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Survey on Pediatric Palliative Care Care For Healthcare Providers (SPPCHP): Identifying Knowledge, Barriers, and Support Needs

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UNIVERSITY OF MIAMI

SURVEY ON PEDIATRIC PALLIATIVE CARE FOR HEALTHCARE PROVIDERS
(SPPCHP): IDENTIFYING KNOWLEDGE, BARRIERS, AND SUPPORT NEEDS

By

Mary Elizabeth Grimley

A DISSERTATION

Submitted to the Faculty
of the University of Miami
in partial fulfillment of the requirements for
the degree of Doctor of Philosophy

Coral Gables, Florida

August 2011

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SURVEY ON PEDIATRIC PALLIATIVE CARE FOR HEALTHCARE PROVIDERS
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Survey on Pediatric Palliative Care for Healthcare
Providers (SPPCHP): Identifying Knowledge, Barriers,
and Support Needs

(August 2011)

Abstract of a dissertation at the University of Miami.

Dissertation supervised by Professor Alexandra L. Quittner
No. of pages in text. (105)

Objective: A significant number of children suffer from life-limiting illnesses, with many dying each year in the U.S. Services, beyond standard medical care, aimed at increasing overall quality of life for children with life-limiting illnesses, are greatly needed within and outside of our hospitals. Palliative care is conceptualized as treatment provided to relieve symptoms and improve quality of life. Despite the empirically supported benefits of providing pediatric palliative care, only a small percentage of pediatric patients actually receive these services. Thus, there is a great need for the development and provision of these services. The first aim of the current study was to compare results from Holtz Children's Hospital (HCH) at the University of Miami with those from Lucile Packard Children's Hospital (LPCH) at Stanford University, where a survey assessing pediatric healthcare providers' palliative care needs was originally developed. The second aim was the modification and further development of the measure, including an evaluation its psychometric properties. The third aim was to identify the educational and training needs of healthcare providers in providing pediatric palliative care. The fourth aim was to evaluate whether completing the survey improved awareness of a palliative care team. **Method:** Two hundred and twenty five healthcare providers at HCH completed the Survey on Pediatric Palliative Care for Healthcare

Providers (SPPCHP). Participants were diverse with regards to ethnicity/race and profession. **Results:** Healthcare providers at both hospitals reported feeling inexperienced in similar aspects of delivering palliative care and desired further training and support. The SPPCHP demonstrated strong internal consistency and good construct validity, evidenced in factor analyses. Pediatric healthcare providers at HCH reported only feeling “somewhat” experienced in all aspects of pediatric palliative care and rated families’ inability to accept terminal diagnosis as the top barrier to providing this care; half of healthcare providers reported not receiving adequate support. Although referrals did not increase six months after study completion, awareness at the hospital was improved. **Conclusions:** Clinical implications include the need for systematic training and support in palliative care for a range of pediatric professionals, with an emphasis on addressing key barriers to care. Given the similarity of the findings at HCH and LPCH, these results appear generalizable to a variety of children’s hospitals.

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Chapter 1: Introduction

Despite the certainty of death, defying it remains one of our central goals. Those who “never give up” and “fight until the end” are often praised in society (Tanner, 2010). Dying, however, is not equivalent to giving up or losing a fight; it is a natural, inevitable part of life. Perhaps because of our unwillingness to accept death, care for pediatric patients with life-limiting illnesses often focuses on “cures” rather than palliation (Kane & Primono, 2001). Consequently, palliative care, or holistic care aimed at improving *quality* of life despite prognosis, is often lacking in the delivery of healthcare today; few children with life-limiting conditions receive these services (Hinds, Pritchard, & Harper, 2004). Thus, there is a need to identify effective palliative care, better train healthcare staff in its delivery, and understand the barriers to providing it.

The current study took an initial step toward addressing these issues by evaluating the knowledge and support needs of pediatric healthcare providers. Previous research conducted at Stanford University was replicated at a diverse children’s hospital in South Florida, with critical updates made to reflect the current definition of palliative care.

Pediatric Deaths & Illnesses

Recent advances in the treatment of chronic and terminal pediatric diseases have dramatically increased rates of survival. In 1900, children five years or younger accounted for 30% of all deaths in the United States; by 1999 they only accounted for 1.4% (Korones, 2007). Medical and scientific advances have also improved the prognosis for many illnesses, such as pediatric cancer. With new therapies and treatments, many of these once incurable cancers now have survival rates that approach

80-90% (Hendrickson & McCorkle, 2008). Genetic discoveries have also helped scientists to better understand and treat illnesses, such as cystic fibrosis (CF), a hereditary disease that primarily affects the lungs and digestive system. New medications and aggressive treatments have increased the median life expectancy for CF from school-age in 1955 to 37.4 years in 2008 (Cystic Fibrosis Foundation, 2008). Public health efforts have also aided in earlier identification and prevention of many diseases. Infections, for example, once a major cause of pediatric mortality, are rarely a cause of death today due to vaccinations and better infection control procedures.

However, despite these advances, approximately 53,000 children in the U.S. die each year and more than 500,000 suffer from life-threatening conditions (Toce & Collins, 2003; Korones, 2007). In 2000, the five leading causes of children's deaths in the U.S. were accidents, homicide, cancer, suicide, and congenital abnormalities, respectively (Harris, 2004). Thus, there is a great need for services which help pediatric patients and their families cope with chronic and terminal illnesses. Palliative care, which aims to reduce symptom severity and increase quality of life, addresses many of these needs (Lanken, Terry, DeLisser, Fahy, Hansen-Flaschen, Heffner, et al., 2008).

Pediatric Palliative Care

Palliative care originated in the 1960's as end-of-life care for adults (Lanken et al., 2008). Although it was first developed for terminally ill patients, it was recently expanded to include the treatment of chronically ill individuals. Thus, unlike hospice, palliative care is no longer limited to dying patients (Field & Behrman, 2003). The Institute of Medicine (IOM) recently defined palliative care as "that [which] seeks to

prevent, relieve, reduce, or soothe the symptoms produced by serious conditions or their treatment and to maintain patients' quality of life" (Field & Behrman, 2003, p.33). It is care that addresses physical, social, emotional, and spiritual suffering of patients and families at all stages of illness (www.moffitt.org).

Pediatric palliative and hospice care services have only been developed in the last 40 years. The pediatric end-of-life care movement began in 1972 in Minnesota, with the development of home care for children dying of cancer (Hendrickson & McCorkle, 2008). Healthcare providers identified a void in the medical treatment of pediatric patients and slowly began addressing pediatric palliative care needs, primarily by applying adult models of care to the pediatric population (Hendrickson & McCorkle, 2008). Since its inception, approximately 250 exclusively pediatric hospice and palliative care centers have opened in the U.S., and 23% of pediatric hospitals have some type of palliative care program in operation or development. Furthermore, more than 450 adult hospice providers now offer services to children (Sheetz & Bowman, 2008). The current goal of pediatric palliative care, according to the American Academy of Pediatricians, is to "add life to the child's years, not simply years to the child's life" (AAP, 2000, p. 353).

Given the recent expansion of pediatric palliative care services, the range of knowledge and skills needed by healthcare professionals has increased. Previous research by Contro et al. (2004) revealed several areas in which healthcare providers lacked experience when providing services to dying children. This study, however, was conducted prior to the new definition of palliative care to include services beyond end-of-

life. In the current study, the IOM's definition of palliative care was applied, defined as care provided to children with life-limiting conditions (i.e. diseases which could shorten or limit the lifespan of a child, from chronic conditions to trauma). This definition was adopted after reviewing the literature and consulting with staff from Hospice of South Florida. Thus, one aim of this study was to examine how the new definition has impacted the knowledge of and care provided by pediatric staff.

Benefits of pediatric palliative care. Research supports the benefits of pediatric palliative care programs for patients, families, and healthcare providers. After implementing a pediatric palliative care program at one hospital, researchers found that health-related family satisfaction and quality of life significantly improved (Hays, Valentine, Haynes, Geyer, Villareale, McKinstry, et al., 2006). Another hospital found similar results after families received pediatric palliative services: hospice discussions occurred more often and earlier, DNR (Do Not Resuscitate) orders were documented sooner, and a larger proportion of parents felt more prepared during their child's last month of life and at the time of death (Wolfe, Hammel, Edwards, Duncan, Comeau, Breyer, et al., 2008). They also found that the number of pediatric deaths in the hospital decreased (Wolfe et al., 2008). Research has shown that dying at home, a transition aided by palliative care, can have positive effects on siblings and parents of pediatric patients. Better coping, less residual guilt, and stronger marital relationships have been found among the family members of children who died at home instead of in the hospital (Lauer, Mulhern, Bohne, & Camitta, 1985; Zwerdling, Hamann, & Kon, 2006).

A recent meta-analysis also found significant improvements in pain management for children receiving palliative care services (Higginson, Finlay, Goodwin, Hood, Edwards, Cook, et al., 2003). This is critical because Himmelstein et al. (2004) found that 89% of children and adolescents died while experiencing 2-8 troubling symptoms (e.g., pain) and were described as having suffered a “great deal.” Thus, palliative care services may reduce a key challenge in managing end-of-life care, quality pain management.

Despite the impressive advantages of palliative care, such as improving pain management, less than 1% of dying children in the U.S. receive these services (Hinds, Pritchard, & Harper, 2004). Thus, there is a continued need for the initiation and provision of palliative care services to pediatric patients and families (Hutton, 2002). In order to improve the services provided, the knowledge of healthcare providers must first be assessed, in order to guide future training and intervention.

Aims of the Current Study

Stanford’s key findings & hospital comparisons (Aim 1). Recently, research has begun to examine the training, skills, and emotional needs of pediatric hospital staff in providing palliative care (Contro, Larson, Scofield, Sourkes, & Cohen, 2004). For example, prior to implementing a pediatric palliative care team at Lucile Packard Children’s Hospital at Stanford University, the Caregiver Survey on Palliative Care was administered to measure needs of healthcare providers (LPCH; Contro et al., 2004). Items were developed to reflect themes identified during interviews conducted with families who had lost a child at the hospital, providing initial content for the measure. The survey was designed for all hospital staff members, and thus was not limited to a

specific discipline. The current study modified the original measure, now the Survey on Pediatric Palliative Care for Healthcare Providers (SPPCHP), to reflect the newer definition of palliative care. The measure was then implemented with providers at a children's hospital (HCH) serving minorities and those from lower socioeconomic groups. The psychometric properties were also evaluated for the revised measure.

The LPCH study included a good representation of disciplines and professions with a large sample size ($n = 446$). Respondents were 110 attending physicians (25% of sample), 48 residents (10%), 191 nurses (43%), 17 social workers (4%), 21 psychosocial support staff members¹ (5%), and 42 ancillary support staff members (5%); 17 respondents did not disclose their occupation (9%). Researchers surveyed an extensive variety of specialties, including neonatology, hematology/oncology, cardiology, surgery, and general pediatrics. Approximately 20% of hospital staff completed the questionnaire, and 74% of respondents were female (26% male). Respondents had been employed by the hospital for an average of 8.31 years and had experienced between 2 and 19.3 deaths (averages) over the past year.

There were several areas in which providers reported that they lacked knowledge about palliative care. Specifically, respondents reported inexperience (defined as "beginner or somewhat experienced") in four different aspects of interacting with patients and families: 1) communicating with patients about end-of-life issues, 2) communicating with families about end-of-life issues, 3) discussing the transition to palliative care, and 4) discussing DNR status. No differences were observed between professions.

¹ Psychosocial support staff includes psychologists.

Healthcare providers also reported feeling inexperienced in managing symptoms (43% attending physicians, 56% residents, and 50% nurses) and pain (49% physicians, 54% residents, and 30% nurses) of dying pediatric patients. They reported feeling particularly distressed when children appeared to be suffering, but adequate care (e.g., pain management) was not available or delivered.

This study also highlighted the lack of services for healthcare providers who work with children facing life-limiting illnesses. Slightly more than half (54%) of the participants did not feel that adequate support was provided to them by the hospital. They also reported feeling that they did not have a place to discuss their experiences, were required to put their grief aside immediately and return to work, and were troubled by painful experiences. When asked about their most difficult experience, emotional pain and lack of support were cited most often by participants. Sixty two percent of the attending physicians, 85% of the residents, 73% of the nurses, and 80% of the “others” reported that they would “welcome consultation” from the new team.

The first aim of the current study was to compare data from the SPPCHP from two demographically distinct populations of pediatric healthcare providers (i.e., Palo Alto, CA and Miami, FL). It was hoped that this would increase our knowledge of the universality of the education and training needs of providers, and offer new data on the key barriers to providing this type of care to children and families.

Measure development of the SPPCHP (Aim 2). The second aim of the current study was to further develop the SPPCHP. Modifications were made to the measure to reflect current issues in pediatric palliative care and the unique demographic

characteristics of the South Florida population served by Holtz Children's Hospital at the University of Miami (HCH). Several changes were made to the survey (discussed in the Measures section) to encompass the new definition of palliative care and to expand the information assessed by the instrument (i.e., address limitations of the previous version). To our knowledge, there was no other standardized pediatric palliative care assessment for hospital staff. The psychometric properties of the SPPCHP had not been previously examined and thus were evaluated in this study.

Assessment of knowledge, barriers, and support needs of healthcare providers (Aim 3). The third aim of the study was to examine the palliative care needs of healthcare providers. Specifically, the SPPCHP assessed knowledge deficits, barriers to care, and the support services they desired.

Knowledge. Palliation has recently been identified as an emerging field of care; the American Board of Medical Specialties first recognized palliative care as a specialty in 2008 (MacLeod & James, 1997; www.abms.org). There has also been a growing awareness among healthcare providers of their ethical obligation to provide options for, and thus be knowledgeable about, palliative care (Zwerdling, Hamann, & Kon, 2006). In accordance with the Accreditation Council on Graduate Medical Education and the Ambulatory Pediatrics Association, pediatricians need to be instructed during their residency training in how to care for terminally ill children (Khaneja & Milrod, 1998). Unfortunately, this guideline is not always followed; many healthcare professionals never receive formal training in palliative care.

In a study of Children's Oncology Group (COG) members, the majority of physicians (75%) reported no formal end-of-life training (Fowler, Poehling, Billheimer, Hamilton, Wu, Mulder, et al., 2006). Another survey of pediatric oncologists found that only 2% reported a rotation on a palliative care or hospice service (Hilden, Emanuel, Fairclough, Link, Foley, Clarridge, et al., 2001). Residents have also reported inadequate training in palliative care (McCabe, Hunt, & Serwint, 2008). A recent study found that they desired more training in pain management and communication skills, two components of palliative care (Kolarik, Walker, & Arnold, 2006). These results parallel those of the study at LPCH which highlighted providers' lack of experience and training in several aspects of palliative care (Contro, et al., 2004).

Lack of knowledge and training in palliative care has also been linked to several negative outcomes. Care providers with insufficient training in end-of-life care have reported feeling less competent in this role along with feelings of "burnout" (Graham, Ramirez, Cull, Finlay, Hoy, Richards, 1996). This, in turn, may lead to emotional distancing and depersonalization, which can adversely impact interactions with patients and families (Bagatell, Meyer, Herron, Berger, & Villar, 2002). Given the inconsistency between the ethical obligation to provide care and the levels of knowledge and competence, an evaluation of gaps in knowledge appeared to be an important first step. This study sought to identify healthcare providers' current level of palliative care knowledge and training, as well as areas in which they desired further education. This information may be helpful for designing formal education and training experiences for providers caring for children and families.

Barriers. A number of factors, related to patients, families, and the healthcare system, can complicate implementation of appropriate care to chronically and terminally ill children (Docherty, Miles, & Brandon, 2007). Identification of these barriers may facilitate the improvement of palliative care services.

Several barriers to providing palliative care have been identified, including stigmas associated with referrals to palliative care, identification of “true dying points,” acceptance of terminal diagnosis, and hospice regulations. Unfortunately, many parents and professionals continue to equate the term “palliative care” with end-of-life and perceive a referral to these services as giving up hope and/or a failure on their part (Fowler et al., 2006). Last year, a bill was introduced in Congress which would have allowed doctors to be reimbursed by Medicare if they initiated discussions related to palliative care (e.g., living wills); this was dismissed, however, due to the enormous stigma surrounding these “death panel” discussions (Tanner, 2010).

The course of a child’s illness is often difficult to predict, and it is nearly impossible to foresee deaths due to trauma and emergencies (Korones, 2007; Hendrickson & McCorkle, 2008). Integrating palliative care discussions with parents at the point of diagnosis may reduce these stigmas and alleviate pressure on physicians to identify a “true dying point” (Docherty, Miles, & Brandon, 2007). For example, healthcare providers may explain the role of palliative care to a youth and/or her family when she is first diagnosed with CF, rather than when all curative efforts have ended. Furthermore, even when physicians are able to establish that a child’s death is imminent, parental recognition of terminal status often lags behind (Mack, Wolfe, Cook, Grier,

Cleary, & Weeks, 2007). This delay in recognition has been linked to aggressive care at the end-of-life, as well as parental perceptions that the dying trajectory was abrupt and precipitous (Hinds, Pritchard, & Harper, 2004; Mack, Hilden, Watterson, Moore, Turner, Grier, et al., 2005). Thus, training providers to communicate the benefits of palliative care to families early on may improve end-of-life quality of life for patients and families (Davies, Sehring, Partridge, Cooper, Hughes, Philp, et al., 2008).

