provide lower care levels than locally owned facilities (Greene & Monahan, 1981). One of the main differences in the hospices studied was the geographic proximity of their management.

Location of authority was found to be an important variable in effecting the care provided at the different hospices studied. When the higher administration of a hospice is not on site, it is more likely that the administration is not closely or emotionally connected or committed to the hospice care provided at that site. It might be easier for on off site administrator, who is not personally connected to the everyday work, hearing the stories of patient's needs, etc, to be able to send down mandates reducing the level of care

provided. An administrator on site might be more likely to be personally connected to the care that is provided and might be less likely to allow a lower level of care for cost considerations.

At hospice A, the administrator was on site and was closely connected with the everyday workings of the organization. At hospice A the staff felt warmly toward their administrator and felt that their administrator supported them in providing the care they wanted to provide. They did not feel that the administration made rules or sent down mandates that were at odds with their particular goals. Repeatedly in interviews nurses and social workers talked about their wonderful administrator who "lets us do the work we know how to do." It was clear that there was consensus between the hospice staff and administration at hospice A about their goals for the organizations.

"(Administrator) is a great leader. She is really good. She has foresight too. It's really nice. So this is my place."

"I think the leadership chain follows the formal leadership structure. It seems like a very personally driven organization. I think because this is a small agency. (Administrator) is a great hospice advocate. And (Administrator's) philosophy and management style seems to filter through the whole agency."

" (The administration) is very accommodating toward the staff. Not just with the work but with our personal lives. (Staff member) is taking time off due to chronic fatigue syndrome. Employees are offered a standard 12 week package of disability time off and then (this employee) was offered a lot of extra disability coverage. I don't think (this employee) will ever come back to work, and I'm pretty sure (the administration) knows that, but they're saving her job for her anyway since she asked for that option. Most social workers here work 4 days a week, but working 5 days makes more sense for me financially. The administration was happy for me to work 5 days. I think they offer the 4 day week just to avoid staff burnout"

The staff at hospice A did not have negative feelings about their administration and thus, there was no negative impact on their morale. They subsequently had very high morale which in part contributed to their very low turn over rate in staffing.

"And you know, when I came to work here I knew I had made the right decision. Coming back here after six or seven years away and all of the same nurses are still here. If that doesn't tell you something.... I worked with all of them."

At **hospice C**, branch staff were distantly separated from their higher administration[3] and subsequently did not feel supported by them. They felt that they often felt that their goals were at odds with the higher administration. They felt that the higher administration's main priority was cutting costs as opposed to promoting high quality hospice care. The hospice nurses did not feel supported or understood by the higher administration. One staff member described the difference since the parent corporation took over:

"R: It doesn't feel like a family at all anymore. It feels like a corporate job is what it feels like. It doesn't feel like health care. It feels like working for corporate. And it feels awful. It feels awful. And I have not worked for any other hospices, but there is so little regard for the nurses and what they are doing and what it costs. So it is still always about productivity and having everything done perfectly. But there is no understanding about the emotional, spiritual and psychological issues that hospice nurses go through. We do it by choice and we have to find our ways to take care of ourselves. But there are times when I have just felt rage at how insensitive and inhuman it feels like the corporation is."

One example of mandates from the higher administration that made staff feel that administration did not understand the nature of hospice work were the "productivity requirements" described in the last section. These productivity requirements caused a rift between the administration and staff at hospice C because staff felt that the higher administration had different goals for the organization. They felt that the higher administration's focus on productivity reduced the quality of care they were able to provide to patients:

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[3] The term "higher administration" for hospice C is used to talk about the CEO, CFO and hospice director who were located at corporate headquarters. This term does not include the branch manager who was located on site.

" I: do you have to pay attention more to finances more now that you are (parent corporation)? R: That is all we pay attention to now is finances. I: Did you have to when it was (past ownership)? R: No, no. We worked hard to keep up a reasonable productivity but it wasn't the focus. And if we were slacking we would pick it up. But you know it was so much more enjoyable to be a nurse then. Because we weren't killing ourselves. Its just so different. I: So there is more pressure to see more patients, spend less time with patients. R: Yep. I: And are you doing it? Are you spending less time with patients? R: Um, yeah absolutely."

The higher administration would also send down other mandates in an effort to reduce costs such as: cutting back on prescription drug costs or cutting back on expensive durable medical equipment. One nurse described how the higher administration had recently sent down a mandate that the branches could no longer provide patients with diapers in an effort to cut costs.

"There is always tension about money. What's frustrating is that you get these mandates from above that are just ridiculous. Like for example, medications that we can't cover. Or recently we had this big thing about diapers. Diapers! It's so embarrassing. I: You mean they told you you couldn't cover diapers anymore? R: Right. They said we could only cover diapers if the person is on MediCal. If they aren't on Medical, we don't cover them. How do you tell a woman whose husband is dying that we will no longer cover his diapers?"

The branch manager at hospice C saw the rift between the staff and higher administration as partly due to geographic location. Part of the problem, in her words, was that *"They don't see (the higher administration's) faces and so they don't get the sense that they are there to support them."*

Conversely, in interviews, the branch staff reported that they did feel supported by the branch manager who was located on site. Hospice C staff were very verbal about their appreciation for the branch manager, offering unsolicited praise for her.

"It's the people who work here who make it work. I do what I do because the people who work here are so dedicated. Also our supervisor, as you have noticed makes herself very available to us."

The branch manager at hospice C was truly part of the hospice team. Her office was on site and she attended all case conference meetings. She was often out socializing

with the team. The door to her office was usually open and team members felt welcome to go to her with questions and issues. The branch manager was able to make the staff feel supported even though she is required to impose the same productivity standards on her staff that are sent down from the higher administration.

Hospice B had a distantly headquartered higher administration[4]. Their parent corporation was located in another state and their regional director was located in another city. In addition, there were over 100 hospices being administered by the higher administration of hospice B. While the staff at hospice B did not feel warmly toward the higher administration, they also did not report feeling especially constrained by them. At hospice B the higher administration pushed the hospice staff for greater productivity in the form of increasing case loads and there was a push to lower medication costs, but these mandates were not made explicit as they were at hospice C.

Because the administration was so distantly located, hospice B ended up having more freedom from administrative surveillance than did hospice C. Researcher access to the hospices illustrates the differences between hospice B and C with regard to the level of involvement of the higher administration.

When the researcher approached the branch manager at hospice B to ask if she could gain access to the hospice to perform a case study, the branch manager readily agreed and allowed the researcher to begin work immediately. After the case study was performed, the researcher found out that the branch manager had not consulted the higher administration about whether or not it was permissible to allow a researcher access to the

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[4] The term "higher administration" for hospice B includes the officials at the parent corporation located in another state and the regional director who was located at the regional headquarters in another town. This does not include their branch manager who was located on site.

hospice. The branch manager explained that the higher administration would never find out.

A similar request to gain access to hospice C to conduct a case study was received positively by the branch manager, but she was required to consult with the higher administration for approval. Initially the hospice director denied the researchers request for access to the branch, and it was not until the request was made to the CEO that the researcher was granted access almost a year later. These different experiences illustrate the different level of oversight and surveillance experienced by hospice B and hospice C due to their different geographic locations of authority.

In sum, the geographic location of authority was an important factor in the hospices studied. The location of authority in some cases affected the cohesiveness of organizational goals, level of administrative oversight, and moral of staff.

Hypothesis three stated that the level of service delivery in hospice organizations would be affected by their organizational relationships. Data from this study support this hypothesis. Rules imposed by non-hospice organizations (like productivity requirements characteristic of home care) tend to put pressure on hospice workers to cut the level of care they provide. Vertical integration at hospice C clearly was related to greater surveillance of hospice staff, more requirements for productivity that did not fit the staff's ideas of hospice goals, and lowered staff moral. Increased levels of uniformity in the form of protocols, standards of care and medication formularies constrained the staff of hospice C, forcing them to be less innovative in caring for patients than at hospice A, where staff were free of these institutional rules. In sum, vertical integration at hospice C

is another factor that influences the differences in care between the two non-profit hospices.

Section 4. ORGANIZATIONAL MISSION AND SERVICE DELIVERY IN HOSPICE: An institutional approach

I. Introduction

This section addresses the fifth aim of this research which was to examine the relationship between organizational mission and service delivery in the hospices. Institutional theory of organizations is useful for looking at how the ideas and norms of an organization produce or underpin the structures and systems of that organization. The *archetype method*, which was derived from the institutional theory of organizations, is a way of looking specifically at the interpretive scheme, or underlying values and beliefs prevalent in each hospice. The interpretive scheme of each organization includes the goals, method of operation and self-evaluation methods used in each organization. The interpretive scheme is a set of ideas and values that underpin the structure of the organization. The archetype method was used to look at the differences in interpretive scheme of each hospice and how those values and ideas might be related to service delivery. This section compares the interpretive schemes of the hospices studied with the interpretive scheme of the traditional hospice archetype and will argue that a new hybrid archetype (as characterized by hospice B and C) has emerged in the field of hospice care.

Another theoretical approach that is used in this section to compliment the archetype method was the *sociology of knowledge* approach. Sociology of knowledge was used to examine the ideas produced within each hospice about appropriate care and consensus in each hospice. Sociology of knowledge in this section also will be used to

examine how different ideas about end of life care are produced by the social settings of each hospice and might influence patient care in each of the hospices.

This section will conclude with a discussion of *asymmetrical information theory* to explain, not why these organizations behaved differently, but how certain organizations managed to provide fewer services without being detected or overtly stigmatized for that behavior. The theory of asymmetrical information asserts that in the health care sector, and especially in hospice, there is asymmetrical access to information between administrators and consumers that allows an organization to cut back on services that are hard to measure by consumers. Thus, explaining hospice B's ability to cut back on care. This theory is used to examine the differences in service delivery in the three hospices studied.

I. Archetypes in the field of hospice care

Organizational fields are usually characterized by one prevailing archetype, meaning that most of the organizations in that field are characterized by a distinct set of beliefs and values, or interpretive scheme, which underpins the structure of the organizations in that field. As was outlined in the introduction, when hospice first emerged as an organizational field, that field can be said to have been characterized by one distinct archetype. Subsequent to the 1983 Medicare Hospice Benefit, hospices had a well documented, unifying philosophy or mission that underpinned the independent structures and systems of the new organizational field. Since the Medicare benefit, the character of hospice organizations has changed substantially enough to argue that a new hybrid archetype has emerged in the field of hospice care.

The design archetype method of classification is concerned with practical methods of measuring change or differences in organizational forms. It looks at organizational structure as a product of the ideas, values, and goals within an organization. The term, "design archetype" describes a coherent set of structures and systems that is underpinned by sets of values or norms called "interpretive schemes"(Greenwood & Hinings, 1993). This approach to studying organization views the structures and systems of an organization as inextricably linked to the organizational mission, or interpretive scheme. The interpretive scheme of an organization is made up of three sets of ideas. The first set of ideas of an interpretive scheme are the shared goals of the organization. The second set are ideas about the most appropriate method of operation to meet those goals. The third set of ideas that make up an interpretive scheme are the ideas about the best way to evaluating the organizations performance, or how they measure success. The interpretive scheme of an organization is another way to describe the mission of the organization, or the underlying beliefs and values the support the structure of an organization. The archetype method was used in this research to compare the mission of each hospice and how that mission underpinned the structure of the organization and subsequently the care that was provided. In addition, the archetype method provides a structure within which to measure the level of consensus about these interpretive schemes throughout an organization.

In this section, the interpretive scheme of the three organization's studied will be compared to that of the traditional hospice archetype. The interpretive scheme of the traditional hospice was ascertained through reading and writing about hospice, especially that work outlined in the background chapter on early hospice philosophy (see Early

Hospice as Charismatic). While hospice A has deviated somewhat from the archetypal form of the traditional hospice, its interpretive scheme can be considered to be operating within the traditional or "early hospice" model. Hospice B and C have interpretive schemes that have deviated enough to suggest that they represent a new hybrid hospice archetype. This section will contribute to the theoretical thinking on archetype design method by incorporating the sociology of knowledge approach to further elucidate aspects of the interpretive scheme of each hospice.

A. Organizational goals

The first set of ideas that must be examined when assessing the interpretive scheme of an organization are ideas about the goals of the organization. In the traditional hospice archetype, hospice structures were underpinned by a strong philosophy about what constituted a "good death." The goals of early hospices were to provide holistic palliative care to dying patients and their families. Early hospice goals were reactionary in nature, responding to the perceived over-medicalization of dying provided in the medical model of care. Part of the early hospice interpretive scheme was founded on an anti-medical and revolutionary philosophy (Abel, 1986). Hospice leaders argued that the modern medical system had failed to provide adequate care for dying individuals. The aim of the early hospice leaders was specifically stated as an effort "to revolutionize the American health care system from the inside out" (Fulton & Owen, 1977:17).

In the hospices studied, the anti-medical sentiment, while not as strong, was still apparent. The hospices studied worked in cooperation with the mainstream medical establishments, having affiliations with home care agencies and hospitals. The main area where the anti-medical sentiments were revealed was when talking to nurses about the

still prevalent tendency for physicians to refer people too late to hospice. From hospice

A:

"Some physicians are reluctant to refer patients to hospice. Their patients will die in their service. Even though they know me and I work for hospice. Because to some degree it is part of the medical system that if you are referring patients to hospice, you have to accept that they are dying and you have to deal with your own feelings of having somebody die on you. And I think people feel that they are giving up. You hear that from doctors a lot. Sometimes from the medical professionals it is hard to get referrals."

"This one guy would have been fine going into hospice but his doctor wanted to do an MRI just in case his illness was being caused by another infection to his brain which could be treated. He was on Medical and it was going to take 6 weeks to get approval to get an MRI and he died before we ever got there. I: So he stayed on palliative care? R: So he stayed on palliative care. And he said, you know it doesn't really matter to me, I don't think they are going to find anything but I have been with this physician a long time and I feel like I would be letting him down if I went to hospice"

From Hospice B:

I: Do you find there are certain doctors out there who buy into hospice in general more than others? R: Oh yes. An example for one. We used to have this one doctor that we would get a lot of referrals from the nursing home for his patients. So we would call...this was back when we did things a little differently...we would call him and ask for the order. "Oh no, that patient is not hospice appropriate." Two or three days later that patient's dead. Well this happened numerous times. And I got another one and I called. And his nurse said just a minute and she went and asked and she said, "No he said this patient isn't hospice appropriate." So I said, "Well that is what he said about so and so, and so and so, and so and so, and they were all dead within two or three days." Well they did finally give us the referral. We are his only referral source now. Once he saw... he was tied in with another hospice, and he saw that we give so much more than the other hospices do...that once he actually saw what we did, now he refers only to us."

I: Do you ever get resistance? R: Like, doctors don't want them to have them on that much Morphine? Oh yeah. For example, I had a patient once who was on a Morphine drip. With a pump. And he was at 15mg per hour. And in just constant excruciating pain. The nurses in the hospital had spent a month getting that doctor to raise him from ten milligrams up to 15 and he wouldn't go any higher. Well the day he was admitted to hospice, I went in we put him up at 25 immediately. And the next day we went up to 35 or 40. We ended up at about 75 milligrams an hour to get this man pain free. That is how much pain he had. And this doctor didn't have a clue. Some of your doctors just have not a clue on pain control. And they are still in the old school, "well they might become addicted to it." Well you know what, the patient is dying, so what? But that doesn't come into their mind. They just don't have the hospice philosophy in their mind. So again, we have to educate doctors. But when it's a pain issue, if they are real reluctant we will go to our medical director."

From hospice C:

R: Well, I mean, my feeling on that is that somebody needs to educate doctors more so that they make the referrals to hospice sooner. Because to me, I mean, there is a lot to get done to get the case open and to make sure that the family really understands what they are getting and that they start to feel comfortable with the nurses and the home health aides and the social worker and the chaplain. And so that they don't feel like they are dying with strangers. I mean, they could stay in hospital and die with a pack of strangers. I: Sure. R: But I don't think that that is the hospice's fault. I think it's the doctor's fault because their attitude is... 'Were going to fix it, were going to fix it, were going to fix it.' What can the hospice do if someone gets here two days before they are going to die?"

