

# PROVIDING HOSPICE CARE FOR CHILDREN: AN ORGANIZATIONAL STUDY

by

Lisa C. Lindley

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Approved by:

Barbara Mark

Shoou-Yih Lee

Marisa Domino

Mi-Kyung Song

Julie Jacobson Vann

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## Abstract

Lisa C. Lindley: Providing Hospice Care for Children: An Organizational Study

(Under the direction of Barbara Mark)

**Background:** Of the 54,000 children, who die in the US, many lack access to hospice care.

As terminally ill children increasingly return home to die, little is known about the hospices that provide care for children and what factors may influence whether care is provided.

**Objective:** To understand the institutional and resource factors that may influence the provision of hospice care for children, while controlling for organizational and market factors.

**Methods:** This study used a retrospective, longitudinal design. The main data source was the California OSHPD –State Utilization Data File of Home Health Agency and Hospice Facilities 2002 to 2008. After applying inclusion and exclusion criteria, the sample size was 1,368 hospice observations over 7 years. Drawing on institutional and resource dependence theory, this study used generalized estimating equations to examine the institutional and resource pressures associated with provision of hospice care. Interaction terms were included to assess the moderating effect of resource pressures on the relationship between institutional pressures and provision of care.

**Results:** The percentage of hospices providing care for children significantly declined from 2002 to 2008. This study found that provision of hospice care for children was positively associated with membership in a professional group, and was negatively related to small-

sized hospice, medium-sized hospices, and increasing competition. There was no effect of accreditation, organization leader, or other income on providing pediatric hospice care. In addition, small size attenuated the accreditation-provision relationship and medium size magnified the membership-provision relationship.

**Conclusions:** The findings of this study provide specific information on the institutional and resource pressures exerted on hospices in the provision of care for children, and suggests organizational and policy level strategies to improve access to and delivery of hospice care for children.

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## **Chapter 1: Background and Significance**

### **Problem Statement**

Children with life-limiting illnesses in the United States (US) often lack access to hospice care at home or in a dedicated facility when they reach the end of their lives (Dabbs et al., 2007; Institute of Medicine [IOM], 2003). Researchers have found that only 60% of pediatric oncology institutions offer hospice care, and as few as 40% of hospice and home health agencies provide hospice care for children (Johnston et al., 2008; Leuthner et al., 2004). Additionally, hospice care is seldom used by children with life-limiting illnesses and their families. In a white paper produced by the Children's International Project on Palliative/Hospice Services (ChiPPs) for the National Hospice and Palliative Care Organization (NHPCO), experts in the field of pediatric, end-of-life care reported that less than 10% of the approximately 54,000 children dying annually receive hospice care (ChiPPs, 2001). Others have drawn similar conclusions in studies of children with cancer and acquired immune deficiency syndrome (AIDS) (Klopfenstein et al., 2001; Lyon et al., 2008).

The rate of children's hospice care utilization often does not match the need. For example, infants have the highest mortality of any pediatric age group but use hospice services the least (Hendricks-Ferguson, 2008; Lindley et al., 2009; Lyon et al., 2008; Martin et al., 2008). Children who do use hospice care are often admitted late in their disease trajectory and have short lengths of stays, typically ranging from 1 day to 4 months (Davies et al., 2008; Fowler et al., 2006; Hendricks-Ferguson, 2008; Knapp et al., 2009; Sheetz &

Bowman, 2008; Thompson et al., 2009; Zwerdling et al., 2000). Although families may choose to forgo hospice care for personal reasons, this evidence suggests a critical problem in access to hospice care for children and their families.

## **Background**

**Child mortality prevalence.** In 2009, children under the age of 20 accounted for approximately 24% of the US population, or 74 million persons (US Census, 2010). Of the 2.4 million deaths in the US, children represented 2%, or 54,000 deaths, annually (Centers for Disease Control [CDC], 2009). Using the CDC age groupings, 55% of children's deaths were infants (< 1 year), 9% were toddlers (1 to 4 years), 11% were school-age children (5 to 14 years old), and 25% were adolescents and young adults (15 to 24 years old) (CDC, 2005; Heron et al., 2010; Kozier et al., 2004).

**Health conditions associated with life-limiting illness.** Even though accidents and injuries are the most common causes of death in children, there are a number of health conditions associated with childhood mortality from disease (Martin et al., 2008). Infants with life-limiting illnesses often die of congenital anomalies, short gestation periods, sudden infant death syndrome (SIDS), and maternal pregnancy complications. Toddlers, school-age children, and adolescents often die of cancer (e.g., leukemia and brain tumors), congenital anomalies, and heart disease (CDC, 2005; Drake et al., 2003; Feudtner et al., 2001; Hays et al., 2006; Hendricks-Ferguson, 2008; Heron et al., 2010; Klopfenstein et al., 2001).

**Evolution of hospice care for children.** Homes for the dying appeared in the US at the turn of the 20th century; however, it was not until the late 1970s that pediatric hospice services emerged in the healthcare landscape (Siebold, 1992). In 1972, pediatric hospice researchers in Minneapolis, Minnesota, found that having a primary nurse support the parents and the availability of a community-based nurse network ensured continuity of care and

made it feasible and desirable for children to die at home (Martinson & Enos, 1985). Based on this research and the groundbreaking hospice work in the United Kingdom (UK), several organizations began serving children in 1979. These early providers included Edmarc, a pediatric-only, home-care hospice in Virginia (Children's Hospice International, 2009; Crenshaw-Cutchins & Mease, 1985); Hospice of Northern Virginia, the first adult-oriented, home care hospice program to develop a children's component (Children's Hospice International, 2009); and the Children's Hospital in Denver, Colorado, the first neonatal hospice program located in a neonatal intensive care unit (NICU) (Siegal et al., 1985). Today, hospice care is provided to children at acute care hospitals and in the community at home or in dedicated hospice facilities (IOM, 2003).

**Benefits of hospice care for children.** Hospice care is most often associated with elderly cancer patients (NHPCO, 2009a); however, recent research suggests that hospice care offers physical and psychosocial benefits for children with life-limiting illnesses and their families through medication management, skilled nursing care, spiritual care, palliative radiation, bereavement care, and respite care (Davies et al., 2002; Dickens, 2010; Kang et al., 2005; Knapp & Contro, 2010; Lyon et al., 2008; McSherry et al., 2007; Wilkinson et al., 2007). Children receiving hospice care generally experience less suffering from pain and other symptoms, and have a higher quality of end of life compared to those who do not receive hospice care (Hays et al., 2006; Hendricks-Ferguson, 2008; Lyon et al., 2008; Wolfe et al., 2008). Experts in the field of pediatric end-of-life care suggest that early hospice care utilization is preferred because it gives families the opportunity to gradually transition to the end-of-life period (Golan et al., 2008; IOM, 2003). It also allows families to learn what to expect during the disease trajectory and communicate with their child about death and dying

through the guidance of the hospice team (Mack & Wolfe, 2006; Steele et al, 2005). In general, families are very satisfied with the care provided to their children through hospice services (Brosig et al., 2007; Davies et al., 2004, 2007; deCinque et al., 2006; Rhodes et al., 2008; Widger & Picot, 2008). Although these studies were not randomized control trials and lacked generalizability beyond a single health care organization, the findings were definitive and applicable to children with life-limiting illnesses.

**Organization of hospice care for children.** Despite the benefits, children rarely access hospice care through community-based hospice providers. Studies show that whether or not children do so depends upon families' acceptance of the children's limited life expectancy, clinicians' referrals to hospice, and health reimbursement policies (Davies et al., 2008; Fowler et al., 2006; IOM, 2003). However, hospice organizations may contribute to the problem depending on the services they provide, location of care, agency type, and decisions whether or not to provide care for children (IOM, 2003).

**Hospice services.** In their design of service offerings, hospice organizations may advertently or inadvertently affect children's access to care. Children with life-limiting illnesses increasingly need more medically complex services even at the end of their lives (Feudtner et al., 2001); however, the range of hospice services offered varies greatly (Carlson et al., 2007). Services such as registered nurse care, spiritual care, and social services were common in the 1990s, but now, child-focused and medically complex services such as blood product support, chemotherapy, play therapy, and physical therapy are needed (Johnston et al., 2008; Leuthner et al., 2004; Mash & Lloyd-Williams, 2006). Although these services are often not reimbursed by health insurance providers, there is a growing consensus in the hospice community about the value and need to offer these services to improve the quality of

end of life (Connor, 2007; Huskamp et al., 2001; Lorenz et al., 2004; Lutz et al., 2004; McCue & Thompson, 2005, 2006; Smith et al., 2008). Knowing more about the changing nature of services available for children at the end of their lives may provide important administrative and policy insight into expanding access to and improving delivery of hospice care services to children.

***Geographic location.*** Children with life-limiting illnesses in rural areas of the US may have increasingly limited or no access to hospice care. Virnig et al. (2006) showed that in 2002, 23% of such areas lacked access to home-based hospice care. By 2006, 62% to 92% of rural counties had no hospice providers (Madigan et al., 2009). Children with life-limiting illnesses from such areas may have an increasing need for rural hospice care as they return home from urban-based children's hospitals once their medical treatments have been discontinued (Feudtner et al, 2002, 2006, 2007; Klopfenstein et al., 2001). Understanding the availability of rural versus urban hospice care may inform policies aimed at improving access to hospice care for children in rural areas.

***Agency types.*** Terminally ill children are increasingly dying at home rather than in the hospital (Feudtner et al., 2002; Feudtner et al., 2007), and they have a need for community-based hospice care as provided by home health, freestanding hospices, or long term care facilities. Several Canadian researchers have reported evidence in support of this assertion (Vandeboncoeur et al., 2009; Widger et al., 2007). International scholars have described the type of organization that provided hospice care to children from Australia, Canada, and the United Kingdom and discovered that care was distributed evenly between home (35.1%), hospice facility (32.1%), and hospital (31.9%) (Siden et al., 2008). Those that have explored this issue in the US have suggested that freestanding hospice organizations

generally provided care more often to children than did hospitals, home health agencies, or nursing homes; however, infants and school-aged children were more often admitted to nursing homes (Lindley et al., 2009). This literature suggests that hospice care may be trending towards community-based providers; however, these studies have been primarily conducted outside the US. Therefore, developing our knowledge of the type of organizations that provide hospice care for children and how those types may have changed over time may provide policy insight necessary to increase access to community-based hospice care in the US.

***Care provision.*** Whether or not hospice organizations actually provide pediatric care is a critical determinant of access (Aday & Andersen, 1974). There is emerging evidence that institutional and resource factors may have a profound and dynamic influence on the provision of hospice care for children. Hospice organizations face institutional pressures from regulatory agencies and professional associations to provide hospice care for all patients regardless of age, disease type, race, and gender (Abel, 1986; Connor, 2007). At the same time, organizations face resource constraints in providing hospice care for high-cost patient populations such as children (McCue & Thompson, 2005, 2006). In the current economic recession, many hospice organizations are reacting to the changing economy and modifying service provision as a means to maintain and enhance resource flows, often contrary to institutional pressures (Bardham & Walker, 2010). A study exploring the provision of hospice care for children over a period of time may provide more information for clinicians and policy makers regarding the dynamic factors that influence their economic decisions (IOM, 2003).

## **Study Purpose and Research Questions**

The purpose of this study was to understand the organization of hospice care provided for children and to explore the dynamic relationships that affect children's access to hospice care. The study sought to answer the following questions:

1. How is hospice care organized for children, and how has it changed from 2002 to 2008?
  - 1.1. What hospice care services are provided for children, and have services changed over time?
  - 1.2. What are the geographic locations where hospice care is provided for children, and have the geographic locations changed over time?
  - 1.3. What community-based agencies are providing hospice care for children, and have the agency types changed over time?
2. What is the nature of the relationships between institutional and resource factors and hospice care provision for children over time?
  - 2.1. Are hospice organizations influenced by the institutional nature of the hospice industry to provide hospice care for children?
  - 2.2. Does a lack of resources inhibit hospice organizations from providing care for children?
  - 2.3. How do hospice organizations respond to institutional pressures when they lack resources?

## **Study Significance**

Examining the organizations that provide hospice care for children is important and timely. First, families of children with life-limiting illnesses should be interested in knowing



about alternative care models at end of life. Until there is a better understanding of community-based hospice organizations that provide care for children with life-limiting illnesses, hospital acute care may continue to be the primary mode of care for those children. All too often hospitalized children do not receive adequate pain and symptom management and suffer significantly from pain, anxiety, dyspnea, and fatigue at the ends of their lives (Drake et al., 2003; Heath et al., 2010; Ullrich et al., 2010b; Wolfe et al., 2008). Although many parents experience discomfort when making decisions about end-of-life care, families who want to bring their children home to die often cannot because they do not wish to discontinue treatments or are unaware of hospice care for children (Beckstrand et al., 2009; Dussel et al., 2009; Hechler et al., 2008; Michelson et al., 2009; Midson & Carter, 2010; Surkan et al., 2006; Vickers et al., 2000; Zelcer et al., 2010). In addition, the delivery of care to children in the acute hospital setting can be costly, averaging up to approximately \$800,000 per child for the last 6 months of life (Ward-Smith et al., 2008). This study may offer insight into another care delivery option for children with life-limiting illnesses that may be more effective in managing quality of end of life and more affordable both to families and the health-care system.

From the perspective of policy makers, it is important to know whether there are desirable as well as undesirable changes in the provision of hospice care for children. The recent economic downturn and subsequent state budget constraints have adversely affected health care availability for children (Johnson et al., 2010). Several states have debated eliminating hospice care from their Medicaid programs, and others have trimmed services and delayed payments (Johnson et al., 2008, 2010; Tuch, 2009). Many states, such as Colorado, have opted to not include the hospice benefit in their Children's Health Insurance

Program (CHIP). Others, such as Texas, have recently eliminated the benefit during budget cuts (Dunkelberg & O'Malley, 2004; Healthinsurancefinders, 2009; Wyses et al., 2003). Likewise, Florida, Iowa, Kansas, Missouri, and South Carolina have debated eliminating hospice care from their Medicaid programs (Hospice & Palliative Care Association of Iowa, 2010; NHPCO, 2003; Shields, 2010; Tuch, 2009). California also has debated benefit changes in Medicaid and CHIP, but instead of eliminating the hospice benefit entirely, it trimmed hospice services and delayed payments (California Department of Health Care Services, 2009, 2010). A study considering hospice care services for children over an extended period and may give policy makers more information on the factors affecting its provision.

For hospice administrators, this study offers timely empirical evidence regarding a specific hospice patient population affected by recent changes in federal and state health care policy. The passage of the Patient Protection and Affordable Care Act (PPACA) of 2010 allows children with life-limiting illnesses who are enrolled in Medicaid or CHIP to receive hospice services without foregoing curative treatment related to the terminal illness (Govtrack, 2010). In addition, the PPACA requires that hospice organizations report quality measures or risk cuts in their Medicare and Medicaid reimbursement (Govtrack, 2010; NHPCO, 2010). In conjunction with health care reform, Florida, Colorado, New York, Massachusetts, and California have recently passed legislation experimenting with modified end-of-life care models for children and reimbursement programs to providers (Dabbs et al., 2007). Evidence from this study may assist hospice organizations in navigating this uncertain funding environment for children.

## Study Definitions

To clarify terminology used in this study, the following definitions are provided.

*Children* are defined as persons under 21 years of age. *Children with life-limiting illnesses* are those that have illnesses or conditions that are fatal or carry a substantial probability of death in childhood (IOM, 2003).

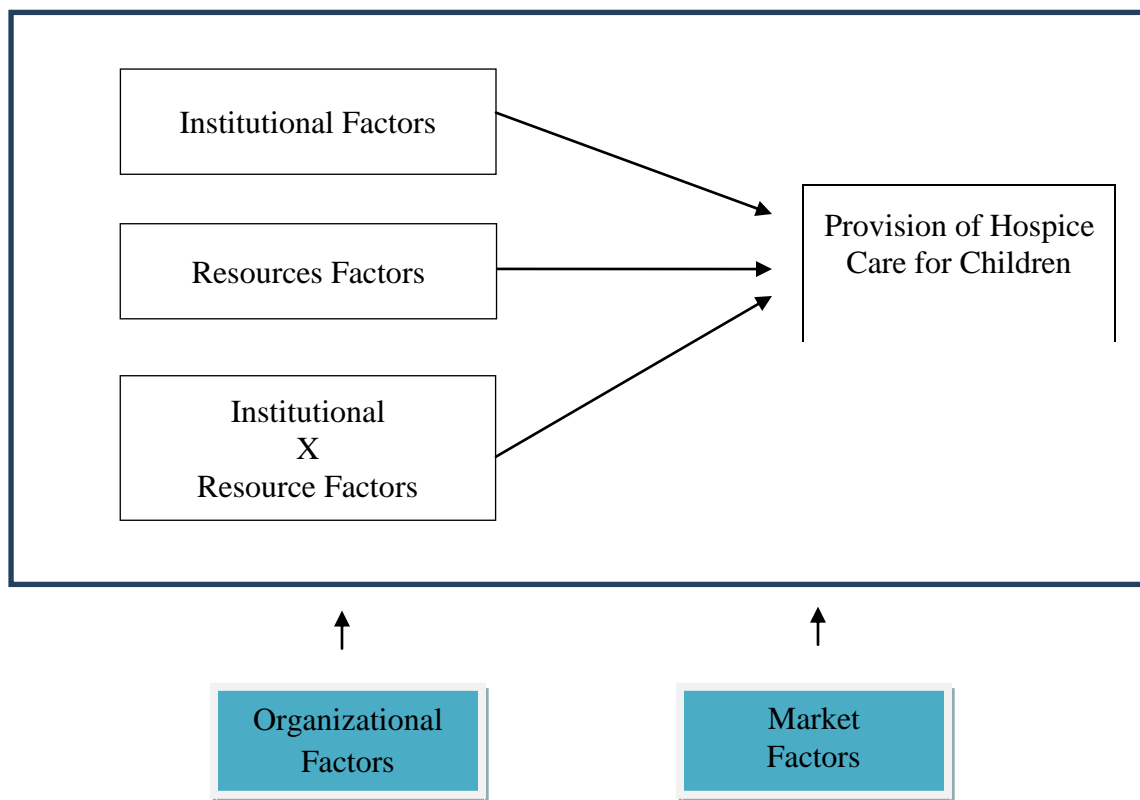
*Hospice care* describes a philosophy, site of care, or program of care (IOM, 2003). Admission to hospice care requires that children have a life expectancy of approximately six months or less as certified by a hospice medical director and an attending physician (Bonebrake et al., 2010). The program of hospice care includes physical, emotional, social, and spiritual support services provided by an interdisciplinary health care team (Children's Hospice International [CHI], 2009; Corr & Corr, 1985, 1988; Hospice Foundation of America, 2010; Martinson, 1976; Martinson et al., 1977). Hospice care for children including infants to adolescents is often referred to as *pediatric hospice care* (Calhoun et al., 2003; Corr & Corr, 1985, 1988; Hoeldtke & Calhoun, 2001; Rousch et al., 2007). For the purposes of this study, the term *hospice care* was used to describe a program of pediatric care provided for children under the age of 21 years.

*Provision of hospice care* is defined as providing hospice care services including core, noncore, and other services to hospice beneficiaries. Based on the Centers for Medicare & Medicaid Services (CMS), hospice organizations must offer core and noncore services to patients (US Government Printing Office, 2010). Core services are those that must be provided by hospice staff—skilled nursing is an example. Noncore services, such as medical equipment, are those that may be outsourced. All other services, such as radiation therapy, are unregulated and nonreimbursable by most public and private insurance plans (US Government Printing Office, 2010).

*Hospice organizations* are defined as community-based hospice and home health agencies that provide hospice care in a non-acute care setting that is centered in or around a community.

### **Theoretical Framework and Conceptual Model**

Drawing on institutional and resource dependence theories, this study conceptualized the provision of hospice care for children as a dynamic interplay between institutional and resource factors while controlling for organizational and market factors. Figure 1 presents the conceptual model. The framework will be discussed in detail in Chapter 2.



*Figure 1.* Conceptual model of provision of hospice care for children.

## **Methodology Overview**

This study was a retrospective, longitudinal study that used data from the California Office of Statewide Planning and Development (CA OSHPD) for the years 2002 through 2008. The unit of analysis was the hospice-year observation. There were six other data sources: California Department of Public Health, California Employment Development Department, United States Department of Agriculture, California Department of Finance, Children's Hospice and Palliative Care Coalition of California, and the National Association of Children's Hospitals and Related Institutions. The statistical analyses included univariate, bivariate, and multivariate analyses.

## **Dissertation Organization**

The remainder of this dissertation is organized as follows: Chapter 2 reviews institutional theory and resource dependence theory and presents a conceptual model. Chapter 3 reviews the literature on institutional, resource, organizational, and market factors associated with the provision of hospice care for children and suggests hypotheses. Chapter 4 discusses the methodology of the study including research design, data sources, sampling, measures, data analysis, and analytical issues. Chapter 5 presents the results of the statistical analyses and Chapter 6 is the discussion of those results.

## **Chapter 2: Theoretical Framework**

### **Introduction**

The objective of this longitudinal study is to describe the characteristics of organizations that provide hospice care services for children and to understand the influence of institutional and resource factors over time on the provision of hospice care for children. The purpose of this chapter is to develop a theoretical framework based on institutional theory and resource dependence theory that poses a logical argument about the relationship between institutional and resource factors and the provision of hospice care for children. It provides a discussion of each theory and the rationale for its use. The chapter concludes by integrating the theories to create a conceptual model that addresses the factors underlying the provision of hospice care for children.

### **Understanding Institutional Theory**

**Theoretical perspective.** With historical roots in the disciplines of economics, political science, and sociology, institutional theory draws from natural- and open-system perspectives that focus on how organizations adapt to the demands of their complex and uncertain environments (Meyer & Rowan, 1977; Scott & Davis, 2007; Zucker, 1977). A natural-system perspective defines organizations as collectives that pursue multiple interests to perpetuate their survival (Scott & Davis, 2007). An open-system perspective, on the other hand, emphasizes that organizations depend on the environment for flows of people, resources, and information (Scott & Davis, 2007). Combining these perspectives suggests

that organizations are responsive to and dependent on other organizations in their environment.

Institutional theory emphasizes that organizations adapt to what society views as the correct way of organizing and behaving to survive (DiMaggio & Powell, 1983; Meyer & Rowan, 1977; Powell & DiMaggio, 1991; Scott, 2001; Scott & Davis, 2007). Institutional theorists have traditionally focused on how organizational structures and processes are put into practice based on the organization's need for legitimacy. With regard to health care organizations, organizational structures refer to the "relatively stable characteristics of the providers of care, of the tools and resources they have at their disposal, and of the physical and organizational settings in which they work." (Donabedian, 1980, p. 81). Processes are defined as an organized group of related tasks and activities that transform inputs into outputs (Daft, 2004). Legitimacy occurs when an organization's actions are seen as appropriate within the norms, values, and beliefs of the organization's stakeholders and their environment (Suchman, 1995). Institutional theory posits that organizational legitimacy and support depends on congruence between stakeholders' expectations and organizational responses. The survival of the organization, therefore, is contingent on conformity to externally imposed requirements such as laws, accreditation criteria, and professional standards.

**Institutional environment.** A basic premise of institutional theory is that organizations operate in an institutional environment. The environment is composed of a set of regulatory (e.g., rules, laws, and sanctions), normative (e.g., professional standards and certification), and cultural-cognitive elements (e.g., common beliefs and values) (Scott, 2001; Scott & Meyer, 1983). These elements are derived from deeply ingrained, socially

constructed realities that become rationalized myths over time (Meyer & Rowan, 1977).

Rational, in this sense, refers to institutional norms and values that are considered true based on laws, standards, and guidelines. Myths are repeated, copied, or widely accepted as social reality, but not tested empirically. Once created, these rationalized myths are reinforced by key stakeholders in the institutional environment (Meyer & Rowan, 1977).

**Institutional demands.** A key concept of the institutional perspective is that organizations encounter three types of demands to which they must conform: coercive, normative, and mimetic demands (DiMaggio & Powell, 1983). Coercive demands are formal and informal pressures exerted on the organization by key regulatory stakeholders (DiMaggio & Powell, 1983). Coercive forces constrain organizations by prescribing uniform standards, mandating compliance with rules and regulations, legislating competencies, requiring ways of deploying resources, and defining what resources are socially acceptable (Oliver, 1997). For example, accrediting agencies do not have legal enforcement power; however, their requirements for accreditation exert a coercive pressure on hospice organizations to comply or risk loss of resources and prestige. Accreditation requires that hospice organizations have established prescribed infrastructures, policies, procedures, and requirements for provision of care (Au et al., 2009; Connor, 2007). In some markets, accreditation is a prerequisite for participation in managed care plans and contract bidding (Joint Commission, 2010). Organizations comply with rules and regulations because key stakeholders have the power to confer legitimacy, legal authority, and/or control over important resources and support (Scott, 2004).

Normative demands are societal expectations of organizations based on what is deemed to be high professional caliber (Scott, 2003). These demands are often the result of



what is taught in schools, researched and reported in books and journals, and advocated among professional groups. The professional environment defines what is valued and expected by organizational members. Compliance is enforced through a sense of social obligation in the profession's members (Scott, 2001). For example, the National Hospice and Palliative Care Organization developed and issued pediatric standards of practice in 2009. These standards require hospice organizations to develop an infrastructure for pediatrics including clinical guidelines, workforce requirements, and performance measures (Friebert & Huff, 2009). Professional groups such as the Children's Hospice and Palliative Care Coalition reinforce these standards among their members through training (Children's Hospice and Palliative Care Coalition, 2010).

Mimetic demands are pressures to copy the behavior of other organizations (Scott, 2004). In an environment with increasing uncertainty, other organizations provide a reference for modeling what works elsewhere (Scott, 2003). Identifying and implementing best practices is an example of organizational imitation (Daft, 2004). However, emulating other organizations may occur without any clear proof that performance will be improved (Daft, 2004). Total quality management and rapid response teams are examples of practices currently being copied by health care organizations without evidence that they improve patient care. Compliance with mimetic demands occurs when other types of action are considered impossible or because routines are taken for granted as the way things are done (Scott, 2001).

**Organizational response to institutional demands.** From the perspective of institutional theory, organizations respond to the institutional environment in a rational and deliberate manner (Scott, 2004, 2008). Responses are developed internally or copied from

successful organizations resulting in uniformity among organizations within an industry. Conforming to societal pressures offers organizations legitimacy and support, buffers them from turbulence, and promotes stability (DiMaggio & Powell, 1983; Meyer & Rowan, 1977). Legitimacy occurs when an organization's actions are congruent with societal expectations (Goodrick & Salancik, 1996; Granovetter, 1985; Meyer & Rowan, 1977; Oliver, 1997; Suchman, 1995). Institutional theorists have asserted that organizations will conform to societal norms and values not because it makes them more efficient, but because violations call into question the organization's legitimacy and its ability to secure resources and support for survival (Deephouse, 1996; DiMaggio & Powell, 1983). Therefore, the most efficient route is not always taken.

Although conformity and isomorphism are major tenets of institutional theory, some theorists have challenged their preeminence and suggested that although all organizations in an industry are subject to institutional demands, they do not all respond in the same manner (Oliver, 1991). They have posited that responses range from acquiesce to defiance (Oliver, 1991). Still, some organizations do acquiesce and conform completely to societal expectations, such as hospice organizations that provide care for children by completely obeying the established rules and accepting the norms within the hospice industry.

More realistically, perhaps, some organizations choose to conform partially to societal expectations. They may consider unqualified conformity unacceptable and respond by compromising with external stakeholders. This allows the organization to buffer itself from unwanted demands from constituents while permitting some organizational autonomy (Westphal & Zajac, 1994). A common compromise tactic is loose coupling. It refers to a process of separating operations of an organization or the technical core from the institutional

environment (Daft, 2004; Mintzberg, 1979). Thus, the technical core can be responsive to the institutional environment, but it is separate and retains its own identity (Weick, 1976). In hospice care, this can take the form of organizations that come under pressure to address patient safety issues. They may continue to care for patients but may allocate resources to staff training and safety monitoring to fit government and accrediting agency expectations of patient safety rather than choosing only one focus over another.