Modification of current hospice regulations, which prevent the use of palliative care services and impede the transition to end-of-life care, would also improve the quality of care provided. Current guidelines present as a barrier to care as they only allow patients medically certified as having less than six months to live and those who forego life-prolonging medical therapies (e.g., palliative or experimental chemotherapy and blood transfusions, emergency department visits, and hospitalizations) to receive Medicare-funded hospice services (Himmelstein, Hilden, Boldt, & Weissman, 2004; Fowler, et al., 2006). Medical professionals, however, often struggle to identify the course of illnesses in children and feel obligated to choose between hospice services and potentially disease-modifying treatments (Toce & Collins, 2003; Korones, 2007). Treatment and palliative care should not be opposing concepts between which medical professionals and families are forced to choose. The current study addressed the possibility of hospice guidelines as barriers to care; these findings may support the need for hospice care to reflect the current definition and goals of palliative care (Toce & Collins, 2003).

While many barriers to care have been previously identified, the roles of culture and religion in children's care have only begun to be examined. Research has shown that there is often a failure to include or meet the needs of non-English speaking family members and that cultural sensitivity is often overlooked in discussions of care (Contro, Larson, Scofield, Sourkes, Cohen, 2002). Furthermore, while religion has been shown to help some patients conceptualize and understand suffering and death, its potential negative impacts (e.g., prohibiting types of treatment) have not yet been thoroughly examined (Corr, 2004). The current study sought to identify how often culture and religion presented barriers to healthcare providers when providing palliative care services.

Support. The SPPCHP also sought to identify services that may be helpful to staff and measured their probability of using them. Working with chronically and terminally ill children can be emotionally difficult and adequate support is rarely provided (Llamas, Llamas, Pickhaver, & Piller, 2001; Vachon, 1995). Pediatric healthcare practitioners have reported needing twice as long to recover from the loss of a child as their medical colleagues who lose adult patients (Storey & Knight, 2003). The original study at LPCH found that many healthcare providers felt adequate support was lacking (Contro, et al., 2004), which can lead to a variety of negative outcomes, including depression and emotional withdrawal (Bagatell, et al., 2002; Vachon, 1995). Thus, providing emotional and social support for staff (e.g., via support groups, forums, and debriefings) is essential. Questions on the SPPCHP directly measured healthcare providers' preferred type and mode of support.

Awareness and implementation (Aim 4). The last aim of this study was to evaluate the effect of the study on healthcare providers' awareness of palliative care services at HCH. The Pediatric Palliative Care Team at HCH began in the fall of 2008 under the direction of Dr. Patricia Cantwell, a pediatric intensivist. The need for this service was identified by healthcare professionals across the hospital; it was clear that the old system did not provide standardized services to children with life-limiting illnesses. Instead, individual departments followed their own standard of care (i.e., notifying parents and children of prognosis, bereavement follow-up), without evaluating its impact on healthcare providers HCPs and families. This led to the development of a palliative care team, with members invited to participate via email and word of mouth. Many different professionals joined, including physicians, psychologists, social workers, and chaplains. The team included thirty-nine hospital employees, three family members of past pediatric patients from HCH, two representatives from Children's Medical Services (CMS), and three staff members from Hospice of South Florida (see Table 1). There was no budget for the team; however, all members had primary appointments in their respective departments (e.g., PICU).

All members of the team were invited to participate in several monthly team meetings. Fliers were posted in various locations throughout the hospital; however, awareness of the program on the campus was limited. The mission statement of the Pediatric Palliative Care Team was as follows:

The Holtz Children's Hospital Palliative Care Team is a group of multidisciplinary personnel led by a dedicated attending physician. Palliative care services are focused upon caring for the patient's and family's body, mind and spirit. Our Team pledges to ensure consistency in providing optimal

resource utilization and will assist the primary medical/surgical team as needed. The Team strives to provide a continuum of care from the hospital to the community.

A secondary aim of this study was to evaluate whether completion of the survey increased referrals to the Palliative Care Team. While this study did not directly measure the benefits of palliative care services, administration of the SPPCHP was expected to increase awareness of this service at the hospital and guide the implementation of future services (e.g., through staff training). Referrals were tracked by Mory Barreto, an assistant to Dr. Cantwell, the intensivist in charge of the team. Ms. Barreto tracked referrals during the survey completion period and for six months afterwards. In addition, the second question on the modified SPPCHP asked participants if they were aware of the Pediatric Palliative Care Team's existence at HCH to directly measure awareness.

Current Study: Aims and Hypotheses

In summary, the current study was the first to examine the knowledge, barriers, and support needs of a racially and ethnically diverse sample of healthcare providers in providing pediatric palliative care using the newly modified SPPCHP. Goals of the current study included comparing data from two diverse pediatric hospitals, improving the SPPCHP, and identifying the education and training needs of healthcare providers. A secondary goal was to increase awareness and use of a newly established pediatric palliative care team.

Aim 1: Comparison between HCH and LPCH. The first aim was to compare results from Holtz Children's Hospital at the University of Miami with those from Lucile Packard Children's Hospital at Stanford University.

Aim 2: Psychometric Properties of the SPPCHP. The second aim was the modification and further development of the SPPCHP, including an evaluation of the measure's psychometric properties. Internal consistency and construct validity were examined.

Aim 3: Knowledge, Barriers, and Support of HCP's. The third aim was to identify the education and training needs of healthcare providers who may be involved in providing pediatric palliative care.

Hypothesis 1. Differences across professions were expected on "Expertise," a latent factor derived from the SPPCHP. It was hypothesized that physicians, psychosocial staff, and nurses would report significantly more overall knowledge than residents and allied health professionals. It was also hypothesized that physicians, nurses, and residents would report more expertise with regard to medical items (e.g., managing symptoms, pain management, discussing DNR) than psychosocial staff and allied health professionals. Psychosocial staff, on the other hand, were expected to report more expertise with regard to communication skills (e.g., communicating with patients and families, discussing transition) than other staff. Differences were also hypothesized, by profession, on the top ranked barriers to providing this service.

Hypothesis 2. Both the number of years worked by healthcare providers and overall "Training," as measured by the SPPCHP, were expected to predict scores on the Expertise Scale and thus provide evidence of convergent validity. More specifically, it was hypothesized that respondents who reported a greater number of years worked, and those who reported greater Training, would have the highest Expertise scores.

Hypothesis 3. Healthcare providers who reported more Expertise were expected to have more training, fewer barriers to providing care, and make more referrals to palliative care services. They were also predicted to report different characteristics of their most difficult experiences, both with a pediatric patient who died and with a pediatric patient with a life-limiting illness.

Aim 4: Improving Awareness and Utilization of a Palliative Care Team. A secondary aim of the study was to evaluate how the survey's administration and provision of a flier on the Palliative Care Team affected awareness of and referrals to the team.

Chapter 2: Methods

Procedures

Holtz Children's Hospital is located in Miami, FL and is affiliated with the University of Miami Leonard M. Miller School of Medicine and Jackson Memorial Hospital. There are more than 100 attending physicians and specialists. Its 254 licensed beds make it one of the largest teaching hospitals and research centers in the country. HCH is a national leader in several pediatric specialties, including diabetes, organ transplant, infectious diseases and immunology, near-drownings, and severe burns ("Holtz Children's Hospital," n.d.). It is one of only three centers in the U.S. that specializes in pediatric multi-organ transplants and is the largest pediatric intestinal transplant center in the nation.

The hospital serves a racially and ethnically diverse population. The majority of patients speak either Spanish or Creole and are of Caribbean or Latin American descent. A large portion of the population served by HCH are from low socioeconomic backgrounds. Many children served by the hospital have no insurance or receive Medicaid, a needs-based social welfare program, with eligibility determined by income.

Both the University of Miami and Jackson Memorial Hospital IRB approvals were obtained. Healthcare providers across departments and disciplines were recruited to participate. Given that the new Pediatric Palliative Care Team aims to provide services to any child seen in the hospital, the measure was administered hospital-wide. Exclusion criteria included healthcare providers who lacked reading skills in English (i.e., survey was in English) and/or lacked involvement in the care of children facing a life-limiting

condition. Thus, the sample only included healthcare providers who had reading fluency in English and interacted with children who had an illness which could shorten or limit their lifespan (e.g., chronic conditions, trauma).

Email lists of professionals in each discipline were generated to ensure adequate sampling across the hospital. These lists included: pediatric faculty, attending physicians, residents, fourth year medical students, nurses, social workers, psychologists, child life specialists, and respiratory therapists. Sampling was purposive, with efforts to obtain representative and complete data. Emails were sent to groups of employees within the same discipline by department managers (e.g., chief residents, nurse managers), as well as by the principal investigator (PI; Grimley) and the director of the Pediatric Palliative Care Team. Monthly reminders were also sent via email lists. Members of the Pediatric Palliative Care Team also recruited within their departments and disciplines, using in-person communication as well as email reminders. Additionally, the PI attended several departmental meetings (e.g., Pediatric Palliative Care Team meeting, Pastoral Care training session, Bone Marrow Transplant weekly staff meeting, inpatient nursing meetings) to present the aims of the study, encourage direct participation, and provide immediate remuneration (\$10 gift card). The modified measure was piloted in September 2010 with six members of the Pediatric Palliative Care Team to assess changes made. Official recruitment began in mid-October and was completed at the end of March 2010. The majority of surveys were completed online (82.2%). The total sample was 225.

The survey was made accessible online using Filemaker and hosted by the University of Miami Psychology Department's web server. Participants were emailed a

link to the online survey. Those completing it online electronically consented to participate in the study; those completing the paper version were provided with a consent letter. Consent was obtained from all participants. After completion of the survey, online participants were given the option of providing their contact information (i.e., mailing address) to receive payment for their time and effort (\$10 gift card). Participant data were not linked with contact information, thus ensuring confidentiality. After completing the questionnaire, participants were also given a flier with the contact information and mission statement for the Pediatric Palliative Care Team at HCH to expand their awareness and use of these services at the hospital. All participants were asked to provide their email address if they desired a summary of the study results. A significant number of healthcare providers provided this information (45%), a testament to the interest in these services. A brief overview of the study results was presented at Pediatric Grand Rounds at HCH by Dr. Cantwell on June 22nd, 2010; results were also made available to hospital staff at a Pediatric Palliative Care Team meeting on July 1st, 2010.

The number of referrals received by the Pediatric Palliative Care Team was also tracked from the beginning of the study through six months after recruitment completion by the director of the Palliative Care Team's secretary and the billing department. Both the number of referrals each month and the number of completed surveys were tracked for six months after survey completion.

Participants

Participants were 225 healthcare professionals working at Holtz Children's Hospital (see Table 2). Although 227 staff members were recruited, two were excluded because they did not have contact with children with life-limiting conditions. Twenty-four percent of the sample was male (71.6% female, 4.4% unknown), and approximately half were younger than 40 years (50.3%). Participants reported being a professional for an average of 13.0 ($SD = 11.3$) years, spending an average of 9.7 years ($SD = 9.3$) at HCH.

Participants came from diverse racial and ethnic backgrounds. Slightly more than 30% were Hispanic, 14% were African American, and 5% were Asian (see Table 2). Healthcare providers also represented many disciplines and departments at HCH, including physicians (15%), residents (18%), and nurses (39%). Special effort was made to recruit psychosocial staff (12%) and allied health professionals (8%), because they are often involved in palliative care. A variety of pediatric clinical populations were represented, such as cardiology, cranio-facial, endocrinology, hematology/oncology, and transplant. Many participants self-identified as working with "all pediatric" populations (36.0%), whereas others indicated primarily working in specific units/clinics (e.g., 11.6% Neonatal Intensive Care Unit (NICU), 12.9% Pediatric Intensive Care Unit (PICU)).

Measure

The SPPCHP was adapted from a questionnaire used by researchers at Lucile Packard Children's Hospital at Stanford University. The original measure was pre-tested with a sample of physicians, nurses, social workers, and a psychologist, after being

developed by a multidisciplinary task force (Contro, et al., 2004). It was then given to 446 hospital staff members and associated community physicians. The survey asked participants to rate their expertise and comfort in working with patients and families within a palliative care framework. It also assessed previous training and current support for providing care. Items were evaluated with Likert-scale responses (i.e., never, sometimes, often, or always). An open-ended question also asked participants to describe their most difficult experience with a dying pediatric patient. Reliability and validity of the measure were not published.

Modifications to the SPPCHP. Several changes were made to the instrument to reflect the current definition of palliative care and new content about barriers faced by healthcare staff. Nancy Contro, a social worker at LPCH and author of the original measure, was consulted by phone and email several times during the modification process. She provided suggestions and reviewed all of the changes that were made. See Appendix for final version of the SPPCHP.

Update and expansion of palliative care definition. The measure was originally developed in 1998 with the results were published in 2004 (Contro, et al. 2004). Since its development over 10 years ago, the field of palliative care has changed significantly. The breadth of services, for example, has expanded. Thus, the IOM's definition of palliative care and two short vignettes of pediatric patients who would benefit from these services were added to the first page of the measure. These vignettes were based on referrals made to the Pediatric Palliative Care Team at HCH over the past year. The measure also asked participants to rate how much they agreed with the new, broadened

definition. Items asking if participants had worked with children facing a life-limiting condition or experienced the death of a pediatric patient were also added to the first page. This ensured that the appropriate healthcare providers (i.e., those providing pediatric palliative care as defined by the IOM) completed the survey.

Wording throughout the measure was changed from “dying children” to “dying children or children facing *life-limiting* illnesses.” After careful review of the literature and consultation with Hospice of South Florida, this terminology was chosen because it best reflected the current goals of palliative care services. An open-ended question, assessing participants’ most difficult experience with a child facing a life-limiting illness, and a small section addressing needs met by the family after the child’s death (e.g., receiving follow-up or bereavement care), were also included.

Tracking palliative care referrals. Three questions, one asking if participants were aware of the hospital’s Pediatric Palliative Care Team and two asking for the number of times participants made referrals to palliative care services within and outside of the hospital, provided baseline data on the current use of pediatric palliative care services. This baseline information was compared to the number of referrals to the team throughout the study recruitment phase and for six months after completion of active enrollment (Aim 4). This information served as an additional measure of the study’s impact on use of these services at the hospital. Participants were also asked to rate their likelihood of making referrals to the team.

Additional barriers and hospital services. Limitations of the previous measure were also addressed by adding several questions. Several new barriers to care were

added, including patient/family finances, religious and cultural beliefs, education, language, communication (distinguished as two separate barriers), conflicting wishes of patient and family, and the child's knowledge of terminal status. Hospital services have also grown in the past decade and were added to the measure (e.g., Psychology, Hospice, and Palliative Care).

Semantic and organizational changes. Questions were grouped together to improve the flow and structure of the measure. A few previously open-ended questions were modified to likert-responses to obtain quantitative data. Additionally, several double-barreled items were disaggregated. For example, two new questions distinguished between formal courses in palliative care and "one time workshop(s)." Barriers related to patients as opposed to family members were also separated. And, the helpfulness, as opposed to the likely use of services, was distinguished (i.e., both are asked). Finally, participant's demographic information was moved to the second page to ensure completion of this information.

Demographics of healthcare providers and patients. Race/ethnicity categories were also included on the demographics page. The use of the measure at HCH provided data from a more racially and ethnically diverse sample than the LPCH, which drew from an area with a relatively high socioeconomic status. Demographics were not reported, however, families are generally upper middle class with private insurance, and primarily Caucasian or Mexican American. In contrast, HCH serves families who come from lower SES backgrounds and often have no insurance; a high proportion of families are

Hispanic and Caribbean Black. Data from the two hospitals facilitated comparison of data across from two demographically distinct regions.

Finally, important demographic information about patients, specifically their age and cause of death, was added. The child's age can be critical because the care of children at different points in the lifespan (infants vs. adolescents) and the focus of palliative care services may be quite different (parents vs. patient). The cause of death is also important, because a child facing a life-limiting illness, for example, may have different palliative care needs than one who was the victim of a trauma.

Pilot data. The SPPCHP was piloted with six members of the Pediatric Palliative Care Team. Participants in the pilot study reflected the multidisciplinary composition of the team, and included two intensivists (including the Director of the Palliative Care Team), a third year resident, a psychologist, a nurse, and a social worker. Following this pilot, three additional changes were made to the SPPCHP, including the addition of an N/A (Not Applicable) column for questions related to opioid analgesia, because these items were not relevant for non-medical healthcare providers (see the SPPCHP section B, Question 1, items v-y). The phrase "Hospital based hospice" was removed because there are currently no hospital-based hospice services at HCH. Finally, the directions for Section F were clarified because several respondents had difficulty understanding them. They reported not knowing if they were to provide ratings or rankings for the services.

Several team members reported that the measure appeared to have face validity and that the IOM's definition and vignettes on the front page were very helpful and

would be useful to other staff members. They also indicated that participation in the study increased their awareness of key issues, such as consulting with the pain team.

Chapter 3: Results

Statistical Approach

Power analyses were conducted a priori to determine the number of participants required for the proposed analyses, particularly those examining group differences by profession. Alpha levels were set at $p \leq .05$, which is considered acceptable for psychological research (Cohen, 1992). Assuming an alpha level of .05, a power of .80, and a medium effect size (.25), the estimated sample needed was 200 (GPower 3.0.10).

Missing data was addressed individually for each type of analysis. Given that most participants completed the survey online, higher rates of missing data were expected (Wright, 2005). To ensure maximum completion, Filemaker was programmed to run error messages between screens/pages whenever participants left an item blank.

Participants were required to either return to the previous page and complete the item, or acknowledge leaving the item(s) blank. When calculating internal consistencies, mean replacement was used when more than 50% of the participant's data was available for that scale (e.g., $n = 3$ replaced data points across participants within the Expertise scale). If more than 50% of a participant's data for that scale was missing, it was excluded from analyses (e.g., $n = 11$ for the Expertise scale). Mean replacement was chosen because it has minimal effects on the results, but preserves the maximum number of responses (Downey & King, 1998). Full information maximum likelihood (FIML), instead of mean replacement, was used to handle missing data when factors were examined using MPlus.