These quotes represent the views from various staff at all three hospices. While current hospices are not separated from the mainstream health care world, there are still some adversarial feelings about the mainstream medical model of care. This was revealed was when talking to hospice staff about the community physicians who they rely on for referrals. Staff described how their effectiveness as hospice care providers was diminished when physicians refer patients too late to hospice. Hospice staff also maintained that community physicians tend provide poor pain control and that hospice can do a better job caring for patients at the end of life. So while hospice has evolved away from being an organization that is completely separate from mainstream, medical model care, there is still some feelings of adversity on the part of hospice staff in the hospices studied toward outside health care practitioners. As a result, part of the goals of the hospice organizations studied was not to "revolutionize health care," but to "educate the doctors" about how and when hospice care is appropriate for their patients.

Specifically in terms of patient care, there were few differences between the goals of the different organizations and the traditional hospice archetype. In both the

traditional archetype and the hospices studied, the goals of the organization were to provide holistic palliative care to dying patients and their families. Staff at all three hospices tended to say that their goals were to keep people comfortable.

Goals from hospice A:

I: Tell me a little bit about the hospice philosophy? R: OK. Um, hospice does...we don't cure people. Its not to cure people. Its to help them be comfortable. Palliative care. That is the goal to help them be comfortable."

Along with this goal at hospice A was an attempt to decrease the technological aspects of dying by reducing the use of things like intravenous drugs and injections:

"Well, our philosophy is not to inflict pain in order to alleviate pain. So, we don't like injections and we don't like IVs because its painful, its in the way, its connected to a machine. And it all depends on how the patient feels about those things...what we do. But ordinarily we try to wean them off the machines and substitute medications through a different route. Orally or rectally."

At all the hospices, the goal was to relieve spiritual and emotional pain as well as physical pain. These three aspects of comfort were recognized by the staff at all three hospices as their primary focus. From hospice A:

"Our families don't just have nursing needs. You know they have spiritual needs. They have spiritual needs, they have emotional, social, financial needs. They have needs for help with personal care. Um, they have changes that come every day in what's happening to them. Their condition is never stable. They are deteriorating all the time."

One nurse described addressing the spiritual pain of a patient:

"And she just was lying there moaning. And when you do a pain assessment you ask questions and I couldn't figure out what was bothering her. And yet she said she was in pain. But I could tell that her pain was controlled. It was. There was nothing physically bothering her. So I really was able to determine that she was comfortable physically. But she was still moaning. And her son is a minister. And she and her husband were charter members of a church nearby. And I thought to myself. Would it be appropriate to read some scripture to her. So I did. I just read the Psalms actually. And she would snore. (laughs) I would be sitting here reading for her and she would snore. So I would say, she is relaxed now she is resting and I'd stop. Then she'd start moaning again. So I'd read again. And she'd stop. I did that about 4 times just to see. Then I went out and told her family what had happened so they could do that for her. And it was really interesting. She had some spiritual pain. So it was interesting that literally you can (inaudible) the last thing you look at. You've got to take care of the physical first and the emotional is easier to think about than spiritual things. So its interesting."

At hospice B, there was a similar a focus on caring for the many aspects of the patient including physical, emotional and spiritual. One nurse at hospice B said:

"That is our number one goal... to keep that patient comfortable. As comfortable as possible. And comfort is not just pain. There is physical comfort, there is emotional comfort, there is spiritual comfort. And we have to address all three issues".

At hospice C, there was a similar focus on both physical and emotional support. One nurse was asked about the goals of the organization in caring for patients and she replied:

" Well, the goals as I see them are...I can't say primarily. Its both symptom control and emotional support and its...to me I can't really say one is more important. It depends on the family or the patient what's most important. Because symptom control is crucial but helping the family cope to me is the most crucial".

Also at all the hospices there was an emphasis on caring for the patient as well as the family, with the family as part of the unit of care. Here are excerpts from interviews with staff at hospice A who are describing the unit of care:

"Well, for us, we have to look at the whole patient. We have to look at the whole body, the whole spirit, the whole everything. And try to figure out how to work with the family and all the people who are involved in that life."

I: Describe the unit of care in hospice, because I know it is not just the patient. R: Whoever the patient says is family. And that could be the next door neighbor or it could be a dear, dear friend."

At hospice C, the unit of care also included the family. But there, the goal was to provide excellent patient care not only to the patient and family, but the unit of care was extended to include serving the whole community: One nurse said:

"The goal is to provide excellent patient care. I mean that is really the goal of the organization. And then within that there are all kinds of things we have to deal with. But the main goal is to provide care in our community, which we serve."

So in terms of the overall goals of the organizations, all three hospices had the overarching goal to provide palliative care to patients. They wanted to provide comfort, rather than a cure. Similar to the traditional hospice archetype, they all felt that

addressing spiritual and emotional issues was as important as addressing physical discomfort. They also included the family members as a central part of the unit of care, an undertaking that has been part of the philosophy of care since the early days of hospice. Hospice C extended that a little farther to include the community in the unit of care. In sum, using the archetype design method, the goals of each of the organizations were very similar and were similar to the traditional hospice archetype.

B. Method of operation

The second realm of ideas that make up the interpretive scheme are the ideas about the best ways for the organization to achieve their goals. In the traditional hospice archetype, the method of operation encouraged the individualization of care by promoting flexibility and innovation. An early hospice leader was quoted as saying, "*The primary message that must be conveyed to the dying patient is that he is unique and that his needs are special and will be met in an individual way*"(Buckingham, 1983:6). Data was collected in this research to ascertain each hospices "method of operation" for meeting their goals. The hospices studied varied in terms of how close they were to the traditional hospice archetype, with hospice A having a stronger sense of the importance of innovation and flexibility, while hospice B and C less focused on the importance of innovation.

For hospice A, the best way of achieving their goals was to be flexible and innovative. For the staff to be flexible in allowing the patient to achieve their goals:

> *"Um, our mission is to introduce a team that provides excellent care for patients at home so that they can die at home. To have the services available to them to meet as many of their needs as they can so that they can accomplish their goals."*

At hospice B and C, individual staff members wanted to be flexible in caring for patients, but this desire was often overrun by the constraints of complying and documenting compliance with Medicare regulations. At hospice B one nurse described how being flexible, or "letting go" was one of the main tasks of hospice care.

"Um, so basically the philosophy is to allow the patient to die where he or she wants to die in the way in which he or she wants to die. Not in pain...because our goal is to have no pain. But if people just want to be comfortable and they want to have somebody support the family. And if this is really what they want to do then we are here to help them...and the family. The family is a big component. And sometimes the family are the ones who need more help. You know, if they are not accepting, if they don't want to let go...and that is another thing about hospice. Hospice is all about letting go. Its letting go...the patient letting go of life. The family letting go of the patient. Doctors and nurses letting go of "what we think they should do."

At hospice B and C, their method of operation, the way to achieve their goals, while certain individuals might want to be flexible and innovative in the way they cared for patients, staff were constrained by the need to follow the regulations and guidelines. This usually was displayed in their efforts to document a patient's hospice appropriateness. Documentation and paperwork were more a focus of care at hospice B and C than they were at hospice A. Because there was a great fear of not being reimbursed for care, the nurses especially were forced to constantly document certain aspects of the patient's condition that would prove hospice appropriateness to the regulatory agencies. For example, the physician at hospice B required nurses to bring tape measures with them to visit patients so that they could continually measure the circumference of patient's limbs, thereby documenting a patient's decline and hospice appropriateness. At hospice C documenting hospice appropriateness was similarly dominant in their everyday work practices. They used calipers to measure the fat content on a patient's body.

Hospice A did concern itself with hospice appropriateness, however, they had other programs like the palliative care program, so that patients who stopped being hospice appropriate for some reason could be switched from the hospice program into the palliative care program. It was therefore less urgent for hospice A to focus on hospice appropriateness. As was described in an earlier section, hospice A was also less reliant on government funding for solvency, which contributed to their less intensive focus on documenting regulatory issues.

In sum, the ideas at the three hospices about how to meet their goals as measured by the archetype design method differed slightly. All three hospices hoped to meet their patient's needs by being as flexible as possible, but hospice A had an infrastructure that supported a greater level of flexibility in contrast to hospice B and C. Thus, hospice B and C everyday work practices were more dominated by addressing the concerns of the regulatory/financing agencies by measuring and monitoring hospice appropriateness.

C. Self evaluation: Measuring Success

The third major query used in the archetype method is to ask participants to describe their self-evaluation methods. In order to do this, staff at each hospice were asked in interviews to describe the ways that they measured their own success. Measuring success can be very difficult in a health care organization where the expected outcome for each patient is death. In health care organizations, this sort of task is usually referred to as measuring quality.

In the traditional or early hospice archetype, hospices were not surveyed or monitored by any outside sources. Quality of care or success was measured by the

satisfaction of the patient and family as well as by the perceptions of care by the hospice workers.

In the hospices studied, staff members were interviewed and asked how they measure their own success, or how they know when they have done a good job. Probably because the goals of care were so similar across the three hospices, the methods of measuring success were also similar. In addition, they were also not specific. Because there tended to be no script for the goals of hospice, there also tended to be very little specific criteria for measuring success. Care was considered a success if the hospice team met the goals of the family...whatever those goals might be.

"I: How do you measure quality of care here. Or in other words, how do you describe success in caring for a dying patient. R: Well mostly we... it is successful if the family thinks so. And when we first go out we ask them what their goals are and they tell us and we keep asking them because as time goes on they change. So if we help them meet their goals then that is a success.

Feedback from the family was often the most common way of measuring success for hospice workers in all three hospices:

"Well, I had a patient who just died and the feedback I got was, this worked much better than we thought it was going to work. This wasn't as terrifying as we thought it was going to be."

At each hospice in this study, patients and families were sent satisfaction surveys, both during their time of care, and after the death of the patient. Satisfaction surveys are required by Medicare to be sent to patients and families. These satisfaction surveys were often mentioned by staff as a way of measuring success, but they were by no means a definitive measure of how an individual staff member measured their performance. It was widely recognized that hospice work occurs at a time of deep crisis and intense grief for a patient and family, which is likely to affect their level of satisfaction with the care

they received. While most of the hospices reported receiving mostly positive satisfaction surveys, negative reviews were sometimes received and those were taken very seriously. One manager describes how the hospice uses the information they get from patients and families:

"Any time we get any kind of complaint we do have a process we call "unusual currents" which is like an incident report. And we will investigate it and see if there is anything that warrants any change in our practice. We also send out 60 days after a patient dies to the caregiver a questionnaire. We get some feedback....some really valuable feedback. Because sometimes we don't look at ourselves. Not in the same way as a patient or family sees us. So it has given some really valuable feedback. The comment section is the best. It gives you the true picture."

On the other hand, negative reviews could also be dismissed as a product of the grief being experienced by the family. Some nurses from hospice A describes why the feedback from the family may not be the most accurate measure of success:

"I think for a family some times it never feels real good because they are losing a family member. And that doesn't feel very good and in the end it feels very very sad. And also I think we have to take that into consideration. We may have done a very good job of taking care of that patient and helping that patient to stay at home. But at the end, that family still looses that patient and that feels very bad. Of course real success would be that the patient would survive and get well and the family would feel wonderful. That is not going to happen."

"I: Are their times when you are not successful in that way? does it happen and how does that get dealt with? R: Well sometimes the family is so stressed that no matter what happens they are not going to be satisfied. And I think that is their personalities. So you have to just deal with that. You know, you do your best. But sometimes people just can't be pleased."

Another common way of measuring success was to measure symptom control in patients:

"R: Basically if I can go into a family that is in great distress, get that patient pain free and comfortable...that is extremely successful. That is extremely rewarding."

Another nurse from hospice A described how usual aspects of measuring quality of care in hospice like measuring pain control can be misleading. She believed that success in hospice care was a matter of continually addressing the changing condition of a patient:

I: How do you measure quality of care. Or another way of asking this is how do you describe success in caring for a dying patient? R: Our patients are changing all the time. So for someone who is not right there involved in the patient care, it may not look like a successful situation is going on. But I measure success in that as the changes are coming for a family, that we are on top of those changes and that we are addressing those changes. And what it can look like is, "Well gee, this patient's pain is out of control and you are not doing anything about it." Well, you may be doing a lot about it but it is changing very fast. What it means is that the pain is changing everyday because the disease is changing every day And that you are also changing what you are doing for that patient, if need be, every day. And if we are doing that, then I think that is success. So when we are talking about success, success for us is that we have stayed very close to that family and we have addressed these (new issues) as fast as we can to take care of what is going on. And then after that patient dies we continue to stay involved through bereavement in whatever way is helpful to that family.

Another feature of measuring success that was common among all the hospices was to look at the level of resolution reached by the family:

"You are with a family that is in just total chaos and you get the social worker, maybe the chaplain in there and get this family kind of calmed down a little bit. That is success."

" I feel like I am successful when I hear back from the patient, 'That helps. That made a difference. This issue that has been bothering me is resolved.' But other things that (tell me I am successful are) resolved issues with family members. Or having everybody on board with what their issues are. That jumps out. Like when I have a family meeting where patients want to say something to their family but they feel it is just too hard to say on their own. Or family members will say something that the feel they always wanted to say. So, getting resolution is a big part of it."

When asked to describe success, many hospice workers found it easier to describe times when they felt the were not successful. These situations usually occurred when a patient chose to abandon hospice care by engaging in activities that would necessitate their discharge from hospice. For example, calling 911 or going to the hospital are activities that are not allowed by the hospice Medicare benefit. In these situations, staff often felt like they had failed to achieve success in caring for patients.

"One of my first patients when I started was a young woman and she had breast cancer with metastases to the brain. And she was having excruciating nerve pain. And I was trying to work with her medication and work with her and work with her family. And what they wanted was for her to go to the hospital and she did and they were delighted. And I, being a new hospice nurse, thought I had failed because she didn't die at home. But her family was very happy. And you know, from years of doing this I realize that the was really the right outcome for them."

Length of service was not a measure that was typically used by staff to determine whether or not they had been successful at their work. Because length of service is often used in hospice research as a proxy for quality of care, staff at the hospices studied were asked in interviews to talk about what they felt length of service indicated in terms of the quality of care of their hospice. One staff member said:

R: I don't see length of service as something that could indicate quality of care. Because it is not a matter of how many days a patient is alive with us. It's a matter of what care did we give for two days or two hundred days. We do have satisfaction surveys. And that helps measure some of the quality of care from just a personal viewpoint of a family member after the patient dies. And we do telephone surveys seven to ten days after a patient has been opened up, just to kind of, well is everything sort of smooth from the beginning sort of questions.

Length of service was also a measure that the staff felt they had no control over. While they did feel that patients who stayed longer in hospice were able to reap more benefits, it was an issue they felt was controlled by the referring physician. There was a lot of frustration toward the community physicians who did not refer patients early enough to hospice.

"Well unfortunately we get a lot of these last minute cases. The doctors, especially oncologists are really reluctant to admit that there is nothing else they can do. And so we get 24 hour patients, 2 or 3 day patients, couple week patients. We really don't have time to do a lot of good work with the families of those patients. We generally can get the patient comfortable within a couple of days. Generally, not always. But, with the family. Ideally we like to have about six weeks. That really gives us time to really get in with this family and get all their ducks in a row. Get the funeral arrangements made. Get everybody in a good place for the death. But we have no control over that. We just keep trying to educate the doctors and the nursing homes. What are the criteria? Get these people in a little bit sooner. You are waiting too long!"

In general, at all three hospices, success was measured in a similar fashion. A hospice worker tends to feel she is successful when a patient's symptoms are controlled, when there is resolution and acceptance in the family, when the patient and family have met their own goals, whatever those goals may be. Some of these things are quantifiable, but most are not. In the end, most of the hospice workers who were interviewed replied that they felt they were successful in their work when they had done all they could for a

patient within the circumstances that the were working. The next section will address how the goals, method of operation and measures of success in these organizations did not always permeate throughout the higher levels of administration.