Organizations can avoid conformity by concealing their nonconformity through decoupling. It differs from loose coupling in the degree to which the technical core is separated from institutional stakeholders. Organizations may appear to institutional constituents as if they are conforming to their demands; however, they are completely isolating and protecting internal operations from the external environment (Meyer & Rowan, 1977). They may engage in "window dressing," ritualism, ceremonial pretense, or symbolic acceptance of the rules and norms but are not pursuing such changes in reality (Meyer & Rowan, 1977). During a government inspection, an organization engaged in decoupling may show inspectors the procedures and protocols that are not part of their normal patient care routine. In such cases, the appearance rather than the fact of conformity may be sufficient for attainment legitimacy (Oliver, 1991).

Finally, organizations can respond by defying institutional stakeholders and not conforming to rules and norms at all. This more active form of resistance allows organizations to completely separate their technical core from the institutional environment. They may view the costs of conformity as outweighing adherence to the accepted practices. Organizations that fail to treat health care records with confidentiality in accordance with

professional standards, for example, may view the likelihood of getting caught low. And if caught, the fines may be perceived as inconsequential.

### **Rationale for Using Institutional Theory.**

*The institutional nature of the hospice industry.* Institutional theory is particularly useful in designing research that examines the relationships between institutional forces and the provision of care for children because the hospice industry is highly institutionalized. For example, the Medicare Conditions of Participation (CoP) for hospice organizations are composed of 7 sections and 49 subsections of rules and standards (US Government Printing Office, 2010). Key institutional constituents, such as the Centers for Medicare & Medicaid Services, demand conformity to rules, standards, norms, and beliefs

Additionally, hospice associations and coalitions are powerful normative influences on member hospice organizations (Ginn & Moseley, 2004; Olden & Clement, 2000; Proenca et al., 2003). These professional groups are often deemed the experts on the rules, regulations, and policies of the hospice industry (Reinhart, 1983). For example, the National Hospice and Palliative Care Organization issued standards of practice for pediatric palliative and hospice care in 2009, and the American Academy of Pediatrics endorsed these standards (American Academy of Pediatrics, 2010), giving significant cause for hospice organizations to adopt them.

Hospice organizations also look and act like one another - an outgrowth of the institutionalization of the environment. This is partly because hospices have copied the structures and processes of other organizations due to mimetic pressures throughout the history of the hospice industry (Abel, 1986). For example, hospice organizations typically care for very few children and they often use other hospices or hospitals as role models for

delivering that care (Armstrong-Dailey & Zarbock, 2001; Corr & Corr, 1985). On April 23, 2010 representatives from more than 25 hospice agencies, home health agencies, and hospitals attended a full day conference to learn about best practices in perinatal hospice care at the University of North Carolina Hospitals (University of North Carolina School of Nursing Continuing Education Program, 2010). In this case, organizations adopted University of North Carolina Hospitals' care practices with limited or no evidence of their performance, but based their adoption on the perceived success of University of North Carolina Hospitals in caring for children with their years of experience, dedicated facilities, and trained staff.

Consistent with institutional theory, hospice organizations respond in a variety of ways to the pressures of the institutional environment. A recent study showed that many hospice organizations do not fully comply with the CoP requirement of an initial pain assessment upon hospice admission (Herr et al., 2010). This suggests that compliance with rules, norms, and standards may not be uniform in the hospice industry. In other words, hospice organizations may adopt different strategic choices in how they respond to societal constituents.

Finally, institutional theory suggests that failure to conform to regulations can result in the loss of legitimacy and resources. Hospice organizations that do not comply with the demands of institutional constituents risk losing Medicare and Medicaid funding, state licensure, and prestige. Therefore, the tenets of institutional theory are quite evident in and applicable to studying the hospice industry.

***Usefulness of institutional theory.*** Institutional theory is a useful theoretical framework for understanding and explaining the behavior of organizations. The basic tenets

of the theory have been supported in numerous research studies (Scott, 2008). Its key concepts can be applied when examining the institutional demands within the environment that shape organizational provision of hospice services for children. A number of other theories - including transaction cost, ecology, and contingency theory - were considered for this research project. Although these theories provide insight into organizational behavior, they do not emphasize the environmental pressures and the construct of isomorphism articulated in institutional theory. These constructs are essential to understand in examining the relationship between institutional factors and the provision of hospice care for children.

There are limitations to using institutional theory as a theoretical framework. It has been criticized for its inability to address dynamic issues of nonconformance in the organizational environment (Zucker, 1997). The assumption that organizations become more alike over time stifles examinations of change and innovation. However, recent studies using institutional theory have attempted to challenge the static appearance of the theory (Dacin et al., 2002; Kirby et al., 2007; Lounsbury & Crumley, 2007). As examples, Lounsbury and Crumley (2007) used institutional theory to explain innovation in the US mutual fund market, and Kirby et al. (2007) explored innovation in hospice organizations with it.

In addition, studies of organizational performance and strategic decision making utilizing institutional theory are emerging from the health care literature (Ashworth et al., 2007; Choi & Brommels, 2009; Kirby et al., 2007; Yang et al., 2007). Yang et al. (2007) recently offered a set of propositions that explicated the relationship between institutional pressures, strategic choice, and organizational performance in the health care industry. These recent studies sought to create new knowledge about health care organizations within the framework of institutional theory.

In summary, the rationale for using institutional theory is based on the institutional nature of the hospice industry and usefulness of the theory. Institutional theory provides an appropriate framework to examine hospice organizations' decisions on whether or not to provide hospice care for children.

### **Understanding Resource Dependence Theory**

**Theoretical perspective.** As a macro-organizational theory, resource dependence theory provides another perspective on organizations and their responses to the environment (Davis & Cobb, 2009). Similar to institutional theory, it is both an open- and natural-systems model that posits organizations continuously seek resources in a complex and uncertain environment to survive and succeed (Pfeffer & Salancik, 1978). Several business theorists are associated with the development of resource dependence theory (Hasenfield, 1972; Jacobs, 1974; Thompson, 1967). The works of these authors represent some of the earliest attempts to examine resource flows into organizations.

Resources are defined as a group of tangible and intangible elements an organization owns or controls that are externally available and transferable (Amit & Shoemaker, 1993; Araya et al., 2007). Resources consist of financial or physical assets (e.g., property, facility, equipment), human capital, technology, and other organizational resources (Grant, 1991). Capabilities refer to the organization's capacity to deploy resources. They are often developed in functional areas such as brand management in marketing. From a resource dependence perspective, no organization is self-sufficient and able to satisfy all its resource needs internally.

**Resource interdependencies.** Resource dependence theorists have suggested that organizations develop interdependent relationships with other entities because they do not

have all their needed resources and capabilities (Pfeffer & Salancik, 1978). Pfeffer (1992) distinguished three types of interdependencies: asymmetric, symbiotic, and competitive. Asymmetric interdependence refers to a power differential between entities. By controlling resources, an entity becomes more powerful and often dictates the behavior of the other entity. For example, private contributions to hospice organizations may create an asymmetrical interdependence. Funds from individual donors, corporate donors, and foundations can be substantial, but they come with restrictions on use and allocation (Froelich, 1999; Zelman et al., 2003).

Entities that need each other to achieve their respective goals exhibit symbiotic interdependence. Hospice organizations are dependent on medical supply companies for resources such as oxygen, and medical supply companies are dependent on health care organizations like hospices to buy their products. If achieving organizational goals is detrimental to one of the entities, however, then competitive interdependence exists. For example, hospitals are a major source of referrals to freestanding hospices in the community, but many hospitals also operate their own community-based hospice in the form of a freestanding hospice facility or home hospice service. As a result, competitive interdependence for patients may exist between freestanding organizations and hospital-based organizations. Thus, resource dependence theory emphasizes that the environment is characterized by varying levels of dependency between organizations and resource holders.

**Resource dependence demands.** The resource dependence perspective posits that organizations are subject to the demands of resource holders. Stakeholders that provide resources frequently seek accommodation from resource recipients in exchange for resources. Changes in organizational structure and behavior may be required to accommodate



the demands of resource providers to secure a stable flow of resources (Oliver, 1991). Organizations will typically accommodate constituent demands to avoid disruptions in operations (Oliver, 1991). The willingness of organizations to do so is dependent on resource munificence and competition (Pfeffer & Salancik, 1978). Munificence refers to the availability of external or internal resources (Hsieh et al., 2010). The availability of financial resources from donors or grants may allow hospice organizations to generate a financial buffer in case of relative resource scarcity. In addition, larger organizations may be able to generate resource substitutes because of their size. For example, such hospices may be able to substitute temporary human resources when regular, full-time human resources are scarce, which smaller hospices may not have the financial resources to do.

According to resource dependence theory, the more competitive the environment, the greater the demands on the shared pool of resources and survival depends on how resources are allocated across competitors (Pfeffer & Salancik, 1978). In highly competitive environments, organizations have almost no market power to control external dependencies and resource streams. As a result, responsiveness to the needs of key resource holders is critical to organizational survival. Therefore, resource dependence theory stresses that accommodations made to resource holders are contingent on the munificence of and competition for resources.

**Organizational response to resource dependence demands.** Resource dependence theorists view organizational actions as rational and deliberate attempts to control the critical resources they need (Pfeffer & Salancik, 1978). The response of organizations can vary from compliance to avoidance. Organizations that have limited choice of suppliers are forced to comply with pricing and delivery schedules because they have no other alternative source for

the resource. However, organizations that develop alternative sources, purchase ownership in the supplier, establish long-term contracts, or negotiate joint ventures can mitigate the demands of resource holders (Daft, 2004).

Organizational responses are generally situational and influenced by the type and intensity of the resource need, the organization's goals and interests, and the organization's power relative to other organizations (Goodstein, 1994; Pfeffer & Salancik, 1978). Responses also vary based on their connections to other organizations, proximity to similar organizations, and exposure to the responses of other organizations (Galaskiewicz, 1991). Consequently, organizations are actively involved in identifying dependencies and deciding which ones are critical. Effective organizations recognize and modify the locus of their dependences in order to survive (Pfeffer and Salancik, 1978).

#### **Rationale for using resource dependence theory.**

*The resource dependent nature of hospice organizations.* Resource dependence theory is appropriate for exploring the relationships between the resource environment and the provision of hospice care for children for several reasons. First, hospice organizations cannot meet all their resource needs internally and are dependent on other entities for resources. For example, organizations that outsource noncore services are dependent on suppliers for home-health care personnel, durable medical equipment and supplies, medications, therapy personnel, inpatient care facilities, and transportation services (US Government Printing Office, 2010).

Second, hospice organizations encounter demands by key resource holders. A common practice is to appease stakeholders. This may include shifting hospice programs into

areas that have greater donor appeal, such as delivering care to AIDs patients or children, to secure financial resources (Froelich, 1999; Orloff, 2001).

Third, hospice organizations strategize ways to reduce resource dependence. For example, Gentiva Health Services recently acquired Odyssey Healthcare and created the nation's largest provider of home health and hospice care (Associated Press, 2010). The acquisition increased Gentiva's annual revenue to roughly \$1.8 billion and their employee headcount to over 15,000 (Associated Press, 2010; Odyssey Healthcare, 2009). Gentiva's response allowed the organization to have control over financial and human resource flows and to reduce dependence on other entities. This shows how hospice organizations' needs directly relate to the tenets of resource dependence theory.

***Usefulness of resource dependence theory.*** Resource dependence theory is a useful theoretical framework to examine the effects of resource demands on organizations. The basic tenets of the theory are supported by empirical research that is discussed in Chapter 3. The constructs of resource dependence theory are essential for explaining and predicting resource factors that correlate with the provision of hospice care for children.

There are limitations to utilizing resource dependence theory. First, critics have asserted that resource dependence theory has not been rigorously tested or explored (Hillman et al., 2009). Indeed, the theory does lack theoretical development and refinement including untested assumptions, unexplored alternative strategies, and gaps in the theory (Casciaro & Piskorski, 2005). Second, resource dependence scholars have voiced concern that there is a relative lack of interest in using resource dependence theory as a theoretical framework (Hillman et al., 2009). However, Davis and Cobb (2009) contended that the emphasis of resource dependence theory on external control and power dependence relationships has

accounted for a recent upsurge in its use by scholars. Although there are limitations, the resource dependence perspective is an appropriate theoretical framework to explore organizational response to the resource environment.

In summary, the rationale for using resource dependence theory is based on the resource dependent nature of hospice organizations and usefulness of the theory. This theory provides an appropriate framework to examine the response of hospice care organizations' decisions on whether or not to provide hospice care for children.

### **Integrating Institutional and Resource Dependency Theories**

Although both theories are appropriate for examining the relationship between environmental and organizational responses, for this study, combining institutional and resource dependence theories strengthens and enriches the theoretical framework. Oliver (1991) suggested that there was value in linking several theoretical models to explain environment-organization relationships. Other scholars have advocated that no one theory can adequately explain organizational behavior in an industry as complex and unique as health care (Flood & Fennel, 1995; Luke & Watson, 2003; Zucker, 1987). As discussed previously, hospice organizations operate in both an institutional and resource dependent environment, and the tenets of both apply to the hospice industry. Therefore, it is fitting to apply both theories to the study of providing hospice care for children.

#### **Usefulness of integrating institutional and resource dependence theories.**

Combining institutional and resource dependence theories offers a stronger theoretical framework for understanding and explaining the behavior of organizations than each theory does on its own. Two theoretical paradigms provide a more comprehensive view of the phenomenon of hospice organizations' provision of care for children. Similar to other

organizations, hospices are influenced by cultural, social, and political demands and by their dependency on resources (Scott & Davis, 2007). An integrative perspective suggests that hospice organizations may exercise choice in the provision of hospice care services for children within the constraints posed by institutional forces and resource needs (Oliver, 1991).

Utilizing institutional and resource dependence theories enhances explanatory power (Balotsky, 2005). Both theories posit that organizations operate in an environment of turbulence and uncertainty with competing environmental pressures. Both approaches recognize that organizations exercise strategic choice within the constraints of resource capabilities, the market, and interest groups (Oliver, 1991; Zinn et al., 1998). They also view organizations as persistent structures under constant reinterpretation and negotiation.

The theories complement each other through their differences. Institutional theory emphasizes conformance with external expectations, whereas resource dependence theory emphasizes the organization's active resource control. They also differ with respect to environmental determinism and the sources of environmental pressure (Oliver, 1991). Institutional theory stipulates that organizations make decisions to claim legitimacy, whereas resource dependency surmises that organizational decision making is motivated by controlling resource relationships. Institutional theory is criticized for its lack of focus on active agency and external exchange relationships; these concepts are the basic tenets of resource dependence theory. Finally, both theories differ in their view of management. In institutional theory, managers are passive instruments of the environment, whereas in resource dependence theory they are active decision makers. Therefore, these theories offset each other's limitations.

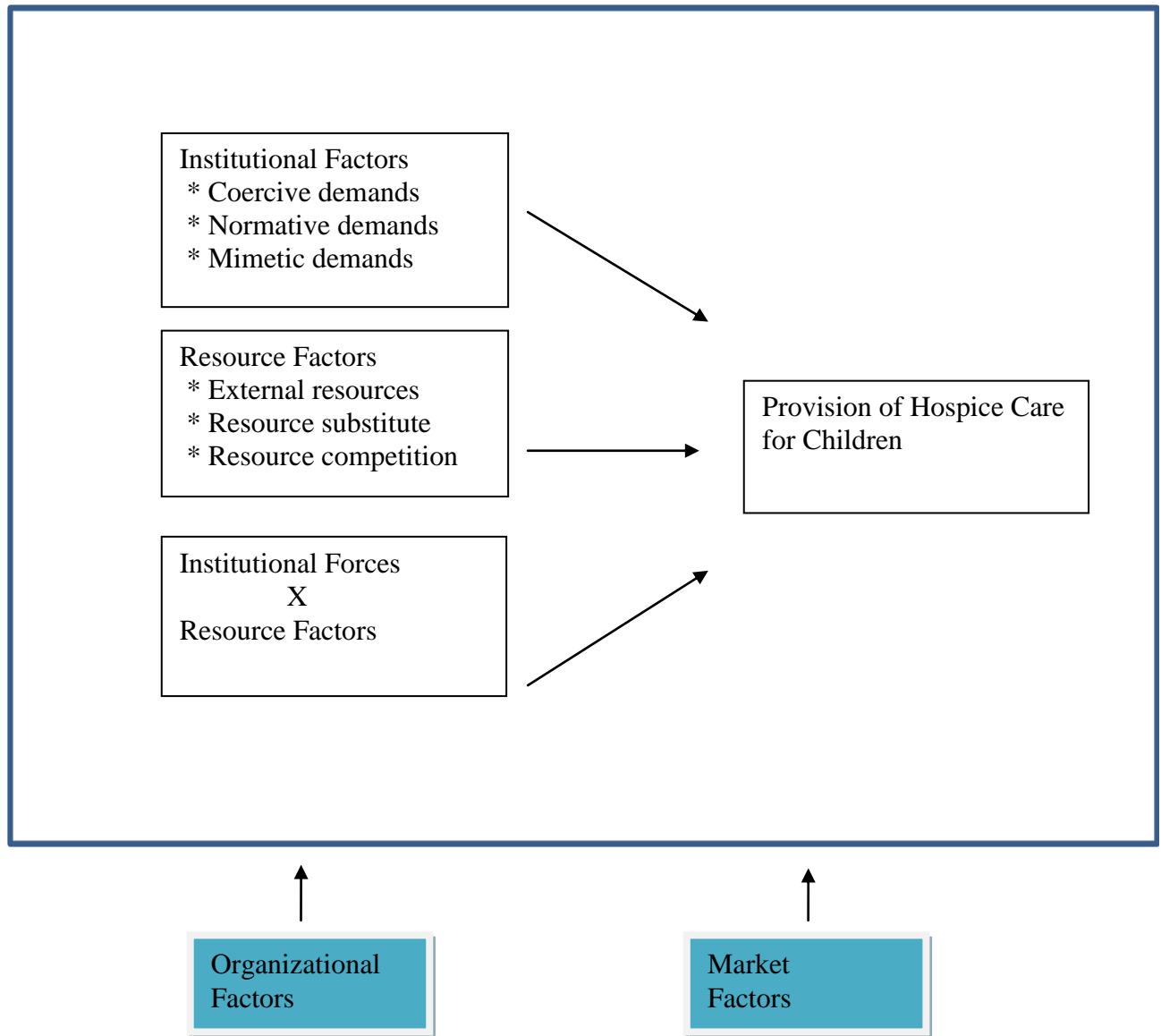
An integrative perspective also provides a basis for exploring factors that may moderate the relationship between environmental and organizational responses. A moderator is defined as a third variable that affects the relationship between two variables so that the impact of the predictor on the outcome varies according to the value of the moderator (Holmbeck, 1997). Moderator variables interact with the predictor variable in such a way that they affect either the direction or magnitude of the relationship between the predictor and outcome variables (Baron & Kenny, 1986). In this study, the response of organizations to institutional demands may be moderated by resource constraints. Thus, the theoretical discussion on the effect of resource factors on the provision of hospice care for children needs to incorporate the resource environment as a moderating factor in the relationship between institutional factors and provision of care.

This coincides with suggestions that resource conditions may act to attenuate or intensify organizational behavior (Park et al., 2002; Wiklund & Shepherd, 2003). An uncertain flow of resources may direct an organization's attention away from rules and regulations imposed by institutional constituents to provide care for children (Luke & Watson, 2003). Conversely, hospice organizations that can afford to improve and refine resource conditions may be viewed by institutional stakeholders as legitimate and worthy of additional support to provide care for children. Therefore, hospice organizations may seek self-interest in response to conflicting demands in the institutional and resource environments (Oliver, 1991).

In summary, the structure of and demands on hospice organizations are well suited for study under the tenets of institutional and resource dependence theories. Additionally, the combination of the theories enhances the explanatory power of this study.

## **Conceptual Model**

Drawing on institutional and resource dependence theories, this study conceptualizes the provision of hospice care for children as a function of institutional and resource factors while controlling for organizational and market factors (Figure 2). The underlying principles of the model highlight that institutional and resource factors vary, and these, in turn, affect hospice organizations' decisions to provide care for children. Based on institutional theory, the model presents coercive, normative, and mimetic demands as institutional influences on the provision of hospice care for children. Based on resource dependence theory, the model shows that an organization's external resources, ability to resource substitute, and competition for resources may impact their provision of hospice care for children. In addition, interactions between institutional and resource factors may exist. The framework also suggests that other factors may be related to the provision of hospice care for children including organizational and market factors. The conceptual model is used in the next chapter to formulate testable hypotheses.



*Figure 2.* Conceptual framework of institutional and resources factors associated with provision of hospice care services for children.

### Summary

This chapter provided an overview of institutional and resource dependence theories. It examined the theoretical perspectives and rationale behind each theory. In addition, it provided justification for integrating the two theories for the development of this study's



conceptual model. With this theoretical framework as a guide, the next chapter examines the hospice and health services literature. The literature is used to provide support for the development of hypotheses explaining how institutional and resource factors influence the provision of hospice care services for children.

## **Chapter 3: Literature Review and Hypotheses**

### **Introduction**

The goals of this chapter are to review the existing literature regarding the provision of hospice care for children and to develop hypotheses tested in this dissertation. Factors influencing the provision of hospice care for children are classified into four major categories: (a) institutional factors, (b) resource factors, (c) organizational factors, and (d) market factors. Hypotheses were developed for the institutional and resource factors with institutional and resource dependence theories in mind. However, hypotheses were not developed for those variables relating to organizational and market factors. Many of the studies investigated multiple factors: therefore, a study may be referred to in more than one section. Detailed descriptions of the study's methods are presented the first time the study is cited, and subsequent citations focus mainly on the findings.

Initially, the literature search focused specifically on examining factors that influence the provision of hospice care for children. However, there was very limited research available on hospice organizations (IOM, 2003). As a result, the broader health services research literature was examined and critically applied to hospice organizations. The rationale for using health services literature was that hospices operate in the US health care system, and thus, it is reasonable to expect that they respond to institutional, resource, organizational, and market influences in a manner similar to other health care organizations. A limitation of using this literature is that many of health services studies were conducted in

health care sectors unrelated to hospice such as substance abuse treatment centers. This makes generalizations to hospice organizations challenging. However, examining the health services literature provided critical information on the relationships that may exist between the study variables and provision of hospice services for children.

### **Influence of Institutional Factors**

Drawing on institutional theory, this study conceptualized the provision of hospice care for children partly as a function of institutional factors. Variables representing institutional factors included accreditation as a coercive demand, membership in professional groups as a normative demand, and the presence of an organization leader to emulate as a mimetic demand.

**Accreditation.** Accredited organizations may be more likely to offer health care services. Organizations may feel compelled to comply with accrediting agencies' rules and regulations because accrediting agencies have the power to confer legitimacy, prestige, control over important resources, or a combination thereof.

Several studies have found that accreditation is associated with the provision of health care, although findings were mixed. Friedmann et al. (1999) found that accreditation was positively related to providing treatment for mental health problems. From the 1995 *National Drug Abuse Treatment System Survey*, they selected a nationally representative sample of outpatient drug abuse treatment organizations ( $N = 597$ ). The provision of the following types of health care services were studied: physical exams, routine medical care, tuberculosis screening, treatment for acute HIV/AIDS conditions, and treatment for mental health problems. The researchers asked outpatient unit directors if their organizations were accredited or not by the Joint Commission, formerly known as the Joint Commission on

Accreditation of Healthcare Organizations (JCAHO). The results of a multivariate regression analysis showed that accredited organizations were more likely to provide mental health care, but not other services. These results suggest that accreditation may exert a coercive pressure on health care organizations to comply with recommended service provisions or risk loss of legitimacy.

Drawing from institutional and resource dependence theories, Campbell and Alexander (2005) also evaluated the influence of accreditation on the provision of health services. Using a sample of outpatient substance abuse treatment organizations from the 1995 and 2000 *National Drug Abuse Treatment System Survey* ( $N= 1,188$ ), the study examined the association of accreditation with the provision of six health services for women: gynecological exams, prenatal care, contraceptive care, physical exams, HIV testing, and mental health care. These services were regarded as sensitive to the needs of women with addiction issues. A logistic regression analysis using generalized estimating equations on the pooled 1995 and 2000 sample was performed. The findings showed that accreditation was positively associated with the provision of two services: contraceptive care and physical exams. The authors concluded that accreditation standards may have exerted coercive demands on health care organizations to provide health care in accordance with industry standards, and they theorized that accreditation standards could be a mechanism for improving access to care.

Wells et al. (2007) also examined the association of accreditation with the provision of health care services in outpatient substance abuse treatment programs. These investigators used the 2000 and 2005 *National Drug Abuse Treatment System Survey* to evaluate the relationship of JCAHO and Council for Accreditation of Rehabilitation Facilities (CARF)

accreditation to provision of six health services: physical examinations, routine medical care, mental health care, individual therapy, group therapy, and employment counseling. They also tested the interactions of each type of accreditation with study years to examine the effects of time. Based on a multivariate logistic regression, accreditation was positively related to the provision of physical examinations and mental health care, but the influence of accreditation on the provision of physical examinations decreased over time.

Pollack and D'Aunno (2010) investigated the role accreditation played in the provision of health care in a longitudinal study of outpatient substance abuse treatment facilities. Also using the *National Drug Abuse Treatment System Survey*, data were collected from a nationally representative sample from 1995 ( $n = 618$ ), 2000 ( $n = 571$ ), and 2005 ( $n = 566$ ). A single item on the questionnaire was used to measure the provision of HIV testing and counseling. A dummy variable was created for whether or not a facility was JCAHO accredited. The multivariate regression analysis indicated that accreditation was positively and significantly associated with the provision of those health care services. The authors posited that health care organizations may comply with accreditation standards because they do not want to risk losing the prestige or the perception of being a quality provider.

Contrary to these findings, Li (2010) found that accreditation had no influence on the provision of health care services. This researcher conducted a longitudinal analysis from 1995 to 2004 using the *National Nursing Home Survey*. Nursing home directors were asked if they provided on-site mental health care to nursing home residents. Accreditation was measured by whether or not a nursing home was accredited by JCAHO, the CARF, or Continuing Care Accreditation Commission. Based on a multivariate regression analysis that accounted for the complex sampling design, Li found that accreditation had no significant

relationship with the provision of health care services over time. The author suggested that the policies on and initiatives for promoting mental health care were inconsistent over the study period, which may have created disincentives for health care organizations to comply with accreditation standards and provide services.

In summary, the literature mostly supported the idea that accredited health care organizations were more likely to provide recommended health care services than those without accreditation. It is reasonable to assume that this finding would extend to the provision of hospice care for children. However, whether or not a service is provided by a hospice organization as a result of accreditation may depend upon whether the service is deemed necessary for patients and clients of the organization based on industry standards and the consistency of those recommendations, as concluded by Li's (2010) study on nursing homes.

**Membership.** Health care organizations that are members of professional groups, alliances, and coalitions may be more likely to offer health care services recommended by those groups. The professional environment defines what is valued and expected by organizational members, and members may feel obliged to comply with normative expectation because of social obligation.

Olden and Clement (2000) examined whether membership in an alliance was associated with the provision of health-promoting services. Data from the 1996 *American Hospital Association (AHA) Annual Survey of Hospitals* were used for this study. Eighteen measures of health-promoting services were studied along with whether or not a hospital was a member of an alliance. Cross-tabulations were performed to analyze the provision of service type by alliance membership. Chi-square and likelihood ratio analyses were

computed for each cross-tabulation. The results of the analyses indicated that members of alliances were more likely to offer health-promoting services compared to nonmembers.