Factor analyses. Scales were constructed a priori, based on both prior literature and the conceptual framework tested in the Stanford study. Next, exploratory factor

analysis (EFA) was used to identify items that formed cohesive scales. EFA's were constructed using maximum likelihood factor analysis with oblique rotation (direct oblimin); scree plots were examined to determine the number of factors (Costello & Osborne, 2005). The sample size did not allow EFA's to be conducted on a smaller, random sample; thus, the entire sample was used in these analyses (Costello & Osborne, 2005). Internal consistency of each scale was then calculated and confirmatory factor analysis (CFA) was used to evaluate the construct validity of each scale. Changes were made based upon the modification indices (e.g., allowing errors to correlate), when theoretically appropriate. For example, the errors for items pertaining to communicating with patients and communicating with families were correlated in the final factor model. Overall model fit was evaluated in MPlus using Chi-square tests and three indices: the Standardized Root Mean Squared Residual (SRMR; cut off < .08), the Bentler Comparative Fit Index (CFI; cut off > .95), and the Root Mean Square Error of Approximation (RMSEA; cut off < .06; Muthen & Muthen, 1998; Bollen, 1989).

Preliminary Analyses

Comparisons were made between those who had complete vs. partial data on the following variables: demographic characteristics and mean item responses. Chi-square tests were used for categorical variables (i.e., demographics) and t-tests were used for continuous variables (i.e., mean item responses). No significant differences were found between those who did and did not have complete data. However, some important trends in the types of missing data were observed. For example, participants were less likely to answer the open-ended than likert ratings scale responses, which may have been due to

the extra effort required. Two of the open-ended questions also asked participants to discuss difficult, personal experiences that may have been upsetting; almost half of the respondents did not answer these items (i.e., 43% child who died, 46% child with life-limiting illness). In addition, Filemaker was not able to alert participants that these open-ended items were blank. Finally, one of the last sections of the measure (i.e., section F) had a higher rate of missing data. This might have been due to the length of the survey and participants' waning attention. This section, however, also appeared difficult for participants to understand. The majority of those who completed this section did so incorrectly, providing ratings instead of rank ordering.

Aim 1: Comparison of HCH and LPCH

The first aim of the study was to compare the results from Holtz Children's Hospital at the University of Miami to those of Lucile Packard Children's Hospital at Stanford University. Barriers to providing pediatric palliative care could not be directly compared between the hospitals because the SPPCHP asked about both dying children *and* children facing life-limiting conditions, whereas the original measure only asked about dying children. Because Stanford's raw data were not available, the majority of the comparisons were descriptive. Despite these modifications and limitations, a number of comparisons were possible (see Table 3 for detailed results).

Both samples were comprised of participants from a variety of specialties, including general pediatrics, PICU, neonatology, hematology/oncology, cardiology, surgery, and nephrology. The sample from HCH included a greater percentage of residents and psychosocial staff, but a smaller percentage of physicians than the sample at

LPCH. Healthcare providers were employed by these children's hospitals for a similar number of years (8.31 at LPCH, 9.68 at HCH) and reported a comparable average number of deaths experienced in the last year (LPCH range, by profession: 2 to 19.3 deaths, HCH: 1.9 to 17.5). A similar percentage of men and women participated in both studies (26% men at LPCH, 24% at HCH).

Many similarities were found regarding number of reported deaths by profession at the two hospitals. Interestingly, social workers and respiratory therapists were among the three professions reporting the highest number of deaths in the past year across both studies. These results highlight the importance of palliative care training and support services for all pediatric professions, not just physicians and nurses. Additionally, within both samples, physicians who reported working for *less* than ten years reported an average of one more death in the past year than those who had worked more than ten years. These results emphasize the need for young professionals across the U.S. to be trained in providing palliative care services, since they often need to use these skills during their first years of training.

One difference between the two samples emerged with regard to the number of deaths experienced by chaplains, with a higher frequency of deaths in the LPCH study than the HCH study. This was likely due to the fewer number of years of experience reported by the chaplains at HCH; many at HCH were new to the field (46.2% had worked for less than three years as a professional; 84.6% had worked less than three years at HCH). Child life specialists, rather than chaplains, experienced the third highest number of deaths at HCH.

Perceived level of expertise was also compared across the two samples.

Healthcare providers at LPCH reported being inexperienced (“beginner” or “somewhat”) in several aspects of interacting with patients and families, including communicating with patients and families about end-of-life issues, discussing the transition to palliative care, and discussing DNR status. Note that the survey conducted at LPCH did not separate communicating with patients vs. families, whereas the revised SPPCHP used two questions to differentiate these responses. While healthcare providers at HCH also reported feeling inexperienced in the latter two areas endorsed at LPCH, they reported slightly greater expertise communicating with dying patients’ families (i.e., “somewhat experienced”). Healthcare providers at HCH reported feeling slightly more experienced communicating with families than patients ($t(214) = 3.36, p < .01$). This provided evidence for separating skills related to patients and those related to families.

Healthcare providers at both hospitals also reported feeling inexperienced in managing the pain and symptoms of dying children. Although a similar percentage of physicians and nurses at HCH and LPCH reported these feelings, the percentage was greater for *residents* at HCH than LPCH (symptoms: 56% at LPCH vs. 87.2% at HCH; $\chi^2(1) = 64.7, p < .01$; pain: 54% at LPCH vs. 82.1% at HCH, $\chi^2(1) = 51.3, p < .01$). The varying levels of residents’ knowledge may be due to their medical school education and/or the amount of training they attained during residency. Although the number of years of training was not reported for the sample at LPCH, a large proportion of residents at HCH were still in their early years of residency (62.5% in first or second year). Thus, the majority of residents at HCH were likely to have additional palliative care training

during their remaining years of residency. Standardized training in pediatric palliative care should be integrated into curriculums across the country to increase the quality of care provided to pediatric families and patients.

Results from the qualitative analysis of the open-ended question, addressing difficulties with children who died, revealed similar results at both hospitals. In the Stanford study, two clinical social workers and one psychologist first reviewed the responses and identified themes. Then, two independent raters coded the responses using these themes; inter-rater reliability was .96 (Contro et al., 2004). In the current study, content analysis was conducted using ATLAS.ti 6.0. Two doctoral level graduate students first categorized the themes that appeared in the responses, coding together as a team. Decisions were made through consensus discussions. All responses were coded twice to ensure accuracy. A postdoctoral fellow then separately coded the responses, using the newly developed categories. Percent agreement was 86% for the item pertaining to the most difficult experience with a child who died. Response rates for this item were similar at the two hospitals (56% of total sample at LPCH, 57% at HCH).

Healthcare providers at LPCH and HCH reported similar themes for their most difficult experiences with children who died; the top two themes were the same at both hospitals: 1) patients' suffering and 2) managing their own distress. While many healthcare providers at LPCH also endorsed lack of support, no healthcare providers at HCH endorsed this theme. When asked directly about support provided by the hospital, a similar percentage reported a lack of support at both hospitals (48.5% at LPCH and 54% at HCH).

Finally, the percentage of healthcare providers willing to use the palliative care team was compared between LPCH and HCH. More than 60% of the professions at both hospitals reported being “likely” or “very likely” to use the pediatric palliative care services at their hospital in the future. Residents in both samples reported being most likely to use these services in the future (see Table 3 for additional frequencies). Thus, many healthcare professionals recognized the need for these services and planned to integrate them into their care of children with life-limiting illnesses.

Overall, the samples from LPCH and HCH were similar in terms of many demographic characteristics and areas of expertise. Although researchers at LPCH did not collect participants’ ethnicity and race, it is likely that they differed from those at HCH (e.g., a large proportion of Hispanic ethnicities at HCH). The two hospitals also serve very different patient populations (e.g., SES). Census statistics for the two counties where the hospitals are located, Santa Clara (LPCH) and Miami-Dade (HCH), are shown in Table 4; the two counties differ greatly with regard to ethnicities/races and income (<http://quickfacts.census.gov/qfd/states>). Despite these differences, participants at both hospitals reported similar difficulties in providing pediatric palliative care. Thus, these findings may generalize to other major children’s hospitals.

Aim 2: Psychometric Properties of the SPPCHP

The second aim of the study was to evaluate the psychometric properties of the SPPCHP. Internal consistency and construct validity were examined for six subscales (i.e., Expertise, Quality of Life, Patient/Family Barriers, HCP Barriers, HCP Team Barriers, and Healthcare System Barriers).

Expertise. The “Expertise” scale measured healthcare providers’ self-reported experience in several facets of providing pediatric palliative care and was composed of all eight items (a-h) from section A, Question 1. An EFA confirmed that one factor adequately accounted for all items, with all factor loadings greater than .75. Cronbach’s alpha for the scale was .96 ($n = 214$), indicating excellent internal consistency. Item-to-total correlations ranged from .75 to .87, supporting the construct validity of the scale. Furthermore, analyses indicated that the removal of items would not improve the scale’s reliability.

A CFA of the Expertise scale was then conducted to further examine construct validity. Three modifications were made to the original model based on the modification indices and underlying theory. Errors were allowed to correlate between several similar items, including: communicating with dying patients and communicating with dying patients’ families; managing symptoms of dying patients and pain management for dying patients; and discussing transitioning to end-of-life care and discussing DNR status. All factor loadings were significant (p ’s $< .01$; see Figure 1).

Results for the final model ($n = 214$) indicated good fit, $\chi^2 (17) = 20.08, p = .27$ (SRMR = .01; CFI = 1.00; RMSEA = .03). Thus, the Expertise scale demonstrated strong construct validity. Furthermore, moderate correlations were found between the latent factor scores for the Expertise scale and the number of years worked ($r = .45, p < .01$) and the Training composite score ($r = .33, p < .01$), providing evidence for convergent validity. The Training composite was calculated by summing the number of

trainings healthcare providers had received (ranged from 1-5; from five items in Question A.2). Overall, results indicated strong reliability and validity for this scale.

Quality of Life. The “Quality of Life” scale measured quality of life for pediatric patients during their last six months of life, mainly at their time of death. It was composed of eight items (a-h) from section C, Question 3. Several items within this scale were reversed scored, so that higher scores reflected better quality of life (C.3. d, e, and f). Overall, this scale did not perform well. First, four different factors emerged in the EFA based on seven items. Second, Cronbach’s alpha indicated poor internal consistency ($\alpha = 0.36$). Finally, the CFA, which was identified a priori, did not provide evidence for construct validity; the model did not fit the data.

Several potential changes to the scale were considered, such as averaging the items concerning “satisfactory end-of-life care” in the hospital and at home, as well as “discussing an advanced care directive” and “wishes/plans for end-of-life care” (Items e & f and g & h). However, these items could not be averaged because the number of patients referenced by healthcare providers was different for each item.

A further evaluation of the scale revealed several reasons for its poor fit. Dying a sudden death, for example, did not appear to have as great of an impact on quality of life for pediatric patients. This item did not correlate significantly with any other items in this scale. Interestingly, however, 15% of healthcare providers identified “sudden/unexpected death” as characteristic of their most difficult experience with a child who died (see Table 6). They described preventable accidents and sudden illnesses as particularly difficult for them and for patients’ families. The child’s age at death and

the type of death may be important to consider. For example, an infant, or a young child who dies suddenly (e.g., drowning) may not have the cognitive capacity or time to process what happened. A healthcare provider or parent, on the other hand, may be traumatized by this situation when considering their role in the event (e.g., feeling responsible for child's drowning). Furthermore, the question asked if the sudden death impacted the patients' last *six months* of life, not only at the time of death. Thus, despite a possibly traumatic death, the last six months of life may have been enjoyable and pain free.

Although the scale did not perform well, several important relationships were observed. Dying in pain and dying with anxiety/fear were highly correlated ($r = .71, p < .01$). Thus, in general, children who died in pain also experienced anxiety/fear during their last six months of life. Furthermore, these items were also *negatively* correlated with discussing an advanced care directive and wishes/plans for end-of-life care (pain: $r = -.20, p < .05$; anxiety/fear: $r = -.19, p < .05$; $r = -.29, p < .01$). Thus, if end-of-life care was discussed with a child, he/she was less likely to die in pain or experience anxiety/fears at the time of death. Despite the small size of these correlations, these results provided support for the positive effects of discussing death with pediatric patients.

Barriers/Problems Scales. The previous version of the measure had two separate questions asking about barriers or problems in providing palliative care. After speaking with the author, it seemed like this distinction was not necessary. Thus, items

identified as “barriers” (B1) or “problems” (B4) were examined together in the following factor analyses.

Results from an overall EFA of barriers/problems to care (Section B, Questions 1 and 4) were examined in conjunction with factor structures that were generated a priori, followed by CFA’s (Floyd & Widaman, 1995). Due to floor effects for the questions pertaining to opioids (e.g., approximately 60% of participants who answered these items indicated that opioids were “never” a barrier to care), these items were not used in the factor analyses. In addition, over 25% of the sample noted that these items were “not applicable” to them.

Patient and Family Barriers. Correlations between patient and family barriers indicated that they measured similar constructs. Previously, the measure grouped patient and family barriers together into single items (e.g., “patient/family prolonged inability to accept terminal diagnosis”). The revised SPPCHP separated them into two items (e.g., “patient prolonged inability to accept terminal diagnosis” *and* “family prolonged inability to accept terminal diagnosis”). Correlations between the patient and family items ranged from .54 to .82 (p ’s < .01; see Table 5). Items with the lowest correlations included patients’ and families’ inability to accept terminal diagnosis ($r = .54$; Section B, Question 1, items a & b) and their unrealistic expectations ($r = .66$; B1, items p & q). These items were entered separately into subsequent factor analyses due to their lower correlations. Items pertaining to patients’ and families’ religion, culture, lack of education/understanding, communication difficulties, and language fluency all exhibited higher correlations (respective r ’s = .73, .73, .72, and .82). Therefore, these items were

combined (e.g., patient's and family's language). Additionally, high correlations indicated that several items should be combined based upon their thematic content. Thus, religion and culture were combined into one factor (i.e., patient/family's religion or culture), as were communication difficulties and lack of education/understanding (i.e., patient/family communication/understanding difficulties).

The "Patient Barriers" scale was designed to assess barriers related to patients, but faced by healthcare providers who provide pediatric palliative care. It was composed of nine items (a, f, h, j, l, n, p, u, v) from section B, Question 1. Similarly, the "Family Barriers" scale measured family barriers, faced by healthcare providers, in providing pediatric palliative care. It was composed of eleven items (b, g, i, k, m, o, q, s, t, u, w) from section B, Question 1. An EFA of these responses, however, indicated that this should be one scale. Additional analyses were subsequently conducted on this scale.

Patient/Family Barriers. This scale measured barriers related to patients and families, including beliefs regarding diagnosis and prognosis. It was composed of ten items, seven individual items from the measure (B1 a, b, p, q, t & u; and B4m), and three composites from previously individual items (averages of: B1f, g, h, and i; B1j, k, l, and m; & B1n and o). Item-to-total correlations ranged from .44 to .74; item B4m, regarding disclosure of terminal status to the child, had the lowest item-to-total correlation. In the future, this item should be reworded to specifically address *parents'* failure to disclose prognosis to the child, rather than global non-disclosure. Cronbach's alpha for the new scale was .89 ($n = 182$), indicating strong internal consistency; the deletion of items would not have significantly improved the scale.

A CFA was then used to examine construct validity. Eight modifications were made to the original model. Errors were allowed to correlate between similar items, such as patients' acceptance of terminal diagnosis and families' acceptance of terminal diagnosis. All of the factor loadings were significant (p 's < .01; see Figure 2). Results for the final model ($n = 199$) indicated a strong fit, $\chi^2(27) = 40.41, p = .05$ (SRMR = .03; CFI = .98; RMSEA = .05). Thus, the new Patient/Family Beliefs Barriers scale demonstrated good construct validity.

Healthcare Provider Barriers. The "HCP Barriers" scale measured barriers/problems related to and faced by healthcare providers in providing pediatric palliative care. It was composed of nine items, five questions (c, d, e, r, y) from section B, Question 1 and four questions (a, b, c, d) from section B, Question 4. After reviewing results from the overall barriers/problems EFA, however, the scale was slightly modified. The new scale included five of the original items, two items (c & e) from section B, Question 1 and three items (b, c, and d) from section B, Question 4. Three items (B1d, B1r, and B4a) were moved to the HCP Team Barriers scale discussed below, while the opioid item (B1x) was deleted due to floor effects. The new scale reflected emotions (e.g., denial and disappointment) experienced by healthcare providers. Item-to-total correlations ranged from .45 to .71. Cronbach's alpha for this scale was .80 ($n = 183$), indicating good internal consistency. The scale did not improve with further deletions.

Construct validity was further examined through a CFA of the new Healthcare Provider Barriers scale. One modification was made to the model. Errors were allowed to correlate between two similar items, healthcare providers' own denial and their own

disappointment. All of the factor loadings were significant (p 's < .01; see Figure 3). Results for the final model ($n = 196$) indicated strong fit, $\chi^2(4) = 4.58$, $p = .33$ (SRMR = .02; CFI = 1.00; RMSEA = .03). Thus, the new Healthcare Provider Barriers scale also demonstrated strong construct validity.

HCP Team Barriers. The “HCP Team Barriers” scale was named “Communication Barriers” at the beginning of the study and measured barriers faced by healthcare providers when providing pediatric palliative care (e.g., families’ communication difficulties). It was composed of eight questions, three items (l, m, u) from section B, Question 1 and five items (b, f, g, h, m) from section B, Question 4. After reviewing results from the overall barriers/problems EFA, however, the scale was modified to include items exclusively related to communication difficulties among healthcare providers and between healthcare providers and families. Thus, the new HCP Team Barriers scale was composed of seven items: three original items (B4f, B4g, and B4h), three items from the original Healthcare Providers Barriers scale (B1d, B1r, and B4a), and an item formerly not included on any scale (B4e). Cronbach’s alpha for the new scale was .81 ($n = 183$), indicating strong internal consistency. Deleting items would not have improved the scale.