D. Consensus

The archetype method not only examines the interpretive scheme of an organization, but it also requires that you look at the consensus of the interpretive scheme throughout the organization. If there is not consensus throughout the organization about certain aspects of the interpretive scheme, that organization is said to be "between types" of design archetypes. It is thus, important to know whether the goals and ideas that make up the interpretive scheme are prevalent throughout the organization or if there is a lack of consensus in these ideas.

In this research, data were collected comparing the goals of the hospice staff to the goals of the higher administration. This study found that the three organizations had different levels of consensus between the clinical staff and the higher administration. At hospice A, there was a high level of consensus, with similar goals throughout the organization.

At hospice B, there was a difference between the immediate administration (branch manager) and branch staff's criteria for measuring of success. While the clinical staff measured success in mostly intangible ways, "doing the most we can for them." The branch manager measured success primarily with data received from patient satisfaction surveys, which she went on to chart for identifiable trends.

"I: From your perspective inside the organization, how do you measure success? What are some things you look for? R: Well, we want to trend everything. I am very organized when it comes to keeping track of patient concerns. Keeping documentation on any complaints. Those are a big way of tracking how your services are provided. And you want to document all those things. We do actually send out a survey to families after we provide the service and also after the patient has expired. And those satisfaction surveys come back to us where we can measure a trend. I think the most important piece is the satisfaction surveys and to make sure you follow up on those things."

At hospice B, the goals of the team (nurses, social workers, etc) were different than goals of immediate administration (branch manager). Unfortunately, no data were collected on the goals of the higher administration at hospice B, because the higher administration was located in a different state and an interview was not available. Occasionally a regional manager visited the office and sat in on a case conference meeting. He was observed at the case conference meetings encouraging the staff to think about cutting medication costs. While he was not available for an interview, his focus on cost cutting in the meetings gave the impression that his goals for the organization were more about cost effectiveness than about meeting patient needs.

At hospice C, goals of team were the same as the immediate administration (branch manager but different or perceived to be different than higher administration (director, CEO, CFO). In hospice C, success is measured by staff in intangible ways such as were described in the preceding section (letting the patient die the way they want to die). On the other hand, observations of the higher administration at management meetings indicated that success for hospice C higher administration is measured by quantifiable productivity standards and financial goals. These excerpts from a meeting where the CEO and CFO were addressing the branch managers of all the hospices reveal the different ways they measure success:

"The first part of the meeting was a CEO update. The next part was CFO reporting on the results from the patient satisfaction surveys filled out by clients of the home health. He showed the different home health branches and showed tables comparing their results and the percentage of satisfaction. It occurred to me that he didn't know how to interpret statistics. Then he was talking about how to "teach the test" in terms of readying the client to take the satisfaction survey. One of his big points was to make sure each patient knew who was who. Make sure they can distinguish in their mind, and with the language used by the survey, the difference between the Aide, the PT person and the nurse."

"The CFO then stated that one goal the branches had was to up "starts of care" meaning increasing the census. The goal of Hospice C was to have 225 starts of care and they had 189 which was 84% of their target goal and was considered a success".

"The next issue was productivity of the clinical staff. The CFO showed a table comparing hospice branches on their productivity. The goal is for each nurse to average 4 patient visits per day. The social worker must average 4 visits as well. The CFO said that the number one problem for hospice is their productivity. He said that NHO sets the standard at 4 per day, its not supposed to be unreasonable. Their goal should be 4 per day. He said, "We can't lower that. We have to meet this goal." He went on to say, "I don't get much receptivity from staff at hospice meetings when I bring this up." He said that he knows that staff is resistant to increasing productivity, "But we've got to get past this in hospice. And I am here to help" he says.

"Next the CFO showed a slide comparing each hospice branches productivity expressed as a percentage of their goal. He said that the hospice goal is 80% of the 4/day requirement. He showed a slide showing how all the branch did with this goal. They ranged from 53% of their goal to 76% of their goal. The branch manager of hospice C, who was sitting beside me looked at the slide and saw that hospice C had only met 65% of this goal. She looked at me and rolled her eyes."

These excerpts from a management meeting show that the higher administration at hospice C tended to measure success through satisfaction surveys, number of "starts of care" and productivity reports. The higher administration at hospice C did not talk about the level of symptom control, family resolution, or "meeting the patient's needs" as indicators of success, all ways that success was measured by the branch manager and staff at hospice C. Thus, their was a lack of consensus at hospice C between the local staff and the higher administration about how to measure success in their organization.

Table 4.21 Interpretive Scheme of hospices studied (Archetype method)

Interpretive Scheme	**Early Hospice Archetype (before 1983)**	**Modified traditional hospice archetype (Hospice A)**	**Hybrid hospice archetype (Hospice B and C)**
Goals	To provide holistic palliative care to dying patients and their families; To revolutionize health care	To provide holistic palliative care to dying patients and their families; To educate physicians and community	To provide holistic palliative care to dying patients and their families; To educate physicians and community
Method of operation	flexibility and innovation	flexibility and innovation; Adherence to Medicare regulations	Strict adherence to Medicare regulations, measuring hospice appropriateness.
Evaluation criteria	Quality of care as determined by hospice nurse, patient and family	Quality of care as determined by hospice nurse, patient and family; Quality of care as determined and assured through govt. regulation and inspection	Quality of care as determined by hospice nurse, patient and family; Quality of care as determined and assured through govt. regulation and inspection Measures of cost cutting **Admin**: same as staff plus productivity reports
Structures	Independent, freestanding non profit. Some affiliated	Independent, freestanding, non profit	Horizontal and vertical affiliations, non profit and for profit. Corporate divisions
Systems	Private pay, donations	Government funding, donations, private insurance	Government funding, private insurance

In sum, this research found that the three hospices in this study have interpretive schemes with some differences. The main area where the interpretive schemes differed was in how they saw their "method of operation." Hospice A staff valued innovation while Hospice B and C staff leaned toward privileging hospice regulations and documentation as their primary method of operation. Since organizational structure is seen as a product of the interpretive scheme, this difference in method of operation might indicate that hospice B and C were more similar to each other than to hospice A, despite their different profit status.

Another main finding was the differences in level of consensus between the two non-profit hospices. While at hospice A, there was consensus throughout the organization, at hospice C, differences occurred in the way that success was measured in the higher levels of administration.

This would indicate that while hospice A is an example of a certain design archetype, hospice C because of its lack consensus may be "between types" of design archetypes, further explaining the difference in service delivery between the two non profits.

Greenwood and Hinings combine the notion of archetypes with the concept of tracks of change to help compare the process of organizational change over time in organizational fields (1993:1055). They distinguish between organizational fields that experience no change (inertia), fields that begin changing but then do not complete the transformation (unresolved excursions), and those organizational fields in which new archetypes emerge (transformations). In this study, data show that hospice B and C had interpretive scheme's that were different enough from the early hospice archetype that they represent a new "hybrid" archetype. If this is true, then findings from this study would suggest that the field of hospice care is in the midst of organizational change that could be described as an "unresolved excursion." It is possible that the field of hospice care has left a state of inertia and is in the midst of organizational change where possibly one or more new archetype is emerging. Because the interpretive scheme's of hospice B and C were found to lack fundamental consensus within the organization, this would suggest that the new archetype identified in this study is a hybrid type and is likely to continue evolving before settling into its final state. Thus, findings to not suggest that a

total “transformation” has occurred in the field of hospice care, but that an “unresolved excursion” is likely ongoing.

In the next section, the interpretive schemes of the hospices studied and the issues of consensus within those schemes will be examined more closely using the sociology of knowledge approach.

II. Hospice Knowledge and the Interpretive Scheme

The *sociology of knowledge* approach looks at how knowledge is produced within organizations. Sociology of knowledge stipulates that ideas in an organization are produced by the social setting. While the archetype method looked at how the ideas within an organization underpin or produce its structure, the sociology of knowledge allows an analysis of the opposite direction, how the organizational structure produces different types of knowledges. The sociology of knowledge approach would stipulate that the knowledge that was produced within a particular hospice organization was constructed by the social setting. The sociology of knowledge approach complements the archetype design approach by going deeper into the relationship between organizational structure and ideas. This approach allows for a deeper examination of aspects of the interpretive scheme by looking at how the structure produces the ideas and the mutual production of the ideas and the structure.

Resource dependency theory’s “enacted environment” is similar to the sociology of knowledge approach. According to RDT, the structure of an organization filters knowledge so that agents within the organization react not to the actual environment, but to the environment as filtered or manipulated by the organizational structure, or the

"enacted environment." Sociology of knowledge takes this approach further, indicating that knowledge is not just filtered or manipulated by the structure, but produced by it. Furthermore, it examines not just how the social structure affects the ideas, but how the ideas and the social structure are mutually constructing. Thus, the sociology of knowledge approach is helpful in contributing to both the RDT perspective and the archetype method in analyzing the relationship between the ideas and the behavior of the hospices studied.

This is a very interesting time in history to look at hospice organizations because they are a relatively new type of health care organization and it can be argued that they are in a very rapid process of producing "hospice knowledge." In other words, hospices are still in the early phases of constructing what it means to provide hospice care. This section will explore how the social setting produces ideas about appropriate care at the end of life…or hospice knowledge.

The most salient types of 'hospice knowledge' uncovered in this research include ideas about: who is appropriate for hospice and what services should be provided to a dying person; both of which are pertinent for aspects of the interpretive scheme of the organization. Some of the main similarities in terms of the ideas about hospice that were present in all three hospices included: seeing the whole family as the unit of care; the goal of care was to let the person die the way they wanted to die (without pushing staff's preferences on them), and an emphasis on comfort rather than cure. On the other hand, there were some interesting differences in the types of knowledge produced by each hospice; knowledge that was a product of the social setting. The sociology of knowledge

approach was also especially helpful in re-examining the lack of consensus in ideas between staff and administration at hospice C.

A. Who is dying? When does dying begin?

While the archetype design method prompts the researcher to look at the ideas within the organization about the goals, method of operation, and self-evaluation method; the sociology of knowledge approach is open to analysis of other aspects of the organizational ideas and values. Particularly, it reveals those ideas and values that are produced by the social setting. Some aspects of hospice knowledge that emerged from the data were ideas about "who is dying" or who is appropriate at the subject for hospice care.

Staff in all three hospices agreed that, to be eligible for hospice, the patient must have a terminal illness. Even in hospice A where they have a palliative care program, the patient still needed to be diagnosed with a terminal illness to be eligible. In all three hospices it was the responsibility of the Medical director to verify if the potential patient had a terminal illness. In all three hospices, the staff agreed that the patient, in most cases, must be aware that they are dying and must be working toward accepting this fact in order to be eligible for hospice.

There were some differences between the hospices, however. Because hospice A had both a hospice and palliative care program, they had a broader view of who was appropriate for their organization. They did not have to be so strict about who they admitted to hospice, because if the person did not deteriorate physically as required, then that patient could easily be transferred administratively to palliative care. Even though

the organization might have less reimbursement available if the person were transferred to palliative care, this was not the concern of the staff.

At hospice B and C, staff were required to be more strict about who was admitted and thus more strict about documenting hospice appropriateness in the chart. It is here that the relationship between social structure, ideas, and work practices becomes apparent. At hospice B and C, the social setting, which did not include "extra hospice" programs produces a more narrow view of who was appropriate for hospice. This translated into different work practices, most notably a tendency to focus on documenting hospice appropriateness. Measuring and documenting hospice appropriateness became an every day work practice of the staff at hospice B and C. It became a rote exercise on their part. At hospice B they would routinely measure patients with a tape measure around their thigh and arm to make sure they were losing weight and thus, hospice appropriate. At hospice C they would use calipers to make these measurements. In hospice B and in hospice C, measuring decline in this way, though it had no benefit for providing better care, was as common a part of the hospice nurse's assessment as was pain assessment. Hospice A staff were less inclined to have hospice appropriateness screening as a main task when they visited patients. The staff would say that patients looked smaller, but measuring patients was not a usual part of the nurses' visit.

The sociology of knowledge approach shows how the ideas and the structures of the hospice are mutually constructed. While the archetype design method looks at how the ideas underpin the structure and systems, sociology of knowledge contributes to the archetype design method by looking at the mutual construction of these elements. That this relationship is not just one direction, but an ongoing mutual constructing process.

The process by which hospice A came to have expanded ideas about who is appropriate for hospice details the mutual construction of the ideas and the structures. In an interview with the administrator, also confirmed in other interviews with staff, this process was described. The administrator described how at hospice A, the staff felt that the eligibility requirement of six month prognosis excluded too many people from hospice. As a result, the administration created the palliative care program. This program allowed them to expand on who they could take care of. And expand their ideas about when dying began. Subsequently, those ideas instigated the production of more programs like the pre and post hospice programs. This example of how the ideas and the social structure are mutually constructed in hospice A resulting in broader ideas about who hospice serves.

Sociology of knowledge expands the idea of the interpretive scheme to include aspects of the ideas and values of the organization that are produced by the social setting. In the case of hospice A, the sociology of knowledge approach reveals that the "goals" of the organization are expanded to include caring for a broader range of patients.

B. What is hospice care? What services are appropriate for dying patients?

Knowledge in hospice organizations about what constitutes appropriate care at the end of life was examined in this study. Because there were differences in the services that were offered, it was assumed that there would be different ideas among the staff at the three hospices about what constitutes good or appropriate care at the end of life. This was not necessarily the case. Differences in the level of care did not always constitute differences in ideas about appropriate care. Though most staff members at hospice B and

C were unaware that they were providing a lower level of care of personal care than other hospices[5] they often stated that they felt that they were providing inadequate care in certain areas. For example, many staff members at hospice B and C expressed dissatisfaction that they could not do more for the patients in terms of personal care or volunteer services. At hospice B and C, there were areas where staff wanted to be providing more care, but felt there were constraints in the form of either Medicare regulations, organizational constraints or finances that prevented them from providing more adequate care. Here is an excerpt from an interview with a nurse at hospice B who wished her hospice could provide a higher level of care:

> *I: Are there ever times that you want to provide care for patients that for whatever reason, you just aren't able to provide it. R: Oh yeah. There are patients that really need almost like full time help. Or need like maybe like eight hours a day help. And unfortunately we can't provide that, and that sometimes is very hard. You just want to give these people everything that they possibly can and you look at them like maybe you have an elderly couple and they are all alone and one is the care taker and the other one probably should have a caretaker, and they could really use some help and about the best we can do is maybe a home health aide maybe a couple hours a day. Which is like a drop in the bucket sometimes.*

This staff member expressed dissatisfaction for the level of services provided by her hospice, indicating that though the level of care was different, her ideas about what services should be provided to dying patients were similar to those at hospice A, where 25 hours a week of personal care were provided.

Among the three hospices, one main difference in ideas about appropriate hospice care was influenced by finances. In chapter one it was described how hospice was inaccurately re-theorized as a lower cost alternative to conventional care in order to obtain Medicare reimbursement in the early 1980's. Thus, cost cutting as a primary goal may be prevalent in some hospice organizations.

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[5] While most staff at hospice B and C did not know that they were providing a lower level of care than elsewhere, there were a few exceptions with nurses who had worked in other states or in other organizations and knew that the services they provided were less than other hospices.

A comparison of the hospices in terms of their focus on cost cutting, illustrates the differences between the hospices studied in terms of prioritizing cost cutting as a main aspect of appropriate hospice care. First, staff at hospice C were more aware of the finances and the importance of cutting costs as a main task of hospice care. At hospice C, cost cutting was an institutionalized part of the hospice mission. The medical director, when describing what the goals of the hospice were said, "*our model is the best possible care in the most cost efficient way*." In addition, hospice C staff did not feel that it took away from the quality of care they provided. At hospice C they were very careful to always use the most cost effective drug for a patient as outlined in their medication formulary. But this formulary was not inflexible (see section 2, medications). Staff at hospice C did have the freedom to use a more expensive drug or drug route if it for any reason was a greater benefit to the patient.