Likewise, Proenca et al. (2003) reported that membership in an alliance was related to the provision of different types of health care services. They used institutional and resource dependence theories to examine the association of alliance membership with the provision of health care. Data for the study came from 3,453 hospitals using the 1995 and 1997 *AHA Annual Surveys*. The surveys asked hospital administrators whether they provided 50 different services. Additionally, they asked whether or not they belonged to an alliance, which was defined as a formal organization that worked on behalf of its individual members. This study used a negative binomial regression model to assess the relationship between alliance membership and the provision of health care. The statistical analysis showed that hospitals' provision of preventive and health-promoting care was positively related to membership.

Similarly, with a sample of 3,447 hospitals, Ginn and Moseley (2004) found that membership in an alliance was associated with the overall provision of health care. The study used data from the 2000 *AHA Annual Survey* and 2000 *Area Resource File* to examine the provision of health care. The multivariate regression results showed that alliance members were more likely to provide health care than nonmembers, after controlling for environmental and organizational factors. Ginn and Moseley concluded that organizations responded to their environments and the demands exerted by alliances. The study provided more support that membership may have facilitated the diffusion of professional expectations, sharing of information, and increased the visibility of industry norms.

Membership in professional groups may have promoted conformity to professional standards and guidelines.

A study conducted in child advocacy centers, however, found that organizations' responses to professional groups' standards are not necessarily uniform. Jackson (2004) explored the adoption and implementation of the National Children's Alliance's standards by its members. The National Children's Alliance adopted standards of care and practice on the investigation, medical treatment, management, and prosecution of child sexual abuse cases in 2000. Using qualitative methods, Jackson interviewed 117 directors of child advocacy centers about the provision of health services they provided for abused children including medical examinations and mental health services. Although Jackson found the standards were widely adopted by members, there was variation in their implementation. For example, all centers provided physical examinations and mental health services, but the numbers and education levels of therapists varied between the centers.

The literature on the relationship between membership in professional organizations and the provision of health care services suggests that hospice organizations that are members of professional groups may be more likely to provide hospice care for children. The power of the professional environment to confer legitimacy may motivate hospice organizations to comply with professional standards and guidelines that recommend providing care for children. Therefore, membership in professional groups, alliances, or coalition may be an important influence on whether or not hospice organizations provide hospice care services for children.

**Organization leader.** Community-based hospice organizations unfamiliar with pediatric hospice care may be influenced to offer care to children when they have an



organization leader in the form of an organization on whom they can model care practices. The hospice care practices of leading children's hospitals are often viewed by the end-of-life community as prototypes to copy (Corr & Corr, 1985). Some recognized institutions include the Cincinnati Children's Hospital Medical Center (Zwerdling et al., 2000), St. Mary's Hospital for Children (Grebin, 2001), Seattle Children's Hospital (Hays et al., 2006), Children's Hospital and Clinics of Minnesota (Friedrichsdorf et al., 2007), and the Children's Hospital Boston (Wolfe et al., 2008). The behaviors of these successful and established hospice programs may provide a reference for other organizations to offer their own services for children.

Health services researchers have shown that organizations are influenced to copy the practices and services of organization leaders. Drawing from institutional theory, Westphal et al. (1997) evaluated the influence of early organization leaders on hospital practices. These investigators used data from the 1985 to 1993 *National Quality Survey* and the JCAHO national accreditation database to evaluate the differences between early and late adopters of total quality management practices ( $N=2,712$ ). The authors developed a scale to measure overall conformity to the 20 quality practices and services. They defined time of adoption as *early adoption* within 2 years of data collection in 1993, or *late adoption*, more than 2 years prior to data collection. The results of a Heckman selection regression model showed that the presence of total management quality practices in early adopters influenced late adopters to mimic these practices.

Krein (1999) conducted an examination of organization leaders' influence on the provision of rural health care services in the US ( $N=13,612$ ) from an institutional perspective. The primary data sources were the 1990 to 1995 *AHA Annual Surveys* of hospitals. The

provision of health care services was defined as whether or not hospitals established rural health clinics. Pressure to imitate other hospitals was measured as the percentage of other rural hospitals within the state that established rural health care services. Based on a logistic regression analysis, the authors found that the provision of rural health care services was related to the pressure to imitate other rural hospitals. The authors suggested that organizations responded to mimetic influences of organization leaders in their area.

The literature supports the notion that the ability to imitate an organization leader's pediatric hospice care may be an important influence on whether or not hospice organizations provide care for children. An organization leader's early experience with pediatric hospice care may be viewed by hospice organizations as a model to follow when faced with the uncertainty of caring for children.

**Critique of the literature.** The review of the literature identified two areas of concern about institutional factors' influences on the provision of hospice care services for children. First, there is a need for studies that specifically examine the provision of care in hospice organizations. No study examined the influence of accreditation or professional membership on hospice organizations. The studies presented here examined outpatient drug abuse centers, outpatient substance abuse treatment facilities, nursing homes, hospitals, and child advocacy centers. The nature and delivery of health care in outpatient substance abuse centers and child advocacy centers, for example, may be sufficiently different from hospice care that generalizing results to hospice organizations should be done with caution.

Second, there is a need for studies that investigate the relationship between institutional factors and the provision of care using current data. Although 80% of the studies were published within the last 10 years, over half used data that were more than 15 years old.

Because of the dynamic and changing environment of hospice organizations, what influenced health care organizations 15 years ago may not exist or be of consequence now. Despite these limitations, this literature provided important evidence of the relationships that may exist between institutional factors and provision of hospice care for children.

**Hypotheses drawn from institutional theory.** Using the hospice and health services literature, key factors based on institutional theory have been identified that may affect the provision of hospice care for children. Institutional theory posits that organizations will comply with the demands of key societal constituents to gain legitimacy for survival (DiMaggio & Powell, 1983). The research reviewed on health care organizations has generally found that accreditation agencies exert coercive pressure on organizations to provide particular health care services. There is sufficient reason to expect the same would hold true for hospice organizations. The organizational literature also reinforced the institutional concept that membership in professional groups typically exerts a normative influence on organizations to provide recommended services. It is logical to anticipate the same response from hospice organizations. Finally, research on organization leaders found that the presence of a successful and established organization leader provided a behavioral example for other organizations to copy. Therefore, the following hypotheses are drawn from institutional theory and prior literature to explain the relation between institutional factors and the provision of hospice care for children:

*Hypothesis 1A(H1A):* Accreditation will be positively associated with the provision of hospice care for children.

*Hypothesis 1B(H1B):* Membership in a professional group will be positively associated with the provision of hospice care for children.

*Hypothesis 1C (H1C):* The presence of an organization leader in pediatric hospice care will be positively associated with the provision of hospice care for children.

### **Influence of Resource Factors**

This study also conceptualized the provision of hospice care for children partly as a function of resource factors based on resource dependence theory. The variables that represented resource factors included other income (i.e., grants and donations) as an important external resource, organizational size as the organization's ability to substitute resources when needed, and competition as the amount of resource competition.

**Other Income.** Hospice organizations often rely on other income sources to fund services. Kozak et al. (2009) described the sources of other income that hospices used to provide complementary and alternative medicine (CAM) hospice services. The sample was 31 hospices offering CAM services in Washington State during 2005. A structured interview was conducted over the phone with a hospice director, administrative nurse, or volunteer coordinator from each organization. The researchers found that 58% of the organizations used donations, special funds, or grants for the provision of CAM services. The authors concluded that income from grants and donations was critical for the provision of costly and unfunded hospice services.

Similarly, a United Kingdom study found that other income was a major source of funding for childhood bereavement services. Using a descriptive study design, Rolls and Payne (2003) explored the location, funding sources, and the range and types of services offered to children who experience the death of a parent or sibling. The authors surveyed 127 hospice organizations. The results were that 13% of the organizations relied solely on external funding in the form of donations and grants to support the services, and a majority

(73%) depended on a combination of external and internal funds. Grants and donations were an important external funding source for the provision of hospice services for children.

These two studies indicate that other income sources may be an important external resource that influences whether or not hospice organizations provide services. Because hospice care for children is often expensive and exceeds private and public insurance funding, hospice organizations use other income such as grants and donations to supplement the financing of their care (Orloff, 2001). Therefore, hospice organizations that lack access to donations and grants may not have the financial resources to provide services for children.

**Organizational size.** Organizational size has been shown to be related to the provision of health care services. Several health services and hospice studies have found that provision of care differs between large- and small-sized organizations (Campbell & Alexander, 2005; D'Aunno et al., 1991; Friedmann et al., 1991; Ginn & Moseley, 2004; Goodrick & Salancik, 1996; Krein, 1999; Li, 2010; Lorenz et al., 2004; Olden & Clement, 2000; Pollack & D'Aunno, 2010; Proenca et al., 2003; Wells et al., 2006, 2007; White et al., 2002). In a study on hospice services provided in acute care hospitals, White et al. (2002) investigated the relationship between organizational size and the provision of hospice care. Data were collected from 3,939 hospitals using the 1998 *AHA Annual Survey*. Organizational size was operationalized as the number of beds in the hospital. The authors created an index of hospice services that included consultation, pain management, and supportive services. Smaller hospitals were significantly less likely than larger hospitals to provide hospice services, as determined by the multivariate regression analysis.

In another hospice study, Lorenz et al. (2004) also showed that organizational size was associated with the provision of hospice care. They analyzed the responses of hospice

organizations ( $N = 149$ ) to the 1997 *CA OSHPD Annual Home Care and Hospice Survey*.

The outcomes of interest included whether or not a hospice provided other hospice services (i.e., chemotherapy, total parenteral nutrition, radiotherapy, transfusions). Organizational size was measured by the log of total patient days. A multivariate regression analysis identified smaller hospice organizations as less likely than larger hospice organizations to provide other hospice services.

The size of hospice organizations, according to these findings, may have an influence on whether or not they provide services. Smaller organizations may not have the flexibility to substitute resources in order to provide care for children. Therefore, the size of a hospice organization may affect whether or not hospice organizations provide care for children.

**Competition.** Competition has been studied frequently in relation to the provision of health care services, although the findings are inconsistent. Thorpe and Phelps (1991) examined the provision of uncompensated care, measured as uncompensated care costs incurred by a hospital, in relation to competition. The study used 1983 data from New York hospitals, and the Herfindahl index was used to measure competition. The regression results showed that hospitals in areas with greater competition were less likely to provide uncompensated care when facility ownership was controlled for. The authors determined that providing uncompensated care services may not have contributed to the organizations' competitive advantage and as a result, organizations were less likely to provide them.

Contrary to that finding, more recent research has shown no effect of competition on the provision of health care services. Using AHA survey data from 2000, Ginn and Moseley (2004) examined the association between competition and provision of health promotion services in hospitals ( $N=3,106$ ). The outcome measure was an index of 14 hospital-based

health promotion services. Competition was measured with the Herfindahl index. A regression analysis showed that competition was not related to the provision of those services.

Lorenz et al. (2004) also examined the relationship between competition and provision of other hospice services. They used data from the 1997 CA OSHPD data set and a telephone survey of hospice chief administrative officers. They defined provision of care as whether or not other hospice services were provided. To determine perceived competition, the survey asked the administrators to estimate the number of hospices against which they competed in their market. Based on a logistic regression analysis, the investigators discovered that competition was unrelated to the provision of other hospice services. These results were contrary to their expectation that competition among hospice organizations would encourage service provision.

Wells et al. (2006) investigated the relationship between competition and the provision of prevention and outreach services in substance abuse treatment centers ( $N = 450$ ). They defined provision of services as whether or not a center provided AIDS-related education, prevention, or outreach services between 1995 and 2000. Competition was measured as the degree of competition perceived by the center director. The results of the logistic regression indicated that competition was not associated with the provision of services.

Drawing from resource dependence theory, Hsieh et al. (2010) explored the association between competition and the provision of uncompensated care in Virginia hospitals from 1998 to 2004. There were between 70 and 74 hospitals studied for each year of the sample with a total of 501 hospital-year observations. Researchers measured

uncompensated care as the total uncompensated care charges divided by the hospitals' average charges per admission and then divided that figure by the number of hospital beds. The Herfindahl index was used to measure competition. Using a bivariate probit model with robust standard errors, Hsieh reported that competition did not affect the provision of uncompensated care. The authors concluded that competition may not lead to fewer resources to subsidize costly, uncompensated care.

Even though the findings from these studies are mixed, it is clear that competition may influence what health care services are provided by organizations. Thus, hospice administrators may reason that providing expensive care to children draws critical financial and human resources away from the main focus of their business, hospice care for the elderly. In addition, providing hospice services for children may not distinguish hospice organizations from their competitors because of the small number of children that utilize hospice care, which therefore, has little competitive benefit. Thus, hospice organizations that experience more competition may be less likely to provide hospice care for children.

**Critique of the literature.** There are a number of limitations identified in reviewing this literature. First, the hospice studies reviewed generally had small sample sizes: 31 organizations (Kozak et al., 2009), 127 organizations (Rolls & Payne, 2003), and 149 organizations (Lorenz et al., 2004). A small sample size may reduce confidence in generalizing results. Therefore, the findings of those studies should be viewed with caution.

Second, the measurement of competition varied across studies. Of the five studies that investigated the relationship between competition and the provision of care, three studies used the Herfindahl index to measure competition (Thorpe & Phelps, 1991; Ginn & Moseley, 2004; Hsieh et al., 2010). One study measured competition based on self-reported responses



from hospice administrators to estimate market competition (Lorenz et al., 2004) and the other study asked directors to self-report the degree of competition they perceived (Wells et al., 2006). The studies with self-reporting did not report the scale used to measure competition.

One study that used the Herfindahl index reported that competition was associated with provision of care (Thorpe & Phelps, 1991) and two other studies found no relationship between them (Ginn & Moseley, 2004; Hsieh et al., 2010). The studies that used self-reported measures all found no relationship (Lorenz et al., 2004; Wells et al., 2006). In comparison to the mathematical formula used to derive the Herfindahl index, the self-reported measurements may not adequately cover the complexities of competition. The validity of the self-reported measures is questionable, and this may provide some explanation for the inconsistent finding in the competition literature. The results of the studies with self-reported measures should be interpreted cautiously. Despite these limitations, the literature provided important evidence of the relationships that may exist between resource factors and the provision of health care.

**Hypotheses drawn from resource dependence theory.** Key factors in the provision of hospice care for children have been identified based on resource dependence theory and the hospice and health services literature. From the resource dependence perspective, hospice organizations that experience a scarcity of critical resources and heavy competition may be less likely to provide resource-intensive care to improve the organization's success and viability (Pfeffer & Salancik, 1978). The theory characterizes three elements of the environment that influence organizations, including external availability of resources, resource substitution, and resource competition. The reviewed studies reinforced that a lack

of financial resources from other income sources may inhibit the ability of organizations to generate a financial buffer in case of resource scarcity, thus making the provision of costly services like children's hospice services unlikely. In addition, researchers found that small organizations were less likely to provide other hospice services, perhaps because they were not able to substitute resources. Finally, the literature indicated that hospice organizations that experience more competition may be less likely to distinguish themselves with service offerings to children. Therefore, the following hypotheses are drawn from resource dependence theory and the reviewed literature to explain the relationship between resource factors and the provision of hospice care for children:

*Hypothesis 2A (H2A):* A lack of other income will be negatively associated with the provision of hospice care for children.

*Hypothesis 2B (H2B):* Small and medium organizational sizes will be negatively associated with the provision of hospice care for children.

*Hypothesis 2C (H2C):* A greater level of competition will be negatively associated with the provision of hospice care for children.

### **Resource Factors as Moderators**

This review of the health services and hospice literature suggests that institutional and resource factors influence the provision of care. Despite the relatively extensive body of literature, it is surprising that there is a lack of research on how these two distinctive forces interact to determine an organization's provision of care. To date most studies have treated institutional and resource factors as independent drivers of provision of care. Yet, resource and institutional forces may interact because of their competing demands on the organization.

Goodrick and Salancik (1986) found that resource constraints diminished the effect of institutional standards on the provision of care. The study used a sample of California hospitals from the California Maternal and Child Health data base ( $N = 319$ ). The investigators examined the direct association of institutional standards, resource constraints, and other organizational characteristics with the provision of cesarean section services from 1978 to 1986. They also tested the moderating effect of resource constraints on the institutional standards - provision of care relationship. A regression model was used to estimate these effects. The researchers found that hospitals with resource constraints were less likely to provide services in the presence of increasing institutional influences. These results suggest that resource factors may interact with institutional factors in health care organizations to influence care provided.

Although this is a single study, it does suggest that resource forces may moderate the institutional demands - provision of care relationship. As Oliver (1991) pointed out, although conformity to institutional pressures may be the most likely response of hospice organizations, organizations may respond by compromise, avoidance, defiance, and manipulation. Resource constraints may act as conditions in which hospice organizations resist conformity to institutional pressures in the provision of hospice care for children. Specifically, the relationship between institutional factors and the provision of hospice care may be weaker when hospice organizations lack access to resources.

**Hypotheses drawn from integrating institutional and resource dependence theory.** The following hypotheses are drawn from institutional and resource dependence theory and the reviewed literature to explain the relationship between institutional factors, resource factors, and the provision of hospice care for children:

*Hypothesis 3A (H3A):* The relationship between institutional factors (i.e., accreditation, membership, and organizational leader) and the provision of hospice care for children will be weaker when hospice organizations lack other sources of income.

*Hypothesis 3B (H3B):* The relationship between institutional factors (i.e., accreditation, membership, and organizational leader) and the provision of hospice care for children will be weaker when hospice organizations are of small or medium size.

*Hypothesis 3C (H3C):* The relationship between institutional factors (i.e., accreditation, membership, and organizational leader) and the provision of hospice care for children will be weaker when hospice organizations face increased competition.

### **Influence of Organizational Factors**

This study also examined organizational factors that may be related to the provision of hospice care. They included geographic location, agency type, ownership, and organizational age.

**Geographic location.** The literature has shown that children, returning to their rural communities from urban-based children's hospitals after medical treatments have been discontinued, increasingly need access rural hospice care (Feudtner et al., 2002, 2007; Lindley et al., 2009). However, many large, rural geographic areas of the US lack hospice care (Campbell et al., 2009; Cox, 1998; Madigan et al., 2009; Virnig et al., 2006). For example, Virnig et al. (2006) demonstrated that most rural areas lacked access to home-based hospice care. In a study of eight states, 62% to 92% of rural counties had no hospice

providers (Madigan et al., 2009). Providing hospice care in rural areas is a challenge because of geography (e.g., driving distance, seasonal driving conditions), practicality (e.g., equipment, power, telephone access) and the inability of rural hospices to attract, retain, and continue providing education for their staff (Campbell et al., 2009; Casey et al., 2005; Heckman, 1998; Lockman-Samkowiak, 1994; McGrath et al., 2007; Waldrop & Kirkendall, 2010). The literature suggests that availability of hospice care service may not match the needs of rural children and their families. Therefore, geographic location may be an important determinant of whether or not hospice care is provided for children.

**Agency type.** Because terminally ill children are increasingly dying at home rather than in the hospital (Feudtner et al., 2002, 2007), they may have a greater need for community-based hospice care provided by home health, freestanding hospice, or long term care facilities. Canadian researchers have reported evidence in support of this assertion. In a study of 317 children, Widger et al. (2007) found that care was received more often in the home (43.9%) as compared to a general hospital unit (27.7%), an intensive care unit (12.3%), a hospice facility (7.7%), or other locations (7.8%). Other researchers reported that between 1999 and 2006, more than 50% of Canadian children received end-of-life care in the hospital, but in 2007 the majority of children received care in a hospice facility (Vandeboncoeur et al., 2009). In another international study, scholars described the types of organizations that provided hospice care to 703 children from Australia, Canada, and the United Kingdom between 2000 and 2006 (Siden et al., 2008). They discovered that care was provided evenly between home (35.1%), hospice facilities (32.1%), and hospitals (31.9%). Researchers in the US suggested that freestanding hospice organizations provided care more often to children than did hospital-based agencies, home health agencies, or nursing homes; however, infants

and school-aged children were more often admitted to nursing homes (Lindley et al., 2009). This literature indicates that hospice care is trending toward community-based providers. Thus, agency type may be related to provision of hospice care for children.

**Ownership.** Community-based hospice organizations are increasingly for-profit organizations (NHPCO, 2009a), and these organizations have been shown to differ in their provision of hospice care compared with nonprofit hospices. Researchers have found that for-profit hospice organizations are often less likely to provide core hospice services (Carlson et al., 2008; Foliart et al., 2001; White et al., 2002) and noncore hospice services (Carlson et al., 2004, 2008; McCue & Thompson, 2005). However, there was no reported difference in their provision of other hospice services (Lorenz et al., 2002). This research suggests that mission differences between nonprofit and for-profit hospice organizations may motivate whether or not hospice care is provided. Therefore, ownership may play a role in the provision of hospice care services offered to children.

**Organizational age.** An organization's age has been associated with its provision of care, although not consistently. Several studies found that the number of years an organization has been in operation was positively related to the provision of health care services (D'Aunno et al., 1991; Dill, 1994; Friedmann et al., 1999). These authors concluded that older organizations may be more willing to provide care to special populations such as children because they have developed ties and a reputation in the health care community for referrals, but less likely to provide new and innovative services because of established routines and practices. Contrary to these findings, other investigators found that older organizations were less likely to provide health care services (Campbell & Alexander, 2005;

Well et al., 2006). This research demonstrates the importance of including organizational age as a variable in this study.

### **Influence of Market Factors**

The market factors that may be associated with the provision of care for children are per capita income, unemployment, and child mortality. The literature on their relationship with the provision of health care services is reviewed in the following section.

**Per capita income.** Several authors reported that increases in county per capita income were associated with the provision of health care services in those counties (Krein, 1999; Wells et al., 2006). In a study of substance abuse facilities, Wells et al. (2006) found that affluent counties were more likely to have available preventive and outreach substance abuse services. Likewise, Krein (1999) reported that per capita income by county was a significant determinant of whether or not organizations provided rural health care. These studies indicate that the ability of families to pay for health care services may motivate providers to supply care services.

**Unemployment.** Similar to per capita income, unemployment is a gauge of the ability to pay for health care services. When families are uninsured, often a consequence of unemployment, they are typically unable to pay medical bills, and the cost of health care is absorbed by the provider. As a result, health care providers, such as hospice organizations, may respond by reducing services, especially ones that are costly and do not generate revenue (Banaszak-Holl et al., 1996; Friedmann et al., 1999; Hsieh et al., 2010; Lee et al., 2004; Orloff, 2001). In a study of outpatient drug abuse treatment organizations, Friedmann and colleagues (1999) found that increases in the percentage of unemployed clients were associated with a decrease in the provision of all health services, especially mental health

care. The authors theorized that the unemployed clients' inability to pay for expensive health care services such as mental health care motivated organizations to curtail their provision of care. This suggests that families without employment may not have the economic means to generate demand for health care services. With limited demand for services, health care organizations may respond by not providing care.

**Child mortality.** A population with more terminally ill children should experience increased demand for hospice care services (Corr & Corr, 1985). When patients have a demand for health care services, provider organizations often meet the demand by providing care. In Wells et al.'s (2007) study of substance abuse treatment centers, the number of HIV-positive patients was positively associated with the provision of a majority of health care services. The authors concluded that when patients have specific health needs, health providers are more likely to offer health services to match the demand. From a hospice perspective, the number of terminally ill children in a community may create a demand for hospice care, and hospice organizations may satisfy that demand by providing services.

## **Summary**

This chapter has reviewed the relevant hospice and health services literature on institutional and resource factors related to the provision of hospice care for children. The review of the literature combined the major tenets of institutional and resource dependency theories and provided support for developing specific hypotheses. The chapter concluded with an examination of organizational and market factors that may also be related to the provision of care for children. A summary of the study hypotheses are presented in Table 1. The next chapter addresses the research methodology used to test the hypotheses developed in this chapter.



Table 1

*Hypotheses and the Expected Influences on the Provision of Hospice Care for Children*

<b>Hypotheses (H)</b>	<b>Factors</b>	<b>Expected Influence</b>
<b>Institutional Factors</b>		
H1A	Accreditation	+
H1B	Membership	+
H1C	Organization leader	+
<b>Resource Factors</b>		
H2A	Lack of other income	-
H2B	Small and medium organization size	-
H2C	Increasing competition	-
<b>Interactions</b>		
H3A	Lack of other income x institutional factors	-
H3B	Small/Medium size x institutional factors	-
H3C	Increasing competition x institutional factors	-

Note: (+) positive association, (-) negative association

## **Chapter 4: Research Methods**

### **Introduction**

This chapter outlines the methods used to describe the characteristics of organizations that provide hospice care services for children and the relationships between institutional factors, resource factors, and the provision of hospice care for children over time. The study design, sampling plan, measures, and data sources will be described. This chapter concludes with a discussion of the data analysis plan.

### **Research Design**

**Study design characteristics.** This research study used a nonexperimental, retrospective design to assess the longitudinal nature of the relationships between institutional and resource factors and the provision of hospice care for children. The study was nonexperimental because the variation in the dependent and independent variables was naturally occurring and there was no intervention (Schutt, 2001; Shadish et al., 2002). The design was retrospective because the provision of hospice care had occurred at an earlier time (Brink & Wood, 1998). Finally, the design was longitudinal because the same hospice organizations were examined over a 7-year time period (i.e., 2002-2008) (Burns & Grove, 2005; Frees, 2004; Ployhart & Vandenberg, 2010). Although experts in longitudinal research suggest that a minimum of 3 years is required to effectively examine change over time (Menard, 2002; Ployhart & Vandenberg, 2010), others have recommended that a minimum of 6 years of data is needed after a baseline measurement to obtain statistically reliable results showing change (Zelinski & Burnight, 1997). Therefore, based on these

recommendations and the work of longitudinal health services researchers (Li, 2010), this study used 7 years of data. The type of longitudinal design was an unbalanced panel meaning that each hospice organization was not observed for each studied year (Menard, 2002).

**Study design and causation.** The extent to which causal explanations could be rendered with a nonexperimental, longitudinal design was limited. There are three necessary conditions for establishing a causal explanation (i.e., a change in one variable leads to a change in another variable with all else being equal) (Schutt, 2001). First, there must be an association between independent and dependent variables. This condition was met by testing whether institutional and resource factors were related to the provision of care. Second, the variation in the dependent variable must occur after the variation in the independent. This condition was addressed by lagging the institutional and resource factors one year prior to the provision of hospice care for children. Third, the relationships between the independent and dependent variables may not have an alternative explanation. This condition was addressed by using statistical controls (i.e., organizational and market factors) to control for the confounding effects on the relationships between independent and dependent variables. Additionally, the possibility of alternative explanations was reduced by testing hypotheses that were deduced from well-established organizational theories (i.e., institutional and resource dependence theories). Although alternative explanations were minimized, it is important to note that nonexperimental studies do not have random assigned control and treatment groups. Thus, there is still present in this study a chance that there is an alternative explanation and that inferences about causation cannot be defended (Brink & Wood, 1998).

**Study design and time.** In line with Polit and Beck's (2004) suggestion on how to treat time in a study, this research used time as a means to enhance research control, establish

the temporal ordering of the independent and dependent variables of interest, and assess change in the dependent variable over time. First, time variables were included to control for the effect of time. Second, the lagged values of the independent and control variables contributed to the temporal ordering necessary for causal explanation (Schutt, 2001). Third, this study examined whether there were changes in the dependent variable over time (Menard, 2002).

### **Data Sources**

This study used six secondary data sets from existing administrative, publicly available sources.

**California Office of Statewide Health Planning and Development.** The main data source for this study was the California Office of Statewide Health Planning and Development (CA OSHPD) *State Utilization Data File of Home Health Agencies and Hospice Facilities* for the years 2002 to 2008. The data files contain information on hospice organizations such as service offerings, agency demographics, and financial information. Participation in the CA OSHPD survey is mandatory for licensed hospice and home health agencies in California, and the survey was administered annually. The quality of the data is assessed through an initial automated review process and then a more rigorous review of potential errors and inconsistencies by OSHPD staff (CA OSHPD, 2006). These files were used to identify the following independent and control variables: accreditation, lack of other income, organizational size, competition, geographic location, agency type, ownership, and organizational age.