Construct validity was further examined through a CFA of the new HCP Team Barriers scale. Two modifications were made to the original model. Errors were allowed to correlate between similar items, co-workers’ denial and staff’s unrealistic expectations, and differences of opinion between staff and between staff and families. All of the factor loadings were significant (p 's < .01; see Figure 4). Results for the final model ($n = 196$)

indicated strong fit, $\chi^2(12) = 9.58, p = .65$ (SRMR = .02; CFI = 1.00; RMSEA = .00).

Thus, the new HCP Team Barriers scale also provided evidence for construct validity.

Healthcare System Barriers. This scale measured barriers related to external factors, such as insurance regulations, faced by healthcare providers when providing pediatric palliative care. It was originally composed of five items, one item from section B, Question 1 (x) and four items from section B, Question 4 (i, j, k, l). One item, laws regarding opioid use, was deleted due to floor effects. One item, family finances, was added to the scale. Thus, the final scale was composed of five items. One item did cross-load with a few other scales (i.e. family finances). Its placement on this scale was based on its thematic relevance to the other items. Item-to-total correlations ranged from .45 to .79, supporting the reliability of the scale. Cronbach's alpha for the scale was .82 ($n = 183$), indicating good internal consistency. Deleting items would not have significantly improved the scale.

A CFA of the Healthcare System Barriers scale was conducted to assess construct validity. One modification was made to the original model. Errors were allowed to correlate between two similar items, insurance restrictions and third party refusals to cover home care. All of the factor loadings were significant (p 's < .01; see Figure 5). Results for the final model ($n = 195$) indicated good fit, $\chi^2(4) = 7.97, p = .09$ (SRMR = .02; CFI = .99; RMSEA = .07). Thus, the Healthcare System Barriers scale also demonstrated construct validity.

Aim 3: Knowledge, Barriers, and Support Needs of HCP's

The third aim was to identify the educational and training needs of healthcare professionals who are providing pediatric palliative care. Specifically, these questions focused on their knowledge regarding delivery of services, barriers to providing care, and personal support needs.

Knowledge. Overall, healthcare providers reported feeling, on average, “somewhat experienced” in all areas of delivering end-of-life care, from communicating with dying patients to pain management (scale anchors range from 1-4; M range = 1.92 ($SD = 1.11$) to 2.50 ($SD = 1.08$)). However, on one item, communicating with patients’ families, healthcare providers rated themselves higher, reporting that they felt “moderately” experienced. The two lowest means were for discussing DNR status and transitioning to palliative treatment with patients and families. These results suggested that healthcare providers require further training in palliative care. Differences in experience by profession are discussed below.

The “Training” composite was then computed to characterize the amount of training healthcare providers had received. This composite was calculated by summing the types of previous training experiences they had, assessed by five items from Question A.2 (a-e). “Other” types of training were not included in the summary score, because only a handful of participants provided additional types of training. Thus, the Training composite ranged from 1 to 5; it did not measure their evaluation of these training experiences, but whether they had utilized them. On average, healthcare professionals ($n = 210$) reported a 3.16 ($SD = 1.39$) on this scale, indicating moderate levels of training.

Clinical experience, personal experience, and mentor/role models were all endorsed by more than three quarters of the sample (88.5%, 81.7%, and 75.8%, respectively). Less than half of the sample, however, reported having a formal course or workshop in palliative care (34.3%, 38.9%). Of those who endorsed these types of training, clinical experience was rated as making the most significant contribution to healthcare providers' level of comfort in caring for dying children, while workshops contributed the least ($M = 3.25$ ($SD = .73$), $M = 2.51$ ($SD = .84$)). These results suggested that many healthcare providers are not receiving formal training in palliative care, but instead gain much of their expertise through clinical experience.

Hypothesis 1: Differences by profession in the Expertise scale and barriers to care. Hypothesis 1 posited that differences would be found by profession on the Expertise latent factor and on the top barriers to providing palliative care. Professions were separated into five categories: physicians ($n = 34$), residents ($n = 40$), nurses ($n = 88$), psychosocial staff ($n = 37$), and allied health professionals ($n = 13$); these were the professional categories used in the Stanford study. Psychosocial staff included social workers, psychologists, child life specialists, and chaplains. Allied health professionals included respiratory therapists and "other." Administrators were not included in the group comparisons because they did not logically fit into any of these groups (e.g., professional responsibilities are very different from five identified groups) and the sample size was small ($n = 5$).

As hypothesized, physicians, psychosocial staff, and nurses, *as a group*, reported more knowledge than residents and allied health professionals, *as a group*. Together,

physicians, psychosocial staff, and nurses had 0.66 more standard deviation units of Expertise than residents and allied health professionals ($p < .01$; $n = 217$, $\chi^2 (24) = 25.19$, $p = .40$; SRMR = .02; CFI = 1.00; RMSEA = .02). A general pattern was observed: physicians reported the most expertise, followed by allied health professionals, nurses, and psychosocial staff, and finally residents (see Figure 6). Note that means for residents were lower than expected. Among those healthcare providers who reported being “moderately” or “very experienced” in all aspects of care ($n = 76$), 31% were attending physicians, whereas only 5.1% were residents. Compared with the overall sample, a higher proportion of physicians and a smaller proportion of residents reported expertise in these areas ($\chi^2 (1) = 13.1$, $p < .01$). These results indicated that training in palliative care may not occur before working in a hospital (e.g., while in medical school).

Medical items. It was also hypothesized that physicians, nurses, and residents would report more knowledge with regard to medical questions on the Expertise scale (e.g., pain management) than psychosocial staff and allied health professionals. Contrary to expectations, residents reported less knowledge than all other groups and they did not report significantly more expertise than any other profession. Group differences were found with large effects, in expertise related to managing symptoms ($F (4, 209) = 13.65$, $p < .01$; $\eta^2 = .20$), pain ($F (4, 209) = 9.33$, $p < .01$, $\eta^2 = .15$), and discussing DNR status ($F (4, 209) = 15.61$, $p < .01$; $\eta^2 = .23$). Bonferroni adjusted alpha levels (.0125) were used to examine item-level group differences in post hoc analyses.

Physicians and nurses reported significantly greater expertise than psychosocial staff in managing symptoms and pain (physicians: $p < .01$, $d = 1.25$ & $p < .01$, $d = 1.11$;

nurses: $p < .01$, $d = 1.00$ & $p < .01$, $d = .99$). Physicians also reported significantly greater skills discussing DNR status than all other staff, including psychosocial healthcare providers ($p < .01$; $d = 1.48$), allied health professionals ($p < .01$; $d = 1.20$), and nurses ($p < .01$; $d = 1.24$). All effect sizes were large. Thus, partial support was found for this hypothesis; physicians and nurses reported more expertise in some medical domains, but surprisingly, residents reported less expertise than all other professionals.

Communication items. Group differences were also expected on items involving communication skills (e.g., communicating with patients). Psychosocial staff were expected to report greater expertise in communication than all other healthcare providers. Large effects were also found for the group differences in communicating with patients ($F(4, 209) = 10.37$, $p < .01$, $\eta^2 = .17$), communicating with families ($F(4, 209) = 11.48$, $p < .01$, $\eta^2 = .18$), and discussing the transition to end-of-life care ($F(4, 209) = 12.64$, $p < .01$, $\eta^2 = .20$). However, contrary to expectations, psychosocial staff reported better communication only in relation to residents (p 's $< .01$); their reported expertise was similar to physicians, nurses, and allied health professionals.

Barriers. Finally, the top ranked barriers to providing pediatric palliative care were compared across professions. No a priori differences by profession were predicted. Partial support was found for this hypothesis; three of the top five barriers were the same for all five groups of healthcare providers. Physicians, residents, nurses, psychosocial staff, and allied professionals all reported that families' inability to accept a terminal diagnosis, families' unrealistic expectations, and families' education were significant barriers to providing palliative care. Patients' level of education was also among the top

five barriers to care for all groups, except allied HCP's. The only statistically significant difference in the top barriers was found for "not knowing what to say." While residents and nurses endorsed this barrier among their top five, physicians, psychosocial staff, and allied professionals ranked this barrier significantly lower ($F(4) = 8.82, p < .01$).

Hypothesis 2: Convergent validity for the Expertise latent factor. Relationships between Expertise and two predictor variables, number of years worked and the composite Training scores, were examined. Both variables were significantly related to Expertise. First, the data were plotted to examine the relationship between the variables; linear relationships were confirmed between both predictors and Expertise. Healthcare providers, who had worked longer and had more training, had higher scores on the Expertise scale (see Figures 7 & 8). Specifically, for every one standard deviation unit increase in the number of years worked, Expertise increased by .46 standard deviation units ($n = 217; p < .001; \chi^2(24) = 30.29, p = .18; SRMR = .02; CFI = 1.00; RMSEA = .04$). In addition, for every one standard deviation unit increase in Training, Expertise increased by .24 standard deviation units ($p < .001; n = 214, \chi^2(24) = 26.10, p = .35; SRMR = .02; CFI = 1.00; RMSEA = .02$). These findings provided evidence for convergent validity of the SPPCHP, and highlighted the effects of training, from clinical experiences to formal workshops, on healthcare providers' knowledge.

Hypothesis 3: Characteristics of HCP's with more Expertise. It was hypothesized that healthcare providers who had higher scores on the Expertise latent factor would report more training in palliative care, more referrals to palliative care services, fewer barriers to care, and different characteristics for their most difficult

experiences (from the open-ended questions). Given the non-normality of these data, a median split was performed on the Expertise latent factor to compare the two groups (i.e., high vs. low Expertise).

As hypothesized, healthcare providers with more Expertise had 0.76 more units of Training than those with low Expertise ($t(208) = 4.08, p < .01$), which equates to approximately one more training experience in palliative care (e.g., formal course). Additionally, as predicted, those with high Expertise reported significantly more referrals to palliative care services both within and outside of the hospital ($t(203) = 3.08, p < .01$; $t(190) = 3.59, p < .01$); on average, those with high Expertise made 1.83 more referrals within the hospital (e.g., Palliative Care Team) and 0.77 more referrals to palliative care services outside of the hospital (e.g., hospice), than those with low Expertise.

Contrary to expectations, healthcare providers with greater Expertise did not report fewer barriers to care. If healthcare providers endorsed barriers as occurring “never,” they were not counted; however, ratings of “occasionally,” “often,” or “always,” were counted as barriers. Barriers were summed for each participant, including items from Section B, Questions 1 and 4. On average, healthcare providers in both groups reported experiencing 28 barriers out of a possible 38. Approximately 18 of these occurred “occasionally,” while the rest were rated as “often” or “always” barriers.

Similarly, no differences were found in the characteristics of healthcare providers’ most difficult experiences with a child who had died and a child who faced a life-limiting condition. Healthcare providers in both groups identified a variety of themes, according to study coders. The higher the scores on the Expertise scale, the less certain aspects of

death/illness were expected to affect healthcare providers (e.g., perhaps healthcare providers become habituated to parents' emotional reactions over time). More detailed results are discussed below.

Overall, partial support was found for this hypothesis. Healthcare providers with more Expertise reported more training and a greater number of referrals to palliative care services within and outside of the hospital. They did not, however, report more barriers to care or exhibit significant differences in the characteristics of their most difficult experiences.

Barriers. The top five barriers to providing pediatric palliative care (Section B, Questions 1 & 4) were: 1) families' prolonged inability to accept terminal diagnosis, 2) families' unrealistic expectations, 3) families' lack of education/understanding, 4) patients' lack of education/understanding, and 5) families' communication difficulties and families' cultural beliefs (*tied* for fifth). Importantly, regardless of the age of the children being cared for, the top barriers remained the same. For example, those working in the NICU reported the same barriers as those working with older children.

All items were endorsed as "often" presenting as barriers to delivering care to dying children or children with life-limiting illnesses. Note that only one of the top barriers involved patients, while the remainder dealt with families. This provides support for distinguishing between patient and family barriers (e.g., acceptance and expectations), a modification made to the SPPCHP. The results also highlighted the importance of including cultural beliefs as barriers to care, which was not assessed in the study at LPCH. The three lowest ranked barriers to care all involved the use of opioid analgesia.

This may reflect changes in attitudes toward providing pain relief to children. On average, all other items provided were endorsed as “occasional” barriers to care.

The top five reasons healthcare providers sought consultation from other services, both within and outside of the hospital, were also examined (e.g., psychiatry, social work, hospice; Section B, Questions 2 & 3). The top factors reasons were: 1) family requests, 2) knowledge of services, 3) patient requests, 4) availability of services, and 5) lack of a palliative care coordinator. The results reflect the sensitivity of healthcare providers to both patient and family requests, and the unfortunate lack of services for patients and families.

Open-ended questions about the healthcare providers’ most difficult experience with a child who died and a child who faced a life-limiting illness (Section D) were answered by slightly more than half of the sample ($n = 129$; $n = 120$, respectively). As previously discussed, content analysis was conducted using ATLAS.ti 6.0. Two doctoral level graduate students first coded themes together, reviewing all items twice. Next, a postdoctoral fellow independently coded the responses, using the newly developed categories. Percent agreement was 86% and 80%, respectively (between the postdoctoral fellow and the doctoral graduate student coding team).

The top four difficulties were the same for experiences with children who died and those who faced a life-limiting illness. These included: families’ emotional distress, healthcare providers’ emotional distress, healthcare providers’ communication with parents/families, and the medical severity of the child’s illness/death. Families’ emotional distress included feelings of denial, anger, blame, sadness, bereavement, fear,

and exhaustion. Healthcare providers' emotional distress also included these emotions, as well as feelings of helplessness and counter-transference. Many healthcare providers reported thinking about their own children when working with their patients.

Communicating with parents and families involved discussions about disease severity, illness course, and death. Healthcare providers frequently reported not "knowing what to say" when working with patients' families. Medical severity of the child's illness most often focused on physical pain and suffering. Overall, these results suggested that health care providers encounter a number of emotional challenges when confronting death or treating children with life-limiting illnesses. See Table 6 for further category descriptions, frequency counts, and participant quotes. Note that response frequencies represent the number of times a theme was independently raised by participants.

Although no participant's response was coded more than once using the same code, a single response from an individual participant was often coded in more than one category.

Support. The SPPCHP examined both the adequacy of the support provided by HCH to healthcare providers and the helpfulness and potential utilization of support services by healthcare staff. Of those who answered ($n = 157$), approximately half reported that the support was "exceptionally" (26.1%) or "mostly" adequate (25.5%), while others felt that support was "somewhat" (38.9%) or "not at all" adequate (9.6%). These results suggested that many healthcare providers think that these services could be improved. Although this question did not assess the types of support healthcare providers desired, these data were obtained in other sections of the survey (Section F).

Unfortunately, 64.8% of the respondents who completed Section F of the SPPCHP did so incorrectly ($n = 103$, incorrectly completed; $n = 56$, completed correctly). Respondents were asked to rank order the helpfulness and likely utilization of support services; however, many assigned a value instead. The majority of respondents who answered the section correctly completed the questionnaire in-person and were given explicit, verbal instructions for this section of the measure. Restructuring these items in the future will be needed. Fortunately, the results were still comparable between the group who completed it correctly and those who did not. Ratings were converted to rankings for each participant; items were allowed to share a similar ranking, if necessary. Overall, healthcare providers indicated that expert, on-the-spot consultation would be the most helpful and most likely type of support they would utilize (see Table 7). This could be accomplished by having a trained, knowledgeable palliative care team that could be “on call” for this type of support. Support groups and counseling, on the other hand, were rated as the least helpful and a service they not likely to use. Healthcare providers indicated that formal courses in palliative care would be very helpful, but they would be less likely to utilize this service. Instead, they stated that they would be more likely to attend a one-time workshop, such as Grand Rounds. This is likely due to the amount of time required for formal courses. While this section of the SPPCHP requires restructuring, the results provided important suggestions for hospital-based training.

Aim 4: Improving Awareness and Utilization of a Palliative Care Team

A secondary aim of this study was to evaluate the effectiveness of conducting this survey and providing a flier about the palliative care team’s mission and contact

information, in increasing awareness of and referrals to a palliative care team. Before the current study was launched, 71.6% of respondents were aware of the newly established Pediatric Palliative Care Team at HCH, while 26.7% had not heard of it (1.8% no response). When asked about their intentions to use the team's services in the future, 71.5% of all respondents reported being "likely" or "very likely" to refer; 11.5% were "unlikely" or "very unlikely;" and 14.2% felt "neutral" in their intentions. Those who were unlikely to use the service included nurses, physicians, psychosocial staff, and allied health professionals. Thus, overall awareness within HCH was improved and a large portion of respondents reported likely use of the service in the future.

Although healthcare providers *overall* reported making approximately one referral to palliative care services within the hospital during the past year (prior to completing the survey), 73.0% of participants indicated not having made any referrals to this service during the past year. Those who made referrals averaged 4.54 ($SD = 7.42$) in the past year. Even more striking, healthcare providers overall reported an average of 0.41 referrals to palliative care services outside of the hospital during the past year. An even greater percentage, 86.6%, reported not having made any referrals to these services outside of the hospital in the past year. Those who made referrals averaged 3.12 ($SD = 3.02$) in the past year. Thus, there seemed to be a discrepancy between those providers who referred to palliative care services and those who did not.