At hospice C especially, ideas about cost efficiency were translated into the staff's every day work practices. The cost consciousness at hospice C was promoted as an everyday work practice, especially when it came to the use of the medication formularies and the use of generic drugs. Hospice C nurses reported that a large amount of their time when admitting a new patient was often spent talking to the patient's doctor and getting the medication orders changed to include generic drugs or substituting a previously prescribed drug for a less expensive drug on the formulary. In addition, the clinical staff reported feeling pressure to reduce visit time and to cut down on durable medical equipment. In this excerpt from an interview, the researcher is verifying with one staff member the observations about cost cutting being a team effort. The staff member goes

on to explain how the structure of the organization affects attitudes and practices about cost cutting at hospice C:

"I: It really seems that the financial stuff is a team effort. The whole team thinks about (cost effectiveness) as opposed to it being on one person's shoulders. Its not behind the scenes. It seems like you have taken the team approach a step farther. R: I think we have had a team meeting where this was discussed. Part of it is the structure. Our work structure. We have a lot of people who work per diem that are still and integral or obvious part of the team. Unlike in other organizations where you might not be as aware of your part time workers. So if they come and go, then you aren't aware of it. Then you don't necessarily take cost cutting as seriously as when you are in a group where, if you don't cut the costs you know that your colleague is not going to have as much work. And if they don't have as much work then maybe they are going to go somewhere else. And there is a big nursing shortage. So we want to be very careful to protect our colleagues. And that is part of it, we would rather have the money going to the people than to pay for a named drug that has been prescribed. It really comes down to...if you can be efficient, everyone can keep their job here."

This staff member believed that having part time workers whose jobs were in jeopardy was an incentive for the rest of the staff to be more cost conscious. An example of how the social setting and hierarchies of the organization produce ideas about organizational goals.

At hospice B, cost cutting, though not as institutionalized in terms of formal medication formularies, was also an everyday part of what the nurses had to think about. One nurse explained:

"I: How much do you have to think about how much stuff costs? R: That is always a part of the picture. We are not going to deny them anything they need because of the cost. Sometimes we will look for a cheaper alternative. You know, an example would be a (inaudible) bed costs about $40 a day to rent. We could put them on a Micron bed for $15 a day. Same bed basically, just different company. So we are going to look for that."

Conversely at hospice A, cost cutting was not a part of what was considered to be appropriate care at the end of life. Here is an excerpt from an interview when I asked one nurse about the goals of care at hospice A:

"I: What are the goals of hospice care here? R: Well, its to give the best possible care to the greatest amount of people we can. From your heart... not worrying about your pocketbook."

This quote accurately reflects the ideas about care and the work practices at hospice A. The staff at hospice A did not make cost cutting a priority when ordering medications or durable medical equipment for their patients. This difference also reveals a difference in what is considered to be appropriate care at the end of life at hospice A. In chapter four, section 2 it was described how the nurses at hospice A felt free to prescribe expensive appetite stimulant drug called Megase, a drug that is not covered by hospice B or C. Data showed that Megase was requested by family of patients at both hospice A and B. At hospice A, the drug was ordered for the patient because the nurse believed it would make the patient's family happy. A families happiness and emotional well-being was considered part of the unit of care at hospice A. At hospice B, because weight loss is often an important criteria for establishing hospice appropriateness, an appetite stimulant (especially an expensive one) is out of the question, even if it conflicts with the family's well being. This difference in prescribing practices shows a difference between hospice A and B in terms of what is considered appropriate care at the end of life. At hospice A, primacy is given to the well-being of the family over financial concerns. At hospice B, financial constraints of the organization prevent this. This difference in ideas was produced by the social settings and translated into different ideas about appropriate care at the end of life.

At hospice A, the structure of the organization, especially its ability to have increased resources through the foundation, creates ideas about appropriate end of life care that do not include cost consciousness (or sometimes even hospice appropriateness) as a predominant element. This allows for other factors, like the emotional well being of the family to take precedence. These ideas translates into work practices that also do not

include attention to cost cutting in the form of medication formularies and limits on durable medical equipment. One nurse described the attitude and work practices at hospice A:

> *"We are frugal. You can't throw your money around but we don't have...you know, if someone needs oxygen, then we will get it for them. What they need is what we give them."*

The sociology of knowledge approach, by looking at how the social setting produces ideas about hospice, enhances the understanding of the interpretive scheme of the hospices. Data showed that in hospice B and C, ideas were produced about both the goals of hospice and the evaluation of hospice that were different than both the traditional hospice archetype and the modified traditional hospice archetype. In hospice B and C, cutting costs was part of both the goals of the hospices and the self-evaluation method. In hospice A, hospice care was not seen as a lower cost alternative to mainstream medicine. Their large foundation allowed them the financial freedom to provide the care they wanted to provide without thinking about costs or increased productivity. In this way, the sociology of knowledge contributes to the understanding of the interpretive schemes of the three hospices.

In conclusion, this study found some differences in hospice knowledge produced by the different social settings of the different hospices. Differences in "hospice knowledge" further explain the differences in the interpretive schemes of the three hospices, especially in how the compare to the traditional hospice archetype. In general, hospice B and C tended to be more similar to each other than to hospice A in terms of their hospice knowledge. Hospice B and C had a more narrow view of "who was dying" or hospice appropriate than hospice A. This was a direct affect of the social setting at hospice A that provided more services to a broader range of patients. In terms of their

definition of what hospice care included, despite its non-profit status, hospice C tended to have cost cutting as part of their goal of care and their self evaluation, a consequence of their access to resources being more restricted than it was a hospice A. Cost cutting was not considered to be part of hospice care at hospice A. Sociology of knowledge states that ideas are produced by the social setting, and this study has shown that the social settings or organizational structures of the hospices studied produced some different ideas about hospice care in the three hospices.

C. Consensus revisited

Another area where the sociology of knowledge approach was useful was for examining the consensus of ideas between the clinical staff and higher administration in hospice C. The section on archetype design showed that hospice C had a lack of consensus in its method of operation and evaluation of success between the staff and higher administration. As reviewed in the chapter on theory, Rene Anspach used sociology of knowledge to look at how the social structure of the neonatal ICU produced different sets of knowledge among the different *types* of staff. Unlike Anspach, this research did not find differences between the different disciplines (physicians vs. nurses). But what was significant, and what the sociology of knowledge approach helped to clarify, was that the different social structures and the location of authority in these hospices tended to produce different sets of ideas between hospice staff and hospice administration. This is most apparent when looking at a comparison between hospice A and hospice C. At hospice A, the administration was on site and intricately involved in the everyday workings of the hospice staff. In hospice A, the administrators and the clinical staff experienced the everyday workings of the hospice very similarly. Due to

this structuring of the organization, the administration had very similar experiences of the hospice work, resulting in similar ideas about hospice (hospice knowledge). Thus, at hospice A, similar experiences with the organization produced consensus between staff and administration.

At hospice C, the administration was off site and had very different experiences of the hospice. Their main experiences with hospice C came from 1) the daily productivity reports; and 2) verbal reports from the branch manager. The productivity reports sent to the administration at hospice A had precedence in the way the administration responded to the hospice. The feedback (in the form of mandates) sent to the branches from the administration was based on these numerical reports of productivity and cost effectiveness. In a meeting where the CFO presented the productivity and cost data from the different hospices to an audience of branch managers, the CFO compared the different branches and gave suggestions for lowering costs and increasing productivity. Some of his suggestions included having the clinical staff do charting during case conference meetings, and reducing driving time. During the presentation at this meeting, it became clear that the higher administration response to the hospice staff was based predominantly on productivity reports as opposed to having an understanding of the everyday work practices, and the exigencies that occur in hospice work.

Productivity reports and data on costs are quantifiable and have the increased power associated with numerical data. Anspach (1993) would call these data "technological cues." The administration at hospice C did not have experiences with the everyday workings of the hospice. They did not experience "interpretive cues," or cues that came from actual interactions with the patients or staff. When they communicated

their understanding of the hospice work to the clinical staff, usually in the form of mandates to cut costs, hospice clinical staff reported feeling misunderstood and unappreciated. In general, the clinical staff at hospice C reported feeling that the administration was overly concerned with numerical productivity. As has been shown in other sections, this created a great rift between administration and staff at hospice C and resulted in some mandates from above that were considered very inappropriate by staff.

The social setting at hospice A created an environment where both the clinical staff and administration had equivalent experiences of the everyday workings of the hospice. The higher administration at hospice A experienced the hospice work through both interpretive and technological cues. The administration could see the nurses and how hard they worked. The administration was around to know when a staff member was having a personal crisis or was reaching a state of burn out due to the emotional extremities of hospice work. At hospice C, the organizational structure and especially the geographic distancing of the higher administration staff caused the administration to receive different kinds of data from hospice C, giving them different experiences with the everyday workings of the staff. They were not on hand to see how hard the staff worked or to empathize with the exigencies of providing hospice care. They received numerical data about whether the staff were meeting productivity and cost goals and responded to the staff based on this data.

The sociology of knowledge approach provides a means for understanding the different ideas about hospice care that arise both between hospice sites and within hospice sites. The most significant finding is the difference in ideas produced between staff and administration in hospices where the administration is off site. Sociology of

knowledge approach and the design archetype method are two approaches that have complimented each other as the theoretical framework for this study. Both approaches have helped in analyzing the data from this research in terms of the relationships between ideas and the social structure and the consequences for service delivery in hospice organizations.

In conclusion, the sociology of knowledge approach contributes to the understanding of archetypes in hospice organizations. This approach helps to reveal how the interpretive scheme and the structures are mutually constructing, in an ongoing process.

Data revealed through the sociology of knowledge approach bolsters the argument that hospice B and C represent a new hybrid archetype in hospice. More information and data showing differences in the interpretive scheme of the hospices were revealed.

Sociology of knowledge also adds to the understanding of the lack of consensus in the interpretive scheme in the new hybrid archetype by showing how the new type of structures in hospice C modify the information received, creating the opportunity for discordance in the interpretive scheme.

Table 4.22 Interpretive schemes of hospices studied (Sociology of Knowledge)

Interpretive Scheme	**Early Hospice Archetype (before 1983)**	**Modified traditional hospice archetype (Hospice A)**	**Hybrid hospice archetype (Hospice B and C)**
Goals	To provide holistic palliative care to dying patients and their families; Revolutionize health care	To provide holistic palliative care to dying patients and their families; To educate physicians and community; Expanded ideas of who hospice could serve and what services are appropriate for hospice	To provide holistic palliative care to dying patients and their families; To educate physicians and community; Cost cutting and profit motive
Method of operation	Flexibility and innovation	Flexibility and innovation. Adherence to Medicare regulations;	Strict adherence to Medicare regulations; Measuring hospice appropriateness.
Evaluation criteria	Quality of care as determined by hospice nurse, patient and family	Quality of care as determined by hospice nurse, patient and family; Quality of care as determined and assured through govt. regulation and inspection.	Quality of care as determined by hospice nurse, patient and family; Quality of care as determined and assured through govt. regulation and inspection; Measures of cost cutting **Admin**: productivity reports, starts of care
Structures	Independent, freestanding, non profit. Some affiliated	Independent, freestanding, non profit	Horizontal and vertical affiliations, non profit and for profit. Corporate divisions
Systems	Private pay, donations	Government funding, donations, private insurance	Government funding, private insurance

In conclusion, the sociology of knowledge approach, in conjunction with the archetype design method provides a rich understanding of the interpretive schemes of the organizations studied. Table 4.22 provides a description of the different interpretive schemes of the hospices studied using both the archetype method and the sociology of knowledge approach. Including the ideas or knowledge that was produced by the social setting added depth to aspects of the interpretive scheme. In this case, the sociology of knowledge approach added to the understanding of the goals of the organization and the

self-evaluation method. The sociology of knowledge approach revealed how hospice A had expanded ideas of who was appropriate for hospice care. It also showed that hospice B and C as representatives of the new hybrid hospice archetype, included measures of cost cutting and increased revenues as part of the way they evaluate their success. The sociology of knowledge approach also helped explicate more deeply the lack of consensus in the self-evaluation method apparent in hospice C by describing how the different types of knowledge produced by the social settings contributes to the lack of consensus between staff and administration. The sociology of knowledge approach also provides a different understanding of the relationship between ideas and the organizational structure. While the archetype design method looks at how ideas produce the structures and systems of an organization, the sociology of knowledge allows for an analysis of how the structures produce the ideas and the mutual construction of the ideas and the social setting.

D. The theory of information asymmetry

It has been clearly established that there were differences in service delivery between the hospices and reasons for that difference have been elucidated. This section will now discuss how hospices might be able to provide lower levels of service and essentially, get away with it. There is a theory that tries to explain differences in quality among profits and non-profits in the nursing home industry called the *theory of information asymmetry.* This theory rests on the basis that in health care, there is an asymmetrical relationship to information between providers and clients. In other words,

clients (patients and families) do not have the same access to information that would let them measure the quality of care provided in a particular organization.

Organizations can respond differently to this phenomenon. They can choose how much they will exploit this information by cutting back on care that is more difficult for clients to measure. Cutting back on things that clients cannot see, but which make a difference in the quality of care is a way to cut costs in a profit seeking or cost minimizing organizations. The theory of information symmetries has been used to explain disparity in costs and quality of care in nursing homes. The general argument is that non-profit institutions may place greater weight on the provision of high quality care (Weisbrod & Schlesinger, 1986). Whereas informational asymmetry provides an opportunity for profit maximizing firms to misrepresent and under-supply hard to measure aspects of a good or service, thereby increasing profits, non-profit institutions may be less inclined to exploit this opportunity (Hansmann, 1980; Easley & O'Haraa, 1983; Hirth, 1991). This means that because it is difficult for health care clients, be they patients or family, to ascertain the quality of the care they receive, it allows certain profit seeking organizations surreptitiously to cut back on certain aspects of care. This theory gives primacy to an organizational mission that would preclude such cutbacks on care. In this study, the theory of information asymmetry is not used to compare the non-profits with the for profit hospices, but is used to compare the modified traditional archetype hospice (hospice A) with the new hybrid hospice archetype (hospice B and C) that were identified by this research.

The theory of asymmetrical information access is especially relevant to the hospice industry. The hospice industry is a relatively new phenomenon and many people

are unfamiliar not only with the level of care that should be provided by hospice, but are totally unfamiliar with the type of services they can expect from a hospice. Theoretically this might make it relatively easy for a hospice to cut back on care because there are very few expectations in the community about what a hospice should provide. [6]

Interviews with hospice nurses showed that part of what hospice care involves is the education of the patient about what hospice entails. Patients and families have rarely had other experiences with hospice organizations to compare the care they are provided. For example, the patient/family may know that hospice is supposed to provide a social worker and bereavement services, but they do not know to what extent. So if the patient receives a phone call from the social worker only once in the 6 weeks that they are using hospice, the patient or family may erroneously feel they have received the care they require. Consumers are not likely to be very experienced with hospice care. Because the nature of hospice care is that it's a relatively new form of care and because patients who use hospice care eventually die, this results in relatively few individuals who have any past experience with hospice. In addition, there are few resources for consumers to compare hospice types. The nature of hospice care is that people tend to be referred when they are in crisis and do not have a lot of time to educate themselves about hospice.

Interestingly, what sometimes happens because of this lack of information, is that patients or families actually expect **more** care than the hospice is able to provide, especially in terms of nursing care and personal care. In interviews at all three hospices,

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[6] The only area where there were some expectations was in the area of personal care. Many staff at hospice B and C complained that families had somehow gotten the impression that hospice staff would provide 24 hour care, seven days a week. Because this was an incorrect assumption, it was easily written off.

nurses reported that they had families who, once signed up for hospice, believed that a hospice nurse would stay at their house for 24 hours a day.