**Children's Hospice & Palliative Care Coalition of California.** The second data source, the 2008 Children's Hospice and Palliative Care Coalition (CHPCC) membership

list, was used to collect data on whether or not hospice organizations were members of the CHPCC. Hospice organizations interested in membership complete an online application. The membership list is updated several times a year. The coalition's professional and volunteer marketing staff maintain the membership list. Member information is checked for accuracy prior to online submission by the staff of the Coalition. Organizational names and addresses are posted for public use on the Coalition's website.

**National Association of Children's Hospitals and Related Institutions.** The 2008 National Association of Children's Hospitals and Related Institutions (NACHRI) *Hospital Directory* was the third data source. This database contains the names and county locations of 218 children's hospitals in the US, Canada, Australia, the United Kingdom, Italy, China, Mexico and Puerto Rico. The directory is based on hospital profiles completed and maintained by member hospitals. It is available for public use. For this study, only children's hospitals in California were accessed to determine whether or not a children's hospital was present in the hospice organization's county.

**California Department of Finance.** The fourth data source was the California Department of Finance (CA DOF) *California Income Data* reports from 2002 through 2006. The data for 2006 are the most current available for this study. These reports provide per capita personal income for California counties. They use estimates of personal income from the US Department of Commerce, Bureau of Economic Analysis to derive per capita county income levels. They are part of ongoing administrative data collection of nonconfidential information for public use.

**California Employment Development Department.** The fifth data source came from the California Employment Development Department (CA EDD). The *Monthly Labor*

*Forces Data for Counties* was used to obtain data on unemployment from 2002 to 2008. This database provides annual unemployment rates for California counties. The data are collected from persons filing unemployment claims. The *Monthly Labor Force Data for Counties* are part of ongoing administrative data collection of nonconfidential information for public use.

**California Department of Public Health.** The sixth data source was the 2002 through 2008 *Death Statistical Data Files* from the California Department of Public Health (CA DPH). These files contain death rates by age at the county level. The vital statistics section of the Office of Health Information and Research compile the death statistics from California death certificates. They also conduct audits of the data prior to public release of the statistics. The *Death Statistical Data Files* are part of ongoing administrative data collection of nonconfidential information for public use. Child mortality was obtained from this source.

## **Sample**

**Sampling plan.** The target population for this study was all community-based hospice organizations in California. The list of hospice organizations was derived from the CA OSHPD's survey data sets of 2002 through 2008. The list of organizations comprised the study sampling frame (N=595). The unit of analysis was the hospice organization per year of observation (hospice organization/year). Inclusion criteria were (a) active hospice program licensure and (b) response to the CA OSHPD survey.

There were several exclusion criteria. First, hospice organization/year observations were excluded if organizations were labeled as unknown business entities in the CA OSHPD survey. This was commonly the result of an entity type change (e.g., from home health only

to home health with hospice) in the prior year. In those cases, CA OSHPD did not remove the organization from the survey.

Second, observations were excluded from the sample if an organization ceased business operations or had no patients. Generally, this was the result of an organization going out of business.

Third, duplicate entries were excluded from the sample. Duplication occurred when hospice organizations moved and were assigned a new CA OSHPD identification number in the same survey year. It also occurred when organizations had a name or ownership change. This was verified by confirming that the same organizational data existed in duplicate record.

Finally, observations were excluded from the sample when organizations did not report financial data (i.e., Kaiser Foundation). After applying the inclusion and exclusion criteria, the sample included 311 unique hospice organizations or 1,368 hospice organization observations over 7 years. Figure 3 depicts the sampling schematic for this study.

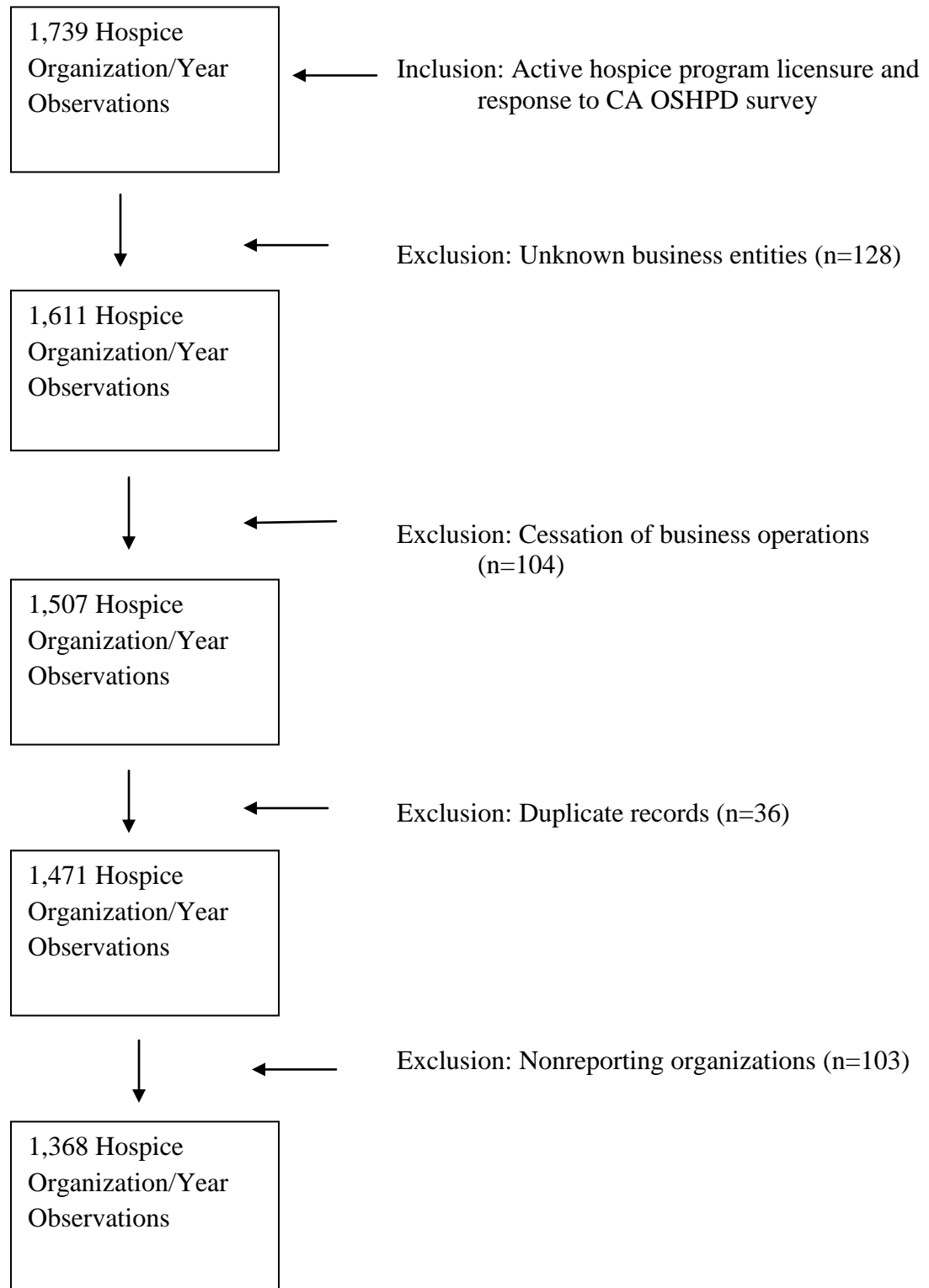


Figure 3. Sampling schematic using the CA OSHPD data set.



**Estimation of sample size.** A power analysis was conducted to determine the minimum sample size necessary to detect a difference in the provision of hospice care for children due to institutional and resource factors, if they existed. Calculations were based on widely accepted conventions for statistical power (0.80), Type II error rate ( $\beta=1-.80=0.20$ ), significance level ( $\alpha=0.05$ ) (Houle et al., 2005). Based on the literature's recommendation, a conservative effect size of 0.20 was used in calculating the sample size (Campbell & Alexander, 2004; McCue & Thompson, 2005, 2006).

A sample size calculator was used for multiple regression (Soper, 2009). Based on 36 regressors (independent variables, control variables, and interaction terms), it was determined that a sample size of 160 hospice organizations or 1,120 hospice/year observations was required. After inclusion and exclusion criteria were applied, the sample size was 311 hospice organizations or 1,368 hospice/year observations. Therefore, this study had sufficient power to detect variation in provision of hospice care at the 0.05 significance level.

## Measures

The measures and sources of the dependent, independent, and control variables are summarized in Table 2.

Table 2.

### *Variables, Definitions, and Data Sources*

Variables	Definitions	Data Sources
<b>Dependent Variable</b> Provision of Care	Whether or not hospice care services were provided for children	CA OSHPD
Core hospice care	Whether or not nursing care, physician, medical social services, or counseling services were provided for children	CA OSHPD

Noncore hospice care	Whether or not home health care, medical equipment and supplies, medications, therapy, inpatient care, or transportation services were provided for children	CA OSHPD
Other hospice care	Whether or not imaging, outpatient care, radiation therapy, or chemotherapy services were provided for children	CA OSHPD
<b>Institutional Factors</b>		
Coercive Demands- Accreditation	Whether or not accredited by ACHC, CHAP, Joint Commission, or other agencies	CA OSHPD
Normative Demands- Membership	Whether or not member of CHPCC	CHPCC
Mimetic Demands- Organization Leader	Whether or not a children's hospital present in the county	NACHRI
<b>Resource Factors</b>		
External Resources- No other income	Whether or not had any other income from grants, donations, unrelated businesses, or other sources	CA OSHPD
Resource Substitute- Organizational size	Small(1-25 patients/day), medium (26-100 patients/day), or large (>100 patients/day)	CA OSHPD
Resource Competition- Competition	1-HHI: Squared sum of each hospice's annual patient days divided by the total patient days in county	CA OSHPD
<b>Organizational Factors</b>		
Geographic location	Urban, rural, or mixed service area	CA OSHPD
Agency type	Freestanding, hospital-based, HHA-based, or LTC-based agency	CA OSHPD
Ownership	For-profit, government, or nonprofit	CA OSHPD
Organizational Age	Log of years licensed to operate in CA	CA OSHPD

<b>Market Factors</b>		
Per capita income	County per capita income	CA DOF
Unemployment	County unemployment rate	CA EDD
Child mortality	Adjusted percentage of child deaths in the county	CA DPH
Time	Years from 2002 to 2008	CA OSHPD

Note. CA OSHPD (California Office of Statewide Health Planning & Development); CA CHPCC (California Children's Hospice & Palliative Care Coalition); NACHRI (National Association of Children's Hospitals and Related Institutions); CA DOF (California Department of Finance); CA EDD (California Employment Development Department); CA DPH (California Department of Public Health); ACHC (Accreditation Commission for Health Care); CHAP (Community Health Accreditation Program); HHA (Home health agency); LTC (Long-term care); HHI (Herfindahl-Hirschman Index).

**Dependent variables.** The primary dependent variable, *provision of care*, was whether a hospice organization provided hospice care for children less than 1 year old to 20 years old in a 12-month period. This binary variable was created by evaluating the number of pediatric patients enrolled in hospice by the hospice organization in the CA OSHPD. The CA OSHPD data set had 12 age groups spanning from 0 to over 91 years of age; however, for this study, only the child age groups 0-1, 2-5, 6-10, 11-20 years old were included. This study coded organizations as "0" if they did not provide service to children, and "1" if they provided care to children.

For the univariate analysis only, additional provision of care variables were created including *provision of core hospice care*, *provision of noncore care*, and *provision of other hospice care*. These variables were created to explore the research question on what hospice care services are provided for children, and whether those services have changed over time.

The variables were derived from detailed financial statements reported by hospice organizations in the CA OSHPD data set. The provision of core hospice care services variable was defined as services that hospice staff must provide to patients per Medicare and Medicaid guidelines. It was operationalized as whether or not a hospice organization provided skilled nursing, physician, social, or counseling services (Carlson et al., 2007; McCue & Thompson, 2005).

Noncore hospice care services included services required per Medicare and Medicaid guidelines, but could be outsourced by the hospice organization. This variable was measured as whether or not home health care/homemaker, medical equipment/supply, medication, inpatient care, transportation, or therapy services were provided (Carlson et al., 2007; McCue & Thompson, 2005). Other hospice care services included services unregulated by Medicare and Medicaid. It was measured as whether or not hospices provided imaging and laboratory, outpatient, radiation therapy, or chemotherapy services (Johnston et al., 2008; Lorenz et al., 2002).

**Independent variables.** The independent variables were grouped into institutional factors and resource factors. All the independent variables were lagged by one year (i.e., the value from the previous year) to assess whether or not the variation in the provision of hospice care for children occurred after the variation in the independent variables (Schutt, 2001). Lagging values enhances causal explanation and minimizes the risk of endogeneity (Menard, 2002). A 1- year lag was selected because organizations typically use the prior year's data to make investment decisions about capital financing, investments, and operational decisions such as providing service (Thorpe & Phelps, 1991; Zelman et al., 2003).

***Institutional factors.*** The first group of independent variables was composed of institutional factors drawn from the constructs of institutional organizational theory that were considered to be associated with the provision of hospice care for children. Coercive demands, as discussed in Chapter 2, are a key construct of institutional theory that explain the constraints placed on organizations to comply with standards, regulations, and rules by key stakeholders. A commonly used variable reflecting coercive demand is *accreditation* (Campbell & Alexander, 2005; Friedmann et al., 1999; Lindley et al., 2009; Pollack & D'Aunno, 2010; Wells et al., 2007). For this study, a binary variable was created based on whether or not a hospice was accredited by the Accreditation Commission for Health Care, Inc. (ACHC), Community Health Accreditation Program (CHAP), Joint Commission, and/or other accrediting agencies. The CA OSHPD provided this measure.

Another construct of institutional theory is normative demands that are derived from pressures exerted by professional groups to conform to a high caliber of professional behavior. *Membership* in professional groups is often used to capture normative demands (Ginn & Moseley, 2004; Jackson, 2004; Lee et al., 2004; Olden & Clement, 2000; Proenca et al., 2003). For this study, a binary measure of whether or not a hospice organization was a member of the CHPCC was created. The membership in professional groups variable was measured by manually reviewing the CHPCC membership list. The names of its member organizations were matched with CA OSHPD list of hospice organizations. Organizations were coded as "1" if they were members of the CHPCC and "0" if they were not.

Finally, mimetic demands characterize the pressure on an organization to imitate the behavior of other successful organizations. A commonly used variable of mimetic demands is the presence of an *organization leader* in the community (Barreto & Baden-Fuller, 2006;

Haunschild & Miner, 1997; Haveman, 1993). For this study, an organization leader was considered to be a children's hospital located in the same county as the hospice from which hospice organizations could copy pediatric care practices. The organization leader variable was measured manually by using the NACHRI hospital directory. Using hospital addresses from the NACHRI directory, the county locations of hospitals were matched with the county locations of hospice organizations in the CA OSHPD database. Organizations were coded as "1" if there was a children's hospital in the county and "0" if there was not.

***Resource factors.*** The second group of independent variables was composed of resource factors drawn from the major constructs of resource dependence theory. The resource dependence theory construct of external resources availability refers to the ability of organizations to access critical resources externally. A number of health care scholars have used *other income* from sources outside of direct patient care as a variable to represent external resources (Beatty et al., 2010; Campbell & Alexander, 2005; D'Aunno et al., 1991; Kozak et al., 2009; Lewis et al., 2003). The lack of other income sources variable was created using the CA OSHPD data set and defined as whether or not the hospice organization had any grant, donation, unrelated business, or other income in a 12- month period.

The construct of resource substitution is generally captured by *organizational size* (Campbell & Alexander, 2005; Goodrick & Salancik, 1996; Lee et al., 2004; Olden & Clements, 2000; Proenca et al., 2003). The organizational size variable was created by calculating total patient days. Using a formula derived from the Government Accounting Office (2004) and commonly used in hospice industry reporting (NHPCO, 2009a), hospice organizations were categorized as small, medium, or large. The guidelines state that small hospice organizations have an average daily census less than or equal to 25 patients per day

in a year. Medium hospice organizations have an average daily census of 26 to 100 patients per day in a year. Large hospice organizations average over 100 patients per day. Large organizations were the referent group. Data on organizational size were obtained from the CA OSHPD.

*Competition* was measured with the Herfindahl-Hirshman Index (HHI), a commonly used economic measure of market competition (Campbell & Alexander, 2004; Carlson et al., 2009; Hsieh et al., 2010; Kim et al., 2009; Lee et al., 2004; Wells et al., 2006). The index is the sum of the squares of the market share of each individual hospice and ranges from 0 (perfect competition) to 1 (monopoly). To calculate the HHI, the total number of patient days for each hospice organization was divided by the total number of hospice patient days in each county. Then, the proportions for each county were squared and summed to create an index for each county. Decreases in the HHI index generally indicate a loss of pricing power and an increase in competition, whereas an increase in the HHI suggests increased pricing power and increased concentration of service. The index was reversed for this study (i.e., 1-HHI) to reflect the shift from monopoly to competition in the market of the hospice. Data for this measure came from the CA OSHPD data set.

**Control variables.** The control variables were grouped into organizational factors and market factors. All the control variables were also lagged by one year.

***Organizational factors.*** Organizational factors were included because they may be associated with the provision of hospice care for children. The *geographic location* variable was categorized by where hospice organizations delivered care: primarily urban, primarily rural, or mixed rural and urban locations (Lindley et al., 2009). Dummy variables were

created for each category, and urban was used as the referent group. Data were obtained from the CA OSHPD data set.

*Agency type* was measured categorically in terms of whether organizations were freestanding, hospital-based, home health -based, or long-term care-based, using data from the CA OSHPD (Kirby et al., 2007; Lindley et al., 2009; Smith et al., 2008; Stevenson et al., 2007). Dummy variables were created for the categories and the referent group was freestanding agencies.

Dummy variables were also created for *ownership*, which was operationalized as to whether a hospice organization was for-profit, government, or nonprofit (Hanson et al., 2010; Olden & Clements, 2000). The referent group was for-profit organizations, and data were obtained from the CA OSHPD.

Additionally, the total number of years a hospice organization was licensed in California was the measure for *organizational age* (Campbell & Alexander, 2005; D'Aunno et al., 1991; Friedmann et al., 1999; Russell et al., 2010; Wells et al., 2006). These data were obtained from the CA OSHPD.

***Market factors.*** The second group of control variables was comprised of market factors likely to be related to the provision of hospice care for children. *Per capita income* was obtained from the CA DOF. The total annual county income was divided by the number of people in the county (Hsieh et al., 2010; Krein, 1999; Magnus et al., 2004; Well et al., 2006). It was then rescaled by a factor of 10,000 because the small coefficient estimate was off scale.



The rate of *unemployment* was the percentage of the work force unemployed in the county annually (Alexander & Wells, 2008; Hsieh et al., 2010; Lee et al., 2004; Magnus et al., 2004). These data came from the CA EDD.

The rate of *child mortality* was the annual percentage of child deaths in the county adjusted for accident- and injury related deaths (Campbell & Alexander, 2005). This information came from the CA DPH. Finally, a set of year dummy variables was included to control for calendar-year specific effects.

### **Data Analysis Plan**

All analyses were conducted using Stata 11.0 (StataCorp LP). Statistical significance was assessed at  $p < 0.05$ .

**Univariate analysis.** Standard descriptive statistics for all study variables were calculated to examine the data for anomalies and to ensure that the assumptions of all analyses were met. The means, percentiles, minimums, maximums, and standard deviations were used to describe sample characteristics. Summary statistics, box plots, and histograms were used to evaluate the distribution of variables and assess the data for outliers.

**Bivariate analysis.** To describe the characteristics of organizations and how they changed from 2002 to 2008, tables, charts, and multiple time-series plots were generated. Trends across years were assessed with an extension of the Wilcoxon rank-sum test (StataCorp, 2009). This test evaluated whether responses systematically increased or decreased. In addition, correlations between study variables were assessed using Pearson product-moment correlation coefficients.

### **Multivariate analysis.**

**Generalized estimating equations.** Generalized estimating equations (GEE) was the primary statistical method used in this study. It was used to test the hypotheses generated from the research question about the nature of the relationship between institutional and resource factors and the provision of hospice care to children and changes in the relationships over time. GEE is a quasi-likelihood and marginal-based method of estimation. Marginal models, sometimes called population average models, generate estimates that describe changes in the population mean given changes in the independent variables (Hardin & Hilbe, 2003). There are two assumptions in GEE: the distribution of the mean of the outcome or variance function is correctly specified, and any data that are missing are missing completely at random (Twisk, 2004). These models do not assume that dependent or independent variables are normally distributed, nor do they assume that observations are independent.

The GEE approach is a widely used statistical method in the analysis of longitudinal data (Liang & Zeger, 1986). It is frequently used to evaluate binary and categorical dependent variables with longitudinal, nested, or repeated measures data (Zeger & Liang, 1986). Such models account for non-independent observations often present in longitudinal studies. A key assumption of ordinary least squares regression analysis is that observations are independent of each other. However, in longitudinal studies subjects are measured over time on the outcome of interest and those measurements are not independent. For example, an organization's provision of hospice care for children in one year may be related to its provision in the next year because the organization has gained the knowledge, skills, and abilities to provide care. The correlation of these errors must be accounted for to obtain valid inferences. If autocorrelation is positive, then the standard errors are too small. If autocorrelation is negative, then standard errors are too large (Woolridge, 2000).

*GEE model specifications.* Fitting a GEE model requires specification of a variance function, link function, and working correlation structure (Ballinger, 2004; Fitzmaurice et al., 2004; Zeger & Liang, 1986). For this analysis, the binary and discrete distribution of the dependent variable suggested a binomial variance function. Although other functions were possible including Gaussian, gamma, negative binomial, and Poisson, the binomial was the best-suited choice. There are no formal tests for the variance function assumption in GEE; however, GEE requires that the variance function is correctly specified for unbiased parameter estimates.

Additionally, this analysis used a logit link function. A link function specifies the regression model. Options for the link function included log, identity, logit, probit, power, odds power, negative binomial, and reciprocal. The link function options were narrowed to logit or probit because of the binary nature of the dependent variable. Logit and probit link functions are the most common. The choice of link function is often motivated by the researcher's field, computational simplicity, and availability of software because there is no formal test for it (Molefe & Hosmane, 2007). Although the estimates obtained from the logit and probit models are almost identical, the reporting of estimates as odds ratios in logit regression makes interpretation of results easier than in probit regression, and the logit link function was chosen for that reason.

Finally, this study used an unstructured working correlation structure to specify the relationship between observations of the same organization. There are four primary options for a working correlation structure including independent, unstructured, autoregressive, and exchange. First, an independent correlation structure assumes there is no correlation between observations on the same hospice organizations or that observations are independent. In other

words, providing care for children in one year would be independent of whether an organization provided care in another year. Second, an unstructured correlation structure imposes no preconceived notions about the correlation among responses over time. Third, an autoregressive correlation structure assumes a decreasing correlation over time between observations. That structure is recommended if measurements are unequally timed. Finally, an exchange correlation structure assumes that observations on the same hospice organization covaried equally across all time points. This structure is equivalent to a random effects model with a random intercept per organization.

When using GEE, the working correlation structure is not required to be correctly specified for parameter estimates to be consistent. However, a misspecified model is less efficient (Kuchibhatla & Fillenbaum, 2003; Lee et al., 2007; Liang & Zeger, 1986; Schildcrout & Heagerty, 2005). Although there are several methods for identifying working correlation structures (Crespi et al., 2009; Hin & Wang, 2009; Shults et al., 2009), the *quasilikelihood under the independence model information criterion* (QIC) is a widely accepted method of comparing and specifying working correlation structures (Cui, 2007; Gardiner et al., 2009; Pan, 2001). For this study, the four working correlation structures were tested in a GEE model using the QIC method. The QIC scores were generated for each working correlation structure (Cui, 2007). The best working correlation structure corresponds to the simplest structure that fits the data well or the lowest QIC value (Kuchibhatla & Fillenbaum, 2003). Table 3 lists the QIC values for each working correlation option.

Table 3.

*Working Correlation Structure QIC Results*

<b>Working Correlation Structure</b>	<b>QIC</b>
Independent	1769*
Exchange	1769*
Unstructured	1769*
Autoregressive	1782

*Note.* QIC = Quasilikelihood under the independence model information criterion. \* Lowest QIC score

Although the QIC scores were the same for independent, exchange, and unstructured working correlation structures, this study used the unstructured working correlation structure because it is the least restrictive and most commonly used working correlations structures.

*GEE model performance.* No standard measures of goodness-of-fit for GEE exists and traditional measures of goodness of fit are problematic because GEE is not based on full information maximum likelihood and no likelihood exists (Hardin & Hilbe, 2003). Thus, likelihood-ratio tests for the model of fit are not available for GEE (Zorn, 2001). Several methods of measuring goodness-of-fit statistics for GEE models have been suggested including covariate partitioning (Barnhart & Williamson, 1998), ranked estimated probabilities (Horton et al., 1999), and residuals (Pan, 2002; Oh et al., 2010).

However, in a comparison of goodness-of-fit statistics for GEE models, Evans and Li (2005) suggested chi-square was most appropriate for models that contained continuous and categorical covariates. Chi-squared is a commonly used measure of goodness of fit in GEE (Hardin & Hilbe, 2003; Horton et al., 1999; Kuchibhatla & Fillenbaum, 2003). Therefore, this study used the chi-square test to measure the goodness-of-fit of the GEE model. The test

was statistically significant ( $X^2 = 174.71, p < .001$ ), and the GEE model with semi-robust standard errors fit the set of observations well.

Although the GEE model performed well, the performance of other statistical models were also evaluated for this study including a fixed effects linear probability model (LPM) with clustered standard errors. First, the mean prediction from the LPM was compared to the mean value of the dependent variable. The predicted and actual probabilities were the same at 0.33. Therefore, LPM provided unbiased estimates. Second, predicted values were assessed for out-of-range values because the dependent variable was binary with values between 0 and 1, and LPM allows values to go outside the range of 0 and 1. Over 25% of the observations in the LPM were outside the range of 0 to 1. Therefore, LPM was not as efficient as models that estimate parameters within the range of 0 to 1. Third, the signs on coefficients were assessed against expectations. Approximately half of the coefficient signs had different signs than expected. As a result, the LPM was not selected as the primary statistical estimation method for this study; however, the LPM was included in a sensitivity analysis to compare how the responses of individual hospices to the provision of hospice care for children differ from the that of a population of hospice organizations in the GEE model.

Other performance assessments included evaluating transformed variables. The untransformed, quadratic, and logarithmic forms of the *organizational age* variable were assessed with the QIC method (Cui, 2007). Based on this evaluation, the logarithmic form of the *organizational age* had the lowest QIC and was included in the model. These results are summarized in Table 4.

Table 4.

*Organizational Age Variable QIC Results*

<b>Variable Forms</b>	<b>QIC</b>
Age	1436.03
Log Age	1432.80*
Age and Age <sup>2</sup>	1433.96

*Note.* QIC = Quasilikelihood under the independence model information criterion. \* Lowest QIC score

*GEE and missing data.* There were challenges in using GEE especially with regard to missing data. To provide valid inferences, the missing data have to meet the assumption of being missing completely at random. However, in longitudinal studies data are often missing by design. For example, organizations may not report financial data because of company policy. This may result in estimates that are unpredictable and invalid (Ballinger, 2004; Twisk, 2004). Several methods of handling missing data within the GEE framework have been proposed including dropping incomplete data, imputation, and weighted estimating equations (Kuchibhatla & Fillenbaum, 2003; Twisk, 2004). For this study, missing data were managed depending upon the frequency and concentration of missing values across observations. Twenty-three observations had missing data for the geographic location of service and these values were imputed with the last observation carried backwards from 2008 because this was the most comprehensive and complete year of data on the geographic location variable (McKnight et al., 2007). In addition, 103 observations from 16 organizations had missing financial data in every year of the study. These observations were

dropped from the study. Therefore, this study presented a minimal risk of violating the GEE assumption of data missing complete at random.