The number of referrals and surveys completed each month was also tracked, from the study's inception through six months post study recruitment. No significant increase in the pattern of referrals was noted (see Figure 9). Overall, the number of

referrals to the team remained low. This may be partially due to the number of healthcare providers who already knew about the team, or the fact that informal consultations were not adequately counted. The effects may also take a few more months, as healthcare providers slowly integrate the service into their care of their patients. Many healthcare providers, for example, may be gradually shifting their conceptualization of palliative care to include those facing life limiting conditions.

Although use of the Pediatric Palliative Care Team was infrequent, participants reported using other services within the hospital (Section B, Questions 2 & 3). Social work, pastoral care, and psychology were used most often; only a small percentage of healthcare providers reported never using the services (7.0%, 7.4%, and 15.4%, respectively). In contrast, those services used least often included the palliative care team, pain service, and home hospice (36.9%, 31.9%, and 25.1% “never” used the respective services). As previously discussed, the top factors affecting healthcare providers’ decisions to use these services included family requests, knowledge of services, and patient requests. Thus, although healthcare providers were consulting other services within the hospital, their use of specialized, palliative care services (including both the pediatric team and home hospice) was minimal; they consistently made few referrals over the past year. Hopefully, further education and improved awareness of these services will increase their use.

Beyond care received during a child’s life, the SPPCHP also asked healthcare providers to provide estimates of the number of families who received services, such as bereavement support, contact with the healthcare team, and counseling/psychological

services, after their child's death. Only 151 healthcare providers answered these questions, possibly because many had no further contact with the family after the child's death. Of those who responded, all services were reported as having been experienced by "some" families ($M = 2.08$ ($SD = .92$), $M = 2.02$ ($SD = .84$), $M = 1.99$ ($SD = .85$)).

Although not all families may require or desire these services, families may not have been aware of them. Healthcare providers should, at a minimum, make families aware of these services before, during, and after a child's death.

The final questions on the SPPCHP asked healthcare providers to identify the components they felt were lacking in their care of dying patients and/or those with life-limiting illnesses. Participants were also asked to identify the services they would like a palliative care team to provide. These responses were content-analyzed using ATLAS.ti 6.0. Two doctoral level graduate students coded all responses twice together as a team; a postdoctoral fellow then coded the responses independently, using the newly developed categories. Percent agreement was 82%. See Table 8 for detailed category themes, frequency counts, and participant quotes. Within the table, frequencies represent the number of times a theme was raised by participants. While no participant's individual response was coded more than once for the same code, the response itself may have been categorized more than once.

The top categories identified by healthcare providers who completed this item ($n = 120$) included better utilization of services, staff education, and the need for a full-time palliative care team. Healthcare providers who wished for better utilization of palliative care services also hoped for an earlier integration of these services and their use beyond

end-of-life care. The modified SPPCHP addressed the recent changes in the definition of palliative care, extending to beyond end-of-life (i.e., includes IOM's definition and two current vignettes). Of the healthcare providers at HCH who completed the SPPCHP, 86.6% "agreed" or "strongly agreed" with the IOM's most recent definition (2003). Although this indicates that most healthcare providers acknowledged this expansion of services, they may not be providing them at this time. It would be interesting to know more about the healthcare providers who reported that they "disagreed" or "strongly disagreed" with the new definition. Perhaps they still believe that palliative care should be limited to the last few months of life.

The second most frequently mentioned category, staff education, highlighted the desire and need for more education and training in providing palliative care. Healthcare providers reported wanting this for themselves and for other staff. Finally, many healthcare providers reported wanting a full-time palliative care team. They described an organized, 24 hour a day, multidisciplinary team, led by a trained coordinator. They also suggested having daily team rounds or a palliative care clinic, so more children would be identified and served by this team. Presently, the team is composed of staff with primary appointments in various departments, who are only able to commit limited time and resources to the team. Participants hoped that a permanent team could better organize the referral process, prevent pediatric patients from being missed by their services, and coordinate care among health care providers. Other categories raised by healthcare providers included family education/support, coordination of services, and emotional

support for staff. Thus, many healthcare providers understood the importance of and need for a pediatric palliative care team.

Chapter 4: Discussion

This study was one of the first to examine the palliative care training and support needs of pediatric healthcare providers across disciplines and professions at an ethnically, racially, and economically diverse children's hospital. Despite numerous advances in medicine, many children still suffer from life-limiting conditions and may benefit from palliative care services (Toce & Collins, 2003; Korones, 2007). Serious illness and death in children are non-normative, leading to high levels of distress, which affect patients, parents, siblings, and healthcare providers. Prior studies have demonstrated that pediatric palliative care provides numerous benefits, including pain reduction and symptom control, improved quality of life for patients and family members, and better preparation at death (Wolfe et al., 2008; Hays et al., 2006; Higginson et al., 2003).

Contro et al. (2004) first developed the Caregiver Survey on Palliative Care at Lucile Packard Children's Hospital (LPCH) in conjunction with a pediatric palliative care team whose focus was to provide support to dying children. Results reflected healthcare providers' lack of adequate training and support in providing palliative care. However, this hospital serves a primarily middle to upper class, largely Caucasian population. Thus, one aim of this study was to examine these issues in a largely Hispanic and lower socioeconomic sample. Further, substantial changes were made to the measure, now titled the Survey on Pediatric Palliative Care for Healthcare Providers (SPPCHP), to reflect the *current*, broader definition of palliative care as holistic care provided to children with life-limiting illnesses (IOM, 2003).

The current study also examined the training and support needs of pediatric healthcare providers. Results showed that healthcare providers lacked expertise in many aspects of palliative care, including managing pain and communicating with patients and their families. Most of the top barriers to providing palliative care involved patients' families (e.g., families' unrealistic expectations). Many healthcare providers reported desiring additional support, particularly on-the-spot consultations from the palliative care team.

Results were fairly similar at the two hospitals, despite the demographic differences between the samples (Contro et al., 2004). The psychometric properties of the SPPCHP had not previously been evaluated, but were found to be strong in the current study. Additionally, the use of the SPPCHP improved awareness of a pediatric palliative care team. Clinical implications include the need for systematic training and support for a broad range of professionals, in palliative care, with an emphasis on addressing key barriers to care (e.g., communication with families). Given the similarity of the results at HCH and LPCH, these findings appear generalizable to a variety of children's hospitals.

Comparisons of Results at HCH and LPCH

Although Holtz and Lucile Packard Children's Hospitals serve very demographically distinct populations, healthcare providers across both hospitals reported feeling inexperienced in similar aspects of delivering palliative care and desired further training and support. Healthcare professionals at both hospitals reported personal and emotional distress and feelings of helplessness as characteristic of their most difficult

pediatric deaths. Approximately half of both samples also reported feeling that their respective hospitals did not provide them with adequate support. Children's hospitals should be encouraged to provide staff with additional support, in order to improve the care for patients and families.

Interestingly, social workers and respiratory therapists at both hospitals reported having experienced the greatest number of deaths in the past year compared to other professionals. These findings emphasize the multidisciplinary nature of caring for children with life-limiting illnesses and the need for training across pediatric professions. Differences between the hospitals, such as residents' reported expertise, also underscored the importance of standardized training in palliative care.

Finally, the majority of healthcare providers in both samples reported being likely to use the palliative care team in the future. In general, these findings indicated that pediatric healthcare providers are receiving similar amounts of training (or lack of), face similar barriers to providing care, desire additional support, and understand and/or appreciate the (potential) positive impact of pediatric palliative care teams.

Modification and Examination of the SPPCHP's Psychometric Properties

Despite the importance of the original study at LPCH, the field of pediatric palliative care has expanded to include children with life-limiting illnesses. Additionally, the psychometric properties of the measure were not examined in the first study. Results from the current study indicated that the newly developed SPPCHP demonstrated strong internal consistency and good construct validity, as evidenced in factor analyses, supporting its utility as a measure of palliative care. The majority of scales, except

Quality of Life, performed well (e.g., Cronbach's alphas were $>.80$ for the five other scales).

The Quality of Life scale had poor internal consistency and there was little evidence of construct validity. Items assessed very different aspects of palliative care and thus, development of this scale may require a complete reconceptualization of the construct.

Although the items on the Quality of Life scale did not work well as a cohesive factor, several items were significantly correlated. Dying in pain and dying with anxiety/fear were positively correlated; the more pain children experienced, the higher their levels of anxiety/fear. Dying in pain and with anxiety/fear were also both *negatively* correlated with discussing end-of-life plans; the more healthcare providers talked about end-of-life, the less patients experienced anxiety/fear and pain. This finding provided evidence for the potential benefits of talking with children about death (i.e., reduced anxiety for patients). Research has shown that terminally ill children as young as three years of age are often aware of their diagnosis and prognosis without having been told by an adult (Bluebond-Langner, 1978; Freyer, 2004). Furthermore, fear of death has been documented in children as young as five years of age, and children as young as six have been able to participate in their own end-of-life decision making (Nitschke, Humphrey, Sexauer, Catron, Wunder, & Jay, 1992; Muris, Merckelbach, Gadet, & Moulaert, 2000).

Discussing advanced directives is one way palliative care providers can alleviate children's fears and provide them with a sense of control over their death (e.g., funeral arrangements). "Five Wishes" is a standardized living will written with the help of the

American Bar Association's Commission on Law and Aging (www.fivewishes.org); it was designed for patients 18 years and older, but can be used as a conversation tool with some children. Although not all children may be able to fully conceptualize death, the benefits of discussing end-of-life plans should be considered given the current study's findings (i.e., decreased physical and emotional pain).

In summary, substantial changes made to the SPPCHP improved its organization and modern day relevance. Its strong psychometric properties support its future use, although changes to the Quality of Life scale are necessary.

Identifying Training and Support Needs of Healthcare Providers

Despite guidelines regarding the need for instruction in caring for terminally ill patients during training, the majority of healthcare professionals never receive formal instruction in palliative care (Zwerdling, Hamann, & Kon, 2006; Khaneja & Milrod, 1998). Numerous barriers, including education, family factors, and child characteristics, can also impede the care provided to pediatric patients and their families (Docherty, Miles, & Brandon, 2007). Identifying these barriers and the support needs of healthcare providers may facilitate improvement of palliative care services. Results from the current study suggested that pediatric healthcare providers desire additional support and training.

Knowledge: Results indicated that healthcare providers only felt "somewhat" experienced in all areas of pediatric palliative care, with discussing DNR status and the transition to end-of-life care rated lowest among these items. These situations require sensitivity, honesty, and good communication skills from healthcare providers, skills that not all providers have naturally. Contro et al. (2004), for example, interviewed sixty-

eight family members of recently deceased children and found that most had experienced incidents in which healthcare providers made careless or insensitive remarks. Family members also reported that these comments continued to cause pain for them and negatively affected their grieving process (Contro et al., 2004). Given the potential consequences of healthcare providers' knowledge deficits, predictors and correlates of knowledge were examined further.

As hypothesized, both the number of years worked and healthcare providers' amount of previous training predicted self-rated expertise (i.e., knowledge). Differences were also found by profession in expertise; residents reported less expertise than all other professionals in both medical and nonmedical skills, while physicians reported being more knowledgeable than all others. These results suggested that training may be primarily occurring informally (i.e. through clinical experiences during residency), despite requirements for standardized training by various medical associations (e.g., Accreditation Council on Graduate Medical Education; Khanega & Milrod, 1998; Fowler et al., 2006). A study of pediatric oncologists mirrored these results, showing that there is often a strong reliance on trial and error in learning to care for dying children (Hilden, Emanuel, Fairclough, Link, Foley, Clarridge, et al., 2001). Surveys of residents have suggested that this on-the-spot training is inadequate and ineffective at improving their ability to provide palliative care during residency (McCabe, Hunt, & Serwint, 2008). When healthcare providers are inadequately trained in providing palliative care, they often report negative emotional consequences for themselves, which ultimately affect

patients and families as well (Graham et al., 1996; Bagatell et al., 2002). Together, these findings provide strong support for the need for formalized training in palliative care.

There are many forums in which healthcare providers' lack of training and knowledge in pediatric palliative care may be addressed. Often, palliative care programs offer presentations to hospital staff to increase education and awareness (e.g., during Grand Rounds; Ward-Smith, Linn, Korphage, Christenson, Hutto, & Hubble, 2007). In a prior study, a hospital provided a daylong educational workshop, which significantly improved physicians' knowledge of palliative care (Baughcum, Gerhardt, Young-Saleme, Stefanik, & Klopfenstein, 2006). Another palliative care program offered six, one-hour sessions for healthcare workers, highlighting topics such as personal coping and being a caring professional (Schiffman, Chamberlain, Palmer, Contro, Sourkes, & Sectish, 2008). Educational modules from the Initiative for Pediatric Palliative Care (IPPC) are often used during these presentations (Ward-Smith, et al., 2007). Hospital quality improvement programs have also provided a mechanism for palliative care education and support; one hospital instituted palliative care rounds, case conferences, and bereavement debriefing sessions to facilitate communication between disciplines and to offer grief support after a patient's death (Rushton, Reder, Hall, Comello, Sellers, & Hutton, 2006).

In collaboration with the newly developed team and this study, efforts are being made at HCH to design a pediatric palliative care curriculum for residents at the hospital. The curriculum will be designed to address numerous aspects of palliative care, such as communicating bad news to families and providing support. Some residency programs have already instituted training in components of palliative care. For example, fourth

year medical students at Albert Einstein College of Medicine participate in mock patient sessions in which they are asked to provide medical results to their patients (Hartocollis, 2009). They are taught basic listening and empathy skills, as well as how to convey honest information while being supportive. Programs like this are designed to improve the quality of care provided to patients and families. In summary, there are several ways to address the newly identified knowledge deficits of healthcare providers.

Barriers. Surprisingly, healthcare providers with more expertise did not report fewer barriers to care. Furthermore, no differences were found by profession in the top-ranked barriers. These findings likely reflected the fact that pediatric healthcare providers will always experience some barriers to care, regardless of training, given the nature of their specialty. The top barrier to providing care in the current study, families' inability to accept terminal diagnosis, has often been identified in the pediatric literature (Mack et al., 2007; Hendrickson & McCorkle, 2008). Most parents confronting the possible death of their child will likely react with shock and disbelief. Healthcare providers who receive specialized training, however, may be better able to clearly and empathetically communicate realistic expectations regarding children's diagnoses to parents (Truog, Christ, Browning, & Meyer, 2006). Thus, these results also supported the importance of having well-trained palliative care teams who can serve as consultants and mentors.

Five of the six top barriers to providing palliative care reported by healthcare providers involved families of patients. Families' emotional distress was also the most frequently raised characteristic of healthcare providers' most difficult experience with a

child who died or experienced a life-limiting condition. Many healthcare providers, however, reported feeling inexperienced in communicating with families. This not only provided support for the decision to separate some family and patient items on the SPPCHP, but also highlighted the importance of training and support that is focused on family-centered care. Palliative care, at its core, is intended to improve the quality of life of children with life-limiting illnesses and his/her family members.

Although not among the top five barriers, a number of respondents also endorsed medical system barriers, such as hospice regulations. In 1982, the Medicare Hospice Benefit instituted a per diem reimbursement for the care of patients believed to have no longer than six months left to live (Himmelstein, Hilden, Boldt, & Weissman, 2004). Furthermore, only medications used primarily for the relief of pain and symptom control related to the patient's terminal illness are covered by Medicare. This model was designed for *adult* cancer patients and has not been modified for children; thus, pediatric patients with a terminal prognosis who have longer than six months to live, or who receive life-prolonging medical treatments, are often unable to receive these services (Fowler, et al., 2006). Hospice of South Florida and Children's Medical Services recently instituted a program allowing children with Medicaid who have *two years* left to live, instead of six months, to receive hospice services (<http://www.hospicecareflorida.org/tilli-kids.php>). Child-specific guidelines are necessary in all states in order to eliminate this barrier to care.

The addition of barriers, such as religion and culture, was also supported in this study. Both were rated as "occasionally" presenting as barriers to care for healthcare

providers. These findings are consistent with research demonstrating a need for cultural sensitivity in healthcare settings (Contro et al., 2002; Davies, Larson, Contro, Reyes-Hailey, Ablin, Chesla, et al., 2009). For example, some individuals in Chinese and Mexican cultures avoid speaking of death; palliative care specialists might be aware of this cultural sensitivity and reduce public discussions of the child's death (Davies et al., 2009). Amish communities often prohibit the use of electricity; however some treatments, such as nebulized medications for pediatric patients with CF, require electricity. Modifications to treatments can be made (e.g., use of metered dose inhalers) but they may negatively impact the child's prognosis. Thus, palliative care training should address these barriers, given the increasing diversity of children who visit the hospital and the national move toward family-centered care.

Support. Given the array of challenges healthcare providers face in providing end of life care, it is critically important to both acknowledge and treat the emotional consequences of caring for dying children (Llamas et al., 2001; Storey & Knight, 2003). Half of the healthcare providers in this study, however, reported feeling that support was lacking at their hospital. Furthermore, healthcare providers' own emotional distress was the second most frequently raised challenge in working with pediatric patients. Although healthcare providers reported being least likely to use support groups or counseling, they reported a need for expert, on-the-spot consultations. As previously mentioned, the Initiative for Pediatric Palliative Care (IPPC) offers individualized and team training in providing palliative care. Trainings, like those offered by IPPC, could aid children's

hospitals in having knowledgeable and accessible palliative care providers who can then offer support to staff and patients.

Improving Awareness and Utilization of a Pediatric Palliative Care Team

The last aim of this study was to evaluate whether completing the survey improved awareness of a palliative care team. Results showed that approximately 25% of participants had not previously been aware of the team. Referrals, however, did not improve in the six months following the study's completion. This may be because informal consultations were not adequately counted or because healthcare providers may have still believed, erroneously, that palliative care services are only for those who are dying. This stigma often prevents the utilization of palliative care teams within hospitals; thus, some hospitals refer to palliative services as “comfort” care instead (Ward-Smith et al., 2007).