"I: So you find family or patient resistance to certain services? R: Yeah. And then some people do, because of misinformation. Well, they said, whoever they were, that hospice is 24 hours. So they are expecting a physical body 24 hours a day. And then you walk in there and you say, "Well see you in a few days." And they are dumbfounded. You know, its...they have only heard what they have wanted to hear, from the beginning of the start of care, even for a few days. We had one situation that really caused us a lot of havoc. They had an expectation. And of course they got mad after the person died."

While an overestimate of hospice services on the part of patients and families was reported by hospice staff in this study, there were few complaints made to regulatory agencies to back up this up. It would seem that if a great number of patients/families felt that they were not receiving the care they were owed, that the hospices would have been the subject of more complaints to regulatory agencies.

An important finding of this study was that hospice staff themselves were often in the dark about the requirements for level of care in hospice. There were many instances where hospice staff interviewed for this study did not know that they were failing to meet the requirements set by Medicare. The fact that it is a relatively new model of care means that many hospice workers are new to the field. Most hospice nurses interviewed for this research were trained "on the job" and received no outside education about hospice care. Once employed, hospice nurses work very hard and have little incentive to obtain further education about the regulations besides those that they have to document. In addition, hospice is multi-disciplinary and data from this study showed that staff from each discipline rarely understand the requirements for the other disciplines. For example, at hospice B, the nursing staff were not aware that the level of bereavement services provided did not meet the requirements set by Medicare. Thus, this study would take the theory of information asymmetry a step further and say that not only are their differences

in access to information between hospice personnel and their clients, there is a difference in access to information between hospice administration and hospice workers.

In addition to being in the dark about the requirement of hospice care, this study found that hospice staff, especially at hospice C, were not aware of the true financial situation of their organization. Observations and interviews revealed that hospice C staff felt that their organization was operating at a significant financial loss and that, because of this, the existence of their organization and their jobs were in jeopardy. At hospice C, despite the fact that figures from the year before indicate that they did not operate at a loss, observations at the management meeting indicated that the branch managers of both the hospice and home health agencies were being told by the higher administration that they were operating at a very significant loss.

The CFO did a session called "back to budget update." He started off by saying that in the year so far they were operating already at a 1.6 million dollars loss. He said, "these are very serious times." One of the main reasons they operate at a loss was that the capitated reimbursement rates for home health are too low. He tried to encourage managers to train their staff to "utilize the caps properly." Meaning billing appropriately or aggressively to get more money for your patients. Make the staff aware of who the payer is and have them watch the capped payers.

In his speech to the branch managers of the hospice and home health agencies, the CFO indicated that the organization as a whole was operating at a loss. From inspection of financial documents and reports to its potential contributors, this research found that hospice C's parent corporation typically excludes foundation funds when it reports its revenues. In 2001, hospice C would have been operating at a loss if it hadn't been for the approximately $750,000 they used from foundation funds. This reporting of revenues in staff meetings was used as a tool by hospice administration to encourage hospice staff to cut back as much as possible on care.

In the case of these hospices, asymmetrical information theory elucidates how the asymmetrical access to information between administrators and consumers that allows organizations to cut back on services that are hard to measure by consumers. Findings from this research would take that theory further to say that asymmetrical access to information exists between administration and staff that further enables the organization as a whole to cut back on care compared to the regulation requirements. This theory would stipulate that the asymmetrical information access allows any organization to cut back on care to cut costs and the only thing preventing this is a desire on the part of the organization to provide high quality care.

IV. Conclusion to section four

In this study, data show a significant disparity in the level of care provided by the three hospices studied. This study found that profit status alone was not a determining factor in the behavior of the organizations studied. Profit status, in addition to the existence of integrations and location of authority had a combined affect on the level of service provided.

Theories like resource dependency theory help to further describe the external factors such as relationships with the outside environment that affect the behavior of the three hospices studied. The archetype method, supplemented by the sociology of knowledge approach were used to compare the hospices studied to the traditional hospice archetype. These methods looked at the relationship between the ideas of the organization and the structures and systems. This research identified hospice A as a modified traditional hospice archetype. It was similar to the traditional hospice archetype

with some differences, most notably being hospice A's expanded views on who hospice could serve. Hospice B and C were identified as a new hybrid hospice archetype. Their goals, method of operation and evaluation methods were different enough from the traditional hospice archetype as to identify them as an emerging new archetype. They are considered to be "between types" or a hybrid type because of the lack of consensus between the staff and higher administration about their evaluation criteria of success.

The significance of identifying two hospices with a "hybrid" archetype is that it suggests that the field of hospice care is undergoing change. While most organizational fields are characterized by just one archetype, data from this study suggest that one or more new archetypes may be in the process of emerging. The fact that the interpretive scheme's of hospice B and C were of a "hybrid" type with a lack of consensus suggests that the organizational change that may be occurring in the field of hospice care is likely ongoing and that a total transformation has not yet occurred. While more research needs to be conducting to make definitive conclusions about the number of archetypes and process of change in the field of hospice care, it is safe to predict that more changes in the field of hospice care can be expected in the future.

The theory of asymmetrical information helps to understand not why, but how hospices are able to provide fewer services, even fail to meet Medicare requirements and not be stigmatized by the community.

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CHAPTER FIVE. CONCLUSION

For this dissertation three hospice organizations, all in the same community and subject to identical Medicare regulations were studied. Each hospice had a different organizational structure and different access to resources. Data showed that despite their similar environment, the hospices studies provided very different levels and types of services. This dissertation, first and foremost sought to understand the relationship between organizational structure and service delivery in hospice organizations. To accomplish this there required many preliminary tasks and modes of inquiry including: describing the organizational structure and describing level and type of service in each hospice.

To conclude this dissertation, this chapter will review and discuss all the main findings of this research with discussions of the implications of those findings for both future research and implications for the hospice industry.

I. Categorizing Hospice: not as simple as it seems

Describing the hospice organizational structure of the three hospices was the first aim of this research. This turned out not to be as straightforward as it might appear. In the background section, it was discussed that there is no uniform way of categorizing hospices in survey research. The data from this research show that categorizing hospices should be done in a much more complex and comprehensive way. One of the main findings of this research was that variables such as profit status, ownership, affiliations and authority are much more complicated than they have been treated in past survey research.

This study showed that categories such as: freestanding, hospital based, and home health agency based are not sufficient to categorize the nuances of organizational structure in each of the three hospices. These categories fail to capture the organization's ownership in terms of the type of parent corporation. They do not describe whether or not the parent corporation owns other types of health care organizations and whether the parent corporation is profit seeking, or not for profit. It also does not capture the scope of the parent organization in terms of the number of other organizations they own. More recently the NHPCO categorized hospices as: freestanding, hospital based, home health based, hospital system, corporate division, nursing home based, VA, or other. This more recent categorization is more comprehensive than earlier CMS categorizations of hospice but still allows for overlap between categories and is incomplete.

It is interesting to examine the ways hospices have been categorized and compare these categories with the hospices studied in this dissertation. Hospice A considers itself a freestanding hospice and is known as a freestanding hospice in the community. Both outsiders and people working within hospice A constantly refer to its structure as, "freestanding." Interestingly, according to the department of Health and Human Services they are licensed as a both a hospice and a home care agency because they receive home care reimbursement for some of their (palliative care) patients. While they do not consider themselves home health agency based, they are categorized as by their home health care license. Although it is unknown how they were categorized in the National Home and Hospice Survey (NHHS), it is likely that they may have been categorized, not as freestanding, but as home health agency based.

Hospice B was owned by a parent corporation that owned skilled nursing facilities and many other hospice/home care agencies. Hospice B was located in an office with a home care agency. In the NHHS, hospice B would probably have been categorized as home health agency based. They would not have been categorized as skilled nursing facility based because they were not an operating unit of a SNF, despite the fact that their ownership structure included predominantly nursing homes. This categorization fails to take into account the nature of the other organizations they were affiliated with through ownership. It also would fail to take into account the fact that they were for profit and part of a chain operation. After this research was conducted, hospice B moved into a separate office and no longer shares a space with the home care agency. One can speculate that this move may change the way their organizational structure could be categorized, despite the fact that the move did not change their relationship with the home health agency (they are still affiliated and still refer some discharge patients there). In more recent research by the NHPCO, hospice B may have been described as a "corporate division" which may have been a more accurate description of their organizational structure.

When Hospice C was first considered as a subject for this research, it was part of a large, statewide health system that was known for its hospitals. Originally it was considered to be an example of a hospital based hospice. But upon closer investigation, hospice B was found to be part of a health system that also owns a chain of hospices and home care agencies as well as some out-patient primary and acute care facilities in addition to the hospitals. Hospice C was structured in a way where the home care and hospice agencies were a single division, separate from the hospital division. Since,

hospice C is located in an office with an affiliated home care agency, it would probably be categorized by CMS as, “home health agency based,” but this categorization would fail to take into account its hospital affiliations and its chain operation. In later reports by CMS it might have been described as “health system based” which would have been a more accurate interpretation.

This qualitative examination revealed that in the case the hospices studied, hospice B and C, which would have both been categorized as chain-operations in a survey study, actually had notable differences in the magnitude and subsequent effects of those chain affiliations. Hospice C was part of a much smaller chain operations with 7 hospices, all nearby. Hospice B was part of a chain of almost 100 hospices spread across the United States. Hospice C had close relationships with the other hospices in its chain and benefited from the information and resource sharing it engaged in. Hospice B was subject to the uniformity imposed by being part of a chain operation without having the positive benefits of information sharing and support from the other hospices in the chain.

In future research on hospice organizational relationships and their affect on service delivery, findings from this study reveal other aspects of the organizational structure that should be measured. In vertically affiliated organizations, hospice should be categorized by the type of parent corporation and the other types of organizations that corporation owns. Horizontally integrated organizations should also be categorized by the type of parent corporation, the number of organizations in the chain and also by a measure of the level of information sharing and resource sharing across chain affiliated hospices.

In addition, when describing organizational structure in survey research, it would be important not only to look at the type of licensing and certification a hospice has, but also to obtain self reports from employees of the hospice to describe the organizational structure. Self report of organizational structure from within the hospice is important because, as has been shown, hospice A may look like a home health agency based hospice, but it truly should be categorized as a freestanding hospice.

In sum, the categorization of hospices based on their organizational structure is more complicated that was first considered. Previous research studies categorizing hospices have failed to take into account some of the salient aspects of organizational structure that have been shown in this study to affect organizational behavior.

II. Level of service in hospice

Describing service delivery was the second aim of this research. It is an important finding of this research that the three hospices studied provided different levels of care and different types of services to their patients. Hospice A provided the highest level of care, in many cases above and beyond the Medicare requirements. Hospice B provided the lowest level of care, often not meeting the minimum requirements of Medicare and definitely not adhering to NHPCO guidelines for nursing caseload. Hospice C was an example of an intermediate level of care. In most cases meeting the Medicare requirements but rarely surpassing them.

Part of the data collected for this research included what was called "textual data." This included any paper or electronic text that the hospice produced and made public. For example, information they put out describing their services, usually disseminated

through pamphlets and marketing materials. Information from the hospices describing their services that was published on their website was also collected. From an analysis of these marketing materials, the services described by the three hospices sound deceptively similar. A consumer perusing these materials in order to choose a hospice would not have been able to discern the differences in service delivery across the three hospices.

The in-depth qualitative case studies conducted in this research revealed differences that also would be difficult to ascertain in survey research, simply because there were often discrepancies between the administration's self report of their level of service and the actual level of service that was being provided. A survey research study that asked each hospice to self-report its services may not have found a significant difference in the services provided between the hospices. In this study, it proved to be very important to collect data about level of service through both interviews and participant observation because often times what was reported by the administrator of the hospice turned out to be inaccurate. For example, in hospice B the administrator always maintained that the nurses case loads were within to the NHPCO guidelines (8-12 patients), but when observing the nurses, this turned out to be false as their case loads were much higher.

In addition, all three hospices reported providing to patients "as much personal care as the patient needs." Observations and interviews with nursing staff subsequently showed that there were informal policies limiting the number of personal care hours available to their patients and that the number of hours available differed significantly across hospices. In addition, all three hospices reported providing bereavement services

to families for a year after the patient had died. But observations showed large discrepancies in the type and magnitude of the bereavement services available at the different hospices. The results from this research found that there were substantial differences in service delivery, especially in terms of nursing case load, number of personal care hours available, social work hours available, volunteer hours and bereavement services across hospices. A related important finding was that self report of service delivery is not an accurate measure of level of service in some hospice organizations.

Another area where the level of care differed across the three hospices was in their ability to raise a home based patient's care from the "routine care" level to the "continuous care" level, which is a level of care that is supposed to be available to home based patients. Continuous care should be provided when a hospice patient is having a crisis (usually a pain crisis or when they are actively dying) that requires at least eight hours of nursing care per day. When a patient is elevated to the "continuous care" level, the hospice receives a much higher reimbursement rate from Medicare. In hospice B and C, it was commonly reported that the hospice did not have the staff to provide the "continuous care" level to patients. Subsequently, hospice B and C patients were much less likely to be provided "continuous care" than the patients at hospice A.

A. Practical suggestions for alleviating barriers to higher levels of care in hospice

The findings from this research also suggest some recommendations for the hospice industry to alleviate some of the barriers to lower level of care. A commonly cited reason by the staff at hospice B and C as to why they provided a lower level of

personal care and why they could not provide "continuous care" was that they lacked the staffing to do so. Both hospice B and C had home health aides (HHA) on staff with their organization who they used to provide care to their patients. At hospice C they were proud of this fact and felt that the hospice trained HHAs were better equipped than HHAs who are contracted out from other agencies. Hospice A, on the other hand contracted out HHAs through other agencies.

The problem with having a finite number of HHAs on staff and having policies against contracting out with other agencies is that the hospice has less flexibility to provide more or less personal care based on the needs of the current patients. Hospice A was able to provide more continuous care because they were willing to contract out for more HHAs when they needed them. Although a hospice training its own home health aides specifically for hospice care has distinct benefits, having more home health aides available with the flexibility provided by contracting out is indispensable when trying to provide continuous care. Developing relationships with home health agencies and doing in-services and hospice training at their agencies might be a way to help the contracted home health aides be better trained to provide hospice care.

III. Profit status and profit seeking in hospice organizations

In this study, it was expected that profit status would be an important factor in determining organizational behavior. It was expected that profit seeking on the part of the for profit hospice would be related to a lower level of care. Data from this study revealed a distinction between profit status and profit seeking. This dissertation described how profit status has major symbolic meaning to hospices. Interestingly, in each hospice

studied, profit status meant different things. Data from this study showed that in hospice A, non profit status was a proxy for their altruistic intentions, for their large foundation and for their freestanding, non-corporate structure. At hospice C, non-profit status meant different things. In hospice C it was also a symbol for their altruistic intentions and foundation funds, but also for their mission for caring for the whole community. Unlike hospice A, hospice C's non profit status did not include being freestanding because they were part of a large corporate structure. At hospice B, their for profit status was seen merely as a tax status.

For the outside world, profit status is also meaningful. This study showed evidence that a hospice's profit status has an effect on their reputation in the community. Hospice B was stigmatized for their for profit status and this stigmatization was partly responsible for their failing volunteer program. Staff at hospice B felt unfairly stigmatized for their profit status and felt that outside individuals and agencies had the wrong idea about what "profit status" really meant.

Profit seeking was also an important factor that affected the care provided in the one profit seeking hospice. Hospice B's parent corporation was investor owned and made a very large profit. Hospice B was able to break even financially despite the fact that they did not have access to foundation funds. This research found that profit seeking was one of the main reasons why hospice B provided a much lower level of care than the other two hospices.

In sum, the profit status in the hospice world can be seen as a discourse. In post structuralist thought, theories have been developed that analyze culture and society in terms of sign systems and their codes and discourses (Best, 1991). Discourse theorists

argue that meaning is not simply given, but is socially constructed across a number of institutional sites and practices. For discourse theorists, an important concern of discourse theory is to analyze the institutional bases of discourse, the viewpoints and positions from which people speak, and the power relations these allow and presuppose. A discourse analysis of profit status in hospice would involve an analysis of the meaning of profit status for the different actors in the hospice industry and with the outside environment. It would conclude with a study of the power relations this discourse creates and reinforces in the hospice industry.