***Moderated regression analysis.*** A moderated regression analysis was used to test the moderating hypotheses in this study that predicted that fewer resources would attenuate the effect of institutional factors on the provision of hospice care for children over time.

Following the approach of Baron and Kenny (1986), this study used interaction terms to test the moderating effect of resource factors. Using block-wise entry of variables into the regression model, the first step was to enter the control variables. The second step was to enter the direct effects of institutional and resource factors. The third step was to enter the multiplicative terms reflecting the interactions between institutional and resource factors.

The Wald test was used to test the statistical significance of the moderator variables (Aiken & West, 1991). If a significant interaction existed, interpretation of the moderating effect included plotting the regression lines representing the relationship between the predictor and the outcome at specific values of the moderator variable (Cohen et al., 2003).

## **Limitations**

There were a number of methodological limitations in this study. The first concern was the potential for measurement error. For example, the CA OSHPD did not use standardized definitions for the geographic location or agency type variables. In the case of geographic location, organizations responded to the survey question whether or not they provided care in primarily urban, primarily rural, or mixed rural and urban areas. No definition was provided specifying what urban or rural meant (e.g., no population size given).

In addition, self-reported data risks response bias that affects measurement quality by introducing a lack of precision into the research. Although data gathered through self-report



methods are relatively easy to collect and come directly from the participant, respondents may be unwilling or unable to respond accurately. For example, hospice organizations might have reported no financial information in years when they experienced negative financial performance. In this study, the potential for measurement inaccuracies may have biased the estimates of the relationship between institutional and resource factors and provision of care. Other risks included incomplete or absent responses to survey questions, lack of objectivity of individual survey respondents, variability in interpretation of item wording and responses, concerns about the possible impact of survey results, and difficulty of respondents in characterizing complex concepts in terms of simple responses.

Finally, there were limitations to using GEE (Ballinger, 2004). Errors in the specification of the working correlation matrix can lead to a loss of efficiency in the model and to different assessments of standard errors. In addition, the form of missing data in the analysis, especially if data are missing completely at random, may result in interpretable results. Unlike longitudinal fixed effects models, GEE does not control for unobserved time-invariant covariates.

Keeping in mind these potential limitations, the use of GEE provided important benefits for this study. First, GEE appropriately addressed the violation of the independence assumption present in this longitudinal study. Second, GEE is applicable to models with dichotomous outcome variables such as whether or not organizations provide hospice care for children (Frees, 2004; Liu et al., 2009). Twisk (2004) suggested that in studies with a dichotomous outcome variable, GEE provides more efficient parameter estimates than linear probability and random coefficient analysis. Finally, GEE uses all available data for analysis by simultaneously estimating the parameters and the covariance structure, and it incorporates

robust standard errors (Horton & Lipsitz, 1990; Twisk, 2004). Therefore, GEE provided efficient and unbiased estimates of the relationship between institutional factors, resource factors, and the provision of hospice care for children, and it improved confidence in the results and conclusions.

### **Summary**

This chapter outlined the specific research methods used in this study. It began with a description of the research design, followed by a discussion of the sampling plan. In addition, the results of the power analysis were presented. Then the chapter introduced the study variables and described how they were measured. The secondary data sources were described. Finally, the data analysis plan was presented and the reasoning behind it was outlined.

## **Chapter 5: Results**

### **Introduction**

This chapter presents the results of the empirical analyses. The following areas are included in the current chapter: description of the final study sample, description of study variables, results of the regression analyses related to the proposed hypotheses, and results of a sensitivity analysis comparing estimation models.

### **Study Sample**

All community-based hospice organizations in the State of California from 2002 through 2008 were the target population for this study. The original study sample contained a total of 1,739 hospice organization-year observations. Of these, 128 observations were omitted because they were labeled as unknown business entities in the CA OSHPD survey. An additional 104 observations were removed because the hospice organization ceased business operations. Observations were also deleted for 36 duplicate organizations. Additionally, all observations with missing data on the dependent variable of the provision of hospice care for children were removed, leaving 1,368 hospice organization observations over 7 years. A slight variation in sample size for the lagged regression analysis was used due to different numbers of hospice organizations with complete data for both panels in the lag. The lagging of all the independent variables by one year resulted in 1,036 observations.

## Description of Study Variables

**Sample statistics.** The characteristics of the study sample are presented in Table 5. These statistics are at the organization-year level ( $N=1,368$ ). Slightly more than 33% of the sample provided hospice care during the study time frame.

Table 5

*Descriptive Statistics of Study Variables (N=1,368)*

Variable	Percentage/ Mean	Standard Deviation	Minimum	Maximum
<b>Dependent Variable</b>				
Provision of care for children	33.6%	---	0.00	1.00
<b>Institutional Factors</b>				
Accreditation	46.5%	---	0.00	1.00
Membership	17.3%	---	0.00	1.00
Organization leader	58.2%	---	0.00	1.00
<b>Resource Factors</b>				
No other income	56.1%	---	0.00	1.00
Organizational size				
Large	17.6%	---	0.00	1.00
Medium	47.7%	---	0.00	1.00
Small	34.7%	---	0.00	1.00
Competition	0.72	0.28	0.00	0.96
<b>Organizational Factor</b>				
Geographic location				
Urban	60.3%	---	0.00	1.00
Rural	8.9%	---	0.00	1.00
Mixed	30.8%	---	0.00	1.00
Agency type				
Freestanding	64.4%	---	0.00	1.00
Hospital-based	15.0%	---	0.00	1.00
HHA-based	17.5%	---	0.00	1.00
LTC	3.1%	---	0.00	1.00
Ownership				
For profit	52.2%	---	0.00	1.00
Government	5.3%	---	0.00	1.00
Nonprofit	42.5%	---	0.00	1.00
Organizational age	9.22	8.12	1.00	42.00
<b>Market Factors</b>				

Per capita income (\$000)	36.1	9.6	18.80	86.10
Unemployment	6.0%	2.0%	3.00	22.00
Child mortality	2.0%	1.0%	0.00	11.00

Less than half of the hospices (47%) were accredited by the ACHC, CHAP, Joint Commission, or other accrediting agencies. Additionally, hospice organizations were commonly not members of the CHPCC. For organization leaders in pediatric care, 58% of hospices had a pediatric hospital that served that function in their community.

Table 5 also summarizes the organizations' resource factors. More than half the hospice agencies in the study did not have access to other income sources in the form of grants, donations, or unrelated business revenue. Most hospices were of medium size with 26 to 100 patient/days. Competition, as determined by the Herfindahl-Hirshman Index, ranged from 0.00 to 0.96, indicating wide variability in the level of competition.

With respect to organizational factors, most hospice organizations provided hospice services in urban communities. Freestanding hospice agencies were the most common, and hospices associated with long-term care were the least common type of facility. Over half of the hospices were for profit. On average, hospices were 9 years old with a range from 1 year to 42 years.

Hospice organizations operated in counties with an average per capita income of \$36,141, but per capita income ranged widely from \$18,829 to \$86,062. Unemployment in the hospice's county also varied substantially from 3% to 22%. The average annual unemployment rate by county was 6%. Although the average child mortality rate in the counties was 2%, some counties experienced no mortalities and the rate in other counties was as high as 11%.

**Sample statistics by year.** Descriptive statistics for the study variables are presented by year in Table 6. These statistics provide information on hospice organizations included in the sample for the years 2002 to 2008. A test statistic (*F*-value) is also provided to assess whether there was a change across years. The average number of hospice organizations offering care for children declined from 40% in 2002 to 28% in 2008. This statistically significant change over study years is graphically illustrated in Figure 4.

Institutional factors were relatively unchanged during the study with the exception of accreditation. In 2002, 56% of hospices in the study were accredited; however, by 2008 only 39% were accredited. This change was statistically significant. On average, most hospices were not members of the CHPCC during the study, and a majority of hospices were located in a county with a pediatric hospital from 2002 through 2008.

Resource factors also remained generally constant from 2002 to 2008. Hospices, on average, did not have other income sources. The organizational size changed little during the study. Competition, however, significantly increased from 0.67 in 2002 to 0.77 in 2008.

Several organizational factors fluctuated during the study period. There was a dramatic and significant increase in the number of freestanding agencies (54% in 2002 and 71% in 2008), and an equally significant decrease in the number of hospital-based agencies (23% in 2002 and 10% in 2008), although the number of HHA-based and LTC agencies remained constant from 2002 to 2008. For-profit ownership steadily and significantly increased each year of the study while nonprofit status steadily declined. From 2002 to 2004 a majority of hospices were nonprofit; however from 2005 through 2008 more hospices were for profit than nonprofit. The most common geographic location of care was urban in all

Table 6

*Descriptive Statistics of the Study Variables by Year (N=1,368)*

	Year		2002		2003		2004		2005		2006		2007		2008		F-statistic
	N	Statistics	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	
<b>Dependent Variable</b>																	
Provision of care for children			0.40	(0.49)	0.44	(0.50)	0.37	(0.48)	0.31	(0.46)	0.33	(0.47)	0.27	(0.45)	0.28	(0.45)	3.48**
<b>Institutional Factors</b>																	
Accreditation			0.56	(0.50)	0.51	(0.50)	0.52	(0.50)	0.49	(0.50)	0.45	(0.50)	0.40	(0.49)	0.39	(0.49)	3.31*
Membership			0.22	(0.42)	0.19	(0.39)	0.20	(0.40)	0.19	(0.39)	0.17	(0.38)	0.15	(0.35)	0.13	(0.34)	1.26
Organization leader			0.53	(0.50)	0.56	(0.50)	0.57	(0.50)	0.59	(0.49)	0.59	(0.49)	0.60	(0.49)	0.61	(0.49)	0.51
<b>Resource Factors</b>																	
No other income			0.54	(0.50)	0.56	(0.50)	0.56	(0.50)	0.53	(0.50)	0.54	(0.50)	0.57	(0.50)	0.61	(0.49)	0.65
<b>Organizational size</b>																	
Large			0.11	(0.32)	0.16	(0.36)	0.17	(0.38)	0.22	(0.42)	0.21	(0.41)	0.17	(0.38)	0.17	(0.38)	1.43
Medium			0.54	(0.50)	0.49	(0.50)	0.50	(0.50)	0.47	(0.50)	0.48	(0.50)	0.47	(0.50)	0.44	(0.50)	0.72
Small			0.35	(0.48)	0.35	(0.48)	0.33	(0.47)	0.31	(0.46)	0.32	(0.47)	0.36	(0.48)	0.39	(0.49)	0.84
Competition			0.67	(0.31)	0.68	(0.30)	0.70	(0.29)	0.71	(0.29)	0.73	(0.28)	0.75	(0.26)	0.77	(0.25)	3.36**
<b>Organizational Factors</b>																	
Geographic location																	

Urban	0.58	0.62	0.61	0.60	0.61	0.61	0.60	0.14
	(0.50)	(0.49)	(0.49)	(0.49)	(0.49)	(0.49)	(0.49)	
Rural	0.10	0.10	0.09	0.09	0.09	0.08	0.08	0.21
	(0.30)	(0.30)	(0.28)	(0.29)	(0.28)	(0.26)	(0.28)	
Mixed	0.32	0.28	0.30	0.31	0.31	0.32	0.32	0.21
	(0.47)	(0.45)	(0.46)	(0.47)	(0.46)	(0.47)	(0.47)	
Agency type								
Freestanding	0.54	0.58	0.62	0.62	0.70	0.71	0.71	3.69**
	(0.50)	(0.50)	(0.49)	(0.49)	(0.47)	(0.46)	(0.45)	
Hospital-based	0.23	0.17	0.19	0.15	0.14	0.12	0.10	2.82**
	(0.42)	(0.38)	(0.39)	(0.36)	(0.35)	(0.32)	(0.30)	
HHA-based	0.23	0.23	0.17	0.19	0.15	0.15	0.15	1.64
	(0.42)	(0.42)	(0.38)	(0.39)	(0.36)	(0.35)	(0.35)	
LTC	0.01	0.02	0.02	0.04	0.04	0.03	0.04	0.94
	(0.08)	(0.15)	(0.15)	(0.20)	(0.20)	(0.17)	(0.19)	
Ownership								
For profit	0.41	0.42	0.47	0.50	0.53	0.61	0.63	6.01***
	(0.49)	(0.49)	(0.50)	(0.50)	(0.50)	(0.49)	(0.48)	
Government	0.06	0.06	0.06	0.06	0.05	0.05	0.04	0.34
	(0.24)	(0.24)	(0.23)	(0.24)	(0.23)	(0.22)	(0.19)	
Nonprofit	0.53	0.52	0.48	0.44	0.42	0.34	0.34	5.12***
	(0.50)	(0.50)	(0.50)	(0.50)	(0.49)	(0.47)	(0.47)	
Organizational age	9.24	9.34	9.44	9.66	9.29	8.85	8.95	
	(8.51)	(8.38)	(8.13)	(7.89)	(7.87)	(7.87)	(8.36)	
Market Factors								
Per capita income (\$000)	32.1	32.8	34.6	36.3	38.6	38.3	37.8	15.31***
	(8198)	(7960)	(8571)	(9512)	(10151)	(9669)	(9592)	
Unemployment	0.07	0.07	0.06	0.06	0.05	0.05	0.07	58.99***
	(0.02)	(0.02)	(0.02)	(0.02)	(0.01)	(0.02)	(0.02)	
Child mortality	0.02	0.02	0.02	0.02	0.02	0.02	0.02	1.02
	(0.01)	(0.01)	(0.01)	(0.03)	(0.01)	(0.01)	(0.01)	

\* $p<0.05$ , \*\* $p<0.01$ , \*\*\* $p<0.001$



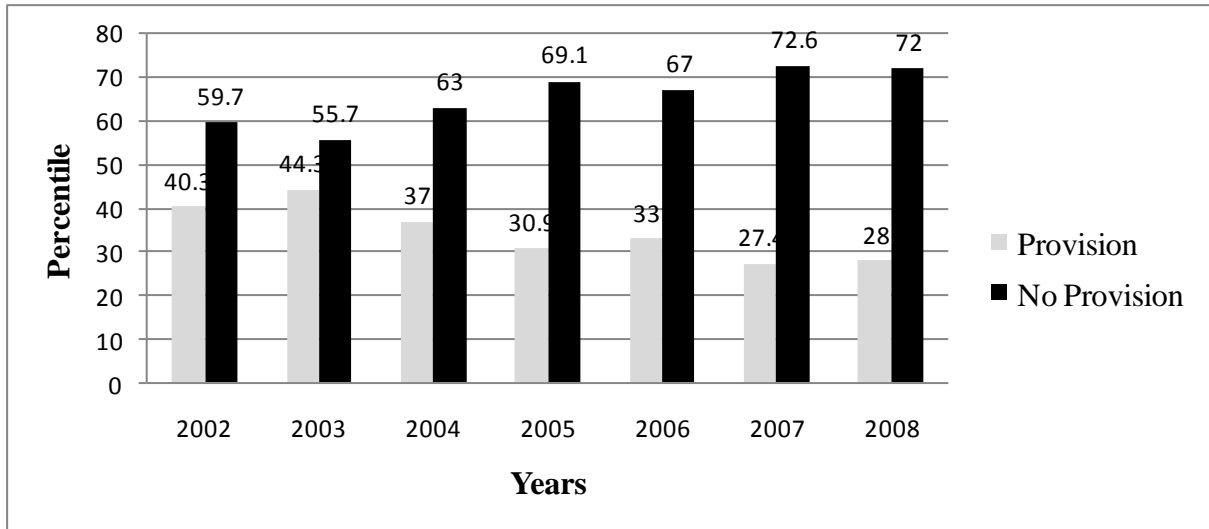


Figure 4. Provision of hospice care for children from 2002 to 2008.

years of the study, otherwise there was very little change in where care was provided.

Finally, the average age of hospices remained constant during the study.

In terms of market factors, the mean per capita income increased gradually from \$32,111 in 2002 to \$38,349 in 2007 and fell slightly to \$37,772 in 2008. The average county-wide unemployment rate declined from 7% in 2002 to 5% in 2007, and then rose again to 7% in 2008. The mean child mortality at the county level was unchanged at 2% during the study period.

**Correlation matrix.** Table 7 displays the correlations (Pearson product-moment correlation coefficients [ $r$ ]) among dependent, independent, and control variables in the study. The dependent variable, provision of care for children, was significantly correlated with many of the independent and control variables. Professional membership ( $r = 0.20$ ), medium-sized organizations ( $r = 0.13$ ), large-sized organizations ( $r = 0.24$ ), nonprofit

organizations ( $r = 0.26$ ), and organizational age ( $r = 0.26$ ) were positively correlated with provision of hospice care for children.

Significant negative correlations were present between provision of hospice care for children and the variable of the presence of an organization leader ( $r = -0.21$ ), no other income ( $r = -0.18$ ), small-sized organizations ( $r = -0.33$ ), competition ( $r = -0.25$ ), and for-profit status ( $r = -0.25$ ).

Additionally, Table 7 shows that many of the independent and control variables are correlated with each other. This raises concerns about multicollinearity. Although study variables strongly correlated to each other do not violate assumptions of GEE, they do have the potential to increase the standard errors of parameter estimates (Woolridge, 2000).

Correlations higher than 0.90 are said to be multicollinear, and one of the two variables must be dropped to determine their independent effects, whereas correlations between 0.70 and 0.90 raise concerns about multicollinearity and are worth investigating (Tabachnick & Fidell, 1996). Only two correlations equaled or exceeded 0.70 ( $r = -0.82$  between urban and mixed service areas and  $r = -0.90$  nonprofit and government). These correlations were accepted as is because no correlations were greater than 0.90 in this study. Therefore, multicollinearity was not a serious problem.

Table 7

*Correlations Between the Study Variables*

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23
1. provision	1.000																						
2. accredit	0.042	1.000																					
3. member	<b>0.198</b>	-0.043	1.000																				
4. leader	-0.212	-0.161	0.059	1.000																			
5. no income	-0.183	-0.121	-0.070	<b>0.212</b>	1.000																		
6. small	-0.326	-0.101	-0.232	<b>0.550</b>	<b>0.125</b>	1.000																	
7. medium	<b>0.131</b>	<b>0.196</b>	0.008	-0.158	-0.118	-0.696	1.000																
8. large	<b>0.236</b>	-0.131	<b>0.280</b>	<b>0.139</b>	-0.001	-0.337	-0.441	1.000															
9. competition	-0.254	-0.076	0.016	<b>0.678</b>	<b>0.342</b>	-0.015	-0.053	0.088	1.000														
10. urban	-0.073	-0.081	0.027	<b>0.438</b>	<b>0.067</b>	-0.018	-0.083	<b>0.131</b>	<b>0.424</b>	1.000													
11. rural	0.019	0.035	-0.129	-0.279	-0.186	<b>0.168</b>	-0.055	-0.137	-0.460	-0.385	1.000												
12. mixed	0.066	0.064	0.051	-0.292	0.044	-0.084	<b>0.122</b>	-0.055	-0.166	-0.823	-0.208	1.000											
13. freestand	-0.025	-0.354	<b>0.135</b>	<b>0.178</b>	<b>0.097</b>	-0.013	-0.082	<b>0.123</b>	<b>0.128</b>	0.019	-0.070	0.023	1.000										
14. hospital	0.034	<b>0.353</b>	-0.144	-0.145	-0.077	0.049	0.061	-0.141	-0.183	-0.085	<b>0.207</b>	-0.037	-0.566	1.000									
15. HHA	0.036	<b>0.135</b>	-0.048	-0.098	-0.105	-0.040	0.058	-0.026	-0.017	0.066	-0.082	-0.019	<b>0.619</b>	-0.194	1.000								
16. ltc	-0.082	-0.047	0.031	0.022	<b>0.123</b>	0.022	-0.026	0.007	0.063	-0.020	-0.055	0.056	-0.239	-0.075	-0.082	1.000							
17. forprofit	-0.247	-0.326	-0.061	<b>0.319</b>	<b>0.443</b>	<b>0.117</b>	-0.186	0.097	<b>0.450</b>	<b>0.134</b>	-0.212	-0.012	<b>0.392</b>	-0.428	-0.146	<b>0.119</b>	1.000						
18. govt	-0.029	0.043	-0.039	-0.013	-0.023	0.124	-0.041	-0.100	-0.126	-0.124	0.261	-0.030	-0.146	0.212	-0.014	-0.004	-0.246	1.000					
19. nonprofit	<b>0.262</b>	<b>0.310</b>	<b>0.079</b>	-0.317	-0.437	-0.174	<b>0.206</b>	-0.053	-0.397	-0.080	0.096	0.025	-0.330	<b>0.336</b>	<b>0.153</b>	-0.119	-0.899	-0.203	1.000				
20. age	<b>0.260</b>	<b>0.173</b>	<b>0.108</b>	-0.250	-0.251	-0.328	<b>0.224</b>	<b>0.117</b>	-0.322	-0.077	0.084	0.030	-0.341	<b>0.238</b>	<b>0.251</b>	-0.100	-0.483	0.054	<b>0.464</b>	1.000			
21. income	-0.071	-0.108	<b>0.187</b>	<b>0.209</b>	0.020	-0.119	0.022	<b>0.120</b>	<b>0.212</b>	<b>0.288</b>	-0.214	-0.173	0.096	-0.159	0.014	0.032	0.010	-0.091	0.031	0.091	1.000		
22. unemployed	0.099	0.062	-0.050	-0.319	-0.097	<b>0.120</b>	0.005	-0.157	-0.357	-0.272	<b>0.214</b>	<b>0.157</b>	-0.031	0.081	-0.025	-0.025	-0.075	-0.033	<b>0.091</b>	0.009	-0.566	1.000	
23. mortality	-0.016	0.028	-0.053	<b>0.164</b>	<b>0.150</b>	0.066	-0.054	-0.011	<b>0.186</b>	0.007	-0.155	0.088	0.072	-0.055	-0.043	0.010	<b>0.252</b>	-0.062	-0.227	-0.209	-0.475	<b>0.298</b>	1.000

The coefficients in bold font are  $p < 0.05$ .

## Description of the Organization of Hospice Care for Children

**Hospice services.** Hospices that provided care for children differed significantly in many services they offered compared to hospices that did not provide care for children as displayed in Table 8. Social services, medication, therapy services (i.e., physical therapy, occupational therapy, and speech therapy), inpatient care, and transportation services along with the other hospice services (i.e., imaging/laboratory, outpatient, radiation, and chemotherapy services) were more common in hospices that provided care for children than those that did not provide care for children.

Table 8

*Comparison of Services Between Hospices Providing and Not Providing Care for Children*

Service	All Hospices (N= 1,368)	Providing care (n= 459)	Not providing care (n= 909)
<b>Core hospice services</b>			
Nursing care	91.5%	93.3%	90.7%
Physician services	70.6%	69.5%	71.1%
Social services	84.1%	88.7%	81.9%*
Counseling	81.4%	79.5%	82.2%
<b>Noncore hospice services</b>			
HHA/homemaker services	83.9%	82.3%	84.6%
Equipment/supply services	91.5%	92.6%	91.0%
Medication services	89.2%	91.7%	87.9%*
Therapy services	52.4%	60.3%	48.4%*
Inpatient care services	48.0%	59.9%	42.0%*
Transportation services	56.0%	62.1%	52.9%*
<b>Other hospice services</b>			
Imaging/laboratory services	54.1%	63.5%	49.8%*
Outpatient services	18.2%	28.3%	13.1%*
Radiation therapy services	7.5%	14.6%	4.0%*
Chemotherapy services	2.0%	3.7%	1.1%*

\* indicates a significant difference at the 0.05 level from hospices that provided care for children.

Table 9 displays the proportion of organizations that provided any core, noncore, or other hospice services, percentage point change in services offered from 2002 to 2008, and predicted trends in service offerings. Although the overall percentage of hospice organizations that provided care for children declined from 2002 to 2008 as noted in Table 6, the organizations that did provide care to children generally offered an increasing array of services.

The provision of core hospice services generally increased during the study period. Core services are those that must be provided by hospice staff as defined by CMS. The most common service provided was nursing care. In most years of the study, over 90% of organizations offered nursing services with the exception of 2003 and 2004. The proportion of organizations providing nursing care increased from 2002 to 2008 by 1.9%, and there was a significant positive trend in providing skilled nursing services. Physician services also steadily increased from 65% in 2002 to 82% in 2008. Physician services were one of the fastest growing with a 16.7% change, a significant positive trend. On the other hand, the proportion of hospice organizations offering social services decreased from 95% in 2002 to 77% in 2003, and rose to 99% in 2008. The change from 2002 to 2008 was 3.6 %, and this was a significant and positive trend in the offering of social services. Finally, there was also a significant positive trend in provision of spiritual, bereavement, and dietary counseling with 75% providing in 2002 and 92% providing in 2008, constituting a 16.6% change.

Provision of several noncore services fluctuated during the study. CMS defines noncore services as those that may be outsourced by the hospice organization, but must be provided (US Government Printing Office, 2010). The proportion of hospices providing

Table 9

Organizations that Provided Any Care for Children: Hospice Service Detail by Year (N=459)

	Year (n)							%Δ from 2002-2008	Predicted Trend <sup>a</sup> (z-value)
	2002 (60)	2003 (74)	2004 (67)	2005 (58)	2006 (67)	2007 (62)	2008 (71)		
<b>Core hospice services</b>									
Nursing care (%)	96.7	85.1	83.6	94.8	97.0	98.4	98.6	1.9%	3.00**
Physician services (%)	65.0	56.8	65.7	72.4	70.2	75.8	81.7	16.7%	3.19***
Social services (%)	95.0	77.0	79.1	86.2	91.0	95.2	98.6	3.6%	3.13**
Counseling (%)	75.0	66.2	68.7	81.0	85.1	90.3	91.6	16.6%	4.45***
<b>Noncore hospice services</b>									
HHA/homemaker services (%)	88.3	73.0	71.6	77.6	86.6	93.6	87.3	-1.0%	2.27*
Equipment/supply services (%)	96.7	82.4	85.1	93.1	98.5	98.4	95.8	-0.9%	2.70**
Medication services (%)	93.3	78.4	85.1	96.6	97.0	96.8	97.2	3.9%	3.58***
Therapy services (%)	65.0	62.2	64.2	55.2	59.7	58.1	57.8	-7.2%	-1.06
Inpatient care services (%)	50.0	59.5	56.7	70.7	59.7	61.3	62.0	12.0%	1.25
Transportation services (%)	50.0	50.0	56.7	62.1	65.7	79.0	71.8	21.8%	4.16***
<b>Other hospice services</b>									
Imaging/laboratory services (%)	55.0	60.8	55.2	56.9	67.2	72.6	69.0	14.0%	2.40*
Outpatient services (%)	15.0	23.8	32.8	36.2	31.3	32.3	28.2	13.2%	1.81
Radiation therapy services (%)	18.3	10.8	13.4	13.8	10.5	17.7	18.3	0.0%	0.57
Chemotherapy services (%)	1.7	5.4	3.0	3.5	4.5	1.6	5.6	3.9%	0.45

Note: <sup>a</sup> Trends were assessed with an extension of the Wilcoxon rank-sum test that evaluated whether responses systematically increased or decreased. \* $p<0.05$ , \*\* $p<0.01$ , \*\*\* $p<0.001$

home health aide and homemaker, durable equipment and supply, and therapy services declined from 2002 to 2008. However, the provision of medication, inpatient care, and transportation services provided all increased. Medication services were the most common noncore hospice service. Therapy services (i.e., physical, occupational, speech) were the least common. There were significant positive trends in the offering of home health aide and homemaker services, equipment and supply services, medication services, and therapy services between 2002 and 2008.