Limitations and Future Directions

Although this study had numerous strengths, including the diversity of healthcare providers who completed the survey, there were also a few limitations. First, it would have been helpful to include a larger sample of physicians ($n = 34$) and allied health professionals ($n = 18$), since their sample sizes were small relative to other groups. It is possible that time constraints reduced physician participation, while sampling biases (e.g., personal contacts within departments) may have limited the number of allied health professionals. In this study, most allied health professionals were respiratory therapists; the perspective of dietitians, occupational, and physical therapists, would strengthen the representativeness of the sample.

Additional selection biases may have affected the results. Healthcare providers who were invested in the further development of the pediatric palliative care services at the hospital may have been over-represented because of their motivation to participate. Although attempts were made to ensure random sampling (e.g., used hospital email list serves), a larger sample would have ensured greater representativeness.

The use of self-report measures can also introduce several forms of bias (Schwarz, 1999). For example, although the surveys were anonymous, social desirability responding may have led respondents to over-estimate their expertise in providing end-of-life care. The order of the questions may have also affected respondents, with items grouped together eliciting more similar responses. In addition, earlier items may have affected responses to later questions, particularly the open-ended questions which required participants to generate their own responses.

Another possible limitation was the method of data collection - which was online, using an electronic version of the measure. Although there are many advantages to collecting data electronically, including the ability to answer the survey questions at a convenient time, and thus, improve the sample size, there were also some disadvantages (Wright, 2005). Most of the missing data in this study occurred for the online surveys. This may have been due to the length of the survey and respondents' ability to "skip" questions (despite prompts to complete them). In the future, the survey could be programmed to require completion of all items prior to receiving the gift card, although this may present a problem for the IRB.

Online data collection has other limitations. For example, in order to preserve anonymity, IP addresses were not collected. Thus, it was not possible to ensure that participants only completed the measure once. Note, however, that addresses to send compensation were checked for duplicates. It was also not possible to verify participants' demographic information, which may have been affected by increased anonymity of online studies. These are common problems in conducting web-based studies (Wright, 2005).

A final limitation was the focus on the healthcare providers' perspectives on knowledge, training, and support needs, rather than the patients' and families'. These perspectives probably differ greatly. Thus, future studies should assess patient and family perspectives on aspects of end-of-life care.

Future directions include use of this survey in other children's hospitals across the U.S. Currently, two children's hospitals, one in Florida and one in California, are planning to use the modified SPPCHP. Additional information on the SPPCHP's psychometric properties could be used to improve the instrument. For example, confirmatory factor analyses could be conducted on the six scales identified in this study. Comparing results across hospitals would also strengthen our understanding of the training and support needs of pediatric healthcare providers. This, in turn, could provide further guidance for standardized training of healthcare professionals in end-of-life care.

In conclusion, the results of this study highlighted the need for additional education and support for pediatric staff, across professions, in providing palliative care. These results are particularly relevant given the recent changes in the field of palliative

care, from end-of-life care to holistic care throughout the lifespan of children with life-limiting illnesses (IOM, 2003). While attempting to find cures for diseases and better medical treatments for patients, it is also important to recognize that children and families continue to experience illness and premature death. Palliative care teams can assist in improving patients', families', and staff's quality of life.

Tables

Table 1. *Pediatric Palliative Care Team at Holtz Children's Hospital*

Profession	N (47)
Physicians	10
Residents	1
Nurses	10
Psychologists	5
Social Workers	4
Child Life Specialists	1
Chaplains	5
Administration	3
Family Members	3
Children's Medical Services	2

Table 2. *Demographics of Study Participants at HCH*

Characteristic	N (225)	%
Age (years)		
20-30	60	26.7
31-40	53	23.6
41-50	62	27.6
51-60	35	15.6
60+	4	1.8
Unknown	11	4.9
Gender		
Male	54	24.0
Female	161	71.6
Unknown	10	4.4
Race/Ethnicity		
American Indian	2	0.9
Asian or Pacific Islander	14	6.2
Black or African American	31	13.8
Black Caribbean	18	8.0
Black Hispanic	2	0.9
White/Caucasian Hispanic	65	28.9
White/Caucasian Non-Hispanic	72	32.0
Other	9	4.0
Unknown	12	5.3
Years worked at HCH	9.7 (9.3)	
Years worked as a professional	13.0 (11.3)	
Occupation		
Community MD	3	1.3
Faculty MD	27	12.0
Fellow	4	1.8
Resident	35	15.6
Patient care Nurse	88	39.1
Psychologist	11	4.9
Child Life Specialist	6	2.7
Social Worker	4	1.8
Pastoral Care	13	5.8
Respiratory Therapist	9	4.0
Student (5 Medical, 3 Graduate)	8	3.5

Administration	5	2.2
Other	4	1.8
Unknown	8	3.6
Pediatric Clinical Populations		
All pediatrics	81	36.0
Adolescent Medicine	5	2.2
Cardiology	5	2.2
Cranio-facial	1	0.4
Critical Care	5	2.7
Endocrinology	2	0.9
Emergency Medicine	1	0.4
Gastroenterology	1	0.4
Hematology/Oncology	27	12.0
Maltreatment/Abuse	1	0.4
Neonatology/NICU	26	11.6
Nephrology	4	1.8
Pediatric Intensive Care Unit	29	12.9
Pulmonology	4	1.8
Special Immunology	7	3.1
Surgery	3	1.3
Transplant	7	3.1
Unknown	15	6.7

Table 3. *Aim 1, Comparison of Lucile Packard and Holtz Children's Hospitals*

Characteristic (%)	LPCH	HCH
Gender		
Male	26	24
Female	74	72
Unknown	0	4
Occupation		
Physicians	25	15
Residents	11	18
Nurses	43	39
Psychosocial support staff	9	16
Ancillary support staff	5	8
Unknown	4	4
Years worked at hospital	8	10
Number of pediatric deaths, past year		
Physicians > 10yrs experience	3	7
Physicians < 10 yrs experience	4	8
Residents	6	3
Overall range	2-19	2-18
Inexperienced managing dying patients' symptoms		
Physicians	43	36
Residents	56	87
Nurses	50	44
Inexperienced managing dying patients' pain		
Physicians	49	52
Residents	54	82
Nurses	30	40
Adequate support provided by hospital	46	52
Use Pediatric Palliative Care Team in future		
Physicians	62	77
Residents	85	88
Nurses	73	66
Others	80	73

Note: Data for University of Miami were rounded for comparison purposes. See Table 2 for exact percentages.

Table 4. *Aim 1, Comparison of LPCH and HCH: Census Statistics*

	Santa Clara County (LPCH)	Miami-Dade County (HCH)
Population estimate (2009)	1.8 million	2.5 million
Race/Ethnicity (2008)		
American Indian/Alaska Native	0.8%	0.4%
Asian	31.2%	1.6%
Black	2.9%	19.5%
Native Hawaiian or Other Pacific Islander	0.4%	0.1%
White Hispanic	26.0%	62.4%
White Non-Hispanic	38.0%	17.8%
Language other than English spoken at home (2000)	45.4%	67.9%
Median household income (2008)	\$88,525	\$43,921
Persons below poverty level (2008)	7.6%	16.5%

Note: The above statistics are from the 2000, 2008, and 2009 censuses (<http://quickfacts.census.gov/qfd/states>).

Table 5. Aim 2, Correlations of Patient and Family Barriers

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	
1. Patient's acceptance	--																		
2. Family's acceptance	.54	--																	
3. Patient's religion	.48	.32	--																
4. Family's religion	.29	.46	.73	--															
5. Patient's culture	.51	.38	.85	.67	--														
6. Family's culture	.29	.46	.62	.81	.73	--													
7. Patient's understanding	.48	.45	.52	.40	.60	.42	--												
8. Family's understanding	.38	.50	.31	.43	.39	.49	.72	--											
9. Patient's communication	.46	.41	.42	.42	.49	.41	.65	.52	--										
10. Family's communication	.35	.42	.32	.42	.36	.44	.57	.57	.82	--									
11. Patient's language	.43	.24	.37	.34	.46	.37	.49	.33	.68	.51	--								
12. Family's language	.34	.25	.30	.34	.37	.40	.35	.34	.54	.60	.82	--							
13. Patient's expectations	.54	.44	.56	.42	.59	.43	.63	.47	.48	.36	.44	.34	--						
14. Family's expectations	.37	.57	.35	.44	.36	.44	.51	.64	.46	.50	.35	.35	.66	--					
15. Family's finances	.29	.20	.25	.23	.31	.36	.39	.29	.44	.45	.51	.53	.35	.24	--				
16. Family conflicts	.32	.36	.42	.47	.45	.49	.41	.41	.42	.44	.42	.41	.46	.41	.49	--			
17. Conflicting wishes	.39	.36	.50	.41	.53	.45	.46	.40	.41	.33	.43	.39	.60	.46	.48	.66	--		
18. Disclosure to child	.37	.33	.28	.28	.32	.31	.30	.26	.21	.20	.25	.25	.41	.34	.16*	.22	.32	--	

*p<.05, p<.01 for all other correlations

Table 6. *Aim 3, Most Difficult Experiences: Rankings of Frequencies of Open-Ended Responses*

Difficult Experiences: Coded Responses	Child Who Died (n = 129)		Child with Life-Limiting Illness (n = 120)		Descriptions & Exemplar Participant Quotes
	# Endorsed	(% Endorsed)	# Endorsed	(% Endorsed)	
Family's Emotional Distress	46	(36%)	21	(18%)	Parents' and siblings' feelings of denial, high hopes, anger, blame, sadness, bereavement, and fear <i>"When he died the mother was screaming in the unit that her life was over, she wanted to die and she wanted a divorce."</i>
HCP's Emotional Distress	43	(33%)	29	(24%)	HCP's feelings of denial, high hopes, first death, unable to help emotionally, countertransference, sadness, and bereavement <i>"To see a child with cancer [who] reminded me of my own kids ..."</i>
HCP's Communication with Parent/Family	24	(19%)	18	(15%)	About disease severity, death; not knowing what to say <i>"It was hard for me trying to explain [to] mom what was going on without breaking her hopes completely but without lying at the same time."</i>
Medically Unable to Help	20	(16%)	14	(12%)	Not sure how to help or cannot help <i>"The frustration of not being able to treat the disease."</i>
Sudden/Unexpected Death	19	(15%)	5	(4%)	Preventable, accident, shock <i>"Unexpected death in patient who had an uncommon complication."</i>
HCP's Relationship with Patient	16	(12%)	7	(6%)	Close bond, attachment <i>"It was very hard and emotional. I cried, I have come to love and care for the patient over a long period (they became like family to me)."</i>

(table continues)

Difficult Experiences: Coded Responses	Child Who Died (n = 129)		Child with Life-Limiting Illness (n = 120)		Descriptions & Exemplar Participant Quotes
	# Endorsed	(% Endorsed)	# Endorsed	(% Endorsed)	
Young Age of Child	12	(9%)	3	(3%)	Loss of future, barely experienced life <i>“Seeing a child that has just come into the world a few years ago and knowing that he/she has a few more days to live.”</i>
Treatments Futile, Overly Aggressive	11	(9%)	9	(8%)	HCP’s questioning treatment decisions <i>“Continuing care that I truly thought was futile ...”</i>
Disease Severity	10	(8%)	5	(4%)	Physical pain, suffering, medication side effects <i>“Patient had severe pain only relieved with very high doses of narcotics which did depress respiratory drive.”</i>
Transitioning/Utilizing Palliative Care	10	(8%)	4	(3%)	When and how; denial by HCP’s and family, preventing transition/use <i>“It was difficult because there was no opportunity for use of palliative care.”</i>
Patient’s Emotional Distress	9	(7%)	13	(11%)	Denial, high hopes, anger, blame, sadness, bereavement, fear, exhaustion experienced by patients <i>“Taking care of a 14yo patient that knew she was dying, had anxiety crisis, but refused to talk with psychology service for a long time. She was not motivated anymore, she was scared ...”</i>
Communication between Child & Parent	8	(6%)	11	(9%)	Regarding disease severity, course, and terminal status <i>“The parents would not disclose to their child that he was dying.”</i>

(table continues)

Difficult Experiences: Coded Responses	Child Who Died (n = 129)		Child with Life-Limiting Illness (n = 120)		Descriptions & Exemplar Participant Quotes
	# Endorsed	(% Endorsed)	# Endorsed	(% Endorsed)	
Child Environment	8	(6%)	11	(9%)	Social support from family, peers, school; socioeconomic constraints; lack of health insurance and coverage <i>“The patient had no direct family support except for medical foster parents who I rarely saw. He died alone, in the ICU ...”</i>
Coordinating Care	5	(4%)	7	(6%)	Among HCP’s, including issues such as disclosure and treatment decisions <i>“Coordinating care among different services.”</i>
Child Characteristics	3	(2%)	6	(5%)	Personality, behavior, cognitive development <i>“Teenager whose cognitive functioning interfered with need/desire/thoughts about telling her that she could no longer receive a transplant and would soon die.”</i>
HCP’s Communication with Patient	3	(2%)	6	(5%)	About disease severity, death; not knowing what to say <i>“The most difficult [part] was not having enough time to discuss end-of-life care with [the] patients.”</i>
Language Barriers	3	(2%)	0	(0%)	Between family and HCP’s <i>“Language barrier meant I did not have as much contact with her as I would have liked.”</i>
Nothing	2	(2%)	4	(3%)	No difficulties <i>“I try to give the best care and not think of anything as difficult.”</i>

(table continues)

Difficult Experiences: Coded Responses	Child Who Died (n = 129)		Child with Life-Limiting Illness (n = 120)		Descriptions & Exemplar Participant Quotes
	# Endorsed	(% Endorsed)	# Endorsed	(% Endorsed)	
Religion	0	(0%)	3	(3%)	Barrier to treatment, acceptance <i>“When the parents refused to allow me to minister to them because they were of a different Faith.”</i>
Adherence	0	(0%)	2	(2%)	To medical treatments <i>“Trying to convince a child with HIV to take their meds ...”</i>
Total Unique Responses	252		178		

Note: Categories were rank ordered according to frequency of responses to the question about a “child who died.” Frequencies represent the different number of times a theme was independently raised by participants. No participant’s response was coded more than once for the same code, although a single response may have received more than one code.

Table 7. *HCP's Rank Ordered Helpfulness vs. Likely Use of Support Services*

Type of Support	Helpful		Utilize	
	Correctly	Incorrectly	Correctly	Incorrectly
Expert, on-the-spot consultation	1	1	1	1
Formal course	2	2	3	3
One-time workshop	3	6	2	2
Educational materials	4	4	4	4
Support groups	5	5	6	6
Counseling	6	3	5	5

Note: Data for participants who completed the measure incorrectly was converted from ratings to rankings. Data is presented by rank-order for "Helpfulness" for those who correctly completed the measure.

Table 8. *Aim 4, Missing Components of Palliative Care Services: Rankings of Frequencies of Open-Ended Responses*

Missing Components: Coded Responses	Section G (n = 120) # Endorsed (% Endorsed)	Descriptions and Exemplar Participant Quotes
Better Utilization of Services	35 (29%)	Better and earlier use of palliative care services by families and staff, beyond end-of-life care <i>“More emphasis and understanding on primary medical team's part that palliative care is not just end-of-life care, but also improving patient's quality of life with any chronic or life-threatening illness.”</i>
Staff Education	34 (28%)	Further education in providing palliative care for all HCP's <i>“Grand rounds or helpful material for the staff would be great. A palliative care course would be good as well.”</i>
Full-time Palliative Care Team	22 (18%)	Organized, 24 hour, multidisciplinary team, with a coordinator, possibly a Palliative Care clinic/rounds <i>“Dedicated, full-time specialists. Nurse/Staff coordinator. More specific, targeted multi-disciplinary input ...”</i>
Family Education/Support	14 (12%)	General and palliative care specific education and support to parents and siblings (e.g., via parent support groups) <i>“More workshops ... available to family so they can also understand the process of comfort & acceptance & treatment.”</i>
Emotional Support for Staff	10 (8%)	Including debriefings, counseling, and support from other staff <i>“Support meetings for palliative care teams ...”</i>
Coordination of Services	10 (8%)	Coordination of care within team, as well as between team and others (e.g., families) <i>“More coordination between family, palliative care team, and medicine team.”</i>

(table continues)

Missing Components: Coded Responses	Section G (n = 120)		Descriptions and Exemplar Participant Quotes
	# Endorsed	(% Endorsed)	
Patient Services/Support	9	(8%)	General resources (e.g., outside play area), group/individual counseling, better pain management <i>“Music therapy, play therapy, dance therapy, pet therapy...would all be very useful ... someone who was designated to take the kids out of the hospital just to walk around and get fresh air ...”</i>
Nothing	9	(8%)	No missing components to current services <i>“We have the essentials of a palliative care team in our unit.”</i>
Financial Support	7	(6%)	For further training, staff support, and resources for families <i>“We could always use more financial support to further develop this program particularly in terms of continuing education ...”</i>
Hospice Services	7	(6%)	Better use and availability of hospice services for children <i>“Appropriate hospice care service specifically tailored to a pediatric population.”</i>
Multicultural/Spiritual Services	5	(4%)	Integrating and being more aware of cultural and spiritual differences, providing informed care <i>“I would like to see a more representative pastoral care component, specifically for patients who are part of minority religious/spiritual groups.”</i>
Total Unique Responses	171		

Note: Categories were rank ordered according to frequency of responses. Frequencies represent the different number of times a theme was independently brought up by participants. No participant’s response was coded more than once for the same code, although a single response may have received more than one code.