This study found that while profit seeking was an important factor in affecting hospice B's level of care, the lower level of care in hospice C (not a profit seeking hospice) shows that other factors are important in determining level of care. In this study, archetype method helped to reveal that, despite their differences in profit status, hospice B and C were more alike than hospice A. Instead of focusing primarily on profit status, it is important to look at the ideas and values of an organization (interpretive scheme) combined with their structures and systems to more closely understand differences in hospice organizational form and subsequent differences in service delivery.

IV. Access to resources in hospice

Not surprisingly, this research found that access to financial resources was directly related to the level of patient care in the hospices studied. Areas where the hospices differed in terms of their access to financial resources included: foundation funds and in their access to financially desirable patients.

A. Competition for the "perfect" hospice patient

An interesting finding from this study was that the different hospices tended to admit different types of patients. This was expected to a certain extend, especially with hospice A. Hospice A had a greater number of end of life care programs that were designed for people who would not fit into a typical hospice program. Thus, hospice A had a broader range of patients, including those who did not meet the hospice eligibility criteria (palliative care patients.). Because of the availability of the palliative care program, they had a longer average length of service because patients could be admitted before they would be eligible at another hospice, resulting in a longer length of service. Another finding was that hospice A admitted a greater number of "uncompensated care" patients than the other two hospices. They admitted more "uncompensated" patients because they had a greater amount of foundation funds specifically designed in part to cover these patients. But interestingly, all the hospices claimed that they were legally obligated to admit any eligible patient despite the patient's ability to pay. The difference in number of uncompensated patients raises questions about possible patient selection bias, cream skimming or patient dumping that could not be answered within the scope of this research.

An unexpected finding in terms of patient selection was Hospice C's high percentage of patient's with "debility and decline" as their primary terminal diagnosis. Data from this study were not sufficient to determine if hospice C's tendency to have patients with a diagnosis of debility and decline was due to a selection bias on the part of their hospice, a difference in diagnostic practices among their medical directors, or the result of some kind of patient selection going on in a competing hospice.

Another unexpected finding was the difference in payer type by hospice. Hospice B had a very large percentage of MediCal patients, much higher than the two other hospices. While different hospices receive different reimbursement rates from MediCal (at hospice A, Medical paid more than Medicare) at hospice B, the MediCal reimbursement was almost $50 less per day than the Medicare rate. Thus, MediCal patients were not financially advantageous for hospice B. Data from this study were not sufficient to make conclusions about why hospice B had more MediCal patents, but it was clear that they received less reimbursement for these patients.

In addition, hospice B had the highest percentage of "non-cancer" patients admitted to their hospice. Theoretically, patients with non-cancer diagnoses can be risky for hospices due to the fear that the fiscal intermediary will be more likely to deny their claims. Anecdotal evidence suggests that non-cancer patients have lower lengths of service in hospice due to the fact that their diseases are more difficult to prognosticate and they tend to be referred later in their course of illness. Despite this, hospice B tended to admit more non-cancer patients. Further evidence to suggest that (among the compensated patients) hospice B was admitting less "financially desirable" patients was that hospice B had a much lower average length of service than the other two hospices. A lower average length of service may indicate more patients who do not stay in hospice long enough for the hospice to break even financially. These findings are contrary to the stigma of "for profits" that usually characterizes for profit hospices as "cream skimming," meaning that they avoid taking less financially desirable patients. On the other hand, hospice B showed no evidence of admitting any uncompensated patients.

If for profit hospices or hospices that provide a lower level of care become a depository for "financially undesirable" hospice patients, this has serious implications for hospice patients who are not financially desirable, including people who have diseases that are difficult to establish hospice appropriateness, or patients who are very close to death. Fortunately, there are already some safeguards against this happening. Reportedly, hospices are legally bound not to turn away patients based on financial desirability. Unfortunately, patients who are marginally hospice appropriate are not well covered by this safeguard. While hospices are legally bound to admit all patients, they are also legally bound not to admit patients who are not hospice appropriate. Ambiguously hospice appropriate patients would be most at risk for "patient dumping" because they can legally be denied admission to a hospice based on their lack of hospice appropriateness. The quasi-hospice programs developed by some hospices like hospice A are another step that has been taken that could act to temper this kind of patient dumping. Despite this, patient dumping or cream skimming in hospice is an area that needs future research.

B. Access to financial resources

This study found that increased access to private financial contributions was directly associated with a higher level of care in the hospices studied. The non-profit hospices studied had access to foundation funds that helped them meet the costs of caring for patients. The for- profit hospice did not have access to those funds, and despite this, they were not operating at a loss as the non-profits would have been if they had not had

foundation funds. Data from this study showed that the lower the access to private foundation funds, the lower the level of care in each of the hospices studied.

It could be argued that hospice B did have access to a great deal of financial resources due to the large profit accrued by its parent corporation that year. Unfortunately, in a profit seeking corporation such as the one that owned hospice B, an agency that does not make a profit is seen as a failed agency. An organization that is part of that parent corporation that does not achieve a profit would likely be put out of business. Thus, the staff of a for-profit hospice likely would be prevented by its corporate policies (and out of fear of losing their jobs) from providing a higher level of care.

V. The problem of asymmetrical information

As was presented in the findings chapter, one problem in the hospice industry, probably because it is a relatively new form of care, is that there is asymmetrical access to information about what to expect from a hospice organization. Among the general public there tends to be a lack of understanding about what type of services to expect. In certain cases where hospices provide a lower level of care than required by Medicare, you would expect to see more consumer complaints filed at the state regulatory and accreditation agencies. In addition, hospice staff reported inaccurate expectations from consumers in the opposite direction. There were many instances where hospice staff in interviews complained that certain patients had unrealistic expectations of constant 24-hour nursing care that would have been impossible for the hospice to provide.

Even more troubling for the hospice industry is the asymmetrical information between hospice administration and hospice staff about the level of care that can be

expected in hospices. Because hospice staff usually receive only "on the job" training in hospice care, they are at the mercy of their own administration to learn about the regulatory requirements of hospice. For example, in the case of personal care, hospices are required to provide "as much personal care as the patient needs." This means that it is illegal to have policies restricting the amount of care to a few hours a week. In hospice B, it is likely that the administrator knew this, which was probably why she denied the existence of such policies when she was interviewed for this study. The staff of hospice B, on the other hand, did not realize that these limitations on personal care were not universal. As a result, they openly reported these "unwritten" policies during interviews. Usually the main requirements that hospice staff are aware of are the ones that they have to document in the charts. They are less aware of things like NHPCO guidelines that are not enforced, but which give an idea of the level of care that can reasonably be expected by a hospice organization.

If hospice staff, especially RN case managers were better educated about the regulations and guidelines for hospice, they would be better able to advocate for their patients in providing adequate levels of care. As has been discussed, almost every hospice RN interviewed for this study described her reasons for becoming a hospice nurse as a "calling" or a personal mission to relieve the suffering of the dying. Keeping hospice staff in the dark about requirements and guidelines can have the effect of preventing hospice nurses from being the patient advocates that they have the potential to be.

Findings from this study about the asymmetrical access to information (between both administrators and consumers and between administrators and staff) suggest some recommendations for further education of consumers and hospice staff. The first recommendation is to provide more consumer information databases available either in hard copy or online. Brides to be can buy guides rating different wedding venues, and the parents of toddlers can purchase comprehensive guides describing different preschools; but the families of dying patients cannot currently find any such ratings or descriptions of hospice organizations. As has been shown, due in part to asymmetrical access to information, the number of complaints filed by consumers about hospices did not correlate with the level of care provided in these organizations. Websites such as those that are currently available for nursing homes in California (www.calnhs.org) describing organizational characteristics and levels of deficiencies for different nursing homes need to be created for hospice organizations. Guides for consumers comparing hospice organizations should include not only the deficiencies and complaints on file with state regulatory agencies, but they should include detailed descriptions of the level of care and types of services provided by each hospice. Since the process of selecting hospice organization is usually occurring at a time of intense crisis for families, a guide of this sort should be available for consumers to provide easy quick ways to compare different hospices in their community.

A second recommendation to alleviate the asymmetrical access to information would be to develop a required training program for hospice staff, educating hospice staff about the exact requirements for hospice including the requirements for the other disciplines. This training should be provided by an outside agency to make sure that there is no incentive to bias the training. Descriptions should be given to staff of "ideal" hospice programs that exist as examples of what it is possible for a hospice to provide.

This way, hospice nurses and social workers would know what is possible to expect from their hospice and quality could be driven from that level. If hospice nurses and staff knew what hospices "should" be doing, this would also empower the hospice staff with the information to adequately advocate for their patients.

VI. New archetype in the field of hospice care

There is a sense among hospice workers that hospice care is fundamentally changing and that the changes are not good. Predictions of this change were first made in the early 1980's when critics of the hospice Medicare benefit theorized about how government regulation and affiliations with mainstream medical organizations would cause a "stripped down" effect on hospice care. Currently, the feelings of many hospice workers can be characterized as a sense of dread that hospice is changing for the worse. This sense of dread is often manifested in a disdain of "for profit" hospice care.

This study used the archetype method in a preliminary examination of whether one or more new archetype might be emerging in the field of hospice care. This study found evidence of two different archetypes existing in the one county studied. Hospice A was found to be a modified traditional hospice archetype; similar to the early hospice archetype, and hospice B and C were found to represent a new hybrid archetype which was distinctly different from the traditional archetype but which lacked consensus enough to be considered a fully new archetype.

In the 30 plus years of the existence of hospice care, it would be expected that the interpretive schemes and structures and systems of hospice care would change somewhat. Of the three hospices studied, hospice A is the most similar to the traditional hospice

archetype. Although there are now some differences due to the regulation by government entities as well as an expansion of the types of patients and services provided, hospice A is considered a modified traditional hospice archetype.

A good example of how the interpretive scheme drives the structure of the organization was at hospice A. Because of their organizational goals and values, the organization created new services to meet the needs of their patients. Most of the extra hospice or quasi-hospice programs at hospice A were ideas that were first manifested among the staff. Those ideas were then brought to the administrator who subsequently presented the ideas to the board of directors. Thus, at hospice A, values about serving patients who are close to the end of life but are not "hospice appropriate" produced an enhanced structure of services at that hospice.

Hospice B and C, while still retaining some elements of the traditional hospice archetype, have an interpretive scheme as well as structures and systems that are divergent enough from the original hospice archetype that they can be considered a new hybrid archetype. Using both the archetype design method as well as the sociology of knowledge approach, the findings showed that in hospice B and C their goals included cost cutting and in hospice B, profit motive. These goals of hospice B and C are sufficiently different from the interpretive scheme of hospice A and the traditional hospice archetype to be considered a different design archetype.

In terms of the method of operation, hospice B and C valued a strict adherence to the Medicare regulations that included prioritizing the measuring of hospice appropriateness as one of the primary tasks of the staff, thus distinguishing it from hospice A and the traditional hospice archetype. The evaluation criteria for the three hospices also differed and provided further evidence that this study has revealed a new hybrid archetype. In hospice B and C, while quality of care was determined first and foremost by the satisfaction of the staff, family and patient as well as by the outcomes of government inspections; they also used measures of cost cutting to measure their success. At hospice C especially, monetary values of monthly pharmaceutical bills and patient care costs were routinely presented to the staff to show whether or not they had been successful in their work. This was not a measure of success either in the traditional hospice archetype or the modified traditional archetype (hospice A).

Another factor that helped to determine that the archetype of hospice B and C was a hybrid type rather than a new type was the lack of consensus between staff and administration in terms of the interpretive scheme. This was especially apparent in hospice C in terms of the evaluation criteria. The administration at hospice C and to a lesser extent, hospice B prioritized increased productivities as a main goal of care that they imposed on the staff. While staff tended to buy into the notion that cost cutting was a goal of care, they were not happy about the productivity standards set by the administration. At hospice B the administration imposed increased productivity on the staff by increasing caseloads to very high levels. Thus, hospice B's push for productivity was to a certain extent, covert. At hospice C, the administration enforced increased productivity through overt productivity standards. These standards, which required a certain number of visits per day by nurses and social workers caused a great deal of animosity on the part of the staff toward the higher administration.

This lack of consensus in terms of the interpretive scheme at hospice B and C leads to the conclusion that hospice B and C constituted a hybrid archetype. Hybrid archetypes are unstable forms. The existence of a hybrid archetype in an organizational field suggests that organizational change is beginning in that field, but that a total transformation, or a totally new archetype has not yet fully formed. Hybrid archetypes can exist for short period of time, but it is safe to assume that the organization is being pulled in different directions and over time, will continue to evolve in one direction or another. Data from this study allows the author to make the prediction that over time, hospice B and C will become more like mainstream health care with goals of cost cutting and increased productivity subsuming the aspects of the interpretive scheme of the traditional hospice archetype.

Both the archetype design method and sociology of knowledge approach were useful for examining the level of consensus in each organization in terms of its goals and organizational mission. The archetype design method revealed some differences in methods self evaluation between the staff and administration of hospice C. The sociology of knowledge approach helped to understand how the different social settings, especially the difference in location of authority produced different "hospice knowledges" in the staff than they did in the administration. Using the sociology of knowledge approach to augment the design archetype method can be seen as a contribution to the theoretical framework of this dissertation. The archetype design method can be limited to one direction of the relationship between ideas and organizational structure and the sociology of knowledge approach allows for an analysis of the mutual construction of these elements.

Using the combined approach, a larger study of hospice organizations and their interpretive schemes would be useful to confirm the emergence of a new hybrid archetype in the organizational field of hospice care. In addition, this study only looked at one county in California. A study of hospices in a larger geographic region might reveal new archetypes or other hybrid archetypes that may be emerging in the field of hospice care in the United States.

VII. Location of authority

Finally, the location of authority, or whether the administration is on or off site is an important variable to look at when trying to understand hospice behavior. This aspect of organizational structure was found to be the main variable related to differences between staff and administration and was the reason why certain organizations lacked consensus between the two levels. The main areas where hospice C lacked consensus between staff and administration were goals and self-evaluation. The sociology of knowledge approach showed that, in hospice C, the social structure which separated the higher administration from the everyday work of the hospice caused the higher administration to receive different information about the hospice work practices. The higher administration thus, had different goals for the hospice staff than they had for themselves. They evaluated the hospice staff's success in different ways, based on quantifiable data; while the hospice staff were evaluating their own performances based on data accrued from their interactions with their patients.

This study showed that the location of authority in a hospice can give insight into the level of cohesiveness and consensus throughout the organization when it comes to the organizational goals and mission. Off site administration have a different view of the organization than the people who work in closer contact with the staff. This results in different ideas about performance, work practices, and reasonableness of goals. Off site administration are also probably more likely to be administering other non-hospice services such as home health care and thus, the possibility for contamination of the hospice mission is more likely. The issue of location of authority is something that has only been studied minimally in health care organizations and the findings from this study show that it is an organizational structural factor that should be looked at in future research on hospice.

VIII. Limitations of study and areas for future research

This study had many limitations and elucidating those limitations helps to identify areas for future research. The first limitation of this study was the study sample. The three hospices in this study did not represent all of the organizational forms that exist in the hospice industry. Most obviously, this sample did not include a traditional hospital-based hospice. It would have been interesting to see how a hospice that operated as a unit of a hospital would have been affected by that close affiliation. Data from this study show that geographic location of authority and close affiliations with non-hospice health care organizations did impact the level of care in some of the hospices studied. Thus it would have been useful to see how these relationships played out in a hospital/hospice organization.

This research showed that even among the hospices that might be categorized similarly in research, there were still significant differences in their organizational structure. This points to the assumption that there are probably many types of variations on organizational form that are not represented in this study. With such variation in the three hospices included in this sample, future research on a larger sample of hospices would probably reveal many, many more organizational forms with distinct consequences for hospice service delivery.