The provision of other hospice services generally increased during the study period as well. Other hospice services are those unregulated and nonreimbursable by private and public health insurance (US Government Printing Office, 2010). The most common services provided were imaging and laboratory services. There was wide variation in the percentage of hospices providing imaging and laboratory services for each year of the study. Overall, however, there was a 14% change from 2002 to 2008, reflecting a significant positive trend. Organizations that provided outpatient services, including emergency room visits, increased from 15% in 2002 to 28% in 2008. There was no change in the percentage of hospices offering radiation therapy services. The least common other service provided was chemotherapy, which ranged from a low of 1.6% in 2007 to a high of 5.6% in 2008. The trend from 2002 to 2008, however, was not statistically significant.

**Geographic location.** Table 10 shows the geographic location where hospice care was provided for children over the course of the study. Hospices that provided care in urban locations were the most common in all the years of the study. In 2002, 57% the organizations were urban; however, in 2005 that dipped to 48% and rose again to 61% in 2008. The change from 2002 to 2008 was 4%.

Table 10

*Organizations that Provided Any Care for Children: Geographic Location of Service by Year (N=459)*

	Year (n)							%Δ from 2002-2008	Predicted Trend
	2002 (60)	2003 (74)	2004 (67)	2005 (58)	2006 (67)	2007 (62)	2008 (71)		
Urban (%)	56.7	58.1	56.7	48.3	53.7	51.6	60.6	3.9	-0.09
Rural (%)	8.3	8.1	9.0	12.1	11.9	9.7	8.5	0.2	0.32
Mixed (%)	35.0	33.8	34.3	39.7	34.3	38.7	31.0	-4.0	-0.10

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$

The percentage of rural providers remained relatively constant during the study period, and it was the least common geographic location. The proportion of hospices that provided care in both urban and rural locations varied during the study from 31% in 2008 to 39.7% in 2005 and declined by 4% from 2002 to 2008. None of the predicted trends for urban, rural, or mixed service areas were statistically significant. Figure 5 displays the trends in geographic location of service over the years of the study.



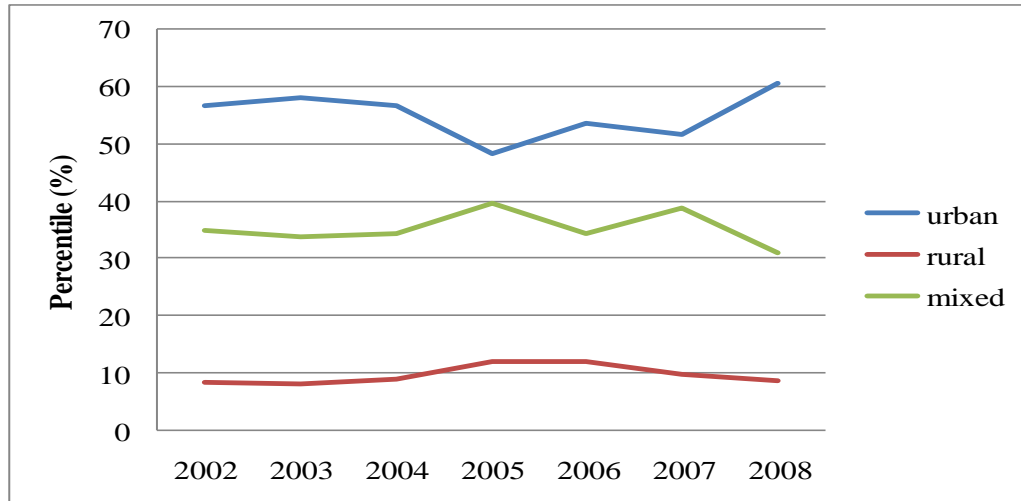


Figure 5. Trends in the provision of hospice care for children by geographic location, 2002-2008.

**Agency types.** Descriptive statistics for each agency type that provided any care for children are presented in Table 11.

Table 11

*Organizations that Provided Any Care for Children: Agency Type by Year (N=459)*

	Year (n)							%Δ from 2002-2008	Predicted Trend
	2002 (60)	2003 (74)	2004 (67)	2005 (58)	2006 (67)	2007 (62)	2008 (71)		
Freestand (%)	43.3	58.1	67.2	70.7	70.1	66.1	63.4	20.1	2.36*
Hospital (%)	28.3	16.2	14.9	13.8	14.9	17.7	12.7	-15.6	-1.70
HHA (%)	26.7	23.0	16.4	15.5	14.9	16.1	22.5	-4.2	-0.98
LTC (%)	1.7	2.7	1.5	0.0	0.0	0.0	1.4	-0.3	-1.13

\*p<0.05, \*\*p<0.01, \*\*\*p<0.001

Freestanding hospices were the most common type of agency providing hospice care for children. At the beginning of the study, 43% of hospices were freestanding and by 2008

that had increased to 63%. The highest percentage of freestanding agencies was in 2005 (71%). The 20% change from 2002 to 2008 was the largest seen and represented a significant positive trend over the study time period.

The percentage of hospital-based agencies providing care to children decreased by 16% from 2002 to 2008. Declines occurred between 2002 and 2003 from 28% to 16%, and between 2007 and 2008 from 18% to 13%. There was a insignificant negative trend in hospital-based agency type.

Similar to hospital-based agencies, the proportion of HHA-based agencies providing hospice care for children also decreased during the study. For most years, there was a steady decline in the percentage of HHA-based agencies, though there was a slight shift upwards in 2008. However, the overall percentage point change from 2002 to 2008 was -4%. This negative trend was not significant.

Finally, LTC agencies were the least common providers of care for children. The proportion of hospices that were LTC agencies ranged from 3% to 0% over the years. From 2002 to 2008, the proportion of LTC agencies dropped 0.3%; however, the trend over the study period was not significant. Trends by agency type are illustrated in Figure 6.

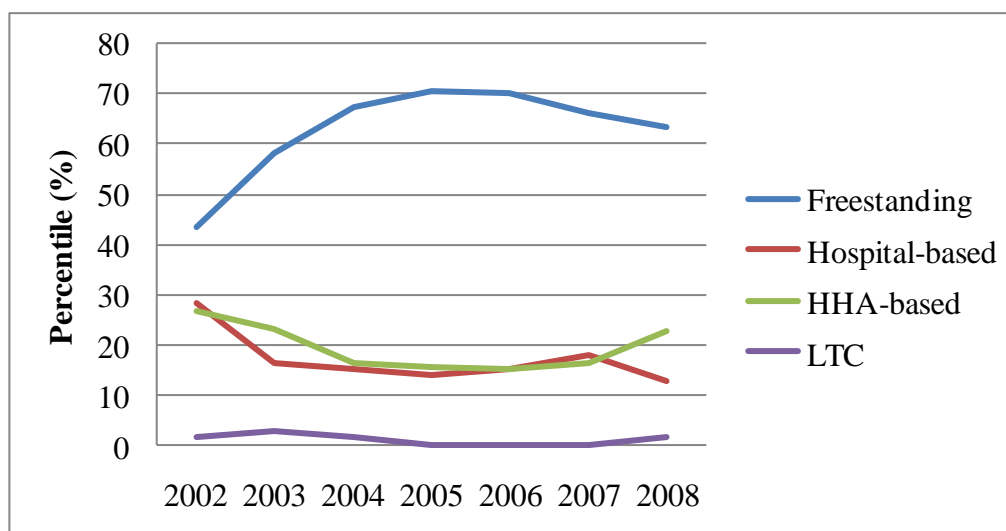


Figure 6. Trends in the provision of hospice care for children by agency type, 2002-2008.

## Multivariate Analysis

Table 12 presents the results of the GEE model using a logistic link, binomial variance, and unstructured working correlation. The hypotheses generated from the research question on the relationships between institutional and resource factors and the provision of hospice care for children were tested using GEE. To test the moderating effect of the resource factors, this study used a blockwise technique. Model 1 included the control variables. Model 2 included the control variables and the direct effects of institutional and resource factors. Model 3 included controls, direct effects, and multiplicative terms reflecting the interactions between institutional and resource factors. The results in Table 12 are reported as odds ratios with standard errors and average marginal effects with delta-method standard errors (i.e., the sample average of the effects of partial or discrete changes in the explanatory variables).

Table 12

*The Effects of Institutional and Resource Factors on Provision of Hospice Care for Children (N=1,036)*

	Model 1 OR (SE)	Marginal effect	Model 2 OR(SE)	Marginal effect	Model 3 OR(SE)	Marginal effect
<b>Organizational factors</b>						
Geographic location						
Urban	(ref)		(ref)		(ref)	
Rural	0.71(.21)	-0.07	0.53(.20)	-0.11	0.50(.20)	-0.12
Mixed	1.16(.28)	0.03	1.02(.26)	0.01	1.02(.27)	0.01
Agency type						
Freestanding	(ref)		(ref)		(ref)	
Hospital-based	0.52(.14)	-0.13*	0.63(.17)	-0.08	0.61(.18)	-0.08
HHA-based	0.71(.19)	-0.07	0.81(.24)	-0.04	0.78(.23)	-0.04
LTC	0.51(.18)	-0.13	0.33(.21)	-0.19	0.24(.19)	-0.24
Ownership						
For-profit	(ref)		(ref)		(ref)	
Government	1.05(.44)	0.01	1.23(.53)	0.04	1.09(.46)	0.02
Nonprofit	1.96(.54)	0.13*	1.81(.52)	0.10*	1.91(.60)	0.11*
Organizational age	1.80(.26)	0.12***	1.42(.21)	0.06*	1.28(.20)	0.04
<b>Market factors</b>						
Per capita income						
Unemployment	0.99(.02)	-0.01	0.98(.02)	-0.01	0.98(.02)	-0.01
Child mortality	1.08(.07)	0.01	1.05(.07)	0.01	1.05(.07)	0.01
	0.93(.11)	-0.01	0.96(.09)	-0.01	0.95(.10)	-0.01
Year						
Year 2002	(ref)		(ref)		(ref)	
Year 2003	0.61(.11)	-0.10**	0.58(.12)	-0.10**	0.58(.12)	-0.09**
Year 2004	0.50(.10)	-0.14***	0.45(.10)	-0.14***	0.44(.11)	-0.14***
Year 2005	0.61(.12)	-0.10*	0.55(.11)	-0.11**	0.56(.13)	-0.10*
Year 2006	0.56(.13)	-0.12*	0.52(.13)	-0.12**	0.53(.14)	-0.11*

Year 2007	0.54(.12)	-0.12 <sup>**</sup>	0.52(.13)	-0.12 <sup>**</sup>	0.53(.13)	-0.11 <sup>*</sup>
<b>Institutional factors</b>						
Accreditation			0.85(.15)	-0.03	0.22(.16)	-0.04 <sup>*</sup>
Membership			2.63(.72)	0.19 <sup>***</sup>	1.03(1.2)	0.18
Organization leader			0.89(.27)	-0.02	2.28(3.5)	-0.04
<b>Resource factors</b>						
No other income			0.80(.14)	-0.04	0.78(.26)	-0.04
Organizational size			(ref)		(ref)	
Large			0.53(.14)	-0.11 <sup>*</sup>	0.33(.15)	-0.12 <sup>*</sup>
Medium			0.27(.09)	-0.22 <sup>***</sup>	0.10(.06)	-0.22 <sup>***</sup>
Small			0.28(.16)	-0.23 <sup>*</sup>	0.23(.22)	-0.25
Competition						
<b>Interactions</b>						
No other income x accreditation					1.08(.33)	
No other income x membership					0.76(.28)	
No other income x organization leader					1.07(.35)	
Small size x accreditation					6.76(3.5) <sup>***</sup>	
Medium size x accreditation					1.29(.52)	
Small size x membership					2.20(2.3)	
Medium size x membership					2.83(1.5) <sup>*</sup>	
Small size x organization leader					0.59(.38)	
Medium size x organization leader					1.05(.48)	
Competition x accreditation					2.96(2.4)	
Competition x membership					1.67(2.2)	
Competition x organization leader					0.24(.43)	

Note. OR = odds ratio, SE = standard error. <sup>\*</sup> $p < 0.05$ , <sup>\*\*</sup> $p < 0.01$ , <sup>\*\*\*</sup> $p < 0.001$ .

**Results for Hypotheses 1A through 1 C: Direct effects of institutional factors.**

*Hypothesis 1A: Accreditation will be positively associated with the provision of hospice care for children.*

*Hypothesis 1B: Membership in a professional group will be positively associated with the provision of hospice care for children.*

*Hypothesis 1C: The presence of an organization leader in pediatric hospice care will be positively associated with the provision of hospice care for children.*

The results for Hypotheses 1A through 1C are summarized in Table 12, Model 2. Hypothesis 1A postulated that accreditation would be positively related to the provision of care for children. The results indicated that accreditation was not significantly associated with the provision of hospice care for children. Additionally, the relationship was negative, the opposite direction hypothesized. Hypothesis 1A was rejected.

Hypothesis 1B argued that membership in a professional coalition would be positively associated with provision of care for children. The findings showed that membership was statistically related to the provision of hospice care for children, and that it was a positive relationship. Members of a professional group were 19% more likely to provide hospice care for children than hospices that were not members of the group. Hypothesis 1B was not rejected.

Hypothesis 1C predicted that the presence of an organization leader in pediatric care would be positively related to the provision of care. However, the presence of an organization leader in pediatric care was not related to provision of care and the negative

direction of the relationship was in a direction opposite to that hypothesized. Hypothesis 1C was rejected.

These findings suggest that the institutional factors of accreditation and organization leader presence had no significant effect on the provision of hospice care for children. However, membership did positively influence the provision of hospice care for children.

**Results for Hypotheses 2A through 2C: Direct effects of resource factors.**

*Hypothesis 2A: The lack of other income will be negatively associated with the provision of hospice care for children.*

*Hypothesis 2B: Small-sized and medium-sized organizations will be negatively associated with the provision of hospice care for children.*

*Hypothesis 2C: A greater level of competition will be negatively associated with the provision of hospice care for children.*

Regression results for Hypotheses 2A through 2C are summarized in Table 12, Model 2. Hypothesis 2A argued that hospices without sources of other income would be less likely to provide hospice care for children. Although the coefficient sign was in the predicted direction, the relationship was not statistically significant. Hypothesis 2A was rejected.

Hypothesis 2B predicted that organizational size would be negatively associated with the provision of hospice care for children. The findings indicated that organizational size was indeed related to the provision of care for children and the results were in the hypothesized direction. Compared to large hospices, small- and medium-sized hospices were less likely to provide care for children (22% and 11% respectively). Hypothesis 2B was not rejected.

Hypothesis 2C postulated that a greater level of competition would be negatively related to the provision of care for children. This study found that an increase in competition in the prior year was associated with a 23% decrease in the probability of providing hospice care for children. Hypothesis 2C was not rejected.

These findings suggest that hospices that have other income sources are no more likely to provide care for children than are hospices that lack other income sources. Small- and medium-sized organizations and increased competition had negative influences on whether hospices provided care for children.

**Results for Hypotheses 3A through 3C: Moderating effects of resource factors.**

*Hypothesis 3A: The relationship between institutional factors (i.e., accreditation, membership, and organizational leader) and the provision of hospice care for children will be weaker when hospice organizations lack other income.*

*Hypothesis 3B: The relationship between institutional factors (i.e., accreditation, membership, and organizational leader) and the provision of hospice care for children will be weaker when hospice organizations are small or medium-sized.*

*Hypothesis 3C: The relationship between institutional factors (i.e., accreditation, membership, and organizational leader) and the provision of hospice care for children will be weaker when hospice organizations face increased competition.*

Hypotheses 3A through 3C examined the moderating role of resource factors on the relationship between institutional factors and the provision of hospice care for children. The moderating effect was examined by creating interaction terms (i.e., multiplying the resource factors by each of the institutional factors) and then including the 12 interactions as a

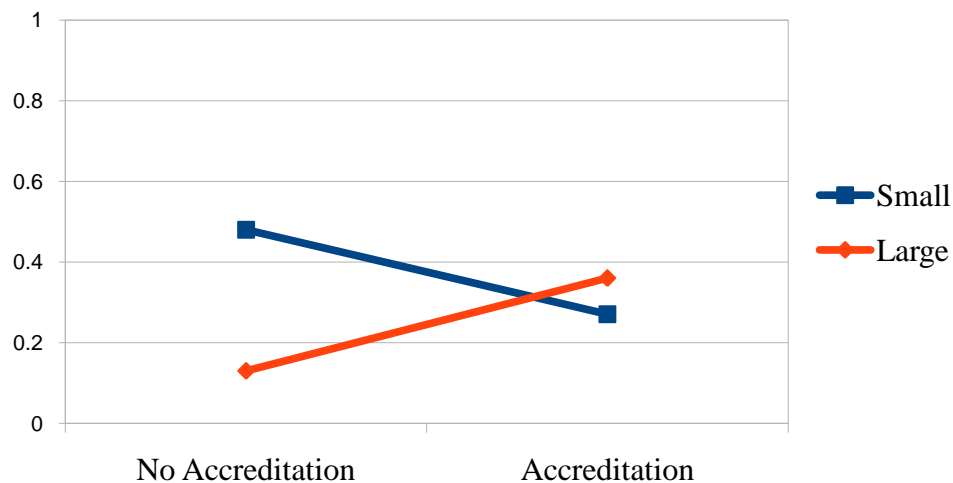


separate set of independent variables in the regression equation. The hypotheses specifically stated that when a relationship exists between one of the three institutional factors and the provision of hospice care for children, the relationship would be weaker when organizations lacked resources. These hypotheses were first evaluated by examining whether the interaction terms were statistically significant.

The results for Hypotheses 3A through 3C are summarized in Table 12, Model 3. Hypothesis 3A stated that the influence of accreditation on providing hospice care for children would be attenuated when hospices had no other income, when they were small or medium size, and when hospices operated in markets with increasing competition. The interaction terms of accreditation and no other income, accreditation and medium size, and accreditation and competition were not statistically significant. The interaction between accreditation and small size was significant. However, because the sign and significance of interactions terms in nonlinear models is not necessarily indicative of an interaction, the accreditation-small size relationship was examined graphically as outlined by Aiken and West (1991) to determine if there was support for the hypothesis.

Figure 7 illustrates the interaction effect of size on the relationship between accreditation and the provision of hospice care for children. The graph shows a significant interaction effect between accreditation and small size, and suggests three points. First, small accredited hospices had a lower probability of providing care for children than small unaccredited hospices. Second, the difference in the provision of care for children between small and larger hospices was greater when hospices were unaccredited than when they were accredited. Finally, when hospices were small, the relationship between accreditation and the provision of care for children was negative. Based on this graphical examination,

organizational size did attenuate the relationship between accreditation and the provision of hospice care for children, so Hypothesis 3B was not rejected.



*Figure 7.* Plot of the interaction between accreditation and small-sized organizations on the provision of hospice care for children.

Hypothesis 3B also stated that the pressures from professional membership to provide hospice care for children would be attenuated when hospices lacked sources of other income, were small-sized, medium-sized, and/or experienced increased competition. The interaction terms of membership and no other income, membership and small size, and membership and competition were not statistically significant. However, the interaction between membership and medium size was significant. This relationship was also examined graphically as recommended by Aiken and West (1991).

Figure 8 displays the interaction effect of medium-sized organizations on the relationship between membership and the provision of hospice care for children. The graph

shows a significant interaction effect between membership and medium size. Medium-sized member hospices had a higher probability of providing care for children than medium-sized nonmember hospices. The difference in the provision of hospice care for children between medium and large hospices was greater when hospices were not members of a professional group than when they were members. In addition, when hospices were medium-sized, the relationship between membership and the provision of care for children was positive. Therefore, the graphical examination shows that instead of attenuating, membership promoted provision of hospice care for children, particularly among medium-sized hospices, so the hypothesis was rejected.



*Figure 8.* Plot of the interaction between organizational membership and medium-sized hospices on the provision of care for children.

Hypothesis 3C stated that the influence of an organization leader in pediatric care on providing hospice care for children would also be attenuated in the presence of no other income sources, in small- or medium-sized organizations, and increased competition. The

interaction terms of organization leader and no other income, organization leader and small size, organization leader and medium size, and organization leader and competition were not statistically significant. As a result, no relationships were graphed. Hypothesis 3C was rejected.

**Results for organizational and market control variables.** Several of the control variables were significantly associated with the provision of hospice care for children. Although there were no specific hypotheses related to these variables, the results for the control variables are included in Table 12, Model 1. The major findings from the analysis of the control variables were that organizational age and nonprofit status were positively related to the provision of hospice care for children, whereas agency type (specifically hospital-based agencies) and the passage of time had negative effects on the provision of hospice care for children.

A 1% increase in organizational age was associated with a 12 % increase in the probability of providing hospice care for children. Compared to for-profit hospices, nonprofits were 13 % more likely to provide hospice care for children. However, the probability that hospital-based agencies provided hospice care for children (i.e., in the community rather than in the acute care setting) was 13% lower than freestanding agencies. Compared to 2002, hospices had a reduction in the probability of providing hospice services for children in 2003 (10%) , 2004 (14%), 2005 (10%), 2006 (12%), and 2007 (12%). Other organizational and market factors in the model (i.e., rural, mixed, HHA-based, LTC, government, per capita income, unemployment, and child mortality) were not significantly associated with the provision of hospice care for children.

### Sensitivity Analysis.

Though this study explored the effect of institutional and resource factors on the provision of hospice care for children among a population of hospice organizations, it is important to assess whether the estimates of the multivariate analysis change when examining an individual hospice organization's response to providing care for children. Thus, a sensitivity analysis was conducted comparing the marginal effects between the GEE method using a population approach and an individual approach using a linear probability model with fixed effects and clustered standard errors. The results of the comparison are summarized in Table 13.

Table 13

*Comparison of the Generalized Estimating Equations (GEE) and Linear Probability Model's (LPM) Parameter Estimates (N=1,036)*

	<b>GEE Marginal effect</b>	<b>LPM Marginal effect</b>
<b>Organizational factors</b>		
Rural	-0.11	(dropped)
Mixed	0.01	(dropped)
Hospital-based	-0.08	(dropped)
HHA-based	-0.04	(dropped)
LTC	-0.19	(dropped)
Government	0.04	(dropped)
Nonprofit	0.10*	(dropped)
Organizational age	0.06	-0.05
<b>Market factors</b>		
Per capita income	-0.01	0.01
Unemployment	0.01	0.01
Child mortality	-0.01	0.01
Year 2003	-0.10**	-0.06
Year 2004	-0.14***	-0.11*
Year 2005	-0.11*	-0.07
Year 2006	-0.12*	-0.11

Year 2007	-0.12 <sup>**</sup>	-0.08
<b>Institutional factors</b>		
Accreditation	-0.03	-0.01
Membership	0.19 <sup>***</sup>	0.24
Organization leader	-0.02	0.19
<b>Resource factors</b>		
No other income	-0.04	-0.08 <sup>*</sup>
Small size	-0.22 <sup>***</sup>	-0.10
Medium size	-0.11 <sup>*</sup>	-0.06
Competition	-0.23 <sup>*</sup>	0.05

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\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$

For comparative purposes, parallel marginal effects using the GEE method are presented in Table 13 alongside the LPM with fixed effects. Although the signs and magnitudes of the marginal effects were similar in the two models for most variables, there were several notable differences in the results. First, in the GEE model, the probability of providing care for children in hospices declined significantly in each year of the study. However, in the LPM model individual organizations had a statistically significant decrease in the probability of providing care for children only in 2004. Controlling for time-invariant observed and unobserved factors in the fixed effects model may have reduced the impact of time on the provision of care for children.

Second, the results of the GEE approach did not lead to the rejection of as many hypotheses as did the LPM approach. With regards to the hypotheses on institutional and resource factors' direct effects, Hypotheses 1A and 1C that assumed the accreditation and organization leader factors would positively affect the provision of hospice care for children were rejected. However, in the GEE model, three direct-effect hypotheses - Hypothesis 1B on membership, Hypothesis 2B on small- and medium-sized organizations, and Hypothesis

2C on competition- were not rejected. In the LPM model, only one direct-effect hypothesis, Hypothesis 2A on the effects of no other income sources was not rejected. A possible explanation for this difference is that GEE estimation provides more efficient parameter estimates than LPMs (Twisk, 2004) because of how the GEE estimation method treated the longitudinal nature of the hospice data. In this study, observations were not independent and the two models controlled for clustering differently. The GEE method managed clustering during the estimation process through the use of the working correlation; LPM controlled for clustering after estimation with a clustered standard errors method. Therefore, the GEE estimation may result in a more efficient estimation process that controls for non-independent observations.

Finally, individual hospices were affected by the same factors and in the same direction as the population of hospice organizations, with the exception of lack of other income. The parameter estimates significant in the LPM method were also significant in the GEE method, and they had the same positive and negative influences on the provision of hospice care for children. These estimation results suggest that in California the individual hospice organization behaved similarly to the population of hospice organizations.

### **Summary**

The major findings of the study hypotheses are summarized in Table 14. Of the proposed hypotheses, four out of nine were empirically supported. Membership in a professional group was a positive and significant influence on hospice organizations' provision of care for children, whereas accreditation and the presence of an organization leader were not significant. Small- and medium-sized organizations, and greater competition were negative determinants of the provision of hospice care for children, but lack of other

income was not significantly related. Contrary to expectation, only two of the interactions were significant - small size and accreditation and medium size and membership. Finally, half of the organizational and market control factors were related to the provision of hospice care for children. Hospital-based agencies and all the year variables were negatively associated with the provision of care for children, and ownership and organizational age were positively related to the provision of hospice care for children. The next chapter will discuss these findings, discuss implications, offer recommendations for the direction of future research, and outline the limitations of the current study.

Table 14

*Summary of Study Hypotheses, the Expected Results and the Final Results*

<b>Hypotheses</b>	<b>Factors</b>	<b>Expected Influence</b>	<b>Actual Influence</b>
<b>Institutional Factors</b>			
H1A	Accreditation	+	-NS
H1B	Membership	+	***
H1C	Organization leader	+	-NS
<b>Resource Factors</b>			
H2A	No other income	-	-NS
H2B	Organizational size		
	Small	-	***
	Medium	-	*
H2C	Increased competition	-	*
<b>Interactions</b>			
H3A	No other income x institutional factors	-	mixed results <sup>NS</sup>
H3B	Small/medium size x institutional factors	-	mixed results
H3C	Increased competition x institutional factors	-	mixed results <sup>NS</sup>

Note. + = positive association, - = negative association, NS = not statistically significant,

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$



## **Chapter 6: Discussion**

### **Introduction**

The purpose of this research was to explore the influences of institutional and resource factors on the provision of hospice care for children in community-based hospices. The types of institutional factors studied were accreditation, membership in a professional group, and the presence of an organization leader in pediatric care. The resource factors were lack of other income sources, organizational size, and competition in the hospice market. The study also explored whether resource factors moderated the hypothesized positive relationships between institutional factors and the provision of hospice care. This chapter summarizes the results presented in the previous chapter, interprets the findings, suggests implications, discusses the study's limitations, and suggests areas for future research.

### **Discussion of Descriptive Analyses**

**Provision of hospice care for children.** Of the hospices in the study, 34% provided care for children. This finding was in line with other researchers (Leuthner et al., 2004) who reported that 40% of hospice and home health agencies provided care for children. The trend data revealed that while the overall number of hospices in California increased during the study, the number of hospices that provided care for children remained relatively unchanged. Additional analyses showed that 61% of hospices that provided care for children always provided care, and that only 21% of hospices had a specialized pediatric hospice program. In other words, more than half of hospices admitted children regularly, while other hospices

may have admitted children selectively. These findings suggest that the availability of hospice care for children may be diminishing and that a core group of providers offer hospice services for children in California.