Figures

Figure 1. *Aim 2, Construct Validity of the SPPCHP: Expertise Scale.* All loadings were significant (** $p < .01$).

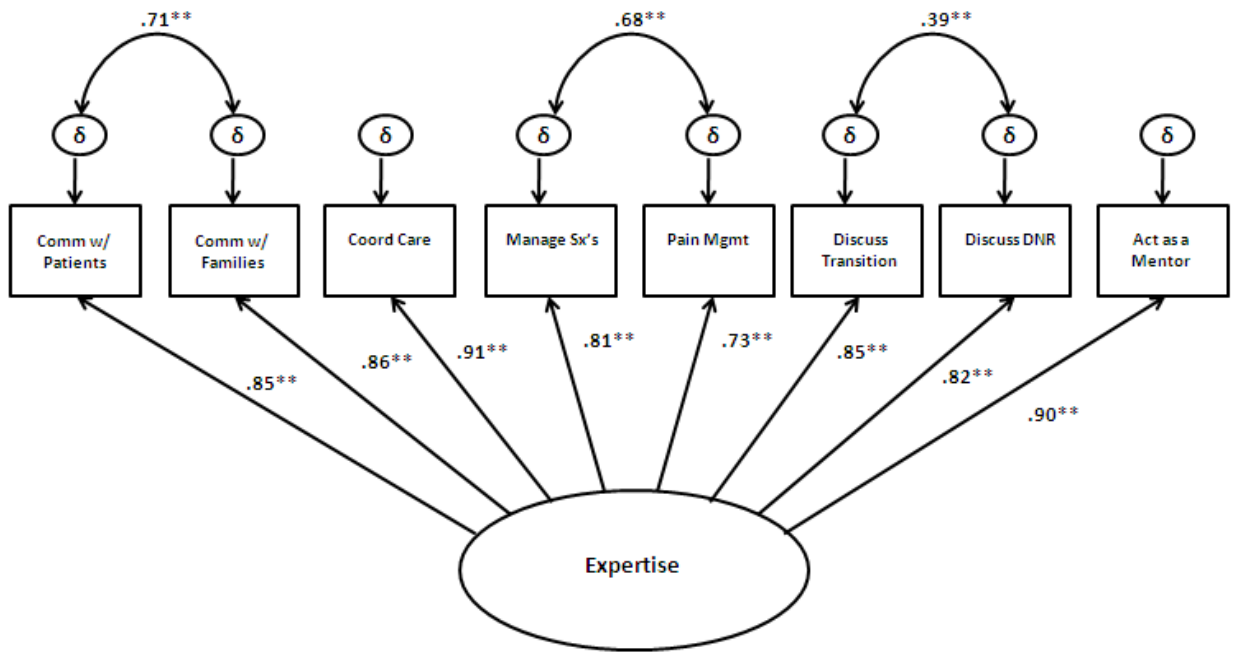


Figure 2. Aim 2, Construct Validity of the SPPCHP: Patient/Family Barriers. All loadings were significant (** $p < .01$, * $p < .05$).

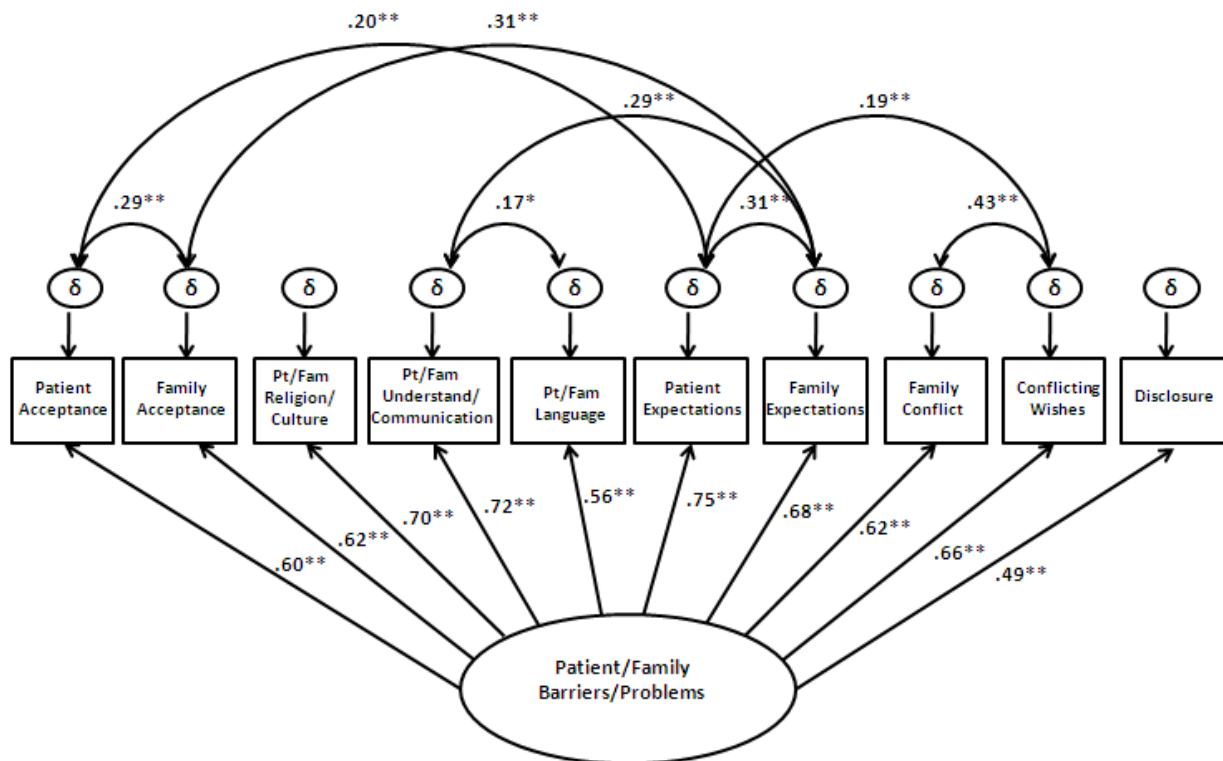


Figure 3. *Aim 2, Construct Validity of the SPPCHP: Healthcare Provider Barriers.* All loadings were significant (** $p < .01$).

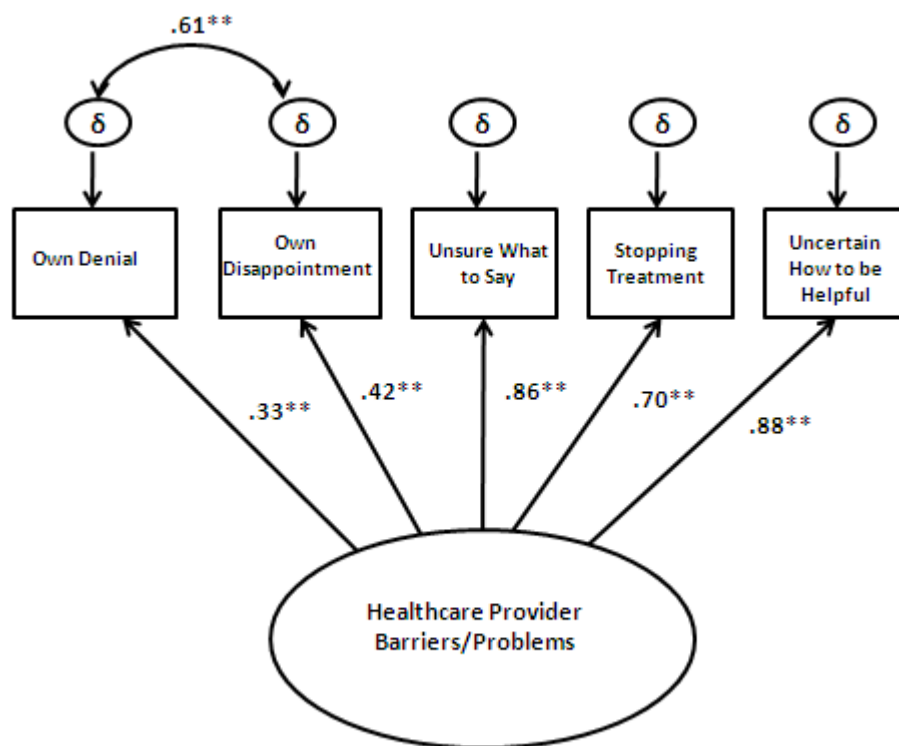


Figure 4. Aim 2, Construct Validity of the SPPCHP: HCP Team Barriers. All loadings were significant (** $p < .01$).

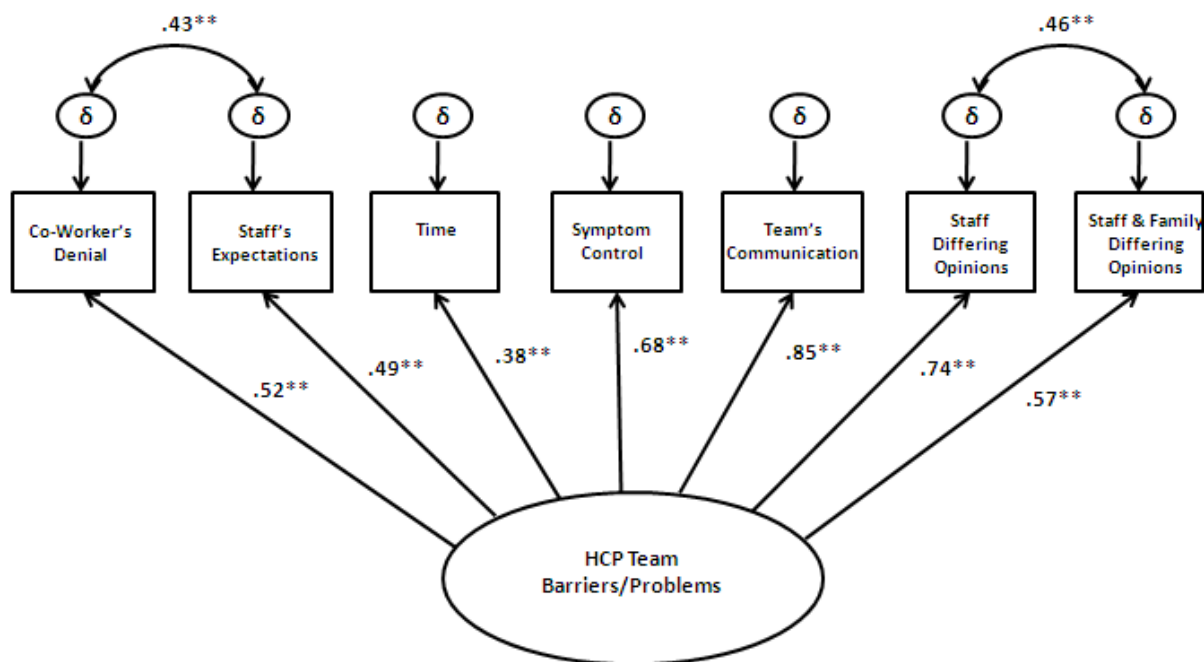


Figure 5. Aim 2, Construct Validity of the SPPCHP: Healthcare System Barriers. All loadings were significant (** $p < .01$).

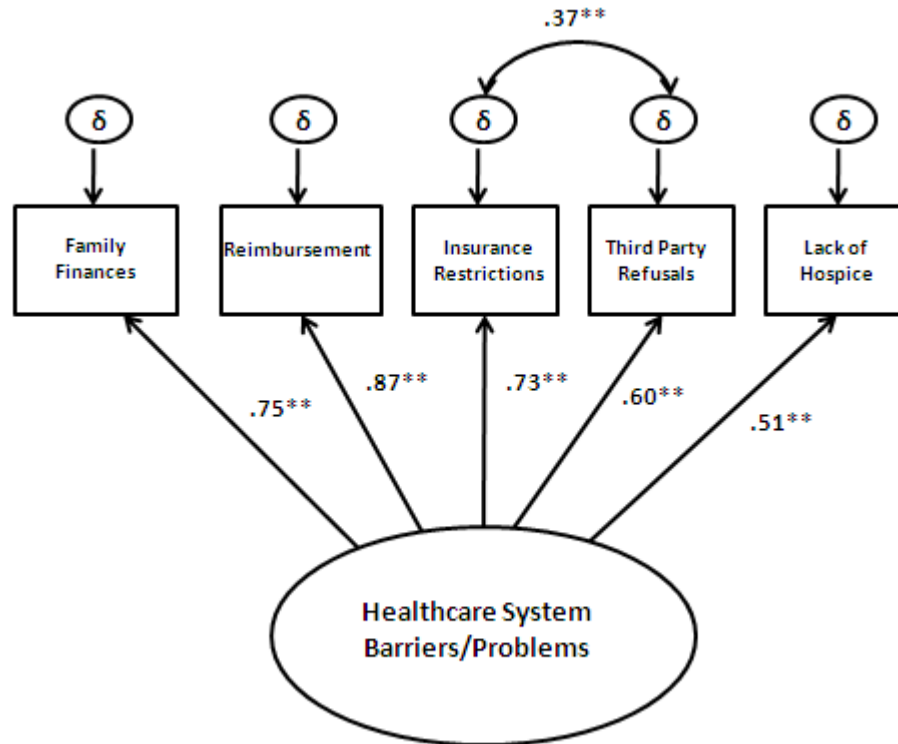


Figure 6. *Aim 3, Hypothesis 1: Differences by Profession in the Expertise Scale. Overall group differences were significant for all items ($p < .01$).*

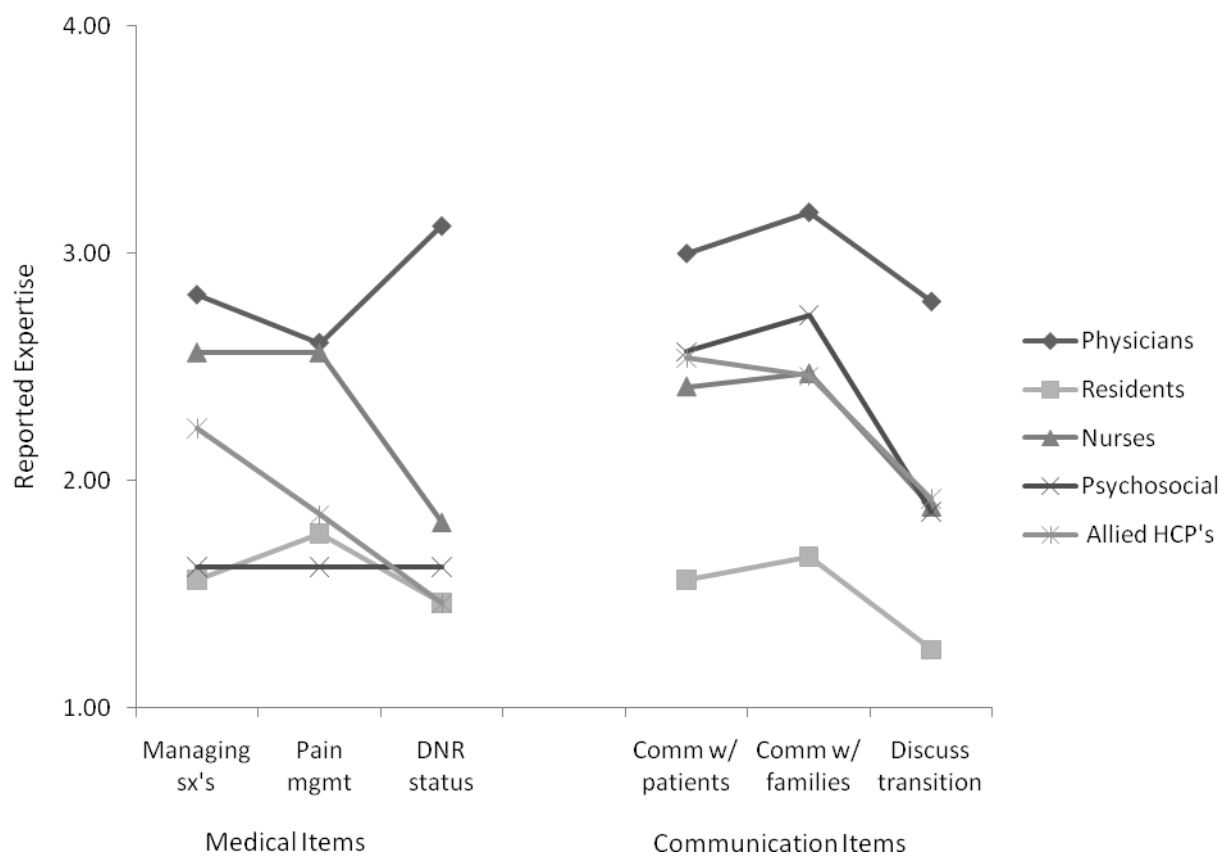


Figure 7. Aim 3, Hypothesis 2, Predictors of Expertise latent factor as evidence for convergent validity: Number of years worked (** $p < .01$).