Another limitation in this study was access to accurate financial information and patient demographics from the hospices. Each hospice was willing to provide a different level of detail about their hospice's finances and patient mix. This resulted in some cases of incomparable data across hospices. Examples of this were: hospice C could not provide financial information at the branch level or a breakdown of foundation fund use. Also, hospice B was not able to provide information about private insurance income. There were two reasons the disparity in data received. First, the different hospices kept track of financial information and patient demographic information differently. Sometimes one hospice was simply unable to provide figures that another hospice did provide because they did not organize the information in the same way. Other times it would have taken a large amount of time and manpower to provide the researcher with the information, a donation of time that the hospice was not willing to make.

Another reason for incomparable data was simply unwillingness to provide the financial or patient mix information. For example, hospice B was a for-profit organization and was not required by law to provide audited financial records to the public as is required by non-profit organizations. Hospice B, knowing that they would probably be compared with non-profit organizations and understanding the stigma of profit seeking in hospice, refused to provide information on the amount of profit accrued by their individual branch.

In addition, it is well known that there are many ways to report financial data and a corporation's financial data can be biased depending on whether or not it benefits the corporation to show a profit or a loss. Many of the financial figures used in the financial analysis for hospice B were figures taken from materials intended for potential investors. The financial figures for hospice C were in part taken from materials intended for potential contributors. As you might imagine, hospice B financial data was probably biased toward exaggerating profits as much as possible to impress future investors, whereas hospice C data was probably biased towards minimizing the appearance of profits in order to prove their need to potential contributors.

In sum, the financial data used in the economic analysis of the hospices studied, while it provided a framework for general comparisons across hospices, was not accurate or comparable enough to sustain a more in depth economic analysis

There are three different research studies that could be proposed as a result of the findings from this dissertation research. First, a large-scale survey study of organizational structure and service delivery in hospices in the US would be recommended. This study revealed both suggestions for better ways of categorizing hospice organizational forms and better ways of measuring service delivery in hospice organizations. A large study combining the results of the first and second aim of this research would be a useful first step in comparing organizational structure and service delivery. Lessons learned from this research about how to more accurately categorize hospice organizations combined with this study's results pertaining to better ways of measuring service delivery as a proxy for quality would be a good framework for a large scale study of hospice organizations in the US.

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The first aim of this proposed research would be to measure aspects of organizational structure in a large sample of hospices in order to find definitive and comprehensive categorizations of organizational forms of hospice. In this proposed study, many aspects of hospice organizational relationships that were revealed as important by this research should be measured. In vertically affiliated organizations, hospice should be categorized by the type of parent corporation and the other types of organizations that corporation owns. Horizontally integrated organizations should also be categorized by the type of parent corporation, the number of organizations in the chain and also by a measure of the level of information sharing and resource sharing across chain affiliated hospices.

In addition, when describing organizational structure, it would be important not only to look at the type of licensing and certification a hospice has, but also to obtain self-reports from employees of the hospice to describe the organizational structure. Self report of organizational structure from within the hospice is important because, as has been shown, hospice A may look like a home health agency based hospice, but it truly should be categorized as a freestanding hospice.

Once the categories of different organizational forms of hospice are established, data collected on quality of care and service delivery could then be compared across organizational forms. Measuring quality outcomes in hospice organizations where patients get sicker and die as a normal course has been difficult. It is ironic that one of the main outcomes used in studies of quality in health care organizations are mortality rates. Obviously, it is not possible to measure quality by looking at mortality rates in hospice. The NHPCO National Data Set (2001) measured quality in hospices by looking at outcomes reported by family members after the patient had died. The outcomes they measured were: percent of patients comfortable within 48 hours; unwanted hospitalizations, unwanted resuscitation, increased confidence in safe care, effective pre-death emotional support, effective post death emotional support, and the family's willingness to recommend the hospice (NHPCO, 2003). Other studies in the past have also focused on family satisfaction, symptom control, and length of stay to measure quality in hospice organizations. While these are all important variables, findings from this study show that detailed measurements of the level of care can also an important aspect of measuring quality of care in hospice organizations.

In this study, hospice staff and administration were asked how they measured their own success, in part as an effort to obtain some insight from within the hospice industry about other ways to measure quality in hospice organizations. One main way that hospice workers in this study measured their own success included: the degree of patient satisfaction, not just after care, but continually assessed throughout the course of care. Similar to the research studies, hospice staff also measured success by looking at the level of symptom control achieved, especially pain control in patients. They also considered the level of "family resolution," indicating a sense of acceptance of or preparedness for the patient's death on the part of the family. Another measure of success or quality of care on the part of hospice staff was whether or not the patient engaged in "anti-hospice behavior" such as calling 911 or going to the hospital. To the hospice nurse, seeking curative treatment was often considered a failure of the hospice team to adequately do their jobs. One of the most significant findings was that length of service was not considered to be an important variable in measuring quality of care by the

hospice staff. While length of service was important to the administration of some of the hospices because it indicated the level of financial liability the patient represented to the hospice, to nurses, this was not an important measure of quality. To the nurses, length of service was a matter that was out of their control. To them it was a measure of the level of acceptance of hospice care by the physicians in the community. Shorter lengths of service meant that the doctors in the community were having trouble "letting go" of their patients.

While staff satisfaction was not measured quantitatively in this study, data from this study suggest that the level of staff satisfaction was related to the level of care provided by the hospice. In the simplest sense, hospice staff who had the time and resources to provide a higher level of care to patients were more satisfied with their jobs. Conversely, hospice staff who felt they were prevented from providing the care they wanted to provide tended to be less satisfied with their jobs. One commonality in almost every interview with hospice staff conducted in this study was the revelation that the staff member was "called" to hospice work out of a sense of personal or spiritual mission. Most staff had had some previous experience with hospice, usually they had a loved one who died under the care of hospice, and after that experience decided to dedicate themselves to providing care to the dying. Because of this sense of "calling," it makes sense that staff who feel prevented from providing the care they want to provide would have a lower sense of job satisfaction. There were very different levels of job satisfaction among the staff of the three different hospices. Interestingly, the nurses who were happiest with their jobs (at hospice A) were also the lowest paid of all the nurses in any of the hospices. Findings from this study suggest that measures of job satisfaction among staff could, in part reveal aspects of the quality of care that was being provided in a hospice. While many hospice staff interviewed did not have an understanding of how their organization's level of care compared to the other hospices in the community, or how it compared to the Medicare regulations, the staff who worked in the hospices with the lower levels of care did have a lower sense of job satisfaction that was directly related to the frustration they felt about the inadequacy of the level of care provided at their hospice.

In addition to the aforementioned measures of quality of care, the current research has shown that level of service can be an important indicator of quality. In the small sample of hospices in the current research, there was a wide disparity in the level of service provided just among the three hospices. This points to an assumption that among a larger sample, there would probably be large differences, both regional differences and differences based on organizational form in the services delivered in hospice.

There are a number of variables that could be measured to determine the level of service in a large survey of hospices including: number of hours of nursing care, personal care, and social work time per patient per week; nursing case load with measures of acuity of the patients. Service delivery can also be measured by examining the level of bereavement services: number and type of support groups administered by the hospice, availability of bereavement volunteers, and whether the bereavement coordinator makes contact with patients before their death (a measure of including anticipatory grief as a part of the bereavement services). The volunteer program should also be examined to determine the level of service at a hospice. Comparisons of the number active volunteers, and volunteer time per patient would be important to measure this variable.

Another area that would be important to measure in this proposed study are financial. It would be important not only to classify hospices by their profit status or profit seeking, it would also be important to measure a hospices access to financial resources through foundation funds. In a study attempting to determine factors affecting quality or level of care, it would be important to measure level of foundation funds available to a hospice. Looking at foundation funding as "dollars per patient" or "dollars per patient day" are good ways to measure foundation funding across hospices. In addition to level of foundation funds, it would also be useful to look at the way the foundation funds were spent, if there were designated uses for those funds, and what the policies were about the use of those funds. This would give insight in to the level of freedom hospice staff have to use those funds in innovative ways for patient care.

Also, it would be interesting to look at the geographic location of authority in a large scale study. It was shown in the current research that the proximity of authority may have an impact on an organization's ability to innovate. It would be interesting to follow up on this in a large-scale survey study to see if the geographic location of authority had an impact on the level of service in hospice organizations.

Finally, measures of staff to patient ratio are relevant when looking at the level of service delivery as a proxy for measuring quality of care in hospice organizations. In terms of collecting data, it would be important to conduct some site visits to make sure that the information being reported by administrators or company spokespeople is accurate. Furthermore, collecting data from two separate informants within the same organization would be a better way to make sure that data on level of service delivery was accurately reported.

In sum, a large scale, nationwide survey of hospices employing the measures of organizational structure suggested by this research as well as measures of quality of care and level of service would be a logical next step in an examination of the relationship between organizational structure and service delivery in hospice care.

Another small-scale study that would follow this research would be a qualitative study looking at patient selection and patient referral in one geographic region. There was much evidence in this research that the different hospices tended to care for different types of patients, but it was out of the scope of this research to understand the processes by which these different patient mix came into being. The purpose of this proposed study would be to understand the processes by which patient selection or cream skimming in hospice are possible and to develop more effective safeguards to prevent this.

The difference in access to "financially desirable" hospice patients found in the current research show that patient selection was occurring. To understand potential patient selection issues including "cream skimming" or "patient dumping," a research study that tracks hospice patients in a particular market, examining trends in the types of patients certain hospices tend to admit would be useful. This research would have to examine the charts of discharged patients, and follow them to see if they were subsequently admitted to another hospice. In addition, a more difficult task would be to examine admission refusals at hospices to determine if certain hospices had a self imposed selection bias. Another aspect of this proposed study to help understand more about patient selection in hospice would be a study of referring agents such as physicians, and discharge planners in one community. Interviews with these referring agents about their hospice referral practices might reveal interesting data about why certain patients get referred to certain hospices, and what aspects of a hospice are important to referring agents when making decisions about hospice referral. Research aimed at understanding how unfair patient selection occurs in hospices would also be a first step in creating more effective safeguards to prevent this practice.

Finally, a third study that would naturally progress from this research would be a larger study of the emergence of new archetypes in the organizational field of hospice care. A larger sample of hospices, possibly including hospices in many states would be required to determine more conclusively whether or not the hybrid archetype identified by this research is truly a representative of the organizational change occurring in the field of hospice care in the United States. A larger scale study where site visits were conducted to measure the interpretive scheme's of many hospices in the United States could possibly reveal one or more new archetypes emerging in the US. A study of this type would be effective in providing an answer to the predictions of the early 1980's about how hospices would change after the implementation of the Medicare benefit and would provide a clear picture of the process of organizational change in the field of hospice care in the US.

IX. Conclusion/Grand Summary

This research was designed to examine aspects of organizational structure and service delivery in a sample of hospices in one county in California. While the study had many limitations characteristic of small-scale qualitative studies, it did produce some useful findings and areas for future research. This study found that there are aspects of organizational structure that have important effects on service delivery that are not commonly looked at in other studies of hospice behavior. Aspects of organizational relationships such as vertical and horizontal integrations were important structural variables that impacted both the ideas and the service delivery in the hospices studied. The geographic location of authority was found to be related to certain constraints on innovation in one of the hospices. Profit seeking was shown to be related to a lower level of care, but it was also shown that profit status alone is not enough to determine whether or not a hospice is providing adequate care. In this study, a non-profit hospice was shown to act very similarly to a for profit hospice mostly because of its organizational relationships and large corporate structure. The findings from this study show that non-profit status can be misleading as an indicator of level of care.

After weeks of in-depth participant observation research and interviews at each of the three hospices, this study found that the freestanding, independent nature of hospice A, in addition to its increased access to foundation resources, were the two main factors associated with its higher level of care for patients and higher job satisfaction among its staff.

Finally, data from this research on the underlying values and beliefs in each hospice that underpin the organizational structure found evidence of organizational change occurring in the field of hospice care. Data from this study suggest that one or more new archetypes may be emerging in the field of hospice care and that further research is needed to fully understand the extent and magnitude of this change at the organizational field level.

References for Chapter Five

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APPENDIX A.

Hospice Administrator Initial Interview

1) I'd like to start by having you tell me a little bit about your training, background, and how you came to work for hospice. Have you worked for any other hospice organizations?

2) Can you tell me about the origins of this hospice organization? How long has it existed?

3) I need to get a list of the contracts and affiliations you have with outside organizations, how do these affiliations affect the way you select patients/care for patients? SNF contracts especially?

4) Who are your principle competitors in terms of other hospices or other health care organizations? How does this organization deal with competition?

5) Where do you get most of your patients? How do you get referrals?

6) Have you had any changes in your census or length of stay in the last few years? If so, is there an explanation for this? What does LOS measure exactly?

7) This organization has just experienced a change in ownership. How has this changed the way you work here? Are there new incentives or constraints placed on the work here? New emphases?

Service delivery/ hospice knowledge

8) Does your hospice have a mission statement/philosophy? Describe it.

9) Describe "hospice care" as you see it. What is the unit of care? What services do you provide?

10) Are there any areas where you put limits on certain treatments or medications? What is your philosophy about IV fluids? Are there other controversial treatments in hospice?

11) I have heard the term "hospice appropriate" used here. How do you go about deciding whether someone is hospice appropriate?

12) Are there certain diagnoses or situations in which it is more difficult to establish hospice appropriateness? General debility? COPD? CHF?

13) How do you measure quality of care here?

14) Describe “success” in your mission to care for dying patients.

15) Are there times when you are not successful? What are some of the reasons why that occurs?

16) Are their services which you wish you could provide but cannot? Can you give me an example of a particular patient who you could not care for the way you wished you could? Please describe why not.

17) Is the way you provide care for dying patients in any way different than other hospice organizations?

18) I hear people using the phrase, “good death.” What does that phrase mean to you?

19) Is a good death possible for every patient or are there some conditions that preclude a good death?

Financing

20) Please tell me about the different ways this hospice if reimbursed. Medicare? Medical? Private insurance? PPO? Any HMO reimbursement?

21) How do different payers affect the care you provide for patients?

22) How do Medicare regulations affect the work that is done here?

23) How have the Medicare guidelines affected the way you select patients/care for patients? What are some of the main things you have to do to show compliance with Medicare guidelines?

24) What are some other entities outside of this hospice that affect what you do here? Fiscal Intermediary? HCFA? In what way do they affect what you do, both positively and negatively?

25) If you were here during operation restore trust, how did that affect the work that is done here?

Hospice Staff

26) How are your staff trained? What % trained outside of hospice?

27) Do you have any special programs to support staff for bereavement?

28) What are the educational and training criteria for employment in this hospice. For nurses? Social workers? Etc.

29) What is the usual caseload for a nurse or social worker who works in this hospice?

30) What are the staff to client ratios?

31) Tell me about the turn over rate of staff here. How does that compare to other hospices.

32) Can you tell me about your philosophy as a manager?

33) I am interested in the workings of the interdisciplinary team

APPENDIX B

Staff Interview Schedule

Date ___________

Current census___________

Position________________

Background/Goals of hospice

1) Please tell me a little bit about your training. What is your educational background? Where did you work before coming to work for this hospice?

2) How did you come to work for this hospice? What made you want to work for hospice?

3) Tell me about the kind of work you perform here? What are your goals in caring for patients?

4) How would you describe "hospice care" to a patient? What is the unit of care? What services do you provide?

5) Is the way you provide care for dying patients in any way different than other hospice organizations?

6) How is being a nurse/social worker for hospice different than being a RN/MSW elsewhere?

Self evaluation

7) How do you measure quality of care? Describe "success" in caring for dying patients.

8) Are there times when you are not successful? What are some of the reasons why that occurred?

9) How do you measure success for the organization as a whole?

10) I hear people using the phrase 'good death,' tell me more about what this phrase means.

11) Is a good death possible for every patient or are there some conditions that preclude a good death? If a patient's death is not described as good, does this mean that hospice has not done its job?

12) I hear people talking a lot about whether or not someone is hospice appropriate. Tell me about the criteria for whether someone is hospice appropriate.

Constraints

13) Are their services which you wish you could provide but cannot? Can you give me an example of a particular patient who you could not care for the way you wished you could?

14) I know there are some controversial treatments in hospice care. Describe some of those. What is your philosophy about IV fluids? Other controversial treatments?

15) What do you do if someone needs a treatment that is not allowed by hospice? Calling 911? Going to the hospital? Wants a "curative treatment"?

16) Under what circumstances do you have to discharge a patient? How is that handled?

17) Do you ever have to pay attention to the financing of hospice care? Does that ever change the care you provide?

18) Describe the "hospice philosophy" as you see it? Many people theorized in the early '80s that the Medicare regulation of hospice would somehow erode the traditional hospice philosophy. 20 years later, do you believe this has happened?

19) Are their certain regulations, either from Medicare or the state that affect the work you do here? Describe these and their affects on your work?

20) What are some positive and negative affects of the Medicare regulations?

Authority

21) Is there a single person or a group of people here who are in charge, or are leaders of this organization, either officially or unofficially?

22) How much do you hear from your parent organization about how to do things?

23) How much control do you have over the care of your patients? If there are disagreements over care protocols, how are these resolved within the team?

Affiliations

24) Do you ever have to work with organizations or individuals outside of hospice? SNFs? Acute care hospitals? Tell me about those organizations and how it is working with them?

25) Do you provide care to patients in skilled nursing facilities? How can that be different than caring for patients at home? In what ways is it easier? What are the challenges that arise?

26) Tell me about the new owners of this hospice. What kind of changes have they made?

Staff Support

27) What is your case load like here?

28) What hours do you work?

29) What is done to support the staff in their own bereavement here?

30) How do wages and benefits here compare to other hospice organizations?

31) People talk a lot about burnout for hospice workers? Is that a problem here? What is done to prevent burnout?

Services

32) How many hours a week/month are you required to see a patient?
33) Do you meet or exceed those requirements?
34) How many home health aide hours do patients typically receive here?
35) Do you have your own home health aides or do you contract out?

APPENDIX C

Administrator consent form

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO AND
THE VETERANS AFFAIRS MEDICAL CENTER
CONSENT TO BE A RESEARCH SUBJECT

Organizational Structure and Service Delivery in Hospice Organizations

A. PURPOSE AND BACKGROUND

Carrie Graham, MGS and Charlene Harrington, Ph.D are conducting a qualitative research study of hospice organizational structure, regulation, and financing and how these affect the delivery of services in certain hospice organizations. Your hospice has been selected as a possible case study site because it represents one of the major organizational forms found in the field of hospice care.

B. PROCEDURES

If you agree to be in the study, the following will occur:

1. You, the administrator/director of this organization, will be interviewed by Carrie Graham about your views on hospice care, your background, and your experiences working in this hospice organization. You will also be asked about the history of this hospice organization, and will be asked to describe details of the organizational structure and financing. The interview will last approximately 60 and will be scheduled for a time and location that is convenient for you. The interview will be tape recorded.

2. Employees of your organization will be given an information sheet describing this research. They will be informed that the researchers may approach them and ask them to be interviewed. When an employee agrees to be interviewed, the content of their interviews will remain confidential and will not be shared with any other individual including the hospice administrator or other hospice employees.

3. Carrie Graham will spend approximately 4 weeks observing the daily work practices of your organization. She will ask to observe during staff meetings, case conferences, staff training sessions, and other employee meetings. She will take notes during these observations.

4. Carrie Graham will accompany certain consenting employees on their daily visits to patients. This will be done only after the employee has given verbal consent and the patient and/or patient's family has given consent. Carrie Graham will follow your organizations procedures for obtaining consent from patients to observe their hospice care.

5. Carrie Graham will collect textual information from your hospice organization including: advertisements, pamphlets, training materials, and any other textual material describing the workings of the organization that are given to her by employees of this organization.

C. RISKS/DISCOMFORTS

1. Some of the interview questions may make you uncomfortable or upset, but you are free to decline to answer any questions you do not wish to answer or to discontinue the interview at any time.

2. The presence of an observer may make you or your employees uncomfortable or upset, but you or your employees are free to ask the researcher to discontinue observation at any time.

3. The presence of an observer may make your patients uncomfortable or upset, but the patient, family member or hospice worker is free to ask the researcher to discontinue observation at any time.

4. *Confidentiality:* Participation in research will involve a loss of privacy; however, your participation will be handled as confidentially as possible. The identity of your hospice organization, employees and patients will be kept confidential. Interviews and fieldnotes from this research will be kept in a locked file cabinet for the duration of the research study. Only Carrie Graham will have access to the transcribed interview and fieldnotes. After the completion of the research, all materials will be destroyed. Something you or an employee said during an interview or observation may be quoted verbatim in a publication resulting from this research. No individual identities will be used in any reports or publications that may result from this study. Efforts will be made to change the identities of any organization described or person quoted in a publication resulting from this research. However, the researcher cannot fully guarantee that the identity of your organization will not be ascertained by someone who reads a publication resulting from this study.

D. BENEFITS

There will be no direct benefit to you from participating in this study. However, the information that you provide may help health professionals and consumers better understand how organizational structure, regulations and financing affect the care provided in hospice organizations.

E. COSTS

There will be no direct costs to you as a result of taking part in this study. There may be indirect costs to your organization because the presence of a researcher may be inconvenient and may hamper work efficiency.

F. PAYMENT

You will not be paid for your participation in this study.

G. QUESTIONS

You have talked to Carrie Graham about this study and have had your questions answered. If you have further questions, you may call her at (510) 845-7990

If you have any comments or concerns about participation in this study, you should first talk with the researchers. If for some reason you do not wish to do this, you may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. You may reach the committee office between 8:00 and 5:00, Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco/San Francisco, CA 94143.

H. CONSENT

You will be given a copy of this consent form to keep. PARTICIPATION IN RESEARCH IS VOLUNTARY. You are free to decline to be in this study, or to withdraw from it at any point.

If you agree to participate you should sign below.

Date	Signature of Study Participant
Date	Signature of Person Obtaining Consent

APPENDIX D.

Research Information Sheet

Organizational structure, financing and regulation of Hospice care

Study Aims

Carrie Graham, MGS is conducting a research study of hospice organizational structure, regulation, and financing and how these affect the delivery of services in hospice organizations. The administrator of this hospice has generously granted approval for Carrie Graham to conduct research in this organization. This is one out 3 hospices which she will study for her dissertation. The aim of this research is twofold. First, this research aims to simply describe some of the incentives and constraints felt in different types of hospices due to organizational, regulatory or financial factors. For example, this research will look at the differences between a freestanding and hospital based hospice in terms of the financial incentives they feel. The second aim of this research is to look at how employees of each type of hospice organizations negotiate the pressures they feel and the subsequent consequences for the delivery of services in hospice organizations. For example, this research will look at how regulations such as those required by Medicare, or an affiliation with a hospital or nursing home might impact the way things work in the organization.

Study Procedures

The research method for this study is called "participant observation." For approximately 3 months Carrie Graham will be making observations of the everyday work practices of the hospice organization. This will include sitting in on staff meetings, case conferences, and training sessions whenever possible. When a staff member consents, the researcher would like to accompany them during their work day. While the researcher will ask occasional questions, she will try to be as unobtrusive as possible. Carrie Graham will also conduct one-on-one interviews with staff members about their views on hospice care and their experiences working in this organization. If you have worked in this organization for over six months, you may be asked to be interviewed. These interviews can be scheduled at your convenience.

PARTICIPATION IN THIS RESEARCH IS VOLUNTARY. You are not required by your employer to participate in this research. Any staff member can refuse to be interviewed or observed at any time. If you agree to be interviewed, you will be asked to read and sign a consent form. During the interview, you can refuse to answer any question or can discontinue the interview at any time. If you agree to let the researcher accompany you during your work day, you can ask the researcher to cease her observations at any time.

Risks/ Confidentiality

Participation in this research will involve a loss of privacy; however, your participation will be handled as confidentially as possible. The identities of individuals and organizations will be changed in any reports or publications that may result from this study. Your decision to participate in this research will not be shared with your employer or co-workers. However, the researchers cannot guarantee that others will not find out about your participation in this research. Something you say in an interview or while you are being observed may be quoted in a publication. While every effort will be made to hide your identity, there is some risk that someone who reads a publication resulting from this research may ascertain your identity.

Benefits

There will be no direct benefit to you from participating in this study. However, the information that you provide may help health professionals and consumers better understand how organizational structure, regulations and financing affect the care provided in hospice organizations.

About the Researcher

Carrie Graham is a doctoral student in Medical Sociology at the University of California, San Francisco. After finishing a masters degree in Gerontological Studies, she worked for two years on a research study of quality of life for seriously ill older adults. After enrolling in the doctoral program, she began studying end of life care. She has participated in studies end of life care in nursing homes, pain management at the end of life, and palliative care consulting teams. Her dissertation research on hospice organizational structure will help her complete her Ph.D. This research is being overseen by Carrie's advisor, Charlene Harrington, Ph.D., a full professor of Sociology and a Registered Nurse at UCSF.

Questions and Concerns

If you have further questions, you may call Carrie Graham at (510) 845-7990 or Charlene Harrington at (415) 476-3040. If you have any comments or concerns about participation in this study, you should first talk with the researcher. If for some reason you do not wish to do this, you may contact the UCSF Committee on Human Research, which is concerned with the protection of volunteers in research projects. You may reach the committee office between 8:00 and 5:00, Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco/San Francisco, CA 94143.

APPENDIX E.

Staff consent to be interviewed

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO AND
THE VETERANS AFFAIRS MEDICAL CENTER
CONSENT TO BE A RESEARCH SUBJECT

Organizational Structure and Service Delivery in Hospice Organizations

I. PURPOSE AND BACKGROUND

Carrie Graham, MGS and Charlene Harrington, Ph.D are conducting a research study of hospice organizational structure, regulation, and financing and how these affect the delivery of services in hospice organizations. The administrator of this hospice has agreed to allow the aforementioned researchers to conduct a case study of this organization. Part of this case study involves interviews with the employees of this organization. You are being asked to participate in this study because you have been an employee of this organization for at least six months. You are not required by your employer to participate in this research study.

J. PROCEDURES

If you agree to be in the study, the following will occur:

6. You will be interviewed by Carrie Graham about your views on hospice care, your training, and your experiences working in this hospice organization. The interview will be scheduled at a time and location that is convenient for you. The interview will last approximately 45 minutes. The interview will be tape recorded.

7. You may be asked to allow Carrie Graham to accompany you during your visits to patients. Your organization's protocols for obtaining consent from patients will be followed.

K. RISKS/DISCOMFORTS

5. Some of the interview questions may make you uncomfortable or upset, but you are free to decline to answer any questions you do not wish to answer or to discontinue the interview at any time.

6. Confidentiality: Participation in research will involve a loss of privacy; however, your interview will be handled as confidentially as possible. Your decision to participate in this research will not be reported to your employer or co-workers. However, the researchers cannot guarantee that others will not find out about your participation in this research.. When you agree to be interviewed for this research, your name will not be recorded. You will be assigned a code number and that code number will appear on the transcribed interview. After the interview, the audiotape will be transcribed and the tape will be erased. The transcribed interview will kept in a locked file cabinet for the duration of the research study. Only Carrie Graham and Charlene Harrington will have access to the transcribed interview and audio tapes. The researchers will make every effort to keep your identity hidden from others both inside this organization and outside the organization. Something you say in an interview may be quoted verbatim in a publication resulting from this research. No individual identities will

be used in any reports or publications that may result from this study. However, the researcher cannot guarantee that your identity will not be ascertained by someone who reads a report or publication

L. BENEFITS

There will be no direct benefit to you from participating in this study. However, the information that you provide may help health professionals better understand how organizational structure, regulations and financing affect the care provided in hospice organizations.

M. COSTS

There will be no costs to you as a result of taking part in this study.

N. PAYMENT

You will not be paid for your participation in this study.

O. QUESTIONS

You have talked to Carrie Graham about this study and have had your questions answered. If you have further questions, you may call her at (510) 845-7990

If you have any comments or concerns about participation in this study, you should first talk with the researchers. If for some reason you do not wish to do this, you may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. You may reach the committee office between 8:00 and 5:00, Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco/San Francisco, CA 94143.

P. CONSENT

You will be given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You are free to decline to be in this study, or to withdraw from it at any point.

If you agree to participate you should sign below.

__________________ ____
Date Signature of Study Participant

__________________ ____
Date Signature of Person Obtaining Consent

APPENDIX F.

Pre-established codes and categories

Codes and categories were developed around the phenomena of interest, specifically, how the social setting of certain hospice organizations produce categories of knowledge about end of life care and how these knowledges are enacted in practice. Codes and categories were developed prior to the research and then amended and added to as the data collection and analysis continued throughout the research process.

Social setting

-Organizational structure

- Authority
- Ownership
- relationships/contracts

-Financing

- financing incentives
- financing constraints
- profit status
- foundation
- reimbursement (Medicare, Medicaid, private insurance, private pay)

-Politics

- HCFA regulations
- JCAHO, NHPCO guidelines
- Legislation

Institutionalized rules

- Shared ideas, norms, beliefs within an organization
- rules from outside the organization (HCFA, JCAH, NHO regulations)
- rules from within the organization (mission statements, philosophy)

Hospice knowledge

- ideas about organizational goals, method of operation and self evaluation
- ideas about what constitutes a good death
- ideas about how to achieve a good death
- ideas about appropriate care at the end of life
- ideas about who is dying
- ideas about when dying begins

Hospice work practices

- The everyday work of hospice staff to provide care to dying patients

APPENDIX G.

Final Coding Categories used in the research

anti hospice behavior: patient or family behavior that did not agree with the hospice philosophy
authority: discussions of parent corporations or the structure of authority in the hospice
autonomy: the level of autonomy a staff member felt
awareness/acceptance of dying: the importance of a patient's awareness of dying
bereavement program/chaplain: anything pertaining to the bereavement program
burn out: discussions of staff burnout in hospice
called to hospice: a personal sense of mission in working for hospice or care for the dying
case load: the number of patients each staff member cared for at one time
census: the number of patients any hospice cared for at one time
commercial insurance: reimbursement from a private insurance company
community doctors: referring doctors or doctors treating dying patients in the community
community relationships: the hospices relationships or reputation in the community
continuous care: the higher level of care
corporate hospices: hospices that are investor owned and for profit
describing hospice care/goals/philosophy: staff or hospice goals or philosophy
discharging from hospice: when a patient has to be discharged
dissatisfaction with organization
financial constraint: any financially motivated constraint on staff behavior
financial incentive: any financially motivated behavior
flexibility/innovation: new programs or feelings of flexibility
foundation: contributions to the hospice
good death/bad death: descriptions of a good or bad death
hha constraint: the number of home health aides or home health aide time available
history of organization: background on the organization
hospice appropriateness: requirements for a patient to be admitted or kept in hospice
interdisciplinary process: working with other members of the team
Medicare constraints/rules: Medicare regulations and how they are handled or perceived
Medicare positive: positive aspects of medicare regulations
misc constraint: other constraints
multi-institutional systems: working in a system that has many affiliations
negative feelings toward organization
organizational constraint: organizational rules that constrain behavior
other hospices: feelings about, comparisons with or competition from other hospices
personal experiences with hospice: friend or loved one used hospice
positive feelings for organization
profit status: the meaning or consequence of profit status in hospice
quality/success: how the staff member defined success or measured quality of care
restrictions on medications: constraints in prescribing mediations
SNFs: patients in skilled nursing facilities or relationships with skilled nursing facilities
spirituality in hospice: the practice of spirituality in hospice
splitting the patient: treating just part of the patient
staff bereavement: staff feelings of bereavement and how that is addressed
staff feelings for management: positive or negative feelings for administrators
staff support: relationships with other staff members

teaching about hospice: teaching the patient, physician, family or community about hospice
terminal debility/general debility and decline: general diagnostic category for terminally ill patient
time constraint: lack of time affects behavior
uncompensated care: patients who have no reimbursement
volunteers: the role or work of volunteers in the hospice