One possible explanation for the declining provision of hospice care for children may relate to hospice admission practices. The current public and private hospice benefit reimburses hospices at a fixed per diem rate regardless of patient diagnosis, location of care, or hospice length of stay. Under this system, hospices can maximize revenue and profits by caring for patients that require fewer skilled services or patients with longer hospice stays (Huskamp et al., 2001). In fact, the National Hospice and Palliative Care Organization reported an increasing trend in the average length of stay from 59.8 days in 2006 to 69.5 days in 2008 (NHPCO, 2009a). However, children often require skilled care from hospice nurses, physicians, therapists, and social workers. In addition, children are typically admitted to hospice care late in the course of their illness and usually have stays of just days (Davies et al., 2008; Fowler et al., 2006; Hendricks-Ferguson, 2008; Knapp et al., 2009; Sheetz & Bowman, 2008; Thompson et al., 2009; Zwerdling et al., 2000). Therefore, hospices may not be admitting children to hospice care to avoid facing the financial obstacles of providing expensive care for children in a fixed per-diem payment system.

**Organization of hospice care for children.** One of the goals of this study was to understand how hospice care for children was organized and explore changes in care delivery over time. The study specifically examined services provided, geographic location, and the type of community-based agencies that provided care for children.

**Hospice services.** The overall range of services offered at hospices that provided care for children increased from 2002 to 2008. The proportion of hospices offering nursing care,

physician, social services, counseling, medication, inpatient, transportation, imaging/laboratory, outpatient, and chemotherapy services increased in hospices that provided care for children. However, HHA/homemaker, durable equipment/supplies, and therapy services declined, while radiation services remained unchanged from 2002 to 2008.

Although physician services increased by 17%, this service was the least common core service offered by hospices. Given the increases in disease complexity, diversity of diagnoses, and symptom burden seen in children at end of their lives, they likely have an increased need for direct physician care (Brandon et al., 2007). Physician members of a hospice team help formulate and approve childrens' plans of care by approving all orders and evaluating the child's prognosis during hospice enrollment (Connor, 2009b). It is possible that childrens' primary care physicians or oncologists may continue providing ongoing medical care once enrolled in hospices. However, these physicians may not have the education, knowledge, or skills of a trained hospice physician (McCabe et al., 2008). Therefore, children in hospice care may not receive effective care planning or direct patient care at the end of their lives.

The limited provision of inpatient care services for children (i.e., respite care) is consistent with suggestions in the literature that reimbursement policies may create a barrier to the provision of inpatient care (Huskamp et al., 2001). Respite care is designed to give families a break from the intensive care required by terminally ill children (Carter & Levetown, 2004). Many benefit plans require the child be transferred to an inpatient facility in order for the hospice organization to be reimbursed for respite care. The potential for complications and the stress of transferring a child at end of life between home and the inpatient setting may impede families from initiating respite care (Davies et al., 2004).

Revising Medicare and Medicaid policy to allow for in-home respite care may provide families with an important and needed rest from care duties (Davies et al., 2004; Jeon et al., 2005).

***Geographic location.*** Interestingly, this study found that the provision of hospice care services for children was relatively widespread geographically. Although hospice care provided in urban locations was the most common, almost 40% of organizations provided hospice care for children in rural areas (i.e., rural or mixed rural and urban). Further analysis revealed that when there was a lack of competition, hospices often expanded their services for children into rural or mixed areas. Whereas prior studies have raised concerns about access to rural hospice care (Virnig et al., 2006; Madigan et al., 2009), the results from this study are consistent with recent research that has found 88% of the US population lives in communities within 30 minutes driving time of at least one hospice (Carlson et al., 2010), and those who use hospice generally live within 9.8 miles of a hospice (Jenkins et al., 2009). The findings from this study suggest that children returning home to die in rural communities may have better access to hospice care in their community than previously thought.

***Agency type.*** This study found that freestanding agencies were the most common providers of care for children. This was consistent with hospice industry reports and findings from other research that found that the majority of hospices in the US are freestanding agencies (NHPCO, 2009a; Lindley et al., 2009). It was surprising, however, that hospital-based care for children declined from 2002 to 2008. Given that many children in the terminal phase of their illness receive acute care in the hospital prior to hospice admission (IOM, 2003), receiving hospice care outside of the hospital system suggests that care coordination may be an issue for end-of-life patients. In fact, recent studies have shown that most

freestanding hospices are ill equipped to share patient information with hospitals (Jha et al., 2009; Resnick & Alwan, 2010).

Another interesting finding was that a small percentage of nursing homes with licensed hospice programs provided hospice care for children. Because many freestanding hospices only offer home hospice care (Connor, 2009b), a family that requires inpatient hospice care near their home may need to utilize a nursing home for care. In addition, long-term residential care facilities are increasingly becoming a setting of care for children with severe developmental disabilities, such as cerebral palsy, who are often not expected to live into adulthood (IOM, 2003). There is also emerging evidence that nursing home hospice patients receive more of some services such as dietary, physician, and medication services than do home hospice patients (Stevenson et al., 2007; Han et al., 2008). Therefore, receiving hospice care in nursing homes may be an important alternative to the home setting for children.

### **Discussion of Hypothesis Testing**

**Direct effects of institutional factors: Accreditation.** Accreditation, as measured by whether or not a hospice was accredited by ACHC, CHAP, Joint Commission, and/or other accrediting agencies, was not significantly associated with provision of hospice care for children. In addition, the sign on the estimate was in the opposite direction than hypothesized. This finding was consistent with the results from Li's (2010) study on nursing homes, which found that accreditation had no influence on the provision of health care services. However, it was not consistent with the tenets of institutional theory that posited accreditation exerts a coercive influence on provision of care. Nor was it consistent with the evidence from studies on substance abuse treatment centers, which found that accreditation

was related to provision of care (Campbell & Alexander, 2005; Friedmann et al., 1999; Pollack & D'Aunno, 2010; Wells et al., 2007).

One possible explanation for the unexpected negative relationship of accreditation with the provision of hospice care for children may relate to the highly legalistic US business environment. Although accreditation requires hospices to have established and prescribed infrastructures, policies, procedures, and requirements for provision of care, treatment, and services (Au et al., 2009; Connor, 2007), accrediting agencies can only remove accreditation if a hospice does not meet standards. There are no legal or financial sanctions for noncompliance such as fines or fees. Furthermore, most hospices already meet the Medicare and Medicaid hospice certification guidelines and often question the value of accreditation (Connor, 2009b; NHPCO, 2009b). Therefore, the lack of meaningful sanctions related to accreditation may not influence hospice administrators to alter their decisions to provide care for children.

Although this may explain why accreditation did not have a statistically significant effect on provision of care, it does not fully explain why the relationship was negative rather than positive as hypothesized. One possible explanation could be related to quality endorsement. In the hospice industry, the accreditation process is an external evaluation completed through surveys and site visits of a hospice's quality of patient care (e.g., symptom management, medication management, client satisfaction). When accreditation is granted, it is perceived as an endorsement of quality (Connor, 2009b). For hospices that are accredited, providing care for children may jeopardize the quality of care they offer to other hospice patients. Providing hospice care for children often requires an extensive commitment of staff and resources, especially during the admission and final days of hospice enrollment. Staff

members might need to devote time to the children's needs that limits their abilities to attend to the needs of other patients (Hendricks-Ferguson, 2008). As a result, families' satisfaction with adult care may be reduced when hospices provide care for children. Therefore, accredited hospices may not offer care to children for fear of losing their quality endorsement from the accrediting agency.

Another possible explanation for this unexpected result relates to the accreditation measurement used in this study. The binary measure of accreditation was whether or not a hospice was accredited by ACHC, CHAP, Joint Commission, and/or other accrediting agencies. Combining the different agencies into a single measure may have masked the effect of accreditation on the provision of hospice care for children. Friedmann et al. (1999), Campbell and Alexander (2005), and Pollack and D'Aunno (2010) found a significant positive effect of the Joint Commission's accreditation on provision of care, whereas researchers who used a combined measure reported mixed results (Li, 2010; Wells et al., 2007). Li's (2010) accreditation measure was whether or not a nursing home was accredited by JCAHO, CARF, or Continuing Care Accreditation Commission, and it was unrelated to the provision of care. Wells et al. (2007) defined accreditation as whether a substance abuse treatment facility was accredited by JCAHO and CARF, and it was related to the provision of care. These findings suggest that different types of accreditation may have different relationships with provision of care. Therefore, when multiple accrediting agencies are included in a single measure, the influence of hospice accreditation standards on the provision of care for children may not be adequately captured. Future exploration into the relationship between accreditation and the provision of hospice care for children should take into account the different types of accrediting agencies.

**Direct effects of institutional factors: Membership.** Hypothesis 1B postulated that hospices with membership in a professional group, alliance, or coalition would be more likely to provide hospice care for children. The findings for membership were consistent with the study hypothesis. Membership was measured as whether or not a hospice organization was a member of the Children's Hospice and Palliative Care Coalition. Membership has been consistently demonstrated to be associated with the provision of care (Ginn & Moseley, 2004; Olden & Clement, 2000; Proenca et al., 2003).

One possible reason for this finding may be that the training, networking opportunities, and policy updates offered to members of the CHPCC encourage hospices to provide care for children. Through membership, organizations develop an understanding of what is valued and expected in providing hospice care for children. Therefore, membership may remove the uncertainty of providing hospice care for children, and promote conformity to professional standards and guidelines of pediatric hospice care.

**Direct effects of institutional factors: Organization leader.** Hypothesis 1C argued that the presence of an organization leader in pediatric care would be positively associated with the provision of hospice care for children. Organization leader was defined as whether or not a hospice had a children's hospital in its community from which to copy pediatric care practices. The finding for organization leader was not statistically significant and in the opposite direction than hypothesized. This finding was not consistent with the tenets of institutional theory that emphasized that an organization leader exerts a mimetic influence on provision of care. Nor was it consistent with the evidence from hospital studies, which found that an organization leader influenced provision of care (Krein, 1999; Westphal et al., 1997).



One possible explanation for this unexpected finding is that pediatric hospitals may act as substitutes for community-based hospice care at the end of children's lives. Terminally ill children often receive treatments, such as chemotherapy or dialysis, in an acute care setting, and over time families develop relationships with the staff at the hospital (Brandon et al., 2007). Although hospice eligibility criteria require families to discontinue acute care, receiving inpatient hospice care through the hospital may allow families to stay connected to treating staff and provide peace of mind that skilled healthcare professional are available around the clock if the child's condition deteriorates.

Another explanation may be that hospices lack the opportunity to mimic an organization leader. Hospices generally establish relationships with physicians who refer children to hospice and with discharge planners who process the referrals. They do not often establish direct relationships with hospital nursing units such as the neonatal intensive care unit, that have specialty knowledge of caring for seriously ill children. Therefore, proximity of a hospice to a pediatric hospital may not provide sufficient opportunity for the hospice to observe and copy the practices of a pediatric hospital.

**Direct effects of resource factors: Lack of other income.** The findings indicated that a lack of other income sources was not significantly related to the provision of hospice care for children. Its effects were negative as hypothesized, but not significant. One reason for this insignificant effect could be that funds from individual donors, corporate donors, and foundations may have been restricted from use for hospice care for children (Zelman et al., 2003). Individual gifts of cash, appreciated securities, real estate, life insurance, and annuities, for example, may be restricted to specific components of hospice care (e.g., volunteers, grief support, spiritual care, facilities). Additionally, donors are increasingly

concerned about whether their donations are used as intended (Costa, 2005). As a result, hospices may not have the flexibility to shift contributions to the provision of care for children and income from grants and donations may not be available to provide care for children.

Another reason for the lack of other income result may be that hospices that provide care to children generate profits to cover the cost of care for children and do not need other income sources. Further analysis, comparing the mean net income of hospices that provided care for children and hospices that did not provide care for children using a two sample *t*-test, revealed that hospices that provided care for children had significantly higher profits (i.e., net income) than hospices that did not provide care for children. Therefore, hospices may increase revenues in profitable sectors of the business to offset the cost of care for children rather than allocate funds from grants, donations, and unrelated businesses to the care of children.

**Direct effects of resource factors: Organizational size.** Consistent with hypothesis 2B, small and medium sized hospices were less likely to provide care for children than large hospices. This finding is consistent with the tenets of resource dependence theory that emphasize that smaller organizations may have less resources (Pfeffer & Salancik, 1978), and the hospice literature that reported small hospices were less likely to provide services than larger hospices (Lorenz et al., 2004; White et al., 2002).

A possible explanation for the negative relationship in the current study is that small- and medium-sized hospices may not have all the internal resources and capabilities necessary to provide care for children. These organizations may not have financial or physical assets (e.g., property, facility, equipment), human capital, technology, or other organizational

resources to offer pediatric medication, pediatric equipment, pediatric supplies, and trained-nursing care for children (Himmelstein, 2006; Orloff, 2001). Further analyses to compare the average medication, equipment, and medical supply expenses of small, medium, and large hospices found that small- and medium-sized hospices had fewer financial resources than large hospices. Therefore, small- and medium-sized hospices may be pressured not to provide care for children because of the type and intensity of resources required to provide pediatric hospice care.

**Direct effects of resource factors: Competition.** Hypothesis 2C, which purported that competition would be negatively associated with the provision of hospice care for children, was not rejected. This finding is consistent with the tenets of resource dependence theory that competition for resources affects organizational behavior and also with the findings of Thorpe and Phelps (1991) who reported that hospitals in competitive areas were less likely to provide care services.

A possible explanation for the negative influence of competition on the provision of care for children may be that providing expensive hospice care to children draws critical financial and human resources from the main focus of the hospices' business. Hospice care for the elderly represents an important revenue stream for hospices because of Medicare funding and the potential for extended lengths of stay in hospice (Connor, 2009b). Hospices generally compete among themselves for these admissions. In highly competitive markets, hospices may allocate financial and human resources to marketing and providing additional services (i.e., meals on wheels) aimed at attracting elderly patients (Connor, 2009b). Services that do not contribute to the main focus of the business, such as providing hospice care for children, may be perceived by hospice administrators as a drain on resources that creates a

competitive disadvantage. Therefore, providing hospice care for children may not match the survival goals and interests of hospices in a competitive market.

Alternatively, providing hospice services for children may not distinguish the hospice from competitors. A strategy often used by organizations that have a unique strength compared to others in their market is to develop a niche market that focuses on providing goods and services to a pocket of demand in an industry (Hill & Jones, 2008). However, providing care for children may not be an effective niche strategy because of the low volume of children needing hospice care and its high cost. For example, it is common for hospices to enroll only 1 to 3 children a year (Lindley et al., 2009) compared to the average annual enrollment of 150 or more adult patients (NHPCO, 2009a). In addition, the volume of children is not stable over time. An additional analysis was conducted that included an assessment of between and within variation of provision of care: over 30% of organizations did not provide care for children every year. Finally, caring for children can cost hospices 1.08 to 25.4 times as much as the daily per diem reimbursement rate hospices receive for those services (Lindley et al., 2009). Therefore, children are not an attractive and sustainable niche market for hospices. In fact, they may reduce hospices' abilities to compete.

**Moderating effects of resource factors: Lack of other income.** In addition to exploring the direct effects of resource factors on the provision of hospice care for children, this study investigated the moderating effects of resource factors on the relationship between institutional forces and the provision of hospice care for children. Hypotheses 3A, 3B, and 3C claimed that resource constraints may act as conditions under which hospices resist conformity to institutional pressures in the provision of hospice care for children.

Contrary to Hypothesis 3A, there was no significant moderating effect of lack of other income sources. One possible reason that a lack of other income sources did not perform as expected is related to the operationalization of the lack of other income measure. The variable was defined to encompass grants, donations, or income from unrelated businesses, which may have combined too many different sources of other income to effectively capture the munificence construct. Grants and donation income are often sources of additional income for hospices. However, income from unrelated businesses such as operating a thrift shop or restaurant may result in a financial loss for hospices. Information on the availability of other income may be lost when the types of other income are aggregated into a single variable. Therefore, future research should explore continuous, disaggregated measures to see whether they more accurately capture the lack of other income's moderating effects.

**Moderating effects of resource factors: Organizational size.** The results of Hypothesis 3B, which proposed that organizational size would attenuate the relationship between institutional factors and the provision of hospice care for children were mixed. The coefficients of the interaction terms of medium size and accreditation, medium size and organization leader, small size and membership, and small size and organization leader were not statistically significant. However, the interactions between small size and accreditation and medium size and membership were statistically significant. Small accredited hospices had a lower probability of providing care for children than unaccredited small hospices, and when hospices were small, the relationship between accreditation and provision of care for children was negative. This relationship was consistent with findings in the health services

literature that small hospitals experiencing resource constraints were less likely to provide services in the presence of institutional standards (Goodrick & Salancik, 1986).

A possible explanation for this finding may relate to the resource challenges of small hospices. Smaller hospices generally have less access than large hospices to financial and human resources, such as pediatric-trained nursing staff. Although the direct effects of small size and accreditation on provision of care for children were negative, the resource constraints present in small hospices may act as conditions in which these hospices resist conformity to the coercive pressures of accreditation in the provision of hospice care for children. The moderating analysis provided additional insight into the interplay between organizational size and accreditation that may be influencing decisions about providing hospice care for children.

Contrary to expectation, medium size strengthened the relationship between membership and provision of hospice care. In other words, compared to large hospices, medium-sized hospices that were members of a pediatric coalition were more likely to provide care for children. The reason for this is not clear. It may be that instead of organizational size acting as a moderator, membership may have influenced the organizational size - provision of care relationship. Membership in a pediatric end-of-life coalition may provide members with an opportunity to network and obtain knowledge about pediatric end of life that is needed by medium-sized hospices to provide care for children. Medium-sized hospices might be able to respond faster and with more flexibility to the information from professional groups than small or large hospices (Connor, 2009b; Daft, 2004). Therefore, membership may not act as a normative pressure on hospices to provide care for children but rather as a social network that provides critical support and guidance on

issues of caring for children at end of life. The design of future research may need to explore and clarify the role of membership among hospices.

**Moderating effects of resource factors: Competition.** Hypothesis 3C, which examined the moderating effects of competition on the relationship between institutional factors and the provision of care, was also rejected. The findings suggested that competition did not attenuate the effects of institutional factors on the provision of care for children. A possible explanation for this finding may be related to the study time lag. Lagging was used to enhance causal explanation and minimize the risk of endogeneity (Menard, 2002). A 1-year lag was selected because organizations typically use the prior year's data to make investment decisions about special operational decisions such as providing services (Thorpe & Phelps, 1991; Zelman et al., 2003). However, in the increasingly competitive market of community-based hospice care, hospices may be responding to competitive pressures in a time frame shorter than a year. The response time may have been more adequately measured as a fiscal quarter or 6 months. Therefore, the time lag on this variable may not have captured the impact of competition on the institutional factors- provision of care relationship. As researchers continue to explore this topic, in-depth investigation of the appropriate time lag is warranted. Future qualitative research with hospice administrators may be needed to better understand their responses to competition in order to establish the appropriate time lag.

### **Discussion of Control Variables**

A number of control variables were significantly associated with the provision of hospice care for children. Compared to freestanding agencies, hospital-based community agencies were less likely to provide hospice care for children. One possible explanation may relate to hospital's core competencies. Hospitals are increasingly focusing their business

activities on core competencies such as providing acute care and activities in support of those core competencies such as inpatient hospice care (Dressler et al., 2006). Hospital administrators may view providing care for children as a specialty service that does not directly relate to those core services. Additionally, in an era of cost-conscious hospital decision making, the expense of providing hospice care for children may be out of line with hospitals' cost goals (Knapp et al., 2009b). Future research should explore hospital strategies as they relate to providing community-based hospice care for children.

This study also found that provision of hospice care for children decreased over the period of the study. A possible explanation may relate to the economy during this time frame. From 2002 to 2008, the California economy experienced cycles of decline and growth (CA DOF, 2011). California spent much of 2002 and 2003 recovering from the 2000-2001 recession. Although the economy experienced growth during 2005 and 2006, there is evidence that the Great Recession of 2008-2009 started earlier in California than in other states (Bardham & Walker, 2010). Using several key economic indicators, economists reported that California declines in residential construction began in 2006 after their peak in 2005, and housing prices dropped in 2007 after their peak in 2006. In addition, California lost over 1 million jobs from the peak of employment in July 2007 through the end of 2009. Therefore, California hospices may have reacted to the changing economy by modifying the provision of service for children earlier than the Great Recession of 2008-2009.

Finally, the results of this study showed that nonprofit status and organizational age were positively related to provision of care for children. This suggests that differences in the mission of nonprofit and for-profit hospices may motivate whether or not hospice care is provided for children. It may be that nonprofit hospices are generally more responsive to the



unique needs of a local community such as providing care for children, whereas for-profits tend to focus on income-producing services (Connor, 2009b). Likewise, older hospices may be more willing to provide care to special populations such as children because they have developed ties and a reputation in the health care community. Hospital discharge planners needing assistance with the disposition of a child may be more likely to refer to hospices they have worked with successfully over the years.

### **Implications of Findings**

The findings of this study have several important implications. The discussion of the implications is divided into three parts including theoretical implications, implications for policy makers, and practice implications.

**Theoretical implications.** A secondary goal of the study was to gain knowledge about whether current organizational theories were sufficient to understand and explain the organizational behavior of hospices. Specifically, this research tested a conceptual model that combined constructs from institutional theory and resource dependence theory. The basic premise of institutional theory is that organizations operate in an institutional environment composed of a set of regulatory (e.g., rules, laws, sanctions), normative (e.g., professional standards and certification), and cultural-cognitive elements (e.g., common beliefs and values) (Scott, 2001; Scott & Meyer, 1983). A key concept of the institutional perspective is that organizations encounter three types of demands to which they must conform to gain legitimacy and survival: coercive, normative, and mimetic pressures (DiMaggio & Powell, 1983). The current study also used resource dependence theory that posits when organizations do not have all the internal resources and capabilities necessary for survival, they must develop interdependent relationships with other entities (Pfeffer & Salancik,

1978). The fundamental assumptions of resource dependence theory are that organizations make accommodations to resource holders contingent on the availability of external and internal resources and competition for resources. Finally, institutional and resource dependence theories were combined to strengthen and enrich the theoretical framework for explaining the environment-organization relationships (Oliver, 1991). The intent of using two theoretical paradigms was to provide a more comprehensive view of hospice organizations' provision of hospice care for children.

The results of the study indicated that several of the predictor variables were significantly related to provision of care. However, few of the proposed relationships, as predicted by institutional theory and the integrated theoretical framework were not supported. Although possible explanations for these inconsistent results were discussed earlier in this chapter, there may be other explanations that have important theoretical implications for further development and testing of institutional and resource dependence theories.

A possible explanation for the lack of support for the hypotheses may relate to the measurement of key constructs. The dichotomization of variables in this study may have resulted in the less than adequate measurement of institutional theory constructs. This study used 10 binary variables, including all the institutional pressure variables, and 5 continuous variables. Organizational theorists have suggested that the use of simple dichotomies limits the precision of predictions because the organizational environment is often more complex than an "either or" response (Peters, 2000). For example, the construct of mimetic pressures was captured with the organization leader variable that measured whether or not a children's hospital was present to imitate in the hospice's county. However, imitation may not be that simple. Pediatric hospitals provide a range of end-of-life services, such as inpatient palliative

consultations and acute pain clinics, along with hospice care (Friedrichsdorf et al., 2007). In addition, there is confusion about the terminology associated with end of life care for children in the hospital. In some cases, end-of-life care is referred to as hospice care, palliative care, or supportive care (Fadul et al., 2009). Clearly, imitation is a complex and amorphous phenomenon. Ensuring that the constructs are measured adequately is important to drawing correct inferences. In addition, a mismatch between study operations and the constructs used to describe those operations poses a potential threat to construct validity in the study (Shadish et al., 2002). Therefore, future research should continue testing measures of key constructs in institutional theory.

Another theoretical implication of this study concerns the combining of theories. It may be that the theories did not complement each other as anticipated in this research. For example, institutional theory emphasizes conformance with external expectations and resource dependence theory emphasizes the organization's active resource control. In addition, institutional theory stipulates that organizations make decisions to claim legitimacy, whereas resource dependency surmises that organizational decision making is motivated by controlling resource relationships. Finally, in institutional theory, managers are passive instruments of the environment and in resource dependence theory, they are active decision makers. As a result, combining these theories did not offset each others' limitations.

The final theoretical implication relates to the application of the theoretical framework developed in this study to other types of health care organizations. The effects of institutional and resource factors on the provision of pediatric hospice care in a community-based hospice setting may differ in other end-of-life care settings (e.g. acute care). For example, families and clinicians experience different pressures in the acute care setting to

conform to the regulations, norms, and values of traditional medicine in order to cure the child's disease. These pressures may stem from the families acceptance of the child's limited life expectancy and their continuing hope for a medical cure, along with clinicians' focus on curing the underlying medical condition. These alternative forces may influence whether hospice care is provided for children (Davies, et al., 2008; Fowler et al., 2006; Wolfe et al., 2005) and these important forces are not contained within either institutional theory or resource dependence theory. Although there are currently efforts in the end-of-life community to promote clinicians' awareness of and education in pediatric end-of-life (IOM, 2003), there has historically been a divide between traditional medicine and hospice care (Abel, 1986). Hospice care has often been viewed by clinicians and families as "giving up," and an option to pursue only when there are no other alternatives for treating the child's medical condition (Dabbs et al., 2007). As a result, the pressures exerted by key stakeholder in the acute care setting may differ from those in the community-based hospice setting. For this reason, further research should explore provision of hospice care for children in various settings in order to provide a holistic and integrated examination of the provision of hospice care for children.

**Policy implications.** A number of policy implications can be drawn from the findings of this study. First, the findings related to hospice services for children underscore the relevance of recent policy efforts to update the Medicaid and CHIP hospice benefit for children. Effective March 23, 2010, Title II Role of Public Programs, Section 2302 Concurrent Care for Children of the PPACA, permitted terminally ill children on the Medicaid or CHIP hospice benefit to continue receiving treatments that may result in cure or prolongation of life (e.g., chemotherapy, dialysis, bone marrow transplant, antiretroviral

regimens, radiation, transplant rejection medication) while enrolled in hospice care services (US Department of Health and Human Services, 2010). Although the hospice benefit has always been designed to provide any and all services necessary for management of the terminal illness (Connor, 2009b), this study revealed that prior to the PPACA enactment, hospices generally did not provide imaging, laboratory, outpatient, radiation, or chemotherapy services for children to manage or palliate symptoms at end of life. As a result, the change in the federal law to allow concurrent curative care may be an important policy initiative aimed at improving the quality of care for children at end of life. Therefore, this study may provide important baseline data for policymakers and researchers as they assess the impact of the PPACA 2302 on provision of other hospice services for children in the future.

Second, the study findings reinforce the Medicare Payment Advisory Commission's (MedPAC) recent report to Congress recommending changes to the hospice payment system. This study found that most hospices lacked income from donations and grants to assist in offsetting the cost of providing expensive care for children. The hospice per diem in California for routine home care is approximately \$169 per day, whereas the cost of end-of-life care for children can range from \$182 to \$4,296 per day (CA DHCS, 2007; Ward-Smith et al., 2008). MedPAC has recommended that Congress restructure the hospice payment system to provide an increased per diem to hospices at the beginning and end of the hospice enrollment (MedPAC, 2011). Other policy researchers have suggested a carve-out system that would reimburse hospices at an increased per diem rate for the delivery of high-cost care (Harrington & Estes, 2004). Revising the hospice per diem payment structure to cover the cost of expensive care may provide hospice administrators with an important financial

incentive to provide care for children. Future research might examine the financial disincentives in the current reimbursement structure of providing care for children by conducting financial case studies of hospices that provide care for children.

In addition, the findings reported here provide evidence in support of tax-exempt status for hospices. This study showed that nonprofit status was positively related to provision of care for children. The findings from the current study are in keeping with other research that has explored ownership status and provision of hospice care and found that nonprofit hospices were more likely to provide core and noncore hospice services than for-profit hospices (Carlson et al., 2004,2008; Foliart et al., 2001; McCue & Thompson, 2005; White et al., 2002). In addition, other researchers have found that nonprofit hospices were more likely to admit unprofitable patients requiring skilled care and short lengths of stay, such as children (Wachterman et al., 2011). One reason for the difference in the provision of care between for-profit and nonprofit hospices may relate to community benefit. As tax exempt entities, nonprofit hospices play a critical role in providing a community benefit. Nonprofit hospices are typically reliant on their communities for volunteers and funding, and do not have stockholders to satisfy or profits to generate. Their mission is often focused on serving the unique needs of the community (e.g., hospice care for children). Therefore, the tax benefits enjoyed by nonprofit hospices are justifiable given their provision of care to an underserved population whose care is often unprofitable.

Finally, the findings of this study reinforce the need to incorporate defined pediatric hospice standards of care as part of the accreditation process. Similar to Li (2010), this study demonstrated that accreditation was not significantly related to the provision of hospice care for children. This raises the concern that pediatric hospice care is not evaluated by

accrediting agencies. In fact, during the study time frame there were no industry standards for pediatric hospice care (Friebert & Huff, 2009). They have only recently been introduced by the National Hospice and Palliative Care Organization and are now available for voluntary adoption. Though hospice associations are often instrumental in suggesting industry standards to accrediting agencies (Connor, 2009b), pediatric standards have not been adopted by accrediting agencies. Therefore, drawing upon the long-standing collaboration between hospice associations and accrediting agencies, and based on the findings of this study, hospice associations should be a driving force that advocate for pediatric standards to be adopted by accrediting agencies.

**Practice implications.** The results of the current study suggest that if hospices provide care for children, hospice administrators may need to develop specific administrative strategies for pediatric care. This might include developing risk-sharing mechanisms. For example, membership in a chain of hospices may allow small- and medium-sized hospices to effectively distribute the financial risk of high cost care to children across a larger patient population or create economies of scale. Risk sharing through chain membership may provide small- and medium-sized hospices the flexibility to substitute resources in order to provide care for children. Future research might explore other forms of membership on the organizational size - provision of hospice care for children relationship.

Another potential strategy relates to identifying a pediatric hospice champion in the organization. The role of a champion is generally to shape organizational change by protecting those involved in the implementation of change, building organizational support, facilitating the use of organizational resources, and encouraging growth of an organizational coalition that supports implementation of change (Greenhalgh et al., 2004). The importance

of having a champion is well documented in the quality improvement literature (Shortell et al., 2004). However, there is emerging evidence that champions may also be effective in fostering change in health care practices such as providing care for children (Acolet et al., 2011; Doumit et al., 2007). In fact, recent studies have found that although a champion may be effective in implementing new technology, more than one champion is often needed for changes in organizational behavior (Damschroder et al., 2009; Gallagher et al., 2010).

Therefore, hospices may benefit from identifying champions for pediatric hospice care within their organizations. Future research might explore the relationship between champions who join a professional group and provision of hospice care for children.

Finally, hospices assessing whether to provide hospice care for children or to expand services to admit additional children may need to make improvements or modification in their services. For example, hospices may need to establish in-home respite services. Because respite services are generally staffed by volunteers (Claxton-Oldfield & Gosselin, 2010), hospices may need to recruit and train a group of volunteers especially for children (Duggal et al., 2008). This may also include establishing or modifying organizational policies and procedures for volunteers and staff involved in respite care such as having parents sign a waiver of liability form or updating liability insurance policies (Claxton-Oldfield et al., 2011; Corr & Corr, 1985). In addition, until the federal reimbursement policy for respite care is changed, hospices may need to seek donor funding that can be used specifically for in-home respite care.

### **Limitations of Study**

There are several notable limitations to this study. The first limitation relates to misclassification. Because the CA OSHPD uses organizational addresses rather than license



numbers as the hospice unique identifier, hospices might inadvertently be included multiple times in the same year. When hospice offices moved, a new license number was assigned, thereby creating the appearance of two or more entries for the same organization. This generated a false number of hospices providing care. As a result, there is a potential threat to the internal validity of the study as a result of measurement bias. Although the number of duplicate and triplicate provider numbers was relatively small ( $n=30$ ), records had to be verified with the California licensure database and/or contacted by phone to validate information.

The second limitation relates to omitted variable bias. This study examined how well the independent variables predicted the dependent variable. It did not control for every institutional, resource, organizational, or market factor that may have affected the provision of hospice care for children. For example, staff caseload could be a critical factor in whether or not hospices provide care for children, because children often require additional staff resources during their hospice admissions. Yet, this factor was not included in the CA OSHPD data set. This was a limitation of using a secondary data set and presented a potential threat to the internal validity of the study. However, efforts were made to capture as much information about practice and environmental influence as possible within the constraints of available secondary databases. Future research might explore the inclusion of factors from other data sources or by incorporating mixed methodologies.

The third limitation concerns alternative variable measures. For example, this study used the presence of a children's hospital in the local community as a measure of mimetic pressure. However, the study found that the probability of providing care for children was lower in hospices with a children's hospital in their community compared with those without

a children's hospital. This suggested that instead of copying the pediatric practices of a children's hospital, these hospitals may act as substitutes for community-based hospices in providing care for terminally ill children. An alternative measure of mimetic pressures may have been the percent of hospices in the local market with a children's hospice program. Although this measure may have been ideal theoretically, there were so few hospices that had a dedicated pediatric program in this study's data set that the alternative measure was not practical.

The final limitation relates to generalizability. The findings from this study are only applicable to community-based hospice and home health agencies that had a licensed hospice program in the state of California during the study time frame. Although examining organizations that provide hospice care for children in a particular state may not be generalizable to other states and poses a threat to external validity of the study, California has health care policies and patterns that are influential in the national arena and has historically been a leader in hospice care. California has 12% of the nation's hospice patients and one of the highest concentrations of hospice providers in the nation (Lorenz et al., 2004; Hospice Association of American, 2008). The first residential pediatric hospice (George Mark Children's Home) and two of the oldest hospices in the US (Hospice of Santa Barbara and Hospice of Marin) were founded in California. In addition, California often implements new and emerging health care services before they are adopted in other states. Therefore, examining hospice organizations in California provided important insight into the provision of pediatric hospice care for other states and the nation.

### **Suggestions for Future Research**

Further research is needed to advance knowledge of provision of hospice care for children. A challenge faced by researchers conducting health services research in pediatric

hospice care is the lack of data on organizations that offer services to children. The CA OSHPD is one of the few administrative data sets available to researchers. Although there is increasing interest in research on community-based pediatric hospice care (IOM, 2003), researchers face critical data hurdles in obtaining data. As a result, few quantitative research studies in the US have focused on organizations that provide hospice care for children, and there has been negligible attention to the organizational environment of hospices.

Future studies might investigate different constructs such as interorganizational network ties using interorganizational network theory (Katz et al., 2004) or age dependence using organizational ecology (Hannan & Freeman, 1977, 1989). For example, one might hypothesize that ties to other organizations through social networking may reduce the uncertainty of and promote the provision of care for children by increasing communication and information sharing. Alternatively, research questions using these constructs could explore whether providing care for children affects organizational survival in new hospices. Therefore, using alternative organizational theories may yield valuable and enriched information on providing care for children.

Future studies should explore utilization of hospice care among children. There is a lack of understanding about who is using hospice care services and the determinants of utilization among children and their families. In addition, follow-up research should address whether utilization affects the quality and cost of care for terminally ill children. Data collection on outcomes could be conducted through family satisfaction surveys, hospice claims data, or data from state hospice quality reporting.

Finally, more studies are needed to understand the effect of hospice ownership on provision of care for children. This study and previous studies (Carlson et al., 2004, 2008;

Foliat et al., 2001; McCue & Thompson, 2005; White et al., 2002) have empirically demonstrated that for-profit hospice organizations differ significantly from nonprofits in the provision of services. As the number of for-profit hospices grows annually in the US (NHPCO, 2009a), it is important to understand why for-profit hospices are less likely to provide care for children. A deeper understanding of this issue might be gained by using qualitative methodologies such as focus groups, key informant interviews, or document reviews. An increased understanding aimed at improving access to care for children may be gained by additional analyses of ownership type.

### **Summary**

The goal of this longitudinal study was to describe the characteristics of organizations that provided hospice care services for children and to understand the influence of institutional and resource factors on the provision of pediatric hospice care. This is one of the first studies to provide evidence that over a relatively short period of time (2002-2008) terminally ill children and their families have encountered substantial changes in the availability of community-based hospice care. As the number of hospices grew during the study time frame, the proportion of hospices providing care for children significantly diminished. Although hospices that provided care for children responded to the needed for pediatric care with expanded core and noncore services and geographic coverage, there was still room for improvement in services aimed at medically complex patients such as children (i.e., palliative radiation, palliative chemotherapy). It was also evident in this study that hospices faced substantial barriers in providing care for children that worsened in tough economic times, all of which adversely impacted access to care for children. The findings

from this study beg the larger question of whether or not community-based hospices should provide care for children in light of the challenges.

There is no easy answer to this question. If hospices choose not to provide care to children, they risk violating the mission of hospice and damaging the reputation of hospices as a place where end-of-life care is delivery to all in need regardless of age, race, gender, and illness type. Once community-based hospices decide not to provide care for children, what category of patients will be next? Indeed, this slippery slope has the potential to contribute to the disparities already present in end-of-life care (IOM, 2003).

If, on the other hand, hospices choose to provide care or expand services for children, this study showed that these barriers might be modifiable at the organizational level (e.g., identifying a champion) and at the policy level (e.g., reimbursement changes or introducing pediatric standards into accreditation process). Additionally, by engaging in care for children, hospices become an integral part of the pediatric health care system and contribute in a meaningful way to the care continuum as children transition through their disease trajectory (Connor, 2009b). Additional studies that develop our understanding of the role of hospices in the provision of care for children are clearly warranted, and as the science progresses, further inquiries into interventions aimed at improving provision of hospice care for children are needed, if access to and quality of end-of-life care for terminally ill children and their families are to improve.

# Appendix. CA OSHPD Annual Utilization Report of Home Health Agencies/Hospices - 2008

State of California

Office of Statewide Health Planning and Development

## ANNUAL UTILIZATION REPORT OF HOME HEALTH AGENCIES/HOSPICES-2008

1. Facility DBA (Doing Business As) Name:		2. OSHPD Facility No.:	
3. Street Address:		4. City:	5. Zip Code:
6. Facility Phone No.: ( )	7. Administrator Name:		8. Administrator's E-Mail Address:
9. Was this agency in operation at any time during the year? Yes <input type="checkbox"/> No <input type="checkbox"/>		Dates of Operation (MMDDYYYY): 10. From: 11. Through:	
12. Name of Parent Corporation: (If this is a branch or a multiple location, complete lines 12-16)			
13. Corporate Business Address:		14. City:	15. State 16. Zip Code:
17. Person Completing Report		18. Phone No. ( ) Ext.	
19. Fax No. ( )		20. E-mail Address:	
25. Select Entity Type: HHA only <input type="checkbox"/> HHA with Hospice Program <input type="checkbox"/> Hospice only <input type="checkbox"/>			
26. Select Entity Relationship: Parent with Branch/es <input type="checkbox"/> Branch <input type="checkbox"/> Sole Facility <input type="checkbox"/>			
<p align="center"><b>CERTIFICATION</b></p> <p><i>I declare the following under penalty of perjury: that I am the current administrator of this health facility, duly authorized by the governing body to act in an executive capacity; that I am familiar with the record keeping systems of this facility; that the records and logs are true and correct to the best of my knowledge and belief; that I have read this annual report and am thoroughly familiar with its contents; and that its contents represent an accurate and complete summarization from medical records and logs of the information requested.</i></p> <p>_____</p> <p>Date Administrator Signature</p> <p>_____</p> <p>Administrator Name (Please Print)</p>			
<p>Completion of this Annual Utilization Report of Home Health Agencies and Hospices is required by Section 74729, Division 5, Title 22, of the California Code of Regulations for Home Health Agencies and Section 1750(c) of the California Health and Safety Code for Hospices. Failure to complete and file this report by March 15 may result in suspension of the facility's license.</p>			
<p>Office of Statewide Health Planning and Development Healthcare Information Division Accounting and Reporting Systems Section Licensed Services Data and Compliance Unit 400 R Street, Suite 250 Sacramento, CA 95811</p> <p align="right">Phone: (916) 326-3854 FAX: (916) 322-1442</p>			

ALIRTS-HH/H (12-16-08)

Section 1

# HOSPICE DESCRIPTION

ANNUAL UTILIZATION REPORT OF HOSPICES - 2008

## Section 5

OSHDP Facility ID No. \_\_\_\_\_

**DO NOT COMPLETE SECTIONS 5 THROUGH 10 UNLESS YOU HAVE A HOSPICE.**

### LICENSEE TYPE OF CONTROL

Line No.		(1)
1	From the list below, select the ONE category that best describes the licensee type of control of your hospice, i.e. the type of organization that owns the license. (There will be a drop down box in ALIRTS -see list of choices below.)	

### LICENSEE TYPE OF CONTROL CODES

1	City and/or County	6	Investor - Individual
2	District	7	Investor - Partnership
3	Non-profit Corporation (incl. Church-related)	8	Investor - Limited Liability Company
4	University of California	9	Investor - Corporation
5	State		

### MEDICARE/MEDI-CAL CERTIFICATION

Line No.	
5	Select: Medicare only <input type="checkbox"/> Medicare & Medi-Cal <input type="checkbox"/> Medi-Cal only <input type="checkbox"/> Neither <input type="checkbox"/>

### AGENCY ACCREDITATION STATUS (Check all applicable ones.)

Line No.	
10	Accredited by ACHC (1) Accredited <input type="checkbox"/> (2) Deemed <input type="checkbox"/> (3) None <input type="checkbox"/>
11	Accredited by CHAP (1) Accredited <input type="checkbox"/> (2) Deemed <input type="checkbox"/> (3) None <input type="checkbox"/>
12	Accredited by JCAHO (1) Accredited <input type="checkbox"/> (2) Deemed <input type="checkbox"/> (3) None <input type="checkbox"/>
13	Accredited by other: (1) Accredited <input type="checkbox"/> (2) Deemed <input type="checkbox"/> (3) None <input type="checkbox"/>

### AGENCY TYPE AS REPORTED ON MEDICARE COST REPORT

Line No.		(1)
20	From the list below, select ONE category. (There will be a drop down box in ALIRTS.)	

### AGENCY TYPE CATEGORIES

Line No.		Line No.	
1	Free Standing	4	Long-Term Care Facility-based
2	Hospital-based	5	Veteran Administration-based
3	Home Health-based	6	Other

### LOCATION OF SERVICE DELIVERY (Check one)

Line No.	
25	Primarily Urban <input type="checkbox"/> Primarily Rural <input type="checkbox"/> Mixed Urban and Rural <input type="checkbox"/>

**HOSPICE SERVICES**

ANNUAL UTILIZATION REPORT OF HOSPICES - 2008

**Section 6**

OSHPD Facility ID No. \_\_\_\_\_

**BEREAVEMENT SERVICES**

Line No.	Bereavement Services	People Served (1)
1	Survivors of hospice patients	
2	Survivors of persons not receiving hospice care	

**VOLUNTEER SERVICES**

Line No.	Volunteer Services	No. of Volunteers (1)	Volunteer Hours (2)
3	Patient / Family Services		
4	Bereavement		
5	Administrative		
6	Medicare Reportable Hours (sum lines 3-5)		
7	Fundraising		
9	Other		
10	TOTAL		

**ADDITIONAL AND SPECIALIZED SERVICES**

Check all services directly provided by OR contracted for by the hospice.

Line No.	Additional and Specialized Hospice Services	Services (1)
11	Hospice Designated Inpatient Facility / Unit	
12	Specialized Pediatric Program	
13	Bereavement services to survivors of persons not receiving hospice care	
14	Adult Day Care	
15	Specialized Palliative Care Program	
16	Other	

**VISITS BY TYPE OF STAFF (Include After-Hours and Bereavement Visits)**

Line No.	Type of Staff	Visits (1)
21	Nursing - RN	
22	Nursing - LVN	
23	Social Services	
24	Hospice Physician Services	
25	Homemaker and Home Health Aide	
26	Chaplain	
29	Other Clinical Services	
30	TOTAL	



# HOSPICE PATIENT INFORMATION

ANNUAL UTILIZATION REPORT OF HOSPICES - 2008

## Section 7

OSHDP Facility ID No. \_\_\_\_\_

### UNDUPLICATED HOSPICE PATIENTS BY GENDER AND AGE CATEGORY

Line No.	Age Category	Male (1)	Female (2)	Other / Unknown (3)	Total (4)
1	0-1 Years				
2	2-5 Years				
3	6-10 Years				
4	11-20 Years				
5	21-30 Years				
6	31-40 Years				
7	41-50 Years				
8	51-60 Years				
9	61-70 Years				
10	71-80 Years				
11	81-90 Years				
12	91 + Years				
15	TOTAL				

### UNDUPLICATED HOSPICE PATIENTS BY GENDER AND RACE

Line No.	Race	Male (1)	Female (2)	Other / Unknown (3)	Total (4)
21	White				
22	Black				
23	Native American				
24	Asian/Pacific Islander				
25	Other / Unknown				
30	TOTAL				

### UNDUPLICATED HOSPICE PATIENTS BY GENDER AND ETHNICITY

Line No.	Ethnicity	Male (1)	Female (2)	Other / Unknown (3)	Total (4)
31	Hispanic				
32	Non-Hispanic				
33	Unknown				
35	TOTAL				

Hospice - Section 7 (1)

ALIRTS-HH/H (12-16-08)

# HOSPICE PATIENT INFORMATION

ANNUAL UTILIZATION REPORT OF HOSPICES - 2008

## Section 7 (Con't)

OSHPD Facility ID No. \_\_\_\_\_

### HOSPICE PATIENT ADMISSIONS BY SOURCE OF REFERRAL

Line No.	Source of Referral	Patients (1)
41	Home Health Agency	
42	Hospital (Discharge Planner, etc.)	
43	Long-Term Care Facility	
44	Other Hospice	
45	Payer (Insurer, HMO, etc.)	
46	Physician	
47	RCFE / ARF / CLHF	
48	Self / Family / Friend	
49	Social Service Agency	
54	Other	
55	TOTAL	

### HOSPICE PATIENT DISCHARGES BY REASON

Line No.	Reason for Discharge	Patients (1)
61	Death	
62	Patient Moved Out of Area	
63	Patient Refused Service	
64	Transferred to Another Local Hospice	
65	Prognosis Extended	
66	Patient Desired Curative Treatment	
69	Other	
70	TOTAL	

### HOSPICE PATIENTS DISCHARGED BY LENGTH OF STAY

Line No.	Length of Stay (Days)	Patients (1)
71	0-5 Days	
72	6-10 Days	
73	11-15 Days	
74	16-20 Days	
75	21-30 Days	
76	31-60 Days	
77	61-90 Days	
78	91-120 Days	
79	121-150 Days	
80	151-180 Days	
84	181 + Days	
85	TOTAL	

ALIRTS-HH/H (12-16-08)

Hospice - Section 7 (2)

**HOSPICE PATIENT INFORMATION**

ANNUAL UTILIZATION REPORT OF HOSPICES - 2008

**Section 7 (Con't)**

OSHDP Facility ID No. \_\_\_\_\_

**HOSPICE PATIENT ADMISSIONS BY COUNTY AND DISCHARGES BY DISPOSITION**

Line No.	County of Patient's Residence at Time of Admission (1)	No. of Admissions (2)	No. of Deaths (3)	No. of Non-Death Discharges (4)	No. of Patients Served (5)
91					
92					
93					
94					
95					
96					
97					
98					
99					
100	TOTAL				

# HOSPICE UTILIZATION

# ANNUAL UTILIZATION REPORT OF HOSPICES - 2008

## Section 8

OSHPD Facility ID No. \_\_\_\_\_

Please provide the number of patients discharged during calendar year reported regardless of payment source. Count the patient only under the principal diagnosis for which the patient was admitted for hospice care. Report each patient only once. The ICD-9-CM codes are provided only as a guide for you. You may use your hospice's existing definitions for diagnosis groups or the LMRP (Local Medical Review Policy) diagnosis codes from your fiscal intermediary, provided they match in a general way with the ICD-9-CM codes.

### DISCHARGED HOSPICE PATIENTS, VISITS AND PATIENT DAYS BY DIAGNOSIS (do not input any commas)

Line No.	Diagnosis	ICD-9-CM Codes	No. of Patient Discharges (1)	Visits for Discharged Patients (2)	Discharged Patients Total Days of Care (3)
1	Cancer	140.0 - 209.30 230.0 - 234.9			
2	Heart	391.0 - 392.0 393 - 402.91 404.0 - 404.9 with fifth digit 1 or 3 410.00-429.9			
3	Dementia & Cerebral Degeneration	290.0 - 294.9 331.0 - 331.9			
4	Lung, excluding cancer	460-519.9, 573.9			
5	Kidney, excluding cancer	403.00 - 403.91, 404.0-404.9 with fifth digit 0, 2 or 3, 405.0 - 405.9 with fifth digit 1 580.0 - 589.9			
6	Liver, excluding cancer	570-573.9			
7	HIV	042			
8	Brain Stroke and late effects	430 - 436 438.0 - 438.9 997.02			
9	Coma, with or without brain injury	780.01 - 780.09 850.4 851.0 - 854.1 with fifth digit 5			
10	Diabetes	249.00 - 250.93			
11	ALS*	335.20			
19	Other	All other codes that are not in lines 1-11.			
20	TOTAL				

\*Amyotrophic lateral sclerosis (ALS), also called Lou Gehrig's Disease

# HOSPICE CARE AND SOURCE OF PAYMENT

ANNUAL UTILIZATION REPORT OF HOSPICES - 2008

## Section 9

OSHPD ID No. \_\_\_\_\_

Please provide patient days for all patients served, including those in nursing facilities during the calendar year reported. Patients who change primary pay source during the calendar year reported should be reported for each pay source with the number of days of care recorded for each source (count each day only once even if there is more than one pay source on any one day).

### LEVEL OF CARE AND SOURCE OF PAYMENT (do not input any commas)

Line No.	Source of Payment	No. of Patients Served (1)	Days of Routine Home Care (2)	Days of Inpatient Care (3)	Days of Respite Care (4)	Days of Continuous Care (5)	Total Patient Care Days (6)
1	Medicare						
2	Medi-Cal						
3	Medi-Cal Managed Care						
4	Managed Care						
5	Private Insurance						
6	Self Pay						
7	Charity						
9	Other*						
10	TOTAL						

\* Other payment sources may include but not limited to Workers Comp., Home Health benefit, etc.

### LOCATION OF CARE PROVIDED (do not input any commas)

Line No.	Location of Care	Days of Routine Home Care (1)	Days of Inpatient Care (2)	Days of Respite Care (3)	Days of Continuous Care (4)	Total Patient Care Days (5)
21	Home					
22	Hospital					
23	SNF					
24	CLHF					
25	RCFE / ARF					
29	Other					
30	TOTAL					

# HOSPICE CARE AND SOURCE OF PAYMENT

ANNUAL UTILIZATION REPORT OF HOSPICES - 2008

## Section 9

OSHPD ID No. \_\_\_\_\_

Please provide patient days for all patients served, including those in nursing facilities during the calendar year reported. Patients who change primary pay source during the calendar year reported should be reported for each pay source with the number of days of care recorded for each source (count each day only once even if there is more than one pay source on any one day).

### LEVEL OF CARE AND SOURCE OF PAYMENT (do not input any commas)

Line No.	Source of Payment	No. of Patients Served (1)	Days of Routine Home Care (2)	Days of Inpatient Care (3)	Days of Respite Care (4)	Days of Continuous Care (5)	Total Patient Care Days (6)
1	Medicare						
2	Medi-Cal						
3	Medi-Cal Managed Care						
4	Managed Care						
5	Private Insurance						
6	Self Pay						
7	Charity						
9	Other*						
10	TOTAL						

\* Other payment sources may include but not limited to Workers Comp., Home Health benefit, etc.

### LOCATION OF CARE PROVIDED (do not input any commas)

Line No.	Location of Care	Days of Routine Home Care (1)	Days of Inpatient Care (2)	Days of Respite Care (3)	Days of Continuous Care (4)	Total Patient Care Days (5)
21	Home					
22	Hospital					
23	SNF					
24	CLHF					
25	RCFE / ARF					
29	Other					
30	TOTAL					



# HOSPICE INCOME AND EXPENSES STATEMENT

ANNUAL UTILIZATION REPORT OF HOSPICES - 2008

## Section 10

OSHDP Facility ID No. \_\_\_\_\_

DETAIL OF OPERATING EXPENSES (do not input "\$" signs, commas or decimals, round up to whole dollar)

Use data from Medicare Cost Report where applicable.

Line No.		Total (1)
	<b>General Service Cost Centers</b>	
30	Administrative and General	
	<b>Inpatient Care Service</b>	
31	Inpatient - General Care	
32	Inpatient - Respite Care	
	<b>Nursing Home</b>	
33	Room & Board SNF Medi-Cal Pass through Payments	( )
34	Medi-Cal Room & Board Contractual Payments	
	<b>Program Supervision</b>	
35	Hospice Program / Team Supervision (Non-visit wages)	
	<b>Visiting Services</b>	
36	Physician Services	
37	Nursing Care	
38	Rehabilitation Services (PT, OT, Speech)	
39	Medical Social Services - Direct	
40	Spiritual Counseling	
41	Dietary Counseling	
42	Counseling - Other	
43	Home Health Aides and Homemakers	
44	Other Visiting Services	
	<b>Hospice Service Cost Centers</b>	
45	Drugs, Biologicals and Infusion	
46	Durable Medical Equipment / Oxygen	
47	Patient Transportation	
48	Imaging, Lab and Diagnostics	
49	Medical Supplies	
50	Outpatient Services (including ER Dept.)	
51	Radiation Therapy	
52	Chemotherapy	
53	Other Hospice Service Costs	
	<b>Other Hospice Costs</b>	
54	Bereavement Program Costs	
55	Volunteer Program Costs	
56	Fundraising	
	<b>Other Costs</b>	
57	Other Program Costs *	
59	Total Operating Expenses	

\* Program costs including community education and outreach program costs.

Hospices-Section 10 (1)

ALIRTS-HH/H (12-16-08)

# HOSPICE INCOME AND EXPENSES STATEMENT

ANNUAL UTILIZATION REPORT OF HOSPICES - 2008

## Section 10 (Cont'd)

OSHDP Facility ID No. \_\_\_\_\_

HOSPICE INCOME STATEMENT (do not input "\$" signs, commas or decimals, round up to whole dollar)

Line No.		Total (1)
	<b>Gross Patient Revenue</b>	
101	Medicare	
102	Medi-Cal (Excluding Room & Board)	
103	Medi-Cal Managed Care (Excluding Room & Board)	
104	Managed Care (Non Medi-Cal)	
105	Private Insurance	
106	Self-Pay	
109	Other Payers	
110	Total Gross Patient Revenue (sum of lines 101 through 109)	
	<b>Write-offs and Adjustments</b>	
111	Contractual Adjustments	
112	Denials / Bad Debt	
113	Charity	
119	Other Write-offs and Adjustments	
120	Total Write-offs and Adjustments (sum of lines 111 through 119)	
125	Net Patient Revenue (line 110 minus line 120)	
	<b>Other Operating Revenue</b>	
131	Grants	
132	Donations / Contributions	
133	Unrelated Business Income	
139	Other	
140	Total Other Operating Revenue (sum of lines 131 through 139)	
145	Total Operating Revenue (line 125 plus line 140)	
	<b>Operating Expenses</b>	
151	General Service Cost Centers	
152	Inpatient Care Service	
153	Nursing Home	
154	Program Supervision	
155	Visiting Services	
156	Hospice Service Cost Centers	
157	Other Hospice Costs	
159	Other Costs	
160	Total Operating Expenses (sum of lines 151 through 159)	
165	Net from Operations (line 145 minus line 160)	
170	Income Tax	
175	Net Income (line 165 minus line 170)	



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