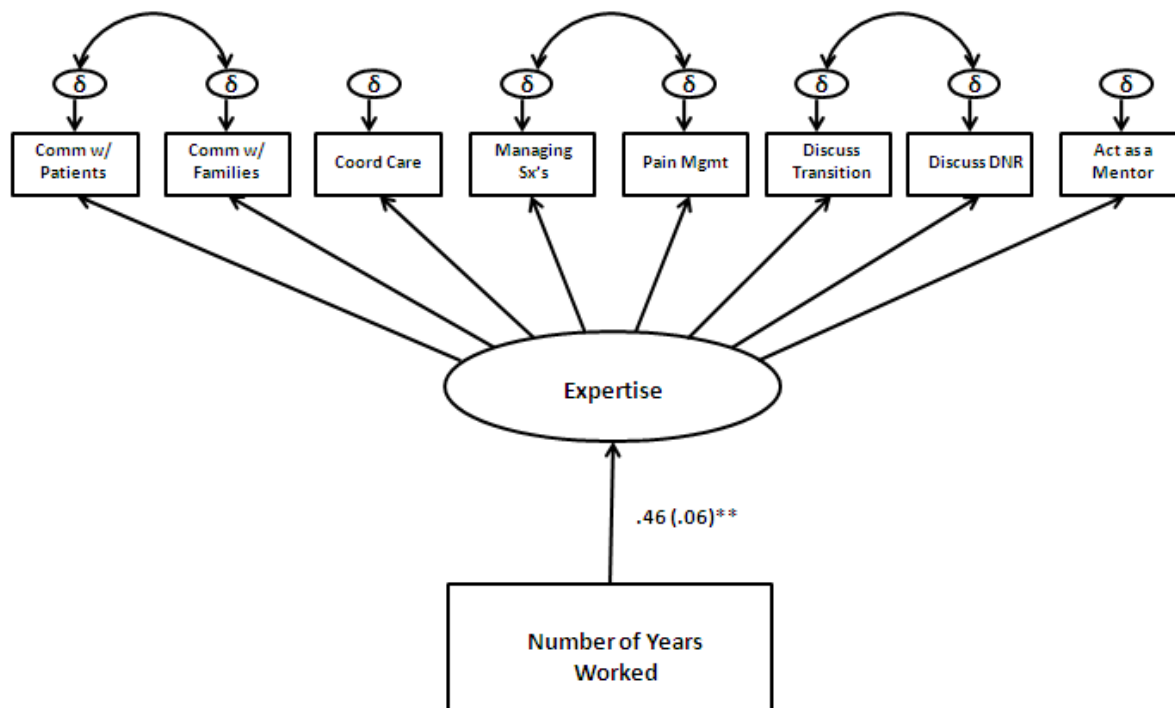


Figure 8. *Aim 3, Hypothesis 2, Predictors of Expertise latent factor as evidence for convergent validity: Training composite (** $p < .01$).*

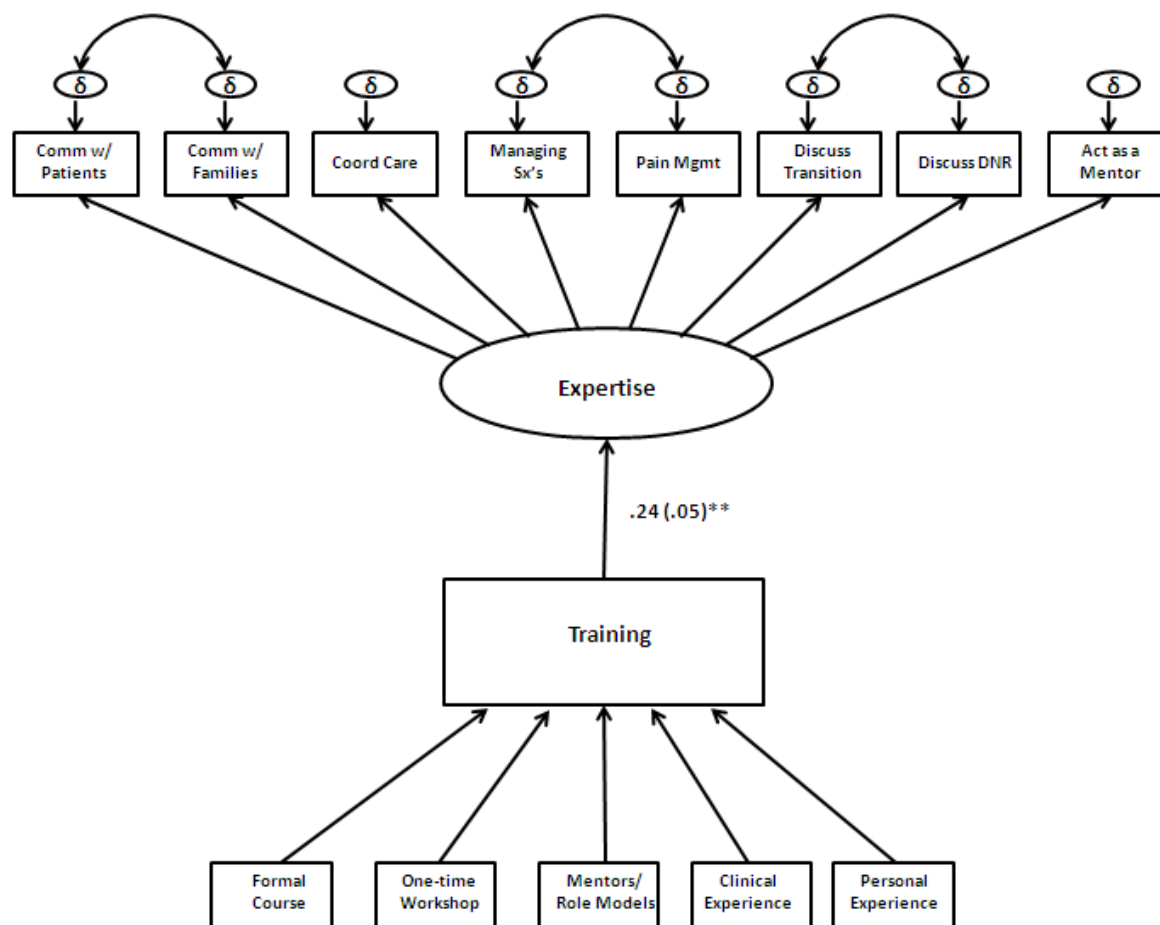
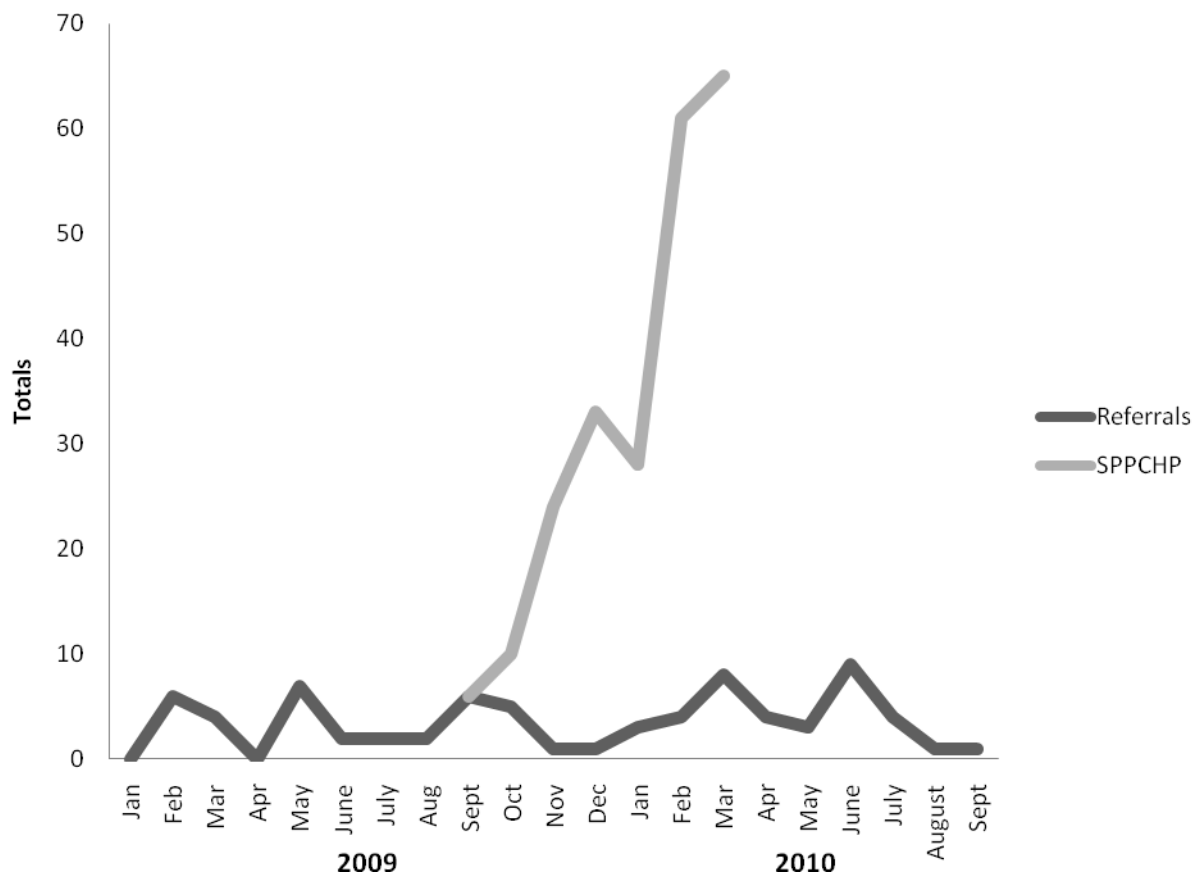


Figure 9. *Aim 4, Improving Awareness and Utilization of a Palliative Care Team: Referrals and Recruitment.*



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Appendix

SURVEY ON PEDIATRIC PALLIATIVE CARE FOR HEALTHCARE PROVIDERS

Adapted from a Stanford University Survey¹

“Palliative care” has several definitions. When filling out this survey, please keep the following definition in mind. The Institute of Medicine defines palliative care as “care that seeks to prevent, relieve, reduce, or soothe the symptoms produced by serious conditions or their treatment and to maintain patients’ quality of life” (IOM, 2003).

Palliative Care Vignettes

Please read the following two vignettes which describe palliative care services as defined above by the IOM.

An adolescent with multi-organ dysfunction is admitted to the hospital. The adolescent is unaware of his terminal prognosis, and his parents are distraught. Palliative care would include discussions of current quality of life with the family and the adolescent (e.g. how the adolescent’s pain may be reduced), as well as providing emotional support for all family members. Palliative care would also entail discussions regarding end of life planning (e.g. transitioning to hospice care, disclosure of terminal status to the teen).

An infant is diagnosed with cystic fibrosis. Palliative care would include providing support to the family in helping to relieve physical, social, emotional, and spiritual suffering. It would be provided in conjunction with curative-restorative therapies throughout the patient’s life.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Do you agree with this definition of palliative care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Prior to completing this survey ...

Were you aware of the Pediatric Palliative Care Team at Holtz Children’s Hospital? Yes No

In the past year, how many times have you made referrals to palliative care services *within* the hospital? ____

In the past year, how many times have you made referrals to palliative care services *outside* the hospital? ____

	Very Unlikely	Unlikely	Neutral	Likely	Very Likely
How likely are you to use the Palliative Care Team at Holtz?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you have contact with children, through your work, who have life-limiting conditions?					<input type="checkbox"/> Yes <input type="checkbox"/> No
Have you ever experienced the death of a pediatric patient?					<input type="checkbox"/> Yes <input type="checkbox"/> No

¹Contro, N., Larson, J., Scofield, S., Soukes, B., & Cohen, H. (2004). Hospital staff and family perspectives regarding the quality of pediatric palliative care. *Pediatrics*, 113, 1248-1252.

Demographics

1. Age 20-30 31-40 41-50 51-60 61+

2. Gender Male Female

3. Race/Ethnicity American Indian
 Asian or Pacific Islander
 Black or African American
 Black Caribbean
 Black Hispanic
 White/Caucasian Hispanic
 White/Caucasian Non-Hispanic
 Other _____

4. How long have you worked at this institution? _____

5. How long have you worked as a professional? _____

6. Occupation?

Community MD Faculty MD Fellow; Primary Unit: _____
 Resident; Primary specialty: _____ Patient care Nurse Nurse tech
 Psychologist Child Life Specialist School Teacher Pharmacist
 Social Worker Case Manager Chaplain
 PT OT RT

Other: _____

7. What clinical population(s) do you work with? (e.g. Pulmonary, Hem/Onc, neonatology, trauma, etc.)

A. Current Delivery of End of Life Health Care

1. What is your current level of expertise with regard to:

	Beginner	Somewhat Experienced	Moderately	Very Experienced
a) Communicating with dying patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Communicating with dying patients' families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Coordinating the care of dying patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Managing symptoms of dying patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Pain management for dying patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Explicitly discussing transitioning from curative treatment to end-of-life care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Discussing DNR status with patients & families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Acting as a mentor or role model to younger colleagues or trainees on these topics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. How much did the following experiences contribute to your level of competence and comfort in caring for dying children?

	No Contribution	Some Contribution	Significant Contribution	Very significant Contribution	Not Applicable
a) Formal course(s) in palliative care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) One-time workshop	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Mentor or role models	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Clinical experience	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Personal experience	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

B. Factors Affecting Your Delivery of End of Life Care

1. How often do the following circumstances create barriers to delivering palliative healthcare to dying children or children with a life-limiting illness?

	Never	Occasionally	Often	Always	
a) Patient prolonged inability to accept terminal diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
b) Family prolonged inability to accept terminal diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
c) Your own denial	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
d) Your co-worker's denial	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
e) Your own disappointment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
f) Patient's religious beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
g) Family's religious beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
h) Patient's cultural beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
i) Family's cultural beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
j) Patient's lack of education/understanding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
k) Family's lack of education/understanding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
l) Patient's communication difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
m) Family's communication difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
n) Patient's language fluency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
o) Family's language fluency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
p) Patient's unrealistic expectations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
q) Family's unrealistic expectations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
r) Staff's unrealistic expectations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
s) Family's financial resources	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
t) Family conflicts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
u) Conflicting wishes of families and patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
v) Patient refusal to take opioid analgesia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A <input type="checkbox"/>
w) Family refusal of opioid analgesia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x) Laws and regulations regarding opioid analgesia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
y) Personal discomfort regarding responsibility for prescribing /delivering doses of analgesics required to relieve pain in palliative care patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
z) Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

2. In caring for dying children or children with a life-limiting illness, how often do you use the following services?

	Never	Occasionally	Often	Always
a) Pain Service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Case management services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Home health care services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Social work services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Psychiatry consult services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Psychology consult services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Chaplaincy services/Pastoral care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Home hospice services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Consultation with the palliative care team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. What factors impact your decision to use (or not use) these services?

	Not at all Important	Slightly Important	Very Important	Extremely Important
a) Patient requests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Family requests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Availability of services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Knowledge of services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Insurance policies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Time management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Lack of a Palliative Care coordinator	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Assumption that services are already being used	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. How often is each of the following a problem in caring for your patients in end of life care?

	Never	Occasionally	Often	Always
a) You don't have the time it takes to adequately discuss end of life issues with patients and families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) You don't know what to say	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) You don't know if life-prolonging treatment should be stopped	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) You are uncertain how to be helpful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Poor symptom control, e.g. pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Poor communication within team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Differences of opinion regarding plan of care among staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Differences of opinion regarding plan of care between family and staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Insufficient reimbursement for coordination of care of dying patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) You are unable to refer because of insurance restrictions and limits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) Third party refusals to cover unskilled home healthcare services alters your preferred treatment plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) Lack of hospice programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) Disclosure of terminal health status (e.g. child does not know he/she is dying)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C. Specific Experiences With Your Patients

For the questions in this section we ask that you give your *best estimates* of how many of your patients fall into each category. You do not need to go to your records to answer these questions.

1. How many of your patients died in the past year? _____

2. What were their ages and causes of death?

Age _____ Cause _____	Age _____ Cause _____
Age _____ Cause _____	Age _____ Cause _____
Age _____ Cause _____	Age _____ Cause _____
Age _____ Cause _____	Age _____ Cause _____
Age _____ Cause _____	Age _____ Cause _____

3. For your patients who died in the past year, please provide your best estimate of how many of them experienced each of the following during their last six months of life.

	None	Some	Most	All
a) Died experiencing pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Died experiencing anxiety/fears	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Died a sudden death	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Died with social support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Died in the hospital with satisfactory end of life care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Died at home with satisfactory end of life care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Discussed an Advanced Care Directive with you (for patients over 18) (living will or proxy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Discussed wishes/plans for end-of-life care (for patients under 18)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. For your patients who died in the past year, please provide your best estimate of how many of their families experienced each of the following after death.

	None	Some	Most	All
a) Received follow-up bereavement support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Maintained contact with healthcare team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Counseling or psychological services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D. What was your most difficult experience with a pediatric patient who died? Briefly describe the situation and what made it hard.

What was your most difficult experience with a child with a life-limiting illness?

E. How adequate is the support for staff working with dying children or children with a life-limiting illness at Holtz Children's Hospital/Jackson Memorial?

Not at all Somewhat Mostly Exceptionally

F. Please rank in order of importance (1 through 6, using each ranking only once) how helpful each of the following would be *for you* in your work with dying children or children with a life-limiting illness, *and* then indicate how likely you would be to utilize them.

Helpfulness: 1 = least helpful, 6 most helpful

- ___ Formal course(s) in palliative care
- ___ One-time workshop(s) (e.g. grand rounds)
- ___ Educational materials
- ___ Support groups
- ___ Counseling
- ___ Expert, on-the-spot consultation
- ___ Other _____

Utilization: 1 = least likely to use, 6 most likely

- ___ Formal course(s) in palliative care
- ___ One-time workshop (e.g. grand rounds)
- ___ Educational materials
- ___ Support groups
- ___ Counseling
- ___ Expert, on-the-spot consultation
- ___ Other _____

G. After reflecting on palliative care, what components do you feel are missing that would improve your care of dying patients and/or those with life-limiting illnesses (both in the hospital and at home)? What services would you like to see in a palliative care team?

H. Other Comments:
