

An Exploratory Study on the Barriers to Pediatric Palliative Care Programs and Their  
Relationships to Funding

A dissertation submitted in partial fulfillment of the requirements for the degree of  
Doctor of Philosophy at George Mason University

By

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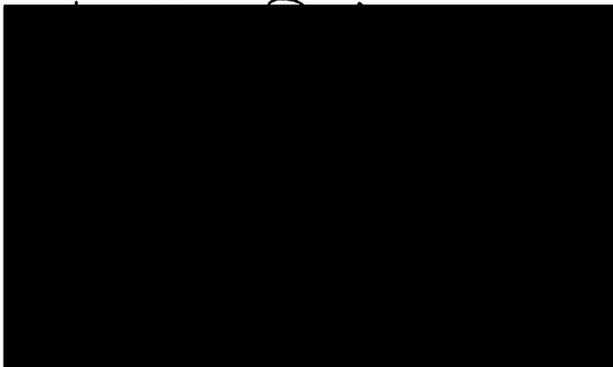
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## Dedication

I would like to dedicate this dissertation to my family:  
In memory of my father, Joseph E. Kirkpatrick, who encouraged and emphasized the  
importance of continuous learning;  
To my mother, Sarah C. Kirkpatrick, for serving as a role model of faith, hope, and love;  
To my husband Jim, “my rock of Gibraltar” and “knight in shining armor” who without  
his support, I would have never finished this dissertation;  
And to my sons, Matthew, Sean, and Aaron who kept reminding me that this dissertation  
process was not supposed to be easy, that it was meant to be a challenge, and that they  
knew I could do it!

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## Abstract

### AN EXPLORATORY STUDY ON THE BARRIERS TO PEDIATRIC PALLIATIVE CARE PROGRAMS AND THEIR RELATIONSHIPS TO FUNDING

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George Mason University, 2004

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Barriers to reimbursement for end-of-life care are systemic throughout the United States. The 2003 Institute of Medicine's (IOM) report, *When Children Die: Improving Palliative and End-of-Life Care for Children and Families*, addressed the complexity of reimbursement issues and recommended further research. This study, a sequential mixed methods design, used quantitative techniques and a qualitative, phenomenological approach. The quantitative phase addressed the research question: Does the reimbursement of services for the delivery of pediatric palliative care differ between types of funding, and is funding related to directors' perceptions of obstacles to the delivery of care? The qualitative phase addressed the research question: What are the barriers that CHI PACC directors' experience in their roles and how do they overcome them? Phase I, a non-experimental, descriptive correlation study identified frequencies and proportions of programs that acknowledged reimbursement barriers and their

relationships to funding sources, and their overall ratings of barriers to deliver pediatric palliative care.

The convenience sample for this study was comprised of 37 respondents from an accessible population of 130 health professionals who were named specifically from a list and were in the role of administrators, directors, or coordinators of palliative care services in a health care facility in the United States. Data were obtained through a self-report instrument. Bivariate descriptive analysis was done using Version 10 of SPSS. A summary of the results included the top three items rated as the most severe barriers for staff to provide care and were (1) the staff being unaware of community funds that may be accessible for palliative care, (2) staff being unaware of foundation funds available within their organization that could be used for palliative care, and (3) the lack of standardized competencies for staff to provide pediatric palliative care. The top three items rated as the most severe perceived obstacles in providing care were (1) the association of hospice or palliative care with death, (2) physicians' reluctance to make referrals for pediatric palliative care, and (3) the family's reluctance to accept palliative care. Other key findings included that the majority of palliative care services reimbursed were for physical care services versus psycho-social services, that there was a significant relationship between some of the specific staff barriers and perceived obstacles, and that there was a significant negative relationship between reimbursement for private insurance with perceived obstacles ( $r = -.449, p < .05$ ), but not for Medicaid or private donations.

Phase II was an interpretive, phenomenological study conducted to better understand the barriers to the implementation of these programs as seen from the experiences of the directors of six federally funded demonstration programs located within the United States. Data were collected using in-depth, semi-structured interviews that were audio-taped, transcribed and interpreted using van Manen's method of thematic analysis. The three themes that emerged were: "Leaders and Labyrinths," "Making Change of Dollars and Sense," and "We Are Just Soldiers." Participants described experiences that reflected challenges in finance, access, communication, and education. Each of the themes was directly linked with the quantitative findings and supported in the literature and indicate a need for further attention on pediatric palliative care in education, practice, research, and policy.

## Chapter 1

### Introduction

Children are dying and not getting palliative care, even though adults who are dying are afforded the hospice and palliative care services they deserve (Field & Behrman, 2003). In 1983, a non-profit organization, the Children's Hospice International (CHI), was founded to promote the inclusion of children into existing and or developing hospice, palliative, and home programs. In this same year it was noted that only four out of 1400 hospices in the U. S. accepted children. CHI as an advocate for children with life-threatening illnesses recognized that there were multiple differences between hospice care for adults and hospice care for children. Some of these differences included issues about patients, families, caregivers, institutions, regulations, and reimbursement. And so, because many dying children and their families were facing many barriers to palliative care, often due to regulatory limitations, CHI began a crusade to institute change. Other catalysts, such as private foundations, joined in the end-of-life (EOL) care movement as well.

More attention was brought to EOL care in the mid 1990s when private foundations began to put their financial resources into studies to help better understand problems associated with dying. Much of the attention on palliative care is due to the

generosity of private foundations, who as catalysts underwrote grants for projects and programs to propel the EOL care movement forward. Major contributors have included: the Robert Wood Johnson Foundation (RWJF), the Nathan Cummings Foundation, the Fetzer Institute, the Commonwealth Fund, and the Project on Death in America (Foley & Gelband, 2001). For instance, the Robert Wood Johnson Foundation alone, funded \$29 million for the 1995 Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT). This was a study of seriously ill hospitalized patients with a focus on end-of-life care issues whose findings demonstrated the lack of communication between physicians and their patients about end-of-life care (Foley & Gelband, 2001; Matzo & Sherman, 2001).

End-of-life care continued to be on the radar screen of policy makers the following year as many of them began to hear more from advocates for children. Among those advocates was CHI, who in 1996, met with Virginia Congressman Jim Moran to seek advice on how to move the pediatric palliative care agenda forward. The Congressman suggested that CHI find a demonstration model of care that could work for children. In response to that advice, CHI held a Summit in 1997 and invited multiple stakeholders, which included representatives from the Health Care Finance Administration (HCFA), whose name has been changed to Centers for Medicare and Medicaid, to discuss the barriers to pediatric palliative care. A task force evolved from this meeting and work began to identify models of care that could work for a pediatric population. In 1999, while CHI continued to be busy at work on models of care, the

Institute of Medicine's (IOM) Board on Health Sciences Policy recommended that the IOM form a committee to investigate care for dying children and their families.

The study began in 2000 and was funded by public and private agencies. It was overseen by 14 experts who represented professionals in the disciplines of nursing, medicine, social work, economics, ethics, academia and research.

The committee had three major goals which were to: (1) "develop recommendations to strengthen the knowledge base for compassion and effective care for dying children and their families; (2) inform health care providers, researchers, medical and nursing educators, state and federal policy makers, insurers, and others about the recommendations; and (3) encourage thoughtful discussion of what constitutes good end-of-life care for children and their families" (Field & Behrman, 2003, p. 445). The product of this committee's work was the IOM 2003 report "*When Children Die: Improving Palliative and End-Of-Life Care for Children and Their Families.*" (Note: Future reference to this report will be listed as the 2003 IOM Report in the text and referenced by the editors, Field & Behrman, 2003).

While the IOM Committee was busy doing their work, CHI and its collaborative partners identified a model of care for adults, the Program of All-Inclusive Care for the Elderly (PACE), which provided flexible solutions while focusing on the individual and their families (A. Armstrong- Dailey, personal conversation, October 21, 2003). After extensive work by stakeholders and a modification to the PACE program, the Children's Hospice International (CHI) Program for All- Inclusive Care for Children and Their Families (PACC) was developed. This model of care provides an interdisciplinary

continuum of care for children and their families at the time of diagnosis of a life-threatening illness through the bereavement process.

Meanwhile, HCFA, later renamed as The Centers for Medicare and Medicaid (CMS) identified the “most burdensome obstacles to pediatric palliative care” as, (1) “requirements that limit hospice eligibility to children certified by a physician as being within six months of death”; (2) “regulatory limits on the array of services a child may need, including skilled, intermittent, and 24 hour nursing care, respite care, music and other therapies, designed to meet children’s developmental needs, and bereavement care”; (3) “payment limits that discourage hospices from accepting children who require expensive care”; (4) “waiver program provisions (e.g., requirements that a child needs an institutional level of care) that are not fitted to the needs of children who could benefit from hospice care”, and (5) early periodic screening, detection and treatment, “EPSDT programs that are inconsistent or too narrow” (Field & Behrman, 2003, p. 259).

In 1999, financial resources were appropriated by Congress through the Department of Health and Human Services for CHI PACC to conduct state demonstration projects that would support the creation of hospice type programs for children (CHI, 2002; Field & Behrman, 2003). These demonstration projects began in Florida, New York, Kentucky, Utah and Virginia, and later in Colorado. Many of the problems that states were facing when trying to provide pediatric palliative care were related to reimbursement and outdated health care regulatory issues (A. Armstrong-Dailey, personal conversation, October 21, 2003; Field & Behrman, 2003). Therefore, it was no surprise, when one of the major goals of these projects was to identify barriers associated

with regulations, such as Medicaid, and develop solutions (waivers for restrictive regulations) for the integration of palliative care for children. These projects were to be budget neutral, that is, programs were “not expected to increase their state’s Medicaid costs” (Field & Behrman, 2003).

Another item on the agenda for these projects was to increase the awareness of others, (e.g., health care professionals and policy makers) in hopes that they too would be catalysts to improve palliative care for children. Projects were also encouraged to utilize more community resources to reduce costly hospital stays by the children so that they could be kept in their home environment, where they would be most comfortable (Field & Behrman, 2003). Fortunately, funding for these projects has continued over the last few years as states continue to identify ways to improve pediatric palliative care through the use of data and systems. In 2004, CHI PACC named the New England region as a new participant of the demonstration projects.

Two common phrases in the 2003 IOM report were “research is limited” and “systematic data are not available.” This same report stated that the “knowledge base for organizational and policy decisions is likewise limited” and that “only a tiny fraction of research involving children is to support improvements in palliative, end-of-life and bereavement care for children and their families” (Field & Behrman, 2003 p. 350 -353). Based on the work done by the committee that created this IOM report, several “directions for future research” were recommended. One of those recommendations was specific to “financing pediatric palliative and end-of-life care” and discussed the importance of identifying reimbursement methods (Field & Behrman, 2003, p. 379).

Because this researcher was already working on national end-of-life education projects, and specifically a pediatric palliative care project, it seemed logical to further the research by conducting a dissertation study on this topic. Likewise, because outcomes of the CHI PACC demonstration projects are expected to provide data which will lead to modification of outdated health care policies, and because this links with the recommendations of the 2003 IOM report, the Longest Model of Public Policy Making was used as the framework for this study.

#### Statement of the Problem

Each year 54,000 infants and children die in the United States, and more than 80% of those deaths occur in the hospital (Feudtner, Christakis, Zimmerman, Muldoon, Neff & Koepsell, 2002; Field & Behrman, 2003; NHPCO, 2000; Solomon et al., 2002). Many of these children are suffering with pain and die in hospitals because it may be the only location (setting) where the services they need, both physical and psycho-social, will be reimbursed. Reimbursement for end-of-life care extends to nearly every setting and is systemic throughout the United States (Addig, 2002). Families of these children, in addition to the emotional pain of losing their child, may suffer financial burdens for many years. This is a result of health care regulations that were formulated and implemented for adults, and do not meet the needs of children.

According to the National Hospice and Palliative Care Organization (NHPCO) 5,000-7,000 children who have life-threatening illnesses are cared for by hospice providers each year. Yet, there are 20,000 more children who could benefit from the services of hospice, and about 8,600 children who could benefit from palliative care

services, and neither receives this care. The NHPCO estimates that more effective allocation of services which now cost \$630 million dollars, not new funding, could provide effective palliative care and end-of-life services for 57,000 children (NHPCO, 2000).

“Access to palliative care for insured children may be restricted by coverage limitations, payment methods and rules of the provider and administrative practices” which can affect communication between families and clinicians (Field & Behrman, 2003, p.12). Reduced payments to providers can impact the delivery of services for some children. Other children who need care may not even be accepted into facilities because the reimbursement payments for services are too low for the high cost of care and would jeopardize the financial status of the facility. Ironically, some “financing policies may promote excessive use of advanced medical technologies and inappropriate transitions between settings of care” while changes in insurance plans for families due to restructuring can also disrupt the continuity of care for their child (Field & Behrman, 2003, p.12).

Private health insurance plans or employment based insurance plans currently cover 66% of children while 20% are covered by Medicaid or other public programs, leaving 14% without any health insurance (Field & Behrman, 2003 p. 12). These diverse and inconsistent methods for payment of services for children’s health are neither cost effective nor efficient and contribute to problems associated with access and payment for care. Recognizing that policies need to change, the 2003 IOM report recommended that public and private insurers should restructure the hospice benefits for children to: (1)“add

hospice care to the services required by Congress in Medicaid and other public insurance programs for children, and to the services covered for children under private health plans; (2) eliminate eligibility restrictions related to life expectancy, substitute criteria based on child's diagnosis and severity of illness, and drop rules requiring children to forgo curative or life-prolonging care, and (3) include outlier payments for exceptionally costly hospice patients." An outlier system will help to decrease problems associated with access for care to children while at the same time help hospice programs by decreasing their financial burdens (Field & Behrman, 2003, p. 13).

#### Purpose of the Study

The purpose of this study was twofold: 1) to explore the barriers to pediatric palliative care programs and their relationships to funding, and 2) to better understand the experiences of the six CHI PACC directors who confront these obstacles.

#### Significance of the Study

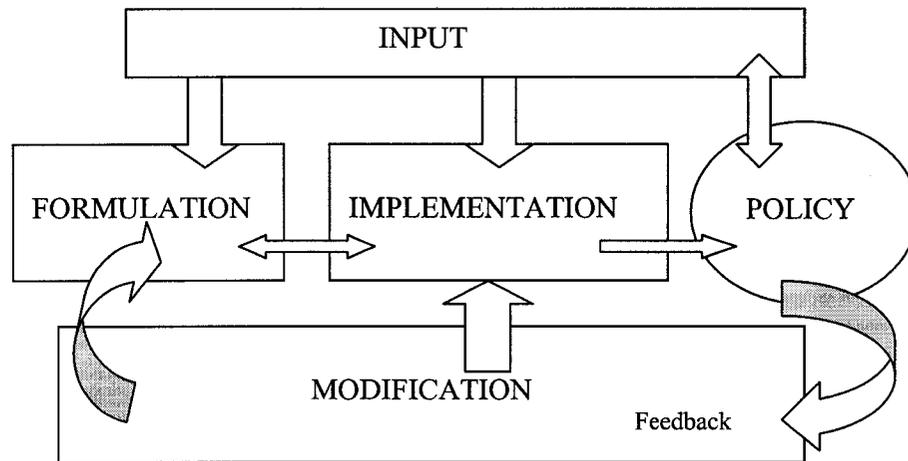
The issues in pediatric palliative care support the public's interest on health policies that specify how these services should be delivered and paid for. The significance of this study is that it is a response to the recommendations in the 2003 Institute of Medicine Report regarding further research on reimbursement issues, and will contribute to other research being conducted on this subject. The benefits of this study are that it will provide knowledge regarding the barriers to the delivery of pediatric palliative care services for those children and families who need it, and may ultimately lead to modification of current health care policies. This could then lead to the

improvement of quality care for children needing palliative care services and lessen the financial burdens of families.

### Theoretical Framework

The framework chosen for this study was the Longest Model of the Public Policymaking Process in the United States (Longest, 1998). It was chosen because it aligns with the goals of CHI PACC and the IOM recommendations "that public and private insurers should restructure hospice benefits for children" and "should modify policies restricting benefits for other palliative services related to a child's life-threatening medical condition" (Field & Behrman, 2003, p. 13).

Further, the IOM report specifically recommended that "federal and state Medicaid agencies, pediatric organizations, and private insurers should cooperate to examine the appropriateness of reimbursing pediatric palliative and end-of-life care ....that were developed for adult services" (Field & Behrman, 2003). This model is comprised of three phases: policy formulation, policy implementation and policy modification as in Figure 1.



*Figure 1.* Adaptation of the Model of the Public Policy Making Process in the United States (Source: Longest, B. 1998. Health Policymaking in the United States. Second Edition).

### Policy Formulation

The policy formulation phase involves agenda setting which is a confluence of three “streams” of activities: problems, possible solutions to the problem, and political circumstances. When all three of these “streams” flow together at the right time, a “window of opportunity” opens. This “window” allows the problem and its solution to either be formulated into a new law or amended into an existing law, or to advance to the next phase of the policymaking process, development of legislation (Longest, 1998, p.91). Policies have already been formulated for regulating reimbursement issues by Medicaid, Medicare, and some private health care plans, and are under scrutiny since their implementation is not meeting the needs of health consumers, specifically children

needing palliative care. In addition, access, cost and quality problems have arisen and a "window of opportunity" appears to be opening where further research on reimbursement issues can help to inform and influence this health policy agenda and help to modify health care policies.

#### Policy Implementation

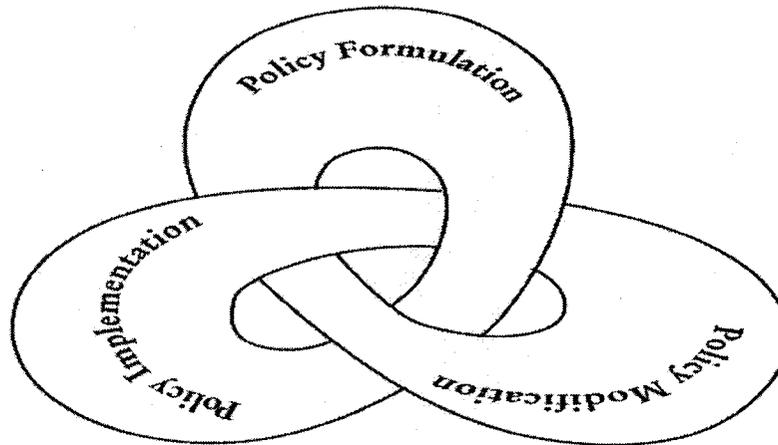
The implementation phase "includes rulemaking in support of implementation and the actual operations of the policy." It is in this phase that the clarity of the problem, and the language used to express the goals and objectives of the policy to be implemented, play a major role with the organizations that have the responsibility to implement the policies (Longest, 1998, p.166-167). It will take collaboration, cooperation and coordination among all stakeholders interested in the improvement of access to pediatric palliative care to implement the recommendations put forth by the IOM. For instance, CMS may need to define the difference in eligibility criteria related to diagnosis related groups (DRGs) and develop improved methods for billing and coding. This could hasten the services that children need, rather than prolong them, due to the increased awareness and new understanding of the required paperwork to ensure payment (Field & Behrman, 2003, p.14).

#### Policy Modification

Because "policymaking is not a perfect process," the modification phase of policymaking "involves the feedback of the consequences of policies and the actions these consequences stimulate" (Longest, 1998, p.239). This results in a "feedback loop" (See Figure 1) where the consequences of the existing policies feed back into the "agenda

setting” or formulation phase and also into the second phase, the implementation phase, where the rules and operations of the policy are stimulated for change (Longest, 1998, p.208). All phases of the Longest Policy Model are intertwined as displayed in Figure 2. The overlapping of each of the three phases, formulation, implementation and modification demonstrates that each are inextricably connected, and that it is an ongoing process with no definitive beginning or end.

The 2003 IOM Report recommended that “in addition to modifying hospice benefits, Medicaid and private insurers should modify policies restricting benefits for other palliative services related to a child’s life-threatening medical condition and that modifications should: (1) reimburse the time necessary for fully informing and counseling parents; (2) make the expertise of palliative care experts and hospice personnel more widely available by covering palliative care consultations; (3) reimburse bereavement services for parents and surviving siblings of children who die; (4) specify coverage and eligibility criteria for palliative inpatient, home health and professional services based on diagnosis to guide specialized case managers and others involved in administering the benefits, and (5) provide the Centers for Medicare and Medicaid Services to estimates of potential costs of implementing these modifications.



*Figure 2. The Intertwined Relationships Among Policy Formulation, Implementation and Modification (Source: Longest, B. 1998, *Health Policymaking in the United States*, 2<sup>nd</sup> ed.).*

It also recommended that The Centers for Medicare and Medicaid (CMS) develop estimates for the modification of Medicaid policies to include communication, counseling and bereavement care. CHI PACC demonstration projects are in the process of identifying the benefits and savings of the efficient use of such resources, along with many others, for pediatric palliative care. There are now two bills in process addressing pediatric palliative care. One is in the House of Representatives called the Pediatric Palliative Care Act (H.R. 3127) and one is in the Senate, The Children's Compassionate Care Act (S.1629). Both of these will be discussed in more detail in Chapter 7.

### Phase I Research Question

The quantitative portion of this study, Phase I, was conducted to address the following question: Does the reimbursement of services for pediatric palliative care differ between the types of funding, and is funding related to directors' perceptions of obstacles to the delivery of care?

### Phase I Research Objectives

The following research objectives used to help guide the quantitative study were:

1. To describe staff barriers as reported by pediatric palliative care program directors.
2. To describe perceived obstacles as reported by pediatric palliative care program directors.
3. To describe the frequencies of the reimbursement of services for pediatric palliative care provided for children by the location of care (inpatient/outpatient/ home).
4. To describe the relationship between staff barrier scores and perceived obstacles to the delivery of pediatric palliative care services, leading to the following questions.
  - a) Is there a relationship between staff education and training barriers and the perceived obstacles to the delivery of pediatric palliative care services? and
  - b) Is there a relationship between the lack of standardized competencies and perceived obstacles to the delivery of pediatric palliative care services?
5. To describe the relationship between funding and obstacles, leading to the following questions:
  - a) Is there a relationship between the percentages of funding from private insurance that directors estimate and their perceived obstacles in pediatric palliative care?

- b) Is there a relationship between the percentages of funding from Medicaid/Medicare that directors estimate and their perceived obstacles in pediatric palliative care?
- c) Is there a relationship between the percentages of funding from private donations that directors estimate and their perceived obstacles in pediatric palliative care?

#### Phase II Research Question

The qualitative portion of this study, Phase II, was conducted to address the following question: What are the barriers that CHI PACC directors experience in their roles and how do they overcome them? This study included individual interviews with six CHI PACC directors of federally funded demonstration programs.

#### Phase II Research Objectives

The objectives for this phase of the study were:

1. To identify barriers that directors experienced when working with pediatric palliative care programs.
2. To identify specific areas of work which gave the directors a sense of well being about the work they were doing.
3. To identify the qualities perceived by directors in the CHI PACC programs that are needed to overcome barriers.

The following three questions were asked to the six directors:

1. Would you tell me, in your own words, about a specific time when you were able to overcome some barrier to pediatric palliative care services?

2. Can you share a story, in your own words, about a particular time you felt good about the work you are doing to make a difference in the provision of pediatric palliative care services, and
3. Can you describe in your own words, the qualities you think it takes for someone like yourself, to overcome barriers in order to provide pediatric palliative care services?

### Summary

This chapter identified the problem that children are dying and not receiving palliative care. It highlighted the CHI PACC demonstration projects and how they are addressing barriers for the delivery of this care. It also discussed recommendations in the 2003 Institute of Medicine Report about the financial barriers for pediatric palliative care and the need for changes to outdated healthcare policies. In addition, the Longest Model for Public Policy Making was introduced as the framework for this study as many of the problems associated with pediatric palliative care are related to funding based on health care policies. This study addressed questions that will improve our understanding of the need for changing these policies and improve pediatric palliative care for children.

## Chapter 2

### Review of Literature

This chapter consists of a review of the literature and includes how the literature search was conducted, key words and databases utilized, along with identification of relevant studies and resources.

Although the researcher knew from work related experiences that there were indeed barriers to pediatric palliative care, an initial review of the literature was done for documented verification and to provide specific examples. A literature search was conducted by accessing the George Mason University library system. The search was initiated with the CINAHL database using the following key words in the search: palliative care, pediatric palliative care, barriers to pediatric palliative care, funding issues, and palliative care. Results of the search for “pediatric palliative care” were 27 journals and three articles for “funding issues and palliative care.” Other national databases and websites were explored and included the National Library of Medicine (NLM).

A search was done in the NLM to the key words “pediatric palliative care” to which it produced 249 journal citations, 10 books/serial items, 873 consumer health related items, eight meeting abstracts and three “other” collections articles. Many of the

citations addressed cancer care, pain and symptom management, use of opioids in children and decision-making. Most of these articles were opinions and descriptions rather than research.

### Financial Barriers

There are large gaps in the literature related to finance and palliative care issues for children. This is partly due to the unavailability of data for these type of services and also because funding sources which reimburse for these services come from multiple payers. According to Field and Behrman (2003), these funding sources include “thousands of private insurers, and a multitude of state Medicaid and other public programs” such as the State Children’s Health Insurance Plans (SCHIP), “that have differing eligibility and coverage policies” (p.235). Other sources of funding may come from Title V of the Social Security Act, federal programs administered by the Maternal and Child Health Bureau which cover children with special needs, private donations from philanthropic organizations within the community, “safety-net providers” and even from the family’s out-of-pocket payments.

Current information on these policies are often not available because of “constant changes to them, poor documentation and unreliable survey data” (Field & Behrman, 2003, p.235). Variations in the amount of reimbursements are dependent on the funding source since many payers have adopted the Medicare reimbursement scale (H.Huskamp, personal communication, November 6, 2003).

There have been extensive discussions in the literature, although little empirical evidence on reimbursement issues in pediatric palliative care.

According to results in the 1998 CHI Report: *Hospice Care for Children*, reimbursement and education were the two main issues identified by directors of pediatric palliative care programs as being necessary to provide quality care for children, even though there is no financial or empirical evidence available (CHI Report, 1998).

The 2003 IOM report: *When Children Die: Improving Palliative and End-of-Life Care for Children and Families*, identified recommendations to not only modify hospice benefits, but also to modify the policies of Medicaid and private insurers which restrict benefits for pediatric palliative care services. Unfortunately, some of these plans adhere to the same regulations as Medicare, which means that children have to be “certified to have a six month or less life expectancy to receive those benefits and must forgo curative or life-prolonging care” (Field & Behrman, 2003, p.12 ). In addition, it recommended that the National Center for Health Statistics, the National Institutes of Health and other relevant public and private organizations, including philanthropic ones, should collaborate to improve the collection of descriptive data, and specifically financial data, to guide the provision, funding and evaluation of palliative, end-of-life and bereavement care for children and families (Field & Behrman, 2003). Most Medicaid and most private health care plans cover hospice care.

It is becoming more evident that reimbursement for health care drives the service it pays for. Stephenson (2000) identified the lack of reimbursement for services as the greatest obstacle to the provision of pediatric palliative care along with federal regulations for Medicare benefits which do not fit the needs of children; the limited

availability of pediatric palliative care services; and the lack of physician training in this field.

It is no surprise that services for children who are facing life-threatening illnesses are subjected to the obstacles related to reimbursement. The American Academy of Pediatrics (AAP) addressed the financial barriers to pediatric palliative care in their 2000 guidelines for children with life-threatening and terminal conditions, and stated that changes needed to be made in the regulation and reimbursement of palliative care services (Stephenson, 2000). Marcia Levetown, a physician advocate who was instrumental in getting the AAP guidelines for palliative care developed, identifies the key barriers in pediatric palliative care as: educational, policy and funding related. Her solutions are increased advocacy and increased research (Levetown, 2003).

#### Access Barriers

Access to data is a major barrier and confidentiality issues often prohibit access to reports that would otherwise provide insight for making improvements in palliative care, especially for funding and policy. There is a need to create new interventions and master databases that will provide assistance to those working with pediatric palliative care issues. According to the End-of-Life Nursing Education Consortium's (ELNEC) Pediatric Palliative Care curriculum, the National Hospice and Palliative Care Organization has defined barriers to pediatric palliative care to include financial, educational and regulatory barriers. However, they also included a psychological barrier due to the discomfort that families face as they are forced to make options for care,

versus cure, and its association with “giving up” (AACN, 2003). This goes beyond simple policy driven reimbursement issues. The authors of the 1997 IOM Report, Field and Cassell, broke new ground when they advocated for insurance to help increase access to care. They reported that financing mechanisms, such as insurance programs can increase access to care, yet also “may encourage use of services of little value, thus raising costs without comparably increasing value.”

According to Solomon and colleagues (2002), empirical evidence is growing to support the fact that health care systems are failing children and families when they are confronted by a life-threatening illness thus causing both emotional and financial consequences. Foley and Gelband, editors of the 2001 IOM Report, *Improving Palliative Care for Cancer*, identified that people were not receiving palliative care when and where they needed it because of barriers with both health care and medical research systems. These barriers included: divisions between hospice and palliative care which impacted reimbursement; inadequate training of health care personnel; inadequate standards of care; disparities of care; lack of resources for the public; lack of reliable data on quality of life; and limited investments in palliative care research by the public sector.

The policies that dictate payment for palliative and hospice care services are outdated and need revised. Ira Byock, a physician leader in pediatric palliative care literature, reported that according to a former president of the American Academy of Hospice and Palliative Medicine, “Medicaid reimbursement structures for Hospice were developed in the mid-1980’s and have not been modified since” (Byock, 1997, p.243). The limitations of funding resources for those who are dying are a result of health care

policies that are inefficient. These sources may be solely or a combination of public and private funds. Public funds include Medicaid, Medicare and State Children's Health Insurance Plans (SCHIPS), which can designate waivers. Private funds are from multiple employer sponsored insurance companies. Another funding source is from philanthropic organizations which provide financial resources that are often used to cover those services that are not reimbursed by either the public or private funds.

Ann Armstrong-Dailey, Founding Director of CHI, advocates for flexible models of care set on standards and principles as programs vary from state to state (and funding sources vary as well). According to Dailey, 30% of children qualify for Medicaid reimbursement dollars if the child and family are followed through the whole continuum of care (personal communication, October 21, 2003).

Numerous other research studies have documented major inadequacies in the care that patients along with their families are receiving. Typically, the following list often cites the concerns of: patients, including children, experiencing too much pain and discomfort, a lack of continuity of care, patients' and families' wishes being ignored, and the devastating financial impact on the families (Field & Behrman, 2003).

#### Communication Barriers

Effective communication between patient and physician needs improvement. Foley (2000) challenged colleagues with her commentary in the *Journal of the American Medical Association* to "dismantle the barriers" that prevent physicians from providing palliative and pain care. She listed barriers such as attitudinal, behavioral, educational and institutional ones as causing problems for physicians being able to provide

compassionate care. (Note: Foley's use of the word "barriers" is more applicable to the word "obstacles" as defined in this study. She suggested that in order to reduce these barriers [obstacles], there needed to be an emphasis on palliative care education in medical schools and noted that role modeling could help improve palliative care as well). This gap in communication between physician and patient, whether a child or an adult, further indicated the importance of the physician's knowing, understanding and respectfulness for the preferences of the family when dealing with end-of-life care issues. Caring for the whole person and being family focused is not a new concept.

Matzo and Sherman (2001) discussed pioneers in palliative care such as Cicely Saunders, Florence Wald, and Jeanne Quint Beneliel, and how each of them emphasized care should be provided in a way that embodies compassion, respect for dignity and an appreciation for the whole person and his or her family. End-of-life education and training programs are making these same concepts a key thread that weaves its way through the palliative care curricula.

Health care professionals need to use resounding united voices to inform the public of the needs for palliative care. Lynn, Schuster and Kabcenell (2001), suggest the following to change the current situation on end-of-life: 1) "advocate for regional and federal health care report cards that include end-of-life issues; 2) push for laws that address genuine choice at the end-of-life, rather than the appearance of choice; 3) expand the content of advance directives; 4) fund public forums, newsletters, and hearings about end-of-life issues; 5) work with state end-of-life commissions. and 6) talk to the media

about improvement efforts under way or problems in end-of-life care in the community” (p.193-194).

Another educational effort to bridge the knowledge gap with pediatric palliative care is the Initiative for Pediatric Palliative Care (IPPC). This project began in 1998 by the Education Development Center (EDC) leading a consortium comprised of seven major children’s hospitals, the New York Academy of Medicine, the National Association of Children’s Hospitals, the Society of Pediatric Nurses and the Association of Medical School Pediatric Department Chairs. IPPC recently conducted their first national symposium in New York this past November where it highlighted one of its videos used for teaching purposes. IPPC has also produced a comprehensive curriculum, a video series, and activities for research and quality improvement tools in hopes to improve pediatric palliative care (Solomon et al., 2002).

#### Educational Barriers

In response to the gaps in education on palliative care issues the RWJF funded the EDC to form a National Task Force on End-of-Life Care in Managed Care. This task force was comprised of an interdisciplinary team of medical directors, nurses and physicians from managed care organizations, experts in palliative care, ethics and quality improvement. The task force’s vision was: all persons should receive humane and effective end-of-life care. This task force developed twelve recommendations proposed to managed care leaders, health care policy makers and consumers of managed care services on how to improve end-of-life care. These recommendations were divided into

three main categories: 1) improve access to comprehensive, high quality care near the end of life, 2) strengthen accountability to determine whether such care is being delivered, and 3) develop and evaluate payment methods to ensure that financial incentives are aligned with the provision of humane and effective care.

In 1997, the IOM called for the nation to address EOL care and special task forces were created throughout the country. Efforts to improve the skills of health care professionals and the way they deliver care to persons, of all ages, in the final stage of life began to evolve from multiple professional medical and nursing societies including: the American Association of Colleges of Nursing, the American College of Physicians, the Board of Internal Medicine, the American Medical Association, the Oncology Nursing Society, the American Nursing Association and the American Pain Society (Solomon, 2000).

Private foundations also played a key role in overcoming the educational barriers of health care professionals. For instance, the Robert Wood Johnson Foundation alone funded \$29 million for the 1995 Study to Understand Prognoses and Preferences For Outcomes and Risks of Treatment (SUPPORT). This was a study of seriously ill hospitalized patients with a focus on end-of-life care issues. The findings demonstrated the lack of communication between physicians and their patients about end-of-life care (Foley & Gelband, 2001; Matzo & Sherman, 2001, p. 185-186). In addition, the RWJF funds the End-of-Life Nursing Education Consortium (ELNEC), a three year training program, administered by the American Association of Colleges of Nursing and the City of Hope, to train registered nurses on how to improve the quality of end-of-life care for

adults, and has recently also provided funding for a pediatric palliative care version of this training because of the outcry from pediatric specialists.

According to Joanne Wolfe, Medical Director of the Pediatric Advance Care Team at Dana-Farber Cancer Institute and Children's Hospital in Boston, MA, there are many needs children with life threatening illnesses and their families face. Too many of these children undergo painful procedures and suffer from the symptoms of advancing disease without adequate pain relief, despite the fact that modern medicine has the means to relieve their pain and improve most symptoms. This lack of education is not unknown. Sahler, Frager, Levetown, Cohn, and Lipson (2000) also recognized training for physicians and nurses includes virtually no opportunities to practice the skills necessary for communicating effectively with dying children and their families.

Demographic changes in the United States offer new challenges as well. Cassidy and Fleischman (1996) reported that practicing health care professionals lack guidance on how best to manage the conflicting goals and values that can arise in difficult cases, and that these types of conflicts are made all the more challenging by the broad cultural and religious diversity represented in the U.S. population. Cultural diversity training has become a standard educational offering in many U.S. hospitals and can be a contributing factor to the improvement of end-of-life care.

#### Research Barriers

Because pediatric palliative care is a fairly new and growing discipline, there is a paucity of empirical evidence to support or refute the delivery of these services. At the

November 2003 IPPC National Symposium in New York, Wolfe reiterated the need for research on pediatric palliative care issues and identified barriers which deterred it from happening. These barriers included: the small numbers of children dying and the diversity of the children's illnesses; geographic diversity; the lack of developmentally appropriate assessment tools and regulatory barriers. Wolfe's solutions to these barriers were that concurrent descriptive, qualitative, quantitative, and intervention studies needed to be done across and within patient populations along with multiple central trials. She informed the audience of health care professionals that they needed to overcome all forms of communication barriers such as avoidance, anxiety, and depression to better control symptoms of their patients and thus improve pediatric palliative care (personal communication, November 6, 2003). (Note. It is my understanding that by Dr. Wolfe used the word "barriers" here as a general term and that it could be interchanged with the word "obstacles" in the context described).

#### Summary

This chapter provided a review of the literature. It was clear that there is a paucity of research based articles related to funding sources and their lack of reimbursement for services. Many of the articles found in the literature review were responses to the 2003 Institute of Medicine Report, *When Children Die: Improving Palliative Care for Children and Their Families* and were opinions and descriptive writings calling for action by health care professionals to improve palliative care, rather than actual research. Numerous other research studies have documented major inadequacies in the care that patients along with their families are receiving, but none

were retrieved during my literature search that addressed reimbursement issues, other than the unpublished CHI Report: Hospice Care for Children (1998). Therefore, this study examined areas that have been recommended by leaders in the pediatric palliative care field, but have not been tested to date.

## Chapter 3

### Methodology

#### Introduction

This chapter addresses the methodology used for this study. It includes: the research design, protection of human subjects, procedures for sampling, data collection and data analysis for Phase I, the quantitative part of this study. Phase II, the qualitative part of the study, will be addressed in Chapter 5.

#### Research Design

This study was a “sequential mixed methods” design which utilized both quantitative techniques and a qualitative, phenomenological approach in two separate phases (Creswell, 2003). According to Tashakkori and Teddlie (1998), “a mixed methods study is one which combines qualitative and quantitative approaches into the methodology of a single study or multi-phased study” (p. 41). Mixed method designs use “triangulation techniques” which originated with Campbell and Fiske in 1959.

Triangulation refers to a process in which two points are used to determine the unknown distance to a third point, and in the research world it involves combining data sources to study the same phenomenon (Tashakkori & Teddlie, 1998, p.41). These techniques were later described into four types of triangulation by Denzin in 1978. Denzin’s four types of

triangulation were data, investigator, theory and methodological triangulation (Tashakorri & Teddlie, 1998). For the purposes of this study, methodological triangulation was used. In 1995, Creswell further defined mixed methods into four designs which included the following: sequential studies (or two-phase studies), parallel or simultaneous studies, equivalent status designs and dominant-less dominant studies. According to Creswell, a sequential mixed methods design is when the researcher conducts one study, in this case, quantitative, followed by a qualitative study, or vice versa, in two separate phases (Tashakorri & Teddlie 1998; Creswell, 2003). For this research, Phase I was the quantitative part and Phase II was the qualitative part of the study. Both phases were given equal status.

Phase I, the quantitative component, was a non-experimental, descriptive study which identified frequencies and proportions of programs that acknowledged reimbursement barriers and their relationships to funding sources, and their overall ratings of barriers to deliver pediatric palliative care. Phase II was an interpretive, phenomenological study which was conducted after the quantitative phase, but prior to any data analysis. The purpose of this interpretive study was to better understand the barriers associated with pediatric palliative programs as seen from the experiences of the six directors of the Children's Hospice International Program for All-Inclusive Care for Children and Their Families (CHI PACC) demonstration programs, located within the United States.

## Phase I: Quantitative Study

### Protection of Human Subjects

This study was submitted to the George Mason University's Human Subjects Review Board (GMUHSRB) prior to any data collection. It was reviewed by the Director of the Office of Sponsored Programs, who determined that based on the GMU human subjects policy, the GMU Human Subjects Review Board did not need to review it, and no further action on the part of the investigator was needed to comply with the human subjects' policy (Appendix A). All participants who agreed to be part of this quantitative study were provided a cover letter and a consent form which included information on the following: the purpose and procedures for the research, any potential benefits and risks associated with the study, confidentiality issues, voluntary participation, and contact names and numbers (Appendix B). The completion and return of the instrument (survey) by the participant, was recognized as consent for their participation

### Research Question:

The following research question served to generate objectives for this study: Does the reimbursement of services for pediatric palliative care differ between the types of funding, and is funding related to directors' perceptions of obstacles to the delivery of care?

Research Objectives:

1. To describe staff barriers as reported by pediatric palliative care program directors.
2. To describe perceived obstacles as reported by pediatric palliative care program directors.
3. To describe the frequencies of the reimbursement of services for pediatric palliative care provided for children by the location of care (inpatient/outpatient/ home).
4. To describe the relationship between staff barrier scores and perceived obstacles to the delivery of pediatric palliative care services, leading to the following questions
  - a) Is there a relationship between staff education and training barriers and the perceived obstacles to the delivery of pediatric palliative care services?
  - b). Is there a relationship between the lack of standardized competencies and perceived obstacles to the delivery of pediatric palliative care services?
5. To describe the relationship between funding and obstacles leading to the following questions:
  - a) Is there a relationship between the percentages of funding from private insurance that directors estimate and their perceived obstacles in pediatric palliative care?
  - b) Is there a relationship between the percentages of funding from Medicaid/Medicare that directors estimate and their perceived obstacles in pediatric palliative care?
  - c) Is there a relationship between the percentages of funding from private donations that directors estimate and their perceived obstacles in pediatric palliative care?

## Procedures for Sampling, Data Collection and Data Analysis

### Sample

A convenience sample was used to survey a target population of 160 health professionals, or identified contacts, who were in the role of administrators/directors/coordinators of pediatric palliative care programs in a health care facility in the United States. This list was generated from known lists that were the best inclusive directories of programs and their associated directors. This final list was a combination of two master lists. One list was comprised of one hundred and forty-three (143) names of pediatric palliative care administrators, directors, coordinators and was provided by Dr. Veronica Feeg, collected over several years of work with Children's Hospice International in 1999. The other list of seventeen (17) pediatric nurse experts, members of the Pediatric End-of-Life Nursing Education Consortium (ELNEC) National Advisory Board, was provided by the investigator.

### Instrument

After obtaining permission from the Children's Hospice International (CHI), a self-report questionnaire was developed by this researcher by modifying the 1999 CHI Survey instrument (Appendix C). The original survey was developed in 1984 by Barbara McCann and marked the beginning of the annual CHI survey (Stewart & Feeg, 1999). Over the past 20 years the Children's Hospice International (CHI) organization has conducted nine surveys on a national and international level. The purpose of those surveys, routinely sent to a compilation of related hospice and children's hospital programs, were to identify who and where programs were located, and what services they

provided. Response rates to these surveys have been low. For instance, in 2004, CHI mailed 3000 surveys to a list that included: the National Association of Children and Hospital Related Institutions (NACHRI), the National Home Care Associations (NHCO,) and the National Hospice and Palliative Care organization (NHPCO). There were 191 responses returned from this survey, or 6%. Another CHI survey that was conducted in 1998 which had a mailing of approximately 6000 surveys had a response rate of 4%. According to Anne Armstrong-Dailey, the Executive Director of CHI, this is due to the fact that members listed in their database are interested individuals and advocates for promoting pediatric issues and not necessarily directors of programs. Although the response rates are low, the findings provide important information indicating the need for future research on barriers, which influence the provision of pediatric palliative care services (A. Dailey, personal communication, April 6, 2004).

The modified questionnaire for this study, unlike the original survey which focused on an international audience, addressed respondents in the United States only. This researcher added six new items to the original questionnaire to modify it to include items which focused on barriers as related to staff. These items were a result of multiple discussions with pediatric palliative colleagues at conferences. These colleagues believed that some barriers in relation to education and financing of pediatric palliative care could be reduced or eliminated, if staff were more informed about these issues. For instance, were staff aware of the differences in services that insurance, Medicaid and private donates could reimburse? Were staff aware of community and foundation funds that could be used to finance pediatric palliative care services when insurance and

Medicaid would not cover them? Six items were added to specifically address these issues and were referred to as “Staff Barriers” because they could hinder the delivery of pediatric palliative care services (See Staff Barriers on the next page).

The modified survey specifically excluded an item related to international funding. Other areas from the original instrument that were deleted were questions related to (a) the types of criteria required for admission to the palliative care program, (b) the frequencies of diagnoses, (c) the use of volunteers, (d) the types of education provided, and (e) the types of education needed (CHI, 1998). In addition, the population that this study focused on was specific to known pediatric palliative care programs only, unlike the original version of the instrument which included known programs, affiliating hospitals and health care institutions and community agencies.

The modified questionnaire for this study is comprised of six sections, namely: a Staff Barrier Scale, an Obstacle Scale, a Services Scale I (Inpatient), a Services Scale II (Outpatient) and a Services Scale III (Home). The sixth section was a question which asked respondents for percentages as related to coverage of pediatric palliative services. (Note. Although the term “barrier” is used in this study to denote overall problems that may affect care, the questionnaire is specific about how “barriers” and “obstacles” is used).

### Variables

There were six general variables in Phase I of this study and included (a) the location of care, (b) the funding sources, (c) the services, (d) staff barriers, (e) perceived obstacles, and (f) the percentages of reimbursement of pediatric palliative care services.

### Location of Care

The location of care, or “settings” as referenced in the IOM report, was defined as the place where pediatric palliative care services were delivered: a) inpatient, b) outpatient or c) home. Respondents were asked to check off all sources of funding for services on three scales that represented the three locations.

### Funding Sources

Funding sources were defined as the method of payment for the reimbursement of the delivery of pediatric palliative care services and included three payment methods, a) insurance, b) Medicaid/Medicare, and c) private donations. Respondents were asked to check off all types of funding used to reimburse for the 13 services in their programs.

### Services

For the purpose of this study, “services” were defined as 13 different types of care, later categorized into two cluster groups, physical (PH) and psycho-social (PS) for ease of statistical reporting. The types of services in the physical (PH) category were seven of the 13 and included (a) diagnostic procedures, (b) equipment, (c) IV therapy, (d) medication, (e) nursing care, (f) occupational and speech therapy, and (g) physical therapy. The psycho-social (PS) category had six of the 13 services and included (a) child life specialist, (b) counseling by physician, (c) counseling by non-physician, (d) palliative care team consults, (e) grief/bereavement support, and (f) complimentary/alternative therapy.

### Staff Barriers

Staff barriers were defined in this study to indicate specific staff issues of the programs that hinder the delivery of pediatric palliative care services. These items were new and added to the modified original questionnaire by the researcher, based on discussions with colleagues at conferences. The staff barrier scale included six items and were coded as SB. The staff barriers ranged from SB1-SB6 according to each of the six barrier item statements. For instance, the statement for the first staff barrier was “staff is not familiar with different types of services covered by insurance plans, Medicaid or private donations” and was coded as SB1. Respondents were asked to place a check mark in the appropriate column that identified the ranking of barriers for staff in the delivery of palliative care services. Below is a list of the six items on this scale along with an explanation for each item.

- SBS 1: Staff is not familiar with different types of services covered by insurance plans, Medicaid or private donations. This item was asked to determine if staff knowledge about the different types of funding for services served as a barrier for children receiving palliative care services.
- SBS 2: Staff is not aggressive in trying to access coverage for services not provided by insurance plans, Medicaid or private donations. This question was asked to determine whether or not staffs were aggressive in finding other sources of funding if the normal channels for payment were not available.

- SBS 3: Staff is unaware of foundation funds available within the organization for palliative care. This question was asked to determine whether or not staff knew that often foundation funds will provide funding for special requests when sought.
- SBS 4: Staff is unaware of community funds that may be accessible for palliative care. Like the previous question, this also was asked to determine whether or not staff was aware that often there are multiple agencies within a community that will come to the aid of a family or organization to provide needed services, especially for children.
- SBS 5: Staff is not educated or trained on how to provide palliative care for pediatric patients. This question was asked to determine whether or not education and training played a role in being a barrier to providing palliative care services for children, since hospice programs most often focus on the adult population.
- SBS 6: Lack of standardized competencies for staff to provide palliative care. This question was asked to identify whether or not the lack of standardized competencies impeded the delivery of pediatric palliative care services.

The directors were asked to respond about their own programs staff barriers using a scale "not applicable," (0), "not a barrier," (1), "somewhat of a barrier" (2) and "severe barrier" (3). The items were summed for testing assumptions of the measure of "staff barriers" as a total. The lowest to highest rating could range from 0 -18 (Appendix D).

#### Perceived Obstacle Scale

This was a ten (10) item scale designed to measure the scores of perceived obstacles that interfere with the delivery of pediatric palliative care services. These

questions were related to issues that impacted the family, the physician or the institutions, whereas the staff barrier scale focused on issues related to staff. Also, as with the Staff Barrier Scale, a coding system was used for reference purposes and the items on the obstacle scale were coded as OBS and ranged from OBS1 –OBS 10. Below is a list of each of the obstacles:

- OBS 1: Absence of an advance directive for the child.
- OBS 2: Lack of family making the child's care preference known to others.
- OBS 3: Lack of clarity by staff regarding the child/family's preferences for care.
- OBS 4: Lack of physician's familiarity with the availability or suitability of palliative care.
- OBS 5: Physician's reluctance to make a referral for palliative care.
- OBS 6: Family's reluctance to accept palliative care.
- OBS 7: Association of hospice or palliative care with death.
- OBS 8: Perception by family that palliative care means health providers are giving up hope.
- OBS 9: Lack of understanding by the family of the severity and/or irreversibility of their child's illness.
- OBS 10: Lack of institutional support or providing palliative care.

Respondents used a rating scale of zero to four and selected from the list of obstacles the degree to which the obstacle posed interference in the delivery of palliative care services. The rating scale ranged from 0 to 4 using the following scale: 0 = not

applicable, 1 = is not an obstacle, 2 = somewhat of an obstacle, 3 = moderately interferes and 4 = is a severe obstacle to services (Appendix E). The obstacles scale score was calculated by summing the numbers for all non-missing data. These data are ordinal by design, but have been reported in the literature, as well as in the original scale score in the CHI reports, and treated as interval.

#### Percentages of Reimbursement of Pediatric Palliative Care Services

This was a three item scale which asked respondents to estimate the percentages of services for children covered by reimbursement for private insurance, Medicaid, and private donations to total 100%. This item was replicated from the original survey and limited only to the U.S. format (CHI Survey: Hospice Care for Children, 1998).

### Operational Definitions of Terms

#### Medicaid

This was defined as a program jointly funded by the states and the federal government that provides medical aid for people who are unable to pay their own medical expenses. The variable for Medicaid is defined as the percentage of care estimated by the respondent, of care that is covered by Medicaid.

#### Pediatric Palliative Care

This was defined as the active total care of pediatric patients whose disease is not responsive to curative treatment.

### Private Donation

This was defined as those funds provided by philanthropic organizations or by private individuals to be used as needed to deliver pediatric palliative care services. The variable for private donations is defined as the percentage estimated by respondents that care is covered by private donations.

### Private Insurance

This was defined as insurance plans, frequently employer sponsored and partially or totally paid for by an individual for him/herself and their family. The variable for private insurance funding is defined as the percentage estimated by respondents that care is covered by private insurance.

### Reimbursement

This was defined as to financially pay back to the organization the costs associated with the delivery of different pediatric palliative care services.

### Services Scale I – Inpatient

This was a thirteen (13) item scale designed to measure services delivered for pediatric palliative *inpatient care* which were reimbursed by insurance plans, Medicaid/Medicare and private donations. Respondents were asked to place a check mark in the appropriate column representing insurance plans, Medicaid/Medicare, or private donations, for which these services were reimbursed. Nominal measurement codes were assigned as 0 = no check mark and 1 = check mark. More than one of the options may have been checked because more than one of the funding sources could be used to cover reimbursement of the services as an inpatient. Frequencies and percentages were calculated using the SPSS

software system. Reported in the data were the number of programs (respondents) who selected if that service was paid for by insurance, Medicaid or private donations for inpatient services.

#### Services Scale II- Outpatient

This thirteen (13) item scale was designed to measure services delivered for pediatric palliative *outpatient* care which reimbursed by insurance, Medicaid/Medicare and/or private donations. Respondents were asked to place a check mark in the appropriate column representing insurance plans, Medicaid/Medicare, or private donations, for which these services are reimbursed. Nominal measurement codes were assigned as 0 = no check mark and 1 = check mark. More than one of the options may have been checked because more than one of the funding sources could be used to cover reimbursement of the services as an inpatient. Frequencies and percentages were calculated using the SPSS software system (Appendix G). Reported in the data were the number of programs (respondents) who selected if that service was paid for by insurance, Medicaid or private donations for outpatient services.

#### Services Scale III - Home

A replication of the previous scale, this thirteen (13) item scale was designed to measure services delivered for pediatric palliative *home* care which is reimbursed by insurance, Medicaid/ Medicare, and/or private donations. Respondents were asked to place a check mark in the appropriate column representing insurance plans, Medicare/Medicaid or private donations. The same nominal measurement codes were assigned, 0 = no check and 1 =check. Frequencies and percentages were calculated using the SPSS software

system (Appendix H). Reported in the data were the number of programs (respondents) who selected if that service was paid for by insurance, Medicaid or private donations for home services.

#### Reliability and Validity of the Instrument

The original instrument, which was modified for this study, had a reliability coefficient alpha (Cronbach's alpha) of  $r = 0.87$  for the obstacles scale. The reliability measure of the modified instrument for this sample will be addressed in Chapter 4. Pre-testing of the instrument to determine content validity was done by five palliative care nurse experts and one nursing doctoral candidate who also worked on end of life issues. All of these experts were contacted by phone or e-mail to determine their availability and willingness to participate. Five of these experts were selected from a group of twenty (20) nurse experts who were part of a national pediatric end-of-life advisory board and who are active in other national efforts to promote quality pediatric palliative care. The sixth nurse expert was a nursing doctoral candidate at George Mason University, at the time of this study, who was doing dissertation work on end of life care. Upon agreement to participate, each of the nurse experts was sent an invitational cover letter (Appendix I), a copy of the instrument and the Evaluation Form for Testing the Content Validity (Appendix J).

The Evaluation Form for Testing the Content Validity was a checklist comprised of the following ten questions. Are the questions clear and easy to understand? Are the questions an appropriate length? Are the questions in an appropriate order? Are the questions comprehensive? Is the number of questions sufficient? Are the questions

relevant to reimbursement issues? Are the questions relevant to pediatric palliative care?  
Are the questions relevant to the purpose of the study? Do any questions reflect a bias?  
Is the survey an appropriate length?

The experts were asked to answer each of the above questions by checking a column designated for a response as “yes” or “no” and “comments”. The expert reviewers returned the form to the investigator with their comments. The instrument was reevaluated based on their feedback and changes were made to the instrument as appropriate.

The revised instrument was then sent to these same experts for a second review and any additional feedback. All six experts, or 100%, validated the questions to be: clear, easy to understand, of an appropriate length, in an appropriate order, comprehensive, sufficient, related to reimbursement issues, related to pediatric palliative care issues, relevant to the purpose of the study, and non-biased. One hundred percent of the experts also reported that the survey itself was an appropriate length. Some comments from these experts about the revised instrument were: it “was much more user friendly,” “greatly improved,” “looks great,” “no further comments.” and “nice job.” A follow up thank you electronic message was sent to each of the expert reviewers within three days of receiving their evaluation form.

#### Data Collection

A cover letter (Appendix K), along with a copy of the questionnaire and postage paid return envelope was mailed via the United States postal service, to the target population of one hundred and sixty (160) identified administrators, directors, or

coordinators of palliative care programs from the list generated for this study. The cover letter informed the administrator director/coordinator that he/she had been identified by a professional colleague as one who might be interested in completing a brief, five-to- ten minute survey associated with pediatric palliative care, answering questions that were aimed at the program, not the director.

The letter went on to explain that the purpose of the non-experimental, descriptive and correlational survey was to identify frequencies and proportions of programs that acknowledged reimbursement barriers, their funding sources and their overall ratings of barriers to deliver pediatric palliative care. The letter identified Maureen McLaughlin as the principal investigator, under the direction of Dr. Veronica Feeg, along with their telephone numbers and electronic addresses where they could be reached, should they have any questions about the study. In addition, the letter informed the respondents that there were no costs, nor risks associated with the study, and that they were free to stop their participation without any penalty. The letter included that the benefits to the respondent for participating in this study were that they would be contributing to the knowledge regarding the barriers to the delivery of pediatric palliative care, which may ultimately help to change and improve health care policy for children in the future.

A statement that the study had been reviewed according to George Mason University procedures governing participation in this research was included along with the sentence "You may contact the GMU Office of Sponsored Programs at 703-993-2295 if you have any questions or comments regarding your rights as a participant in this research." The respondents were asked in the letter whether or not they would like to

receive a copy of the summary of the results of the survey and if so to contact the investigator. The respondents were asked to return the completed survey in an enclosed postage paid envelope within three weeks. A master list was created of all those respondents who requested a copy of the summary of the survey results and was filed for follow up to send them the results of the study.

Within a few days 31 unopened envelopes were returned as undeliverable. Following a few minor revisions to the cover letter and survey form (change of dates and phone numbers) a second survey mailing was conducted in hopes of increasing the response rate. Surveys were resent to the 31 programs whose surveys were returned as “undeliverable,” only this time the name of the addressee was changed to the “Director of” the programs. From this dissemination, one more survey was completed. Seven surveys were returned as undeliverable in the second attempt making the convenience sample a total of 37. The response was calculated by subtracting 30 (non-deliverables) from the 160 on the target population list which reduced the accessible population to 130. The convenience sample of those surveys returned was 37, which yielded a response rate of 28% of known directors from the list of 130. Although the final sample was very small, it was specific to directors by name who could be considered representative of the population of directors by position, professional group and gender.

Another effort to increase data was made by the researcher by making follow up phone calls. The purpose of these follow up phone calls were to obtain answers to the last questions on the survey form which were left blank by approximately nine of the

respondents. Two more responses were the result of this effort, but did not affect the total response rate.

#### Data Screening and Cleaning

Since data entry is prone to errors, preparation of the data for statistical analysis was done through checks to ensure that the data were accurate and internally consistent (Polit, 1996). A screening of all surveys which were returned with a response were reviewed by the investigator. A total of 43 surveys were returned to the investigator. However, 14%, or six of the 43 surveys returned to the investigator had notes that stated why the respondents did not complete the surveys. There were two reasons given for them not completing the surveys. The first reason was because their programs were very small (the last time one respondent served a child was a year ago), and the second reason was because their programs did not provide services for children. However, due to the second attempt to increase the response rate, one more completed survey was received, making the final sample a total of 37.

Following the screening, a review was done to ensure that all the data provided were complete. This was done by conducting a search for any outliers, missing data or wild cards. This search discovered a few errors that needed correction, which were as follows: one incorrect code for a numerical value which was corrected; an incorrect percentage had been entered and was corrected; and missing percentages. The missing percentages alerted the researcher who did follow up phone calls to the respondents to increase the response rate for the percentage question. Once the data were cleaned the analysis was performed.

### Data Analysis

The data analysis for this research was done using Version 10 of the Statistical Package for the Social Sciences (SPSS). Appropriate descriptive statistics were used on the data based on the level of measurement of the variables. Nominal level variables on the services scales were counted and reported as frequencies. Ordinal level measures on the individual staff barriers and obstacles scales were reported in frequency tables, and summarized as descriptive statistics of means and standard deviations.

Pearson's Product Moment Correlation ( $r$ ) and Spearman's Rho ( $r$ ) correlations were both used to test relationships depending on the level of data and meeting assumptions. To test the relationships between staff barriers and perceived obstacles, non-parametric Spearman's Rho ( $r$ ) was used. To test the relationships between the obstacles and insurance, parametric Pearson's ( $r$ ) was used. Funding percentages that were respondent's estimates of reimbursement were each treated as ratio levels of measurement.

### Summary

This chapter discussed why a sequential mixed methods design was used for this study. It identified the procedures used for this non-experimental descriptive study and included, (a) the protection of human subjects, (b) the convenience sample of 37 obtained from the accessible population of 130 known administrators of palliative care programs, (c) the instrument, (d) the reliability and validity of the instrument, and (e) an explanation for how and why the data analysis was done.

## Chapter 4

### Findings Phase I: Quantitative Study

#### Introduction

This chapter provides the findings from the quantitative study and includes the following: the design, assumptions, demographics and the results of the research objectives. Text, tables and figures demonstrate frequencies, percentages, means and standard deviations and correlations appropriate to this study.

This was a non-experimental, exploratory, descriptive study whose purpose was to identify frequencies and proportions of staff barriers and perceived obstacles to pediatric palliative programs and their relationships to funding sources by locations of care. The research question was: Does the reimbursement of services for pediatric palliative care differ between the types of funding, and is funding related to directors' perceptions of obstacles to the delivery of care? The research objectives were (1) To describe staff barriers as reported by pediatric palliative care program directors; (2) To describe perceived obstacles as reported by pediatric palliative care program directors; (3) To describe the frequencies of the reimbursement of services for pediatric palliative care provided for children by the location of care (inpatient/outpatient/ home.); (4) To describe the relationship between staff barrier scores and perceived obstacles to the

delivery of pediatric palliative care services which led to the following questions: a) Is there a relationship between staff education and training barriers and the perceived obstacles to the delivery of pediatric palliative care services, and (5) To describe the relationship between funding and perceived obstacles in pediatric palliative care. This led to other sub-questions (a) Is there a relationship between the percentages of funding from private insurance that directors estimate and their perceived obstacles in pediatric palliative care? (b) Is there a relationship between the percentages of funding from Medicaid that director's estimate and their perceived obstacles in pediatric palliative care? and (c) Is there a relationship between the percentages of funding from private donations that directors estimate and their perceived obstacles in pediatric palliative care?

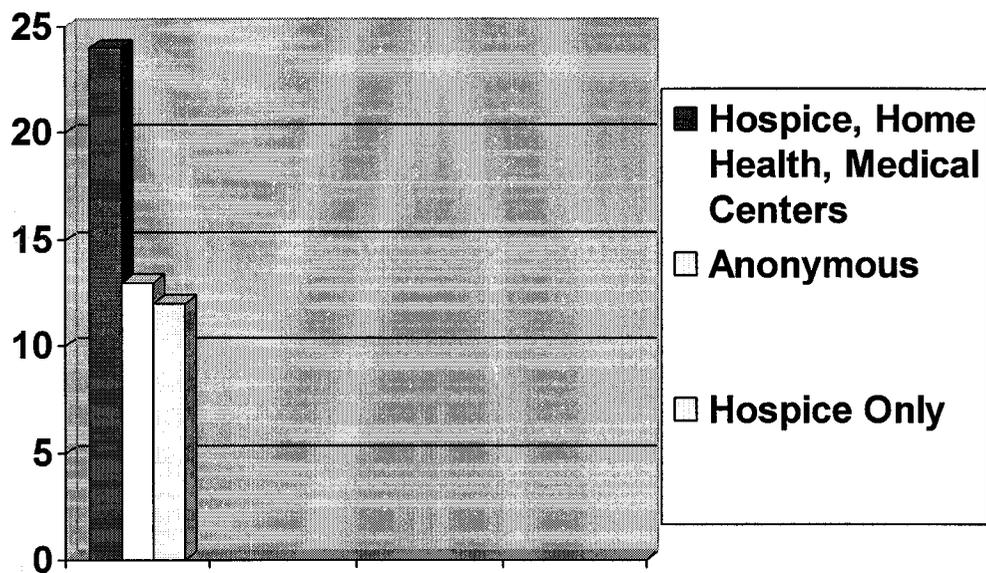
A self report instrument, comprised of six sections, was completed by a convenience sample of 37 respondents from an accessible population of 130 directors of pediatric palliative care programs in February, 2003. The findings from this study are organized by demographics followed by the results of each research objective.

#### Assumptions

The following assumptions were made in the design and execution of this study. First that the persons who responded to the survey were in roles as directors, administrators, or coordinators of the program and were therefore knowledgeable about the practices of the program, and responded to the survey to the best of their knowledge. Second, that the master list used to disseminate the instrument was current, meaning that the list had been updated and the names and addresses were in fact those of the current directors/administrators or coordinators of the programs.

### Demographics

Surveys were sent via U.S. mail to the target population of 160 program directors that represented 80% (40/50) of the United States. The final convenience sample of 37 respondents represented 41 cities from the following 22 states: Arizona, Arkansas, California, Colorado, Florida, Iowa, Kentucky, Maine, Maryland, Massachusetts, Mississippi, New Hampshire, Nebraska, New Jersey, New York, Ohio, Oklahoma, Pennsylvania, South Carolina, Texas, Virginia, and Washington.



*Figure 3.* Number of Identified Organizations Responding to Survey

### Represented Organizations

Respondents were asked to provide information which included their names, titles and organizations, if they wished to receive a copy of the study findings. As indicated above in Figure 3, 35% (or 13/37) of the responses were anonymous. The remaining 65%, (or 24/ 37) indicated they were employed by a hospice, a home health agency, or a medical center. Of these, 50% represented hospice programs.

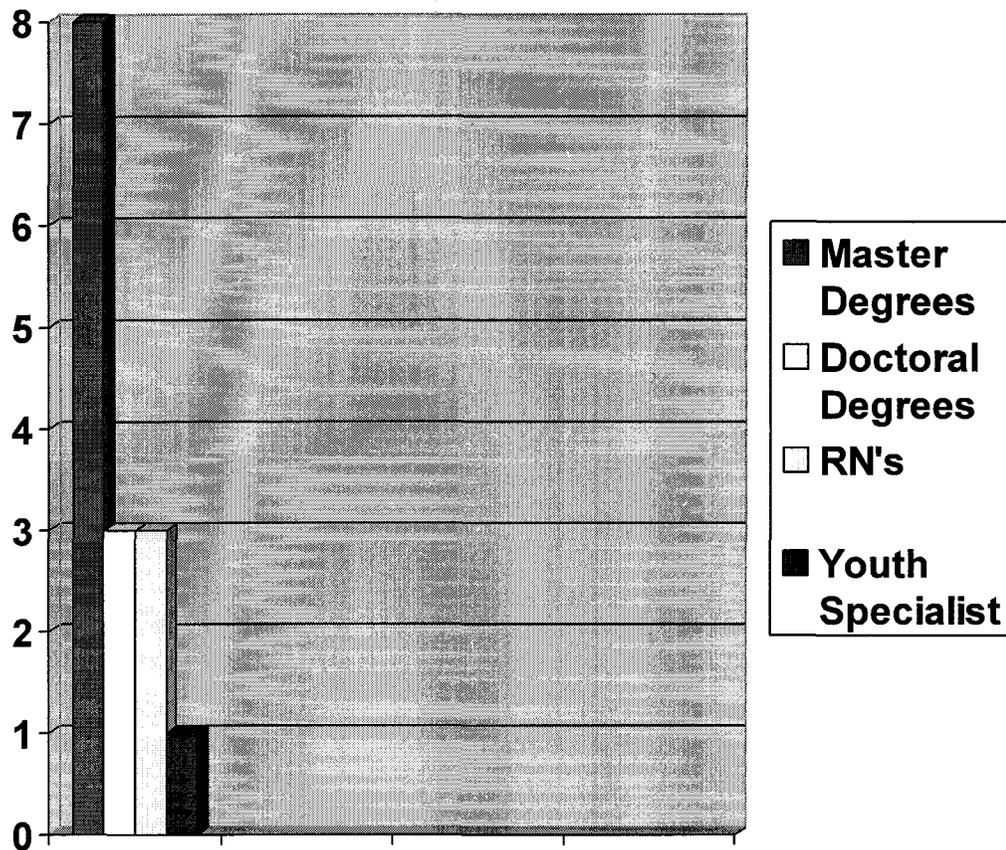


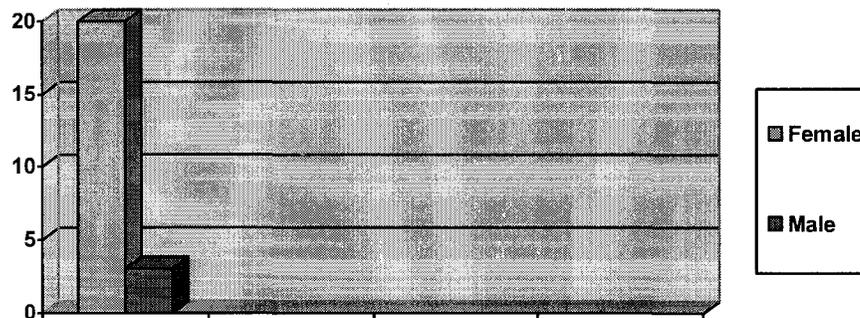
Figure 4. Number of Identified Respondents with Education Credentials

Respondents Credentials

Sixty-five percent, or 24/37 of the respondents, completed the demographic section. Of these, 63%, or 15/24 provided both position titles and their professional credentials, namely: president, executive director, medical director, and director, director of clinical services, nurse manager, nursing supervisor, clinical manager and clinical coordinator. Professional credentials included: eight with Master Degrees, three with Doctoral Degrees, three Registered Nurses and one Youth Specialist as listed in Figure 4. Professional positions of the persons who responded to the survey demonstrate the variety of administrative titles across the country. All of the reported surveys were completed by either nurses or physicians, with the exception of two, which were completed by a master's prepared social worker and a youth specialist.

#### Gender

Sixty-two percent, or 23/37, of the respondents provided information which was used to identify their gender. Of these, 86%, or 20/23, were female and 13% (3/23) were male (See Figure 5).



*Figure 5.* Number of Identified Female and Male Respondents

Findings: Research Objective #1:

The first research objective, “Describe staff barriers as reported by pediatric palliative care program directors” (data n =37) was addressed by using Version 10 of SPSS to determine the frequencies, means and standard deviations of the six items on the staff barrier scale. Table 1 demonstrates that almost a fourth, or 24% of the respondents, rated staff unawareness of foundation funds to be a “severe barrier” for the delivery of pediatric palliative care services. Forty-eight percent (48%) of respondents, rated the lack of standardized competencies for staff as “somewhat of a barrier,” compared to 35% who rated it as “not a barrier.” Thirty-two percent (32%) of the respondents rated staff’s unfamiliarity with insurance plans as “somewhat of a barrier.” More than a third, or 35% of respondents, also rated staff and their non aggressiveness in seeking access for coverage as “somewhat of a barrier.” More than half of the respondents, 59%, 54% and 54% respectively, rated staff who were not aggressive in trying to access coverage for pediatric palliative care services, the unfamiliarity of staff with different types of funding sources and staff not being educated or trained in pediatric palliative care, as “not being a barrier.”

Table 1. *Frequencies and Percentages of Staff Barriers*

Staff Barrier Scale (SBS)	Not a barrier		Somewhat of barrier		Severe Barrier	
N = 37	Freq.	%	Freq.	%	Freq.	%
SBS 1: Staff is not familiar with different types of services covered by insurance plans, Medicaid or private donations.	20	54%	11	32%	4	10%
SBS 2: Staff is not aggressive in trying to access coverage for services not provided by insurance plans, Medicaid or private donations.	22	59%	13	35%	1	02%
SBS 3: Staff is unaware of foundation funds available within the organization for palliative care.	18	48%	4	10%	9	24%
SBS 4: Staff is unaware of community funds that may be accessible for palliative care.	17	45%	10	27%	8	21%
SBS 5: Staff is not educated or trained on how to provide palliative care for pediatric patients.	20	54%	11	29%	5	13%
SBS 6: Lack of standard-sized competencies for staff to provide pall. care	13	35%	18	48%	4	10%

#### Means and Standard Deviations of Staff Barrier Scale Items

Table 2 describes the means and standard deviations of all the staff barrier items. In order to rank them from the highest to lowest mean ratings. Item four on the staff barrier scale, staff unaware of community funds had the highest mean of 1.74 with a

standard deviation of .817. This was followed by two other items with a mean of 1.71 which were staff unaware of foundation funds available within the organization with a standard deviation of .902 and the lack of standardized competencies for staff with a standard deviation of .667.

Table 2. Means and Standard Deviations of Staff Barrier Scale Items

Staff Barrier Scale (SBS) N =37	Mean	SD
SBS 4: Staff is unaware of community funds that may be accessible for palliative care.	1.74	.817
SBS 3: Staff is unaware of foundation funds available within the organization for palliative care.	1.71	.902
SBS 6: Lack of standardized competencies for staff to provide palliative care.	1.71	.667
SBS 5: Staff is not educated or trained on how to provide palliative care for pediatric patients.	1.56	.735
SBS 1: Staff is not familiar with different types of services covered by insurance plans, Medicaid private donations.	1.56	.695
SBS 2: Staff is not aggressive in trying to access coverage for services not provided by insurance plans, Medicaid or private donations.	1.42	.554

#### Reliability of Staff Barrier Scale Total

The total score for staff barriers was calculated by summing the responses on the items. A reliability analysis for the staff barrier was done by using the Coefficient Alpha Scale in SPSS with six items for an  $r = .8252$ . Generally, reliability coefficients should be at least .70, so in this case, it means there is acceptable reliability (Polit, 1996).

#### Findings: Research Objective #2:

The second research objective, “Describe perceived obstacles as reported by pediatric palliative care program directors” was addressed by using Version 10 of SPSS

to determine the frequencies, means and standard deviations of the perceived obstacles. Table 3 displays these findings and identified the association of hospice or palliative care with death as having the highest degree of interference at 48%. This was followed by physicians' reluctance to make a referral for palliative care at 40%. The third highest frequency rate of the perceived obstacles was the family's reluctance to accept palliative care at 35%.

Two of the same obstacles that were rated as "severe barriers," physicians' reluctance to make a referral to palliative care, and the family's reluctance to accept palliative care, were also rated at 43% and 40% respectively as "moderately interfering" with the delivery of pediatric palliative care services. Furthermore, three obstacles were each rated at 32% and were perceived by the respondents to cause "somewhat interference" with the delivery of pediatric palliative care services. Those three moderate obstacles were first, the lack of family making the child's care preferences known to others, second, the lack of clarity by staff regarding the child/family's preferences for care, and third, the lack of the physicians' familiarity with the availability or suitability of palliative care for the child. Finally, 51% of the respondents rated the absence of an advance directive for the child as not being an obstacle to the delivery of pediatric palliative care services.

Table 3. *Frequency and Percentages of Perceived Obstacles*

Obstacle Scale (OBS)	Not an Obstacle		Somewhat obstacle		Moderate interferes		Severe obstacle	
	Freq.	%	Freq.	%	Freq.	%	Freq.	%
N = 37								
OBS 1	19	51%	7	18%	5	13%	2	5%
OBS 2	15	40%	12	32%	4	10%	0	0%
OBS 3	15	40%	12	32%	5	13%	3	8%
OBS 4	3	8%	12	32%	10	15%	12	32%
OBS 5	2	5%	4	10%	16	43%	15	40%
OBS 6	4	10%	4	10%	15	40%	13	35%
OBS 7	3	8%	8	21%	8	21%	18	48%
OBS 8	2	5%	10	15%	13	35%	12	32%
OBS 9	3	8%	13	35%	15	40%	6	16%
OBS 10	11	29%	7	18%	9	24%	6	16%

### Means and Standard Deviations of Obstacle Scale

Table 4 describes the means and standard deviations of the three perceived obstacles with the highest ratings. Item five on the obstacle scale, physician's reluctance to make a referral for palliative care had the highest mean of 3.19 and a standard deviation of .845. This was followed by the association of hospice or palliative care with death, with a mean of 3.11 and a standard deviation of 1.022. The item with the third highest mean was the family's reluctance to accept palliative care with a mean of 3.03 and a standard deviation of .971.

Table 4. *Means and Standard Deviations of Obstacle Scale*

OBSTACLE SCALE (OBS)	N =37	Mean	SD
OBS 1: Absence of an advance directive for the child.		1.70	.951
OBS 2: Lack of family making the child's care preference known to others.		1.65	.709
OBS 3: Lack of clarity by staff regarding the child/family's preferences for care.		1.89	.963
OBS 4: Lack of physician's familiarity with the availability or suitability of palliative care.		2.84	.986
OBS 5: Physicians' reluctance to make a referral for palliative care.		3.19	.845
OBS 6: Family reluctance to accept palliative care.		3.03	.971
OBS 7: Association of hospice or palliative care with death.		3.11	1.02
OBS 8: Perception by family that palliative care means health providers are giving up hope.		2.95	.911
OBS 9: Lack of understanding by the family of the severity and/or irreversibility of their child's illness.		2.65	.857
OBS 10: Lack of institutional support or providing palliative care.		2.30	1.13

### Reliability

The total obstacles score was calculated by summing responses. A reliability was tested for the obstacle scale by using the Coefficient Alpha in SPSS with 10 items for an  $r = .8549$ . Generally, reliability coefficients should be at least .70, and in this case indicates there is acceptable reliability (Polit, 1996).

### Findings: Research Objective # 3:

The third research objective, “Describe the relationship between staff barrier scores and perceived obstacles to the delivery of pediatric palliative care services” was addressed using computer calculations (SPSS) to measure these two variables (obstacles on an interval scale) and (staff barriers on an ordinal scale) to determine appropriate correlation. There were two sub-questions for specific items on the staff barriers scale (a) Is there a relationship between staff education and training barriers and the perceived obstacles to the delivery of pediatric palliative care services and (b) Is there a relationship between the lack of standardized competencies and perceived obstacles? The variable “obstacles” was treated as interval as the total summed score as on the original obstacles scale. It was used to test the correlation between obstacles and staff barriers. Staff barriers were the summed items on the staff barrier scale and treated as ordinal. Each item was also treated as ordinal level.

The total barriers scale was ordinal and each item was ordinal. Therefore, the Spearman’s Rho statistic was used to test relationships between each of the variables. Using a two-tail test and setting at  $p < .05$ , there was a statistically significant relationship between the total staff barriers with the total obstacles scale ( $r = .327, p < .05$ .)

The total obstacles score was statistically significant for these two staff barrier items: SB #5, staff not trained or educated in providing pediatric palliative care, ( $r = .443$ ,  $p < .05$ ), and SB #6, the lack of standardized competencies ( $r = .423$ ,  $p < .05$ ). No other correlations were significant. In summary, total perceived obstacles and total reported staff barriers were statistically related and the items related to education and competencies were statistically related to the perceived obstacles.

Table 5. *Spearman's Rho Correlations of Staff Barriers and Perceived Obstacles*

Variables	Correlations	Perceived Obstacles
Staff barrier: not trained or educated on providing pall care	Correlation Coefficient	.443*
	Sig. (2-tailed)	.007
	N	36
Staff barrier: lack of standard competencies	Correlation Coefficient	.423*
	Sig. (2-tailed)	.011
	N	35
Total Staff Barriers	Correlation Coefficient	.327*
	Sig. (2-tailed)	.048
	N	37

\* Correlation is significant at the 0.05 level (2-tailed).

Findings: Research Objective #4:

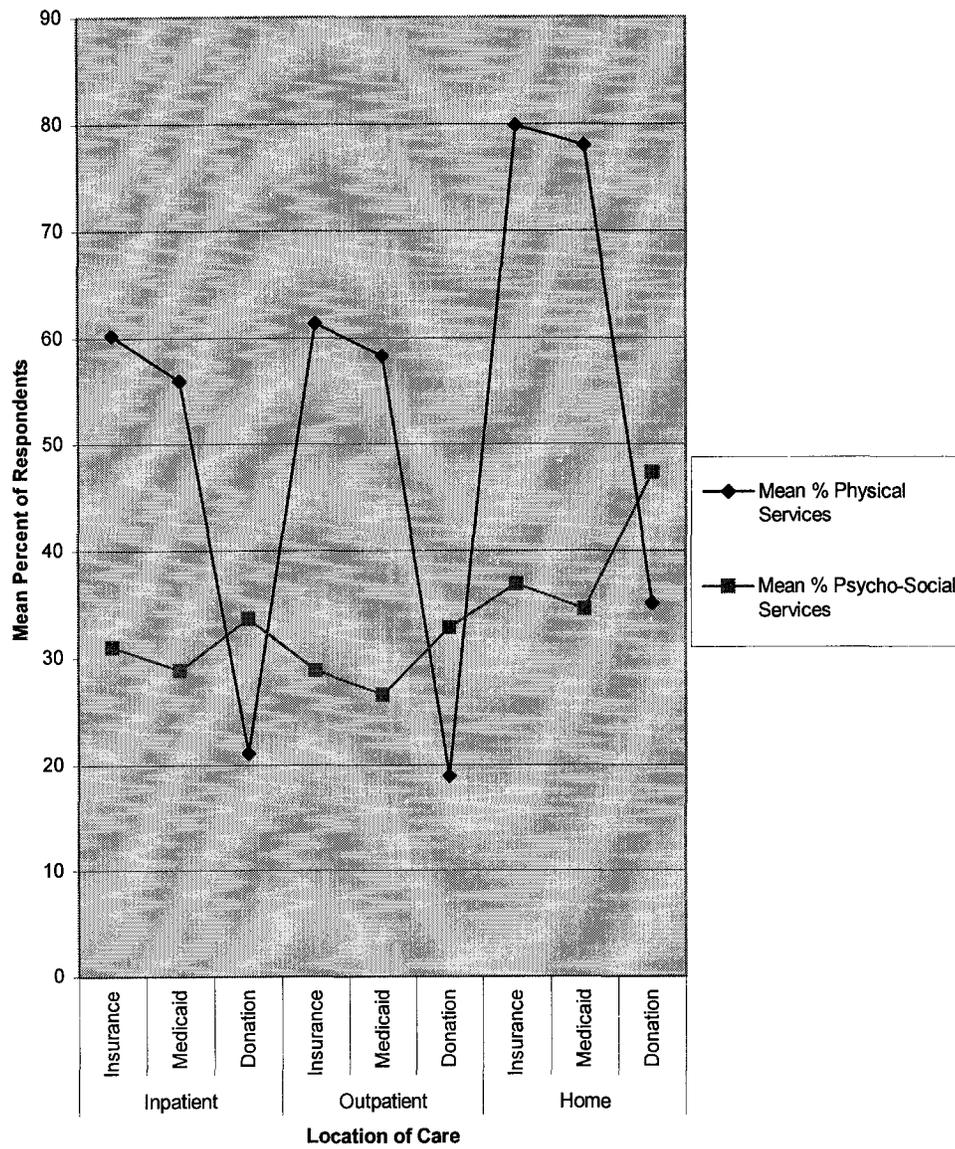
The fourth research objective was to “Describe the frequency of the reimbursement of services for pediatric palliative care provided for children by the location of care as an inpatient, outpatient or home.” Table 6 demonstrates the aggregate frequency number of responses from programs across the seven services for physical services (PH) and across the six services for psycho-social services (PS). Physical services were defined for this study as (a) diagnostic procedures, (b) equipment, (c) IV therapy, (d) medication, (e) nursing care by an RN, (f) occupational and speech therapies and (g) physical therapy. Psycho-social services were included (a) child life specialist, (b) counseling by physician, (c) counseling by non-physician, (d) palliative care team consults, (e) grief/bereavement support, and (f) complimentary/alternative therapy. Table 6 also reflects the funding sources, (insurance, Medicaid and private donations), and the location of care (inpatient, outpatient or home).

Table 6. *Number of Programs that Reimburse for Physical and Psycho-Social Services by Location of Care N =37*

Funding Sources	Insurance		Medicaid		Donations	
	Average Freq.	%	Average Freq.	%	Average Freq.	%
<b>Physical Services (PH)</b>						
Location						
Inpatient	22.3	60%	20.7	56%	7.8	21%
Outpatient	22.7	61%	21.6	58%	7.0	19%
Home	29.3	80%	28.8	78%	13.0	35%
<b>Psycho-social Services (PS)</b>						
Location						
Inpatient	11.5	31%	10.6	29%	12.5	34%
Outpatient	10.6	29%	9.8	27%	12.1	33%
Home	13.7	37%	12.8	35%	17.5	47%

The highest frequency that was reported was for physical services being covered by insurance whether the service was provided as an inpatient (60%), outpatient (61%) or in the home (80%). More than half of the respondents reported that Medicaid reimbursed their physical services when these services were provided as an inpatient (56%), or outpatient (58%), and even higher rates for care in the home at 78%. Conversely, the lowest frequency of respondents reported that donation funds reimbursed for physical services as inpatients (21%), or outpatients (19%) and 35% for services provided in the home.

Psycho-social services (PS), were defined for this study as (a) child life specialist, (b) counseling by physician, (c) non-physician, (d) palliative care team consults, (e) grief and bereavement support, and (f) complimentary/alternative therapy. In general, fewer respondents reported psycho-social services were reimbursed by insurance and Medicaid for all three locations of care. However, more respondents reported that their programs were reimbursed by private donations for psycho-social services than physical services. as provided for inpatients (34%), outpatients (33%) and in the home (47%). See Figure 6 below.



*Figure 6.* Programs that Reimburse for Physical and Psycho-Social Services by Location of Care.

Table 7 demonstrates the average frequencies reported by the highest number of programs for the aggregate of inpatient reimbursement of physical services are paid at the highest rates by Insurance and Medicaid at 60% and 56% respectively, as compared to reimbursements by private donations for physical services with a average frequency of 21%. The top three physical services most frequently reimbursed by all three funding sources are medication, IV therapy, and equipment.

Table 7. *Number of Programs that Reimburse for Services as Inpatient N=37*

Funding Sources	Insurance		Medicaid		Donations	
	Freq.	%	Freq.	%	Freq.	%
<b>Physical Service (PH)</b>						
Diagnostic Procedure	21	57%	21	57%	6	16%
Equipment	23	62%	22	60%	10	27%
IV Therapy	24	65%	22	60%	8	21%
Medication	24	65%	22	60%	8	21%
Nursing Care by RN	21	57%	20	54%	9	24%
Occupational/Speech therapy	21	57%	19	51%	7	18%
Physical therapy	22	60%	19	51%	7	18%
<b>Average (%) Responses for Physical Services</b>	<b>22.3</b>	<b>60%</b>	<b>20.7</b>	<b>56%</b>	<b>7.8</b>	<b>21%</b>
<b>Psycho-social Service (PS)</b>						
Child Life Specialist	5	13%	5	14%	11	30%
Counseling by physician	21	57%	19	51%	11	30%
Counseling by non-physicians	17	46%	14	38%	13	35%
Palliative Care team Consult	12	32%	12	32%	11	30%
Grief/bereavement support	6	16%	6	16%	19	51%
Complimentary/alternative therapy	8	22%	8	22%	10	27%
<b>Average (%) Responses for Psycho-social Services</b>	<b>11.5</b>	<b>31%</b>	<b>10.6</b>	<b>29%</b>	<b>12.5</b>	<b>34%</b>

However, reimbursement for psycho-social services has the highest mean frequency percentage for reimbursement by private donations at 34%, versus insurance at 31% or Medicaid at 29%. The psycho-social service most frequently reimbursed by

insurance companies is counseling by physicians 57%, followed by Medicaid reimbursement for this same service at 51%. Grief and bereavement support is most often reimbursed by private donations with a frequency of 51% compared to reimbursement by Insurance and Medicaid, both at 16%.

Table 8 demonstrates the specific services reimbursed by insurance, Medicaid and private donations as an outpatient. Physical services reimbursed by insurance (61%) are slightly higher than Medicaid (58%) and much less by private donations at 19%. However, private donations reimbursed for psycho-social services at 32% exceeds the amount reimbursed by Insurance at 29% and Medicaid at 27%.

Table 8. *Number of Programs that Reimburse for Services as Outpatient N =37*

Funding Sources	Insurance		Medicaid		Donations	
	Freq.	%	Freq.	%	Freq.	%
<b>Physical Services (PH)</b>						
Diagnostic Procedures	21	57%	19	51%	5	14%
Equipment	24	65%	22	60%	7	19%
IV Therapy	24	65%	23	62%	7	19%
Medication.	25	68%	24	65%	7	19%
Nursing by RN	22	60%	22	60%	9	24%
Occupational/Speech therapy	21	57%	20	54%	7	19%
Physical therapy	22	60%	21	57%	7	19%
Average (%) Responses for Physical Services	22.7	61%	21.6	58%	7	19%
<b>Psycho-social Service (PS)</b>						
Child Life Specialist	4	11%	4	11%	13	35%
Counseling by physician	17	46%	18	49%	8	22%
Counseling by non-physicians	15	41%	13	35%	12	32%
Palliative Care team Consult	14	38%	11	30%	9	24%
Grief/bereavement support	7	19%	8	22%	18	49%
Complimentary/alternative therapy	7	19%	5	14%	13	35%
Average (%) Responses for Psycho-social Services	10.6	29%	9.8	27%	12.1	33%

Table 9 demonstrates the mean percentage of physical services reimbursed in the home by insurance at 80%, Medicaid at 78% and private donations at 35%. Medication, IV Therapy, and equipment continue to be the top three physical services reimbursed. Psycho-social services are less than half as likely to be reimbursed by insurance (37%) or Medicaid (35%) while private donations reimburse the most often with a mean of 47%.

The psycho-social service reimbursed the most often by private donations in the home is grief and bereavement services at 68%.

Table 9. *Number of Programs that Reimburse for Services in the Home N=37*

Funding Sources	Insurance		Medicaid		Donations	
	Freq.	%	Freq.	%	Freq.	%
<b>Physical Service (PH)</b>						
Diagnostic	23	62%	23	62%	10	27%
Equipment	31	84%	31	84%	13	35%
IV Therapy	33	89%	31	84%	12	32%
Medication	33	89%	32	87%	12	32%
Nursing Care by RN	29	78%	29	78%	16	43%
Occupational/Speech therapy	28	78%	28	76%	14	38%
Physical therapy	28	78%	28	76%	14	38%
<b>Average (%) Responses of Physical Services</b>	<b>29.3</b>	<b>80%</b>	<b>28.8</b>	<b>78%</b>	<b>13</b>	<b>35%</b>
<b>Psycho-social Service (PS)</b>						
Child Life Specialist	5	14%	5	14%	15	41%
Counseling by physician	21	57%	21	57%	12	33%
Counseling by non-physicians	22	60%	19	51%	17	46%
Palliative Care team Consult	14	38%	14	38%	17	46%
Grief/bereavement support	12	32%	11	30%	25	68%
Complimentary/alternative therapy	8	22%	7	19%	19	51%
<b>Average (%) Responses of Psycho-social Services</b>	<b>13.7</b>	<b>37%</b>	<b>12.8</b>	<b>35%</b>	<b>17.5</b>	<b>47%</b>

#### Findings: Research Objective #5

The fifth objective, generated the general question: "Is there a relationship between the percentage of funding from the three sources (private insurance, Medicaid, private donations) that directors estimate to pay for their programs and their perceived obstacles in pediatric palliative care?" Each of the

bivariate relationships were plotted to examine the scatterplots for outliers (See Figures 7, 8, and 9). Identifying the two outliers for the pairs of variables, analyses were done including all data, as well as analyses after removing the two outliers. Each bivariate relationship was subjected to correlation using Pearson Product Moment Correlation and Spearman Rho as appropriate. The percentages of funding variables (insurance, Medicaid and private donations) were treated as interval data. The total obstacles scale was treated as interval data as it was done in the previous literature. The correlation matrix without the two outlier cases is presented in Table 10. The funding sources were inter-correlated as expected except for donations, which is not significant with insurance although it is significant with Medicaid ( $r = -.711, p < .05$ ).

Table 10. *Correlations Without Two Outlier Cases*

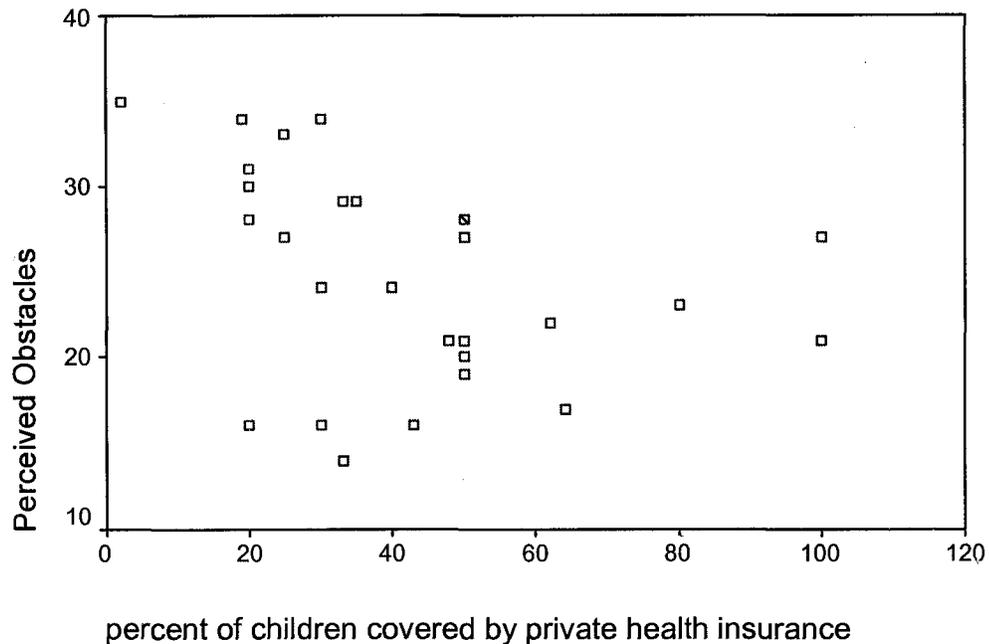
		Correlations			
		Perceived Obstacles	percent of children covered by private health insurance	percent of children covered by Medicaid	percent of children covered by private donations
Perceived Obstacles	Pearson Correlation	1	-.471*	.001	.341
	Sig. (2-tailed)	.	.013	.996	.082
	N	35	27	27	27
percent of children covered by private health insurance	Pearson Correlation	-.471*	1	-.416*	-.339
	Sig. (2-tailed)	.013	.	.031	.084
	N	27	27	27	27
percent of children covered by Medicaid	Pearson Correlation	.001	-.416*	1	-.711**
	Sig. (2-tailed)	.996	.031	.	.000
	N	27	27	27	27
percent of children covered by private donations	Pearson Correlation	.341	-.339	-.711**	1
	Sig. (2-tailed)	.082	.084	.000	.
	N	27	27	27	27

\*. Correlation is significant at the 0.05 level (2-tailed).

\*\*. Correlation is significant at the 0.01 level (2-tailed).

The next research objective tested was “Is there a relationship between funding from private insurance that director’s estimate and their perceived obstacles in pediatric palliative care?” To test the relationship between respondents’ estimates of private health insurance coverage with perceived obstacles, the Pearson Product Moment Correlation was used, yielding a significant negative correlation ( $r=-.471$ ,  $p<.05$ ). The scatterplot for all data ( $n=29$ ) suggested that there was a correlation although 2 outliers existed at 100% (See Figure 7). Removing those outliers improved the correlation from  $r=-.300$  (NS) to  $r=-.471$  ( $p<.05$ ). Applying the Spearman Rho correlation to accommodate all of the data even if with the outliers if they did not meet assumptions for Pearson  $r$ , the correlation was still significant with all 29 responses ( $r=-.449$ ,  $p<.05$ ). These findings based on these analyses demonstrate that the relationship of private insurance coverage with perceived obstacles are statistically significant. The less private insurance there is to pay for services for the children, the higher the perceived obstacles are related to pediatric palliative care. The more private insurance pays for the services for the children, the lower the obstacles. The correlation is weak to moderate so with the small sample size, results should be interpreted with caution.

## Scatterplot of Percentage Private Insurance to Perceived Obstacles



*Figure 7.* Scatterplot of Percentage of Private Insurance with Perceived Obstacles

The next research objective tested was, “Is there a relationship between funding from Medicaid that director’s estimate and their perceived obstacles in pediatric palliative care”? To test the relationship between respondents’ estimates of Medicaid coverage with perceived obstacles, the Pearson Product Moment Correlation was used, yielding a non-significant correlation ( $r=.001$ , NS). The scatter plot for the data ( $n=29$ ) suggested that there was no relationship between Medicaid coverage with perceived obstacles with all

the data and no apparent outliers (See Figure 8). With the small sample size, results should be interpreted with caution.

### Scatterplot of Percentage Medicaid to Perceived Obstacles

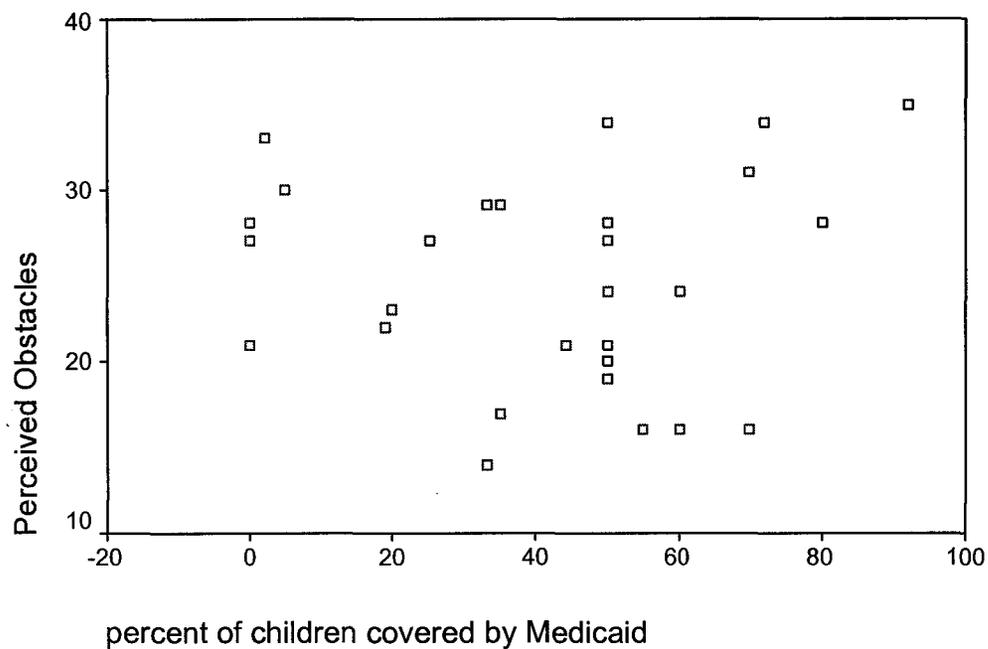


Figure 8. Scatterplot of Percentage of Medicaid with Perceived Obstacles

The next research objective was to test the relationship between respondents' estimates of private donation coverage with perceived obstacles, the Pearson Product Moment Correlation was used, yielding a non-significant positive correlation ( $r=.341$ , NS). The scatter plot for the data ( $n=29$ ) suggested that there was no correlation between private donation coverage with perceived obstacles with all the data and no apparent

outliers (see Figure 9). With the small sample size and strength of the correlation, results should be interpreted with caution. The possible positive relationship that may exist between private donation coverage and perceived obstacles may suggest that directors who struggle to receive private donation for funding constantly face the obstacles to providing palliative care services and their successes influence their perceptions of these obstacles.

### Scatterplot of Percentage Private Donations to Perceived Obstacles

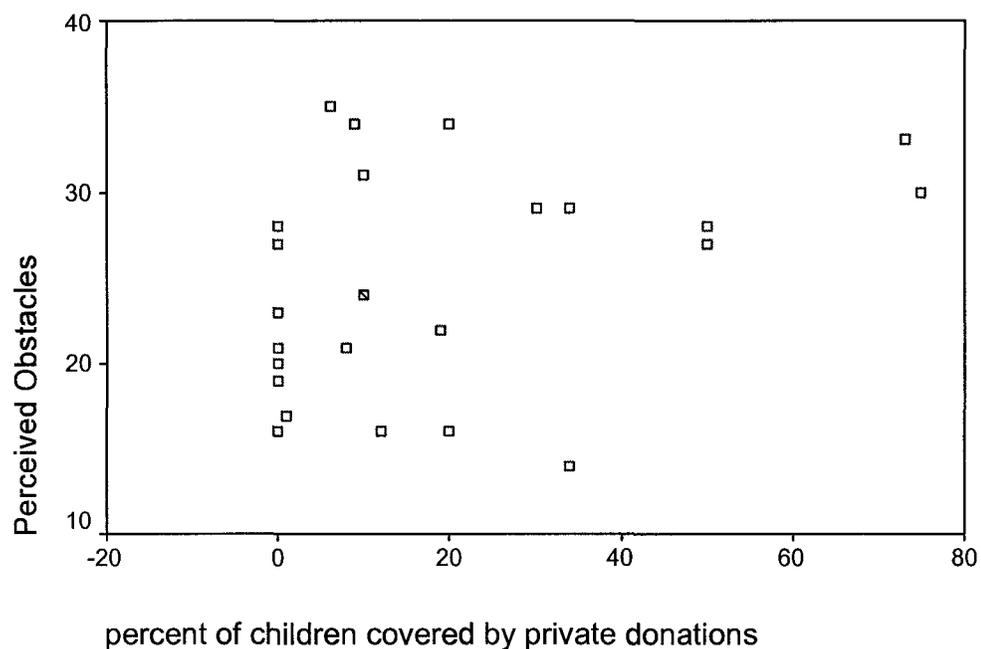


Figure 9. Scatterplot of Percentage Private Donation with Perceived Obstacles

### Summary

This chapter reported the results of the quantitative portion of this study using text, tables, and figures from SPSS analyses. It reported frequencies, percentages, means and standard deviations, and correlations. A summary of the results included the top three items rated as the most severe barriers for staff to provide care and were, (1) the staff being unaware of community funds that may be accessible for palliative care, (2) staff being unaware of foundation funds available within their organization that could be used for palliative care, and (3) the lack of standardized competencies for staff to provide pediatric palliative care.

The top three items rated as the most severe perceived obstacles in providing care were (1) the association of hospice or palliative care with death, (2) physicians' reluctance to make referrals for pediatric palliative care, and (3) the family's reluctance to accept palliative care. Other key findings from this study included (1) that the majority of palliative care services reimbursed was for physical care services versus psycho-social services, (2) that private donations are more likely to be the sources of funding for psycho-social services, and (3) that there is a significant relationship between reimbursement by private insurance with perceived obstacles to pediatric palliative care ( $r = -.471, p < .05$ ). Recognizing that these findings are limited by the size of the sample, they are nonetheless important in this exploratory study to support the need for further research.

## Chapter 5

### Methodology: Qualitative Study

#### Introduction

This chapter describes the methodology used for Phase II, the qualitative study. It includes information about the pilot study, the procedures used for sampling, data collection, data analysis, ethical considerations and trustworthiness of the study.

For this portion of the study the writing is in first person singular. This is in keeping with the philosophy that the interviewer “be an active participant in interactions with respondents” (Denzin & Lincoln, 2000, p. 663) and the concept of “the interviewer as the instrument” (Sorrell & Redmond, 1995).

I used an interpretive phenomenological approach and gathered the data for this study by using a semi-structured face-to-face interview with each of the six directors of the six CHI PACC projects. These six directors were not part of Phase I of this study and therefore did not complete any surveys. I chose these six directors because it is the directors who experience the cumulative knowledge of the barriers experienced by children and families in palliative care programs. I believed it was important to hear and

document their stories in order to better understand their experience with barriers to pediatric palliative care.

#### Research Question

What are the barriers that CHI PACC directors experience in their roles and how do they overcome them?

#### Research Objectives

The objectives for the qualitative phase of this study were:

1. To identify barriers that directors, experienced when working with pediatric palliative care programs.
2. To identify specific areas of work which gave the directors a sense of well being about the work they were doing.
3. To identify the qualities perceived by directors in the CHI PACC programs that are needed to overcome barriers.

The directors represented the following states: Colorado, Virginia, Florida, Kentucky, New York and Utah. Three of the director participants were female and three male. Five of these participants were Caucasian, and one was Asian. The ages of the participants ranged from early forties to the mid - sixties. Education backgrounds of the participants included two with doctoral degrees (one in medicine and one in philosophy), three with master's degrees and one with a bachelor's degree. Three of the participants represented employment with state health departments, two with a Hospice organization and one with a hospital (see Table 11). All discussions were audio-taped. A pilot study was conducted to test the interview process.

### Pilot Study

The interview process was piloted with two female participants, whose ages ranged from early to mid -fifties, and who were colleagues from George Mason University. One of the participants holds a doctorate in nursing and is a member of the adjunct faculty, the other pilot participant was a doctoral candidate at the time of the study. The purpose of the pilot was to practice the interview process to determine if there were any problems that needed to be worked out prior to the study interviews. Each interview with the pilot participants lasted approximately 40 minutes. Both of the pilot interviews went fine from a protocol perspective. However, when it came time to listen back to the taping of the conversations, one of the conversations had not been recorded. I determined that this was due to both play and record buttons not being pressed at the same time. This then led me to practice using the buttons on the audio cassette to ensure proper recordings prior to the actual interviews. No changes were made to the methodology. The pilot study participants' data were not part of the final data analysis.

### Procedures for Sampling, Data Collection, and Data Analysis

#### Sample

A purposive sample of six directors of the Children's Hospice International Program for All-Inclusive Care for Children and Their Families (CHI PACC) demonstration projects were interviewed for this study. In purposive sampling, participants are handpicked to be included based on the researcher's knowledge about the population (Polit & Hungler, 1999). These demonstration projects were a result of

legislation allowing states to develop model programs. These directors represented the following states: Colorado, Virginia, Florida, Kentucky, New York and Utah and were specifically granted special waivers through the CHI PACC demonstration project. For convenience, the collection of the data coincided with the Children's Hospice International's 15<sup>th</sup> World Congress which was held in Alexandria, Virginia on September 14-17, 2003. I identified the directors of these six PACC programs by accessing the website for Children's Hospice International ([www.chionline.org](http://www.chionline.org)) where the CHI PACC programs were listed, along with the director's contact information. Although, I had previously met a few of these directors at professional conferences related to pediatric palliative care within the last two years, it was necessary to confirm that the directorships had not changed.

Approximately, one month prior to the CHI Congress, I sent each of the directors an individual invitational electronic message (Appendix L). This message informed the directors of the study being done by me and requested their participation in a face-to-face, semi-structured interview which would take about 30-60 minutes.

#### Protection of Human Subjects

Since this portion of the study was not part of the original quantitative study, the George Mason University's Human Subjects Review Board (GMUHSRB) reviewed and approved this study separately, and prior to any data collection (Appendix M). I sent all the participants who agreed to be part of this study an electronic copy of the informed consent form which included information on the following: the purpose and procedures for the research, any potential benefits and risks associated with the study, confidentiality

issues, voluntary participation, contact names, and numbers. A hard copy of the consent form was then provided to each of the participants when I met with them in person. At that time I asked them each to review and sign the consent form prior to the start of the interview, which they all did.

All six directors responded via electronic messages that they were willing to participate in this study. Two of the six directors, one from Virginia and one from Colorado provided me with interview days and times in their response messages. The remaining four directors asked me to find them at the CHI Congress and there they would let me know what dates and times would be most convenient for their interviews. The individual interviews took place on September 15, 16, and 17, 2003 at the designated time they arranged with me. Two interviews were conducted on September 15 and included the directors from the states of Colorado and Virginia. Three interviews were conducted on September 16 and included the directors from New York, Kentucky, and Florida. The remaining director, from the state of Utah, was interviewed following the CHI Congress on September 17, 2003.

#### Data Collection

All of the interviews took place at a time convenient to the participant. The data were collected during a face-to-face individual interview with each director. Using a semi-structured format, three specific questions were posed to the participants.

The questions were:

1. Would you tell me, in your own words, about a specific time when you were able to overcome some barrier to pediatric palliative care services?

2. Can you share a story, in your own words, about a particular time you felt good about services?
3. Can you describe in your own words, the qualities you think it takes for someone like yourself, to overcome barriers in order to provide pediatric palliative care services?

After a brief overview of the purpose of the study, I reviewed the consent form with the directors and reiterated the contents of the form which included the following:

- their right to confidentiality,
- the benefits and risks of the study,
- the fact that there was no associated expense to them for participating in the study,
- that the tapes will be kept for three years under lock in my home and then destroyed when the study is completed,
- the right to stop the interview and/or the audio-taping at any time,
- the right to withdraw from the study at any time.

Prior to the signing of the consent form, I clarified that the director understood the purpose of the study and had no questions. I then asked the director to sign and date the informed consent. Following the signing of the consent form by each director, I proceeded with the interview. The interviews varied in length ranging from 20 to 60 minutes and concluded when the participant stated they had nothing further to add to their responses. All interviews were audio-taped and transcribed by a professional transcriptionist. Four of the six tapes were recorded and transcribed without any

problem. However, two of the interviews were not fully captured on the audiotape. I believed this was due to the tape running out of space for one interview, and the other because both buttons for “play” and “record” must not have been pushed correctly when checking the tape recording efficiency mid-interview.

I notified the participants of the two incomplete recordings of this issue by an electronic message and then asked them for a follow up phone interview, on a day and time at their convenience. Fortunately they both agreed. Another piece of good fortune was that I had taken narrative and reflective notes from these interviews and had them available for reference. I conducted the follow up phone interviews with these two directors and then sent them copies of my notes, which were then added to the original transcriptions.

Transcripts were compared to the audiotapes for accuracy and then a copy of the transcript was attached to an electronic message and sent to five of the six directors. One director requested to have a paper copy mailed to her due to her electronic mail box being overloaded. I requested that the participants review the transcripts and respond back to me with any changes within two weeks time. Four of the six directors responded to this request. Additional electronic messages were sent to the two directors who did not respond stating that if I did not hear back within a specific timeframe I would assume that the participant had no changes to the transcribed interview.

Two of these four directors responded with their changes in the actual transcripts and clarified any gaps that there may have been in the transcription. One of the four directors sent a four page memo back to me stating that this director felt embarrassed

when reading the interview transcript and felt a need to capture what was meant in a more concise format. The other director responded with a concern after reading the transcript that perhaps it came across cynical and that was not the intent.

### Data Analysis

The data analysis for this study was based on the van Manen thematic analysis method which is comprised of six steps. Those six steps are (1) turn to a phenomena of interest, (2) inquire and investigate an experience as it was lived rather than conceptualized, (3) reflect and analyze essential themes that characterize the phenomenon, (4) describe the phenomenon through the art of writing and re-writing, (5) maintain a strong and oriented pedagogical relation to the phenomenon, and (6) balance the research content by considering the parts and the whole (van Manen, 1997). This analysis will be discussed in detail in Chapter 6.

### Ethical Considerations

Because the sample size was purposive and small, one of the ethical considerations I was most concerned about was not being able to guarantee confidentiality. However, I made every effort to protect the identity of the participants throughout this study. For instance, there were no names or genders used, nor any association with the state the participant represented when referring to their responses. Identifying information which the participants themselves provided during the interview was also eliminated. The fundamental ethical principles of beneficence, respect for human dignity, and justice were incorporated into the design and I adhered to these

principles throughout this study. The principle of beneficence was addressed in the informed consent where participants were informed of the benefits and risks of the study.

I demonstrated respect for each individual throughout all phases of the study, and in all my communications with each of them. This respect was also conveyed by my notifying them that they had the right to stop participation in the study at any time. The ethical principle of justice was provided by ensuring participants the right to fair treatment and privacy. I provided each participant a copy of his or her transcribed interview and I encouraged each one of them to make any corrections or clarifications to the transcript to ensure I represented it accurately.

#### Trustworthiness

I used 10 of the 11 different methods to establish the trustworthiness of this study as outlined by Tashakkori and Teddlie (1998, p. 90-93). These 11 methods are (1) prolonged engagement, (2) persistent observation, (3) use of triangulation techniques, (4) peer debriefing, (5) referential adequacy, (6) member checks, (7) thick description, (8) dependability audit, (9) confirmability audit, (10) reflexive journal. and (11) negative case analysis.

I used the first method, prolonged engagement, by spending a lot of time with people (other than the six directors) in the palliative care field. This provided the “scope” for me that was needed to gain an increased awareness from the different perspectives of others than the six directors, about the problem. An example of this was my participation in palliative care seminars, conferences and symposiums across the country. The most recent one I attended was “The Initiative for Pediatric Palliative Care National

Symposium” on November 6-7, 2003 in New York. More than 500 interdisciplinary professionals attended this event and I networked with many of them to gain further insight into the barriers related to pediatric palliative care.

Persistent observation to obtain “depth” was obtained through my multiple observations of the problem in various settings and with various professionals who work with palliative care issues. For instance, I met with the Founding Director of CHI, Anne Armstrong-Dailey, who provided the history and the vision of CHI in addressing the lack of reimbursement for pediatric palliative care. I also met with the Director of Child Health and Financing at the National Association of Children’s Hospitals and Related Institutions, Sue Dull, to gain more depth on pediatric palliative care as it relates to health policy. In addition, I had multiple conversations with many of the leading pediatric nurse experts across the country with whom I worked on the Pediatric Palliative Care Training Program.

I used triangulation techniques which included observations, interviews, quantitative and qualitative methods. I consulted with other investigators, considered to be qualitative and quantitative experts, throughout this study to ensure that I was on the right track. Peer debriefings for credibility were done with three colleagues. I provided each of them with two interpretive summaries of the six transcripts and then asked them to report their results back to me. I did this to confirm that my interpretations and identification of themes were similar to theirs, and also to be sure I had not missed anything pertinent. Debriefing meetings were held with these same colleagues to clarify and confirm these interpretations.

Referential adequacy, for credibility, was obtained by my keeping all of the raw data (original transcripts, reflective notes, narrative notes, transcripts, feedback from the participants, electronic communications) and referring back to them several times throughout the analysis. Member checks for credibility were done when I contacted each interview participant and provided them a copy of the transcription for review, clarification and confirmation.

I used “thick description,” for transferability purposes, throughout the study by describing the details that I could, while preserving the privacy of the respondents. For instance, I described the body language, tone of voice and overall demeanor of some of the interview participants to provide a more vivid picture for the reader, but did not disclose the age or gender of the participant.

The dependability audit of this study was followed by my adherence to appropriate processes and methods of inquiry throughout the study. I did this by consulting both with my dissertation committee, qualitative and quantitative experts, and other doctoral colleagues.

A confirmability audit (internal validity of inferences) of this study demonstrates that my products of this inquiry are all supported by data which I myself obtained. I kept everything related to this study from the beginning to the end. For example, some of my comprehensive files, both electronic and hard copies, include the following, (1) communication with participants, (2) communication with my committee members, (3) communications with the HSRB, (4) drafts of the interview questions, (5) the audiotapes used for the interviews, (6) the transcripts of the interviews, (7) the interpretations of the

transcripts, (8) the categories and codes created from the interpretations, (9) all forms associated with this study, and (10) reflective notes and journals. All of these records are available for inspection and review.

In addition to just having all of these records, I actually checked and re-checked each of the documents related to this phase of the study to ensure that the information I was conveying could be confirmed, and it was. For instance, the transcripts were sent to each of the participants who in turn confirmed their accuracy. I also asked nursing colleague researchers to act as “devil advocates” to review the transcripts and identify in writing what they believed to be categories and themes. Their responses confirmed what I had found. I asked these same colleagues to meet with me so we could discuss their finding from the transcripts and again confirmed the results. I also went back and actively searched for anything that would contradict my interpretations and findings and could not find anything that did.

And finally, I kept a reflexive journal for confirmability, credibility, dependability and transferability for myself as the “human instrument,” (Sorrell & Redmond, 1995). This helped me to better understand my conversations with the participants as I re-read, relived, and reflected on the interviews. My reflections, documented into notes, also conveyed my own emotions as I too went through a new growth process documenting the frustration, the pleasure and the pain of being a “human instrument.” (Note: As stated earlier, I used 10 of 11 methods for trustworthiness as described by Tashakkori and Teddlie). The only method that was not used was “negative case analysis” since it did not apply. According to Denzin and Lincoln, “negative cases either disconfirms parts of a

model or suggest new connections need to be made,” neither of which applied in this study (Denzin & Lincoln, 2000, p. 782).

### Summary

The methodology used for this study was an interpretive phenomenological design with a purposive sample of six CHI PACC directors representing Colorado, Florida, Kentucky, New York, Utah, and Virginia. The data collection included semi-structured face to face interviews which were audio-taped and transcribed. The van Manen method of thematic analysis was done for data analysis. Ethical principles were adhered to throughout the study and 10 different methods were followed that established trustworthiness.

## Chapter 6

### Findings Phase II: Qualitative Study

#### Introduction

This chapter discusses the profile of the participants, the interview questions, the coding and categories, the van Manen method of data analysis, the responses to the interview questions and the thematic findings.

#### Participants Profile

Table 11 presents demographic information about the participants. The purposive sample consisted of six directors of the Children's Hospice International Program for All-Inclusive Care for Children and Their Families (CHI PACC) demonstration projects. The directors represented the following states: Colorado, Virginia, Florida, Kentucky, New York and Utah. Three of the director participants were female and three male. Five of these participants were Caucasian, and one was Asian. The ages of the participants ranged from early forties to the mid -sixties. Education backgrounds of the participants included two with doctoral degrees (one in medicine and one in philosophy), three with master's degrees and one with a bachelor's degree ( See Table 11).

Table 11. *Profile of Interview Participants*

Participants	Gender	Age	Ethnicity	Education	Affiliation	# Interview Transcription of Pages
Pilot #1	Female	40's	Caucasian	PhD (c)	University	Not transcribed
Pilot #2	Female	50's	Caucasian	PhD	University	Not transcribed
Participant #1	Male	40's	Caucasian	MD	Children's Hospital	14
Participant #2	Male	60's	Caucasian	MBA	Hospice	13
Participant #3	Female	40's	Asian	BSN	Hospice	7 Problem with taping
Participant #4	Male	50's	Caucasian	PhD	State Health Dept.	18
Participant #5	Female	60's	Caucasian	MS	State Health Dept.	16 Problem with taping
Participant #6	Female	50's	Caucasian	MA	State Health Dept.	32

I interviewed each of the six directors with an average interview time of 40 minutes. I asked the following questions to each participant:

1. Would you tell me, in your own words, about a specific time when you were able to overcome some barrier to pediatric palliative care services?
2. Can you share a story, in your own words, about a particular time you felt good about the work you are doing to make a difference in the provision of pediatric palliative care services?
3. Can you describe in your own words, the qualities you think it takes for someone like yourself, to overcome barriers in order to provide pediatric palliative care services?

With the permission of each director, I audio-taped the conversation, had the tape transcribed by a professional, experienced transcriptionist and then I interpreted the transcripts using the van Manen method for data analysis. The finished product was 100 pages of verbatim text with a range of seven to 32 pages.

#### van Manen Method of Analysis

I began this analysis process with Step 1, “turning to a phenomenon of interest,” when I began working on end of life care while employed at the American Association of Colleges of Nursing (AACN). Although my work at AACN initially started out with a focus on adult end of life care issues, the need for end of life education and research for the pediatric population quickly came to the forefront. This was a result not only of the recommendations in the 2003 Institute of Medicine’s report: *When Children Die*, but also through the expressed concerns of hundreds of nurse educators who attended the adult End of Life Nursing Education Consortium (ELNEC) training. They identified a need for

expansion of this training to be specific for the pediatric population. Thus, my work at AACN soon expanded to include pediatric palliative care as well.

Van Manen's Second Step, "inquire and investigating the experience as it is lived, rather than conceptualized," was followed when I conducted semi-structured interviews with the six PACC directors. The purpose of the interviews was to obtain a better, deeper understanding of what the directors personally experienced in their daily lives as they worked on issues related to pediatric palliative care. The interviews, audio-taped by me and then transcribed by an expert transcriptionist, were verified by each of the participants for accuracy. Furthermore, field and reflective notes, which I had written following each of the interviews, were referenced by me for specific details regarding the participant's body language, tone of voice, and overall demeanor that were expressed during the interviews, to confirm my recollections.

Based on van Manen's third step in the data analysis method, "reflect and analyze essential themes that characterize the phenomenon," I read and re-read each of the transcripts, using a "holistic" or contextual approach (Mason, 1998, p.166). I "noticed" certain features in the data for "tagging" (Tesch, 1990, p. 119) and identified "chunks of text" which were then analyzed, coded, and put into themes (Denzin & Lincoln, 2000). Initially, I identified key words in the context and circled them on each of the transcripts, and made notations on the side of the paper. I then compiled a list of chunks of text to identify repetitive ideas and to think about their meanings. I read and re-read the transcripts, circled meaning units, for "de-contextualization" (Tesch, 1990, p. 115). I then created a numerical organizing system based on where they were located in the

transcripts (Polit & Hungler, 1995, p. 526). For instance, a segment from the first interview that appeared on the first page on line 36 was identified as 1.1.36. These meaning units were then sorted, according to their responses to the three interview questions. Continued reflection and immersion of the transcripts, and the meaning units, led me to identify seven categories: access, advocating, communication, change, education, finance, and leadership, which were then color coded.

### Coding

Codes were then created to reflect these seven categories, and the following colors were assigned:

- Purple = Access = ACC.
- Yellow = Advocate = ADV
- Blue = Communication = COM
- Orange = Change = CHG
- Pink = Education = EDU
- Green = Finance = FIN
- Red = Leadership = LDS

I continued reflecting, analyzing, writing, and re-writing. I cross referenced the color codes with the meaning units in the numerical coding system. I then did interpretive summaries to assist in the formation of themes, which are “abstract constructs investigators identify before, during, and after data collection” (Danzin & Lincoln, 2000, p. 780). I collaborated with three other researchers, each of whom read and interpreted

two of the six transcripts. Overall, their interpretations matched with mine and proved to be very helpful in discussing themes. It was through discussion with these other researchers that my themes solidified. While there were multiple metaphors found within most of the transcripts, the following three themes evolved as being the most representative in the text, (1) Leaders and Labyrinths, (2) Making Change with Dollars and Sense and (3) We Are Just Soldiers. Each of these themes will be discussed in more detail later in this chapter.

I followed Step 4 of the van Manen method for data analysis, to “describe the phenomenon through the art of writing and re-writing,” I made revisions of my writing based on my re-reading the transcripts. I wanted to read between the lines to be sure I did not miss anything. I re-listened to the tapes, in order to hear the silence.

I wanted to be sure I wasn't overlooking key things that may have been purposely omitted, not verbalized. I did all of this to have a better understanding and to make meaning.

Step 5, “maintain a strong and oriented pedagogical relation to the phenomenon,” was followed by my being an active listener and by being “present” as the participants described their human experiences about pediatric palliative care with me.

The last step, Step 6, “balance the research content by considering the parts and the whole,” was done when I used de-contextualization and re-contextualization with the meaning units. By taking the text apart, and putting it back together again, I gained insight into the whole picture.

### Findings: Interview Question #1

The first interview question I asked of participants was for them to tell me about a specific time when they were able to overcome some barrier to pediatric palliative care services. Most of the responses to this question fell under the category of working to overcome financial barriers. Examples of these financial barriers are listed by excerpts from participants' comments below.

#### Financial Barriers

*...There would be no reimbursement...The insurance just stopped. ...There was no sympathy from Medicaid... We looked at ways to reduce costs.*

*We had to learn to define dollars and cents. Insurance doesn't cover it.*

*We had to learn to negotiate the rate. Cost is the major issue. The cost and the control of costs, and who actually would have ultimate control of what, what is being spent and how that would play out as the program evolved. We have tried to use historical data sources to illustrate what it is costing now and what might be saved. In one sense it is hard to imagine we could do any worse financially than we are doing now with these kids.*

*We had to find a code that would fit for reimbursement. To create a new code required an exorbitant amount of time that had to go all the way to the federal level and whether you ever got it approved or not, still would remain a mystery, so finding an existing code was really a monumental task. But there were many obstacles in terms of figuring out the levels of specificity that they required in order to accurately project over five years what our cost neutrality would be. Getting all the finance, accounting, reporting of costs neutrality data in the format the feds want and there are thousands and thousands of*

*codes to go through to find one that would actually fit We have to find out how to do that and we think we have figured out how to do that.*

Other barriers participants included as being challenges to overcome were (a) access to care, (b) the lack of education, (c) challenges with communication, (d) implementing change, (e) advocacy, and (f) leadership. Below are a few excerpts from the transcripts which demonstrate these issues.

#### Access to Care

*One of the challenges that we face is that we have a large catch-net area and so we extend into two other states. One of the problems that we face is children who are terminally ill and need to be cared, or want to go home and be cared for in their hometown, may not have access to Palliative Care Services, particularly agencies that are comfortable taking care of children who are dying.*

*The instance that comes to mind is a young lady who was dying of a metastatic sarcoma. She was only three years old and lived in the middle of the state. We were able to, with the help of our PACC Grant, go to this small town to educate the care providers, and the child was able to die in her own home. Had we not done that, she would have had to have moved, or her family moved two hours away so they wouldn't be around family or friends. I think that just the education piece, of overcoming the fear of taking care of terminally ill children, I think is one, to me, that was a variable that we were able to overcome for this particular family and in this particular town.*

### Lack of Education

*One of the barriers is lack of education on the part of the nursing staff and medical staff on pediatric palliative end of life care. I have no training whatsoever, just on the job training. Educational needs are almost identical for each place because they want everything, they want to hear about everything, all of the aspects of Pediatric Palliative End of Life Care. The education piece was a variable we were able to overcome. I think it is just talking to them. It's really important to talk. We went from Division to Division talking about the program. Many Hospice agencies are uncomfortable caring for children because they just don't have the knowledge. I think it is just talking to them. If people know that consultants are available, and I think just having the knowledge that somebody is there to back you up, is comfortable enough.*

### Challenges with Communication

*The best feeling that I recall was at the end of the first year of the project. The real barrier was Medicaid's understanding of the PACC concept. It was at that point in time that the Medicaid Agency had the lead on this project. They brought in a researcher, who did not have a whole lot of background in Palliative Care or Hospice. We implored all the Hospices with experience, to smother this guy with information. An objective of the PACC project is to allow different things to happen in different states, so we can use the best ideas, but different things cannot happen if you reach an impasse. He was picking up different trees in the forest and trying to see the way out and then after about 10-11 months of the year, it just clicked. We were able to get the providers back around the table and the pediatric physicians, and the researcher*

*laid out a concept and all the heads starting nodding up and down, and we knew we had passed the big one. Sure, the details needed to be worked out and “the devil is in the details,” in a project like this. In something as complex as end of life care, if you can’t feel good about the concept, you are never going to work out the details so that was a milestone for the project.*

Other viewpoints about communication challenges were:

*But there were many obstacles in terms of figuring out the levels of specificity that they required in order to accurately project over five years what our cost neutrality would be. And another’s ..They hadn’t coalesced. So one of my challenges was to ensure that I could get all of these people, at the same table, talking together and heading in the same direction, instead of putting their energies into the internal conflict.*

#### Implementing Change

Another participant describes the importance of knowing what needs to be changed in order to change it—in this case a licensing law.

*You have to know the systems you are trying to change.... being diplomatic is important towards making these changes. We worked with our licensing agency trying to get them to change their mind set. Here the participant recognizes that change takes time. It takes time to build a program such as this because in some ways, you are just changing a whole culture. This participant demonstrated how education was important to making change. By the time we explained what this would be and how it would work there was a willingness to make a change, to allow an exception for this particular group.*

Advocacy in Leadership.

*We see that as our role [advocate]. We were successful in persuading the state government to add a mandated insurance benefit for hospice...to convince them that it can really work. Another participant supports the role of advocates in the statement; I think it is critically important in our state to have primary advocates for the project...so that they can bring together various entities in a much less conflictual and a much less turf-laden kind of way. There is inevitably a different point of view between advocates, people who work in the field, and are very familiar with what is going on the field, and people who in a regulatory way administer that field. I think that it is really important to talk, to continually bring up the program at different times, in different venues, so that as many people that are involved with decision making can see what has been accomplished. It is taking advantage of those opportunities to talk and not turn down speaking engagements, you know, the chance to kind of blow your own horn a little bit. I think being an advocate for your program, believing in it is really important and so that is going to be my next challenge.*

Findings: Interview Question #2:

The second interview question I asked the six directors was: Can you share a story, in your own words, about a particular time you felt good about the work you do to make a difference in the provision of pediatric palliative care services? These responses were related to the first question in that the barriers were also some of the same things

which made them feel good about the difference they were making with pediatric palliative care such as (a) implementing change, (b) accessing data, (c) finding solutions, and (d) talking with families. Below are some excerpts from the transcripts which highlighted these responses.

#### Implementing Change

*One of the neat things that has happened is that the residents and house staff are getting used to calling us and consulting. I am excited that we have been able to affect that change, people understanding that that is important to get people involved to help someone who has a life threatening illness. It's just fascinating to watch the change, referrals are up by about 100%.*

*Another excerpt. It is hard to feel any sense of triumph for what you have achieved with most of these kids, and then you see one Mattie [Stepanek] ... he came weaving through in his wheelchair, in a room of 100 people, he is navigating in between them, and people are giving him high-fives and all that, and that is what this is all about. We need to look at Mattie and say, in his short life, look at what he has accomplished versus what we have all been able to do with our years. When his book comes out [a book authored by Mattie] and he gets a national reputation, that is just frosting on the cake.*

#### Access to Data

*Enlisting the services of an actuary was this project's biggest success. The Medicaid office in any state is under very difficult restraints by the federal government as to how they use this data and how and who they release it to. I think when that actually happened [getting the data], we viewed that as the triumph, regardless of what the data*

*would ultimately show But just actually getting the information, to be able to do so, I think was kind of a first triumph.*

### Finding Solutions

*Nothing has been a major setback. We have found solutions to really everything. I think it was meant to be because we have not come up against anything insurmountable. I do believe this project is meant to be...it's an ethereal kind of thing.*

### Talking to Families

*Talking to the families first hand. Learning what they had gone through, it's kind of the engine that keeps you going. Also, the learning from each other (PACC projects) We are all expendable. It is important to mentor.*

### Findings: Interview Question #3:

The third and final question I asked of the six directors was: Can you describe in your own words, the qualities you think it takes for someone like yourself, to overcome barriers in order to provide pediatric palliative care services? This question produced a plethora of responses from these directors who identified qualities, skills and knowledge, which based on their own experiences, were felt by them to be important when trying to overcome barriers for pediatric palliative care. The major qualities they identified were: resourcefulness, faith, communication skills, flexibility, patience and commitment, modeling, and respect. Their responses also spoke to optimism, sensitivity, being a

systems thinker, a critical thinker, and having the skills of a diplomat for advocacy purposes. Put these all together and you have a dynamic leader! Here are some excerpts from the transcripts:

#### Resourcefulness

*You have to be able to wear a lot of different hats. It isn't just having the right contacts in place, you need to be resourceful and need to delegate to different people with more expertise than yourself. You have to have a concept of grant writing, and financing and doing budgets and things like that. There has to be a willingness to tolerate setbacks, to know that it is going to take time for change. You need to be willing to go to bat for your program. Being clinical, understanding the Medicaid system and being able to delegate were some of the other qualities given as a response.*

*You have to have a bureaucratic mind and understand state and federal government. You've got to know, at the state level, the Medicaid program and how it operates, how it is funded, how it reimburses. You have to have a feel for the whole Medicaid system. It is also extremely helpful to have experience with Medicaid waivers, because there are many different kinds of waivers, and to figure out how to accomplish something via which waiver, what is a good match. ....and having an understanding of the Health Care delivery system*

#### Faith, Unconditional Love and Good Communication Skills

*We are just soldiers, we are not the General. We go in and do the best we know to do and then somebody else controls the outcome. We have the ability to make a difference in people's lives. People have faith in themselves or faith in some higher*

*power and they feel they are just doing their part. This participant went on to say directors are able to reach down for the additional dimension and it extends to the family and so forth. That's where I draw mine from [an additional dimension], knowing people like that. Notes from families, people survive on those notes, because they know what the relationship was. Unconditional love..somebody who asks nothing of you, but is willing to give of themselves are qualities of people who work with palliative care.*

Additional qualities needed by a director as stated by this same participant were: *being a good listener and having good communication skills; working with legislators when talking to them about the business and psychosocial sides, that is the duty I have when I talk to legislators in various capacities over time... explaining to them how much we can do with nothing. We are educators ...we were successful in persuading the state government to add a mandated insurance benefit for the hospice in the state.*

#### Flexibility and High Energy

*In order for someone to survive in a role like this, one has to be comfortable in being flexible, that's the key. Everybody brings their own "gift" to the job, but sometimes because of these different gifts, and a lack of understanding, there might be a rub. You need a high energy level, the ability to be open and honest and the ability to charge in and at things when needed.*

#### Patience and Commitment

*The key word is patience. I think that it is very easy to get frustrated and to kind of throw up your hands and I think that particularly, in a very large agency, you have to*

*find a way to kind of narrow your time frame and your time horizon, so that you don't get frustrated when things don't seem to happen quickly, because they don't happen quickly.*

*...Organizations never act quickly, but particularly when a lot of money is at stake, or the perception that a lot of money is at stake...they move even more slowly. You just have to be very, very patient. I think that patience on everybody's part is required. We have been very, very patient. You need to have patience. Things take a long time to unfold.*

*...I think that is why we have gotten as far as we have and we are optimistic that we are actually going to achieve the kind of program that we think we can achieve. I think you have to have a certain amount of commitment to it [the program]. I think that you have to be committed in the sense that given the glacial time frame that things often move, that you are able to overcome whatever obstacles there are and do what is necessary within the constraints you have as an employee of the bureaucracy. You can't be afraid to say, I really don't know.*

#### Modeling and Respect.

*I think it goes back to modeling. Being respectful of people, being able to listen and really work with them to make them understand. I have this notion that we are expendable and that it is important to mentor.*

#### Theme Analysis

Phenomenological themes, or “structures of experience are ways to describe the lived experience” (van Manen, 1997, p. 79). According to van Manen, “theme analysis is the process of recovering themes that are embodied and dramatized in the evolving

meanings and imagery of the work” (van Manen, 1997, p. 78). The “discovery” of the interpreted meaning from a lived experience, or “grasping and formulating a thematic understanding is a free act of seeing meaning” in the interpretation of the lived experience (van Manen 1997, p. 79). Themes can be incidental or essential. However, it is for the essential themes that a phenomenologist uses “free imaginative variation” to “discover aspects that make a phenomenon what it is and without which the phenomenon could not be what it is” (van Manen, 1997, p.107).

Initially I worked with eight themes which I felt were “knots in the web of the experiences” of the directors (van Manen, 1997, p. 90). However, the more I asked myself questions about whether or not these themes were “incidental or essential” and corroborated with colleagues about the initial themes, I reduced them to three, (1) “Leaders and Labyrinths,” (2) “Making Change of Dollars and Sense” and (3) “We Are Just Soldiers.”

All three themes were part of the original ones identified, but were more finely tuned to better reflect the meaning behind them. For instance, using “free imaginative variation,” I changed one original theme from “Pioneers in a Maze” to “Leaders and Labyrinths.” I did this following a debriefing meeting with my colleagues who suggested that “Pioneers” just didn’t seem to convey the true essence of the experience. I reflected on this theme and considered changing it to “Mysteries and Mazes” or “Meanings in Mazes,” but again I didn’t feel it portrayed the true “essence” of the directors’ experiences. After further discussion and more “free imaginative variation” with a colleague about “mazes” and “labyrinths” the term “leaders and labyrinths” evolved. I

knew when I heard it, that this was an essential theme and one which would best represent the lived experiences of the directors.

The second theme, “Making Change with Dollars and Sense,” originated from preliminary themes entitled, “Duty for Dollars,” “Two Sides of the Coin” and “Catalysts for Change.” However, as with the first theme, the more time and reflection I gave to the names of these preliminary themes, the more I realized that they needed to be strengthened to provide the true meaning. Using “free imaginative variation” again, I believe I came up with a creative, essential theme, “Making Change with Dollars and Sense” because that was exactly what the directors were trying to do – making change to systems using government dollars and cents!

The third theme, “We Are Just Soldiers” was a preliminary and final choice in the data analysis and was a direct quote used by one of the participants in the study.

#### Summary

This chapter discussed participants’ profiles, responses to the interview questions, categories and codes, and the themes Leaders and Labyrinths, Making Change With Dollars and Sense, and We Are Just Soldiers.

## Chapter 7

### Discussion

#### Introduction

This chapter will provide the background and rationale for this study, a general overview and the interpretations of the results of the investigation. Other topics covered in this chapter will be the integration of the findings with the theoretical framework, the limitations of the study and the implications of the study as related to nursing education, practice, research and policy. The chapter will end with recommendations for future research and a conclusion.

#### Background

In 1999, the Institute of Medicine's Board on Health Sciences Policy recommended that the IOM form a committee to investigate care for children who die and their families. The study began in 2000 and was funded by public and private agencies. It was overseen by 14 experts who represented professionals in the disciplines of nursing, medicine, social work, economics, ethics, academics and research. The committee had three major goals which were to (1) "develop recommendations to

strengthen the knowledge base for compassion and effective care for dying children and their families; (2) inform health care providers, researchers, medical and nursing educators, state and federal policy makers, insurers, and others about the recommendations; and (3) encourage thoughtful discussion of what constitutes good end-of-life care for children and their families” (Field & Behrman, 2003, p. 445). The product of this committee’s work was the IOM 2003 report “*When Children Die: Improving Palliative and End-Of-Life Care For Children and Their Families.*”

#### Rationale for the Study

The 2003 IOM report, “*When Children Die: Improving Palliative and End-Of-Life Care for Children and Their Families*” reported that two common phrases in their report were “research is limited” and “systematic data are not available.” This same report stated that the “knowledge base for organizational and policy decisions is likewise limited” and that “only a tiny fraction of research involving children is to support improvements in palliative, end-of-life and bereavement care for children and their families (Field & Behrman, 2003, p. 350 -353). Based on the work done by the committee that created this IOM report, several “directions for future research” were recommended. One of those recommendations was specific to “financing pediatric palliative and end-of-life care” and discussed the importance of identifying reimbursement methods. Because this researcher was already working on national end-of-life education projects, and specifically a pediatric palliative care project, it seemed like a logical fit to further the research by conducting a dissertation study on this topic.

### Overview of Study

Children are dying and not receiving palliative care, often because of barriers to reimbursement for end-of-life care (Field & Behrman, 2003). The purpose of this study was to explore the barriers of pediatric palliative care programs and their relationships to funding, and to better understand these barriers as seen from the lived experiences of six directors of the CHI PACC demonstration projects. This study was a response to the 2003 Institute of Medicine's (IOM) report, *When Children Die: Improving Palliative and End-of-Life Care for Children and Families*, which addressed the complexity of reimbursement issues and recommended further research. This study, a sequential mixed methods design, used quantitative techniques and a qualitative, phenomenological approach to research the question: Does the reimbursement of services for the delivery of pediatric palliative care differ between types of funding, and is funding related to directors' perceptions of obstacles to the delivery of care?

### Phase I

This was a non-experimental, descriptive correlation study that identified frequencies and proportions of programs that acknowledged reimbursement barriers and their relationships to funding sources. The study began with a target population of 160 health professionals and was reduced to an accessible population of 130, yielding a sample of 37 subjects in the role of administrator, director, or coordinator of palliative care services in a health care facility in the United States. Data were obtained through a self-report instrument. Bivariate descriptive analysis was done using Version 10 of SPSS. A summary of the results included the top three items rated as the most severe

barrier for staff to provide care and were, (1) the staff being unaware of community funds that may be accessible for palliative care, (2) staff being unaware of foundation funds available within their organization that could be used for palliative care, and (3) the lack of standardized competencies for staff to provide pediatric palliative care. The top three items rated as the most severe perceived obstacles in providing care were, (1) the association of hospice or palliative care with death, (2) physicians' reluctance to make referrals for pediatric palliative care, and (3) the family's reluctance to accept palliative care. Other key findings included, (1) that the majority of palliative care services reimbursed were for physical care services versus psycho-social services, and (2) there is a significant relationship between reimbursements for private insurance with perceived obstacles.

## Phase II

Phase II was an interpretive, phenomenological study conducted to better understand the barriers to the implementation of these programs as seen from the experiences of the directors of six federally funded demonstration programs, located within the United States. Data were collected using in-depth, semi-structured interviews that were audio-taped, transcribed and interpreted using van Manen's method of thematic analysis. The three themes that emerged were: Leaders and Labyrinths, Making Change of Dollars and Sense, and We Are Just Soldiers.

## Interpretations of the Study

The three themes which evolved from the interpretations of the interview transcripts were: Leaders and Labyrinths, Making Change of Dollars and Sense, and We Are Just Soldiers. Each of these themes will now be discussed and will include the integration of findings from the quantitative study as appropriate.

### Moving From Mazes to Labyrinths

When I interviewed the directors of the CHI PACC programs, each of whom were mature, experienced, skilled and knowledgeable leaders, they related the challenges they faced with getting started on their projects. In many respects, they had gone from being experts, back to being novices. They found themselves in a new environment that wasn't easy to navigate. This was due to what seemed like never-ending obstacles, "dead ends" and the "hitting of walls" they encountered along the way. Hearing it reminded me of a mouse in a maze, scurrying about trying to find the cheese that kept evading the mouse as portrayed in the popular management book, "Who Moved My Cheese?" In this case, six directors were temporarily lost, or at best confused, in a monumental maze of maddening methods; methods that hindered rather than helped in serving the needs of dying children.

People often confuse mazes and labyrinths. In fact, according to the Random House College Dictionary, a "labyrinth" is defined as, a) "a devious arrangement of linear, patterns forming a design," b) "a system of passages or paths having such a design as a maze," and c) "anything that is bewildering by its complexity" (Random House, 1984). I thought that the two terms could be used interchangeably, that was until I

did some further reading on mazes and labyrinths. I discovered that even though the dictionary defines a labyrinth as “having such a design as a maze” this really is not the view of experts who study these ancient symbols. A maze is a like a mystery, “full of twists and turns and blind alleys, a puzzle to be solved”

([www.crystalinks.com/labyrinths](http://www.crystalinks.com/labyrinths)). Entering, following, and finding one’s way into, around, behind, beside, under, or on top of the many paths that intersect in a maze, requires strong critical thinking skills or using the left side of one’s brain. Did I come this way before? Will this path lead me where I need to go? How can I limit the number of dead end paths I take? How did I get myself into this maze in the first place? Who can help me get out of it?

Labyrinths, on the other hand, are unicursal. They only have one well-defined path and that path leads to the center of the labyrinth and back out again. Finding one’s way through a labyrinth requires the use of the right side of the brain, or the use of innovative and creative thinking skills, in balance with left brain thinking. In my opinion, the CHI PACC leaders started out in a maze of policies and procedures that didn’t fit the needs of children. After finding that all those roads went “no where,” they found themselves “now here.” They had crossed over from left brain thinking to right brain thinking into a labyrinth, where creative, innovative and intuitive ideas are balanced with solutions formulated in the left side of the brain. They had become “Leaders in Labyrinths”.

### Leaders in Labyrinths

One participant stated, *I felt like I was a pioneer in terms of trying to identify the target population using only the claims data Medicaid had access to.* This participant goes on to describe the experience associated with being a leader in a new field. *I am a novice in a lot of this stuff. We have started something that other states have modeled and improved on. The first year we were given an opportunity to learn and really get a sense of, what's the population, what's the need, what will it cost, [so that] we will be able to open the door to families whose children do not qualify for Medicaid.*

Another one of the directors recalled, *there was not any specific template [for educating others about palliative care], we just designed it ourselves. I think that the approach to Pediatric Palliative Care is very different from adult palliative end of life care and that this is like kind of the tip of the iceberg. I mean we are just really making some headway, not a whole bunch. I had no training whatsoever [in palliative care] and that is pretty much par for the course, so you kind of learn just on the job training. We've laid a lot of groundwork. It takes time to build a program because in some ways you are changing a whole culture.*

Hitting walls and obstacles, taking a wrong turn or losing one's way, is not uncommon when exploring new paths or trying to find one's way out of a maze, or labyrinth. These types of experiences seemed to be the norm for these "labyrinth leaders." One state representative discussed how *the bringing of different parties together to begin the dialogue about how to create a PACC program, and the various obstacles that might be present and how to overcome them, brought very different*

*agendas and solutions.* This participant went on to say, that *people who worked in the field came to meetings with a rah, rah kind of viewpoint and advocated for finding a way to get this done [creating a PACC program], while other people who worked in the regulatory realm viewed it as one more task that emerged and wondered how they would manage and integrate this with all their other tasks.*

This example demonstrates how people who venture into new and complex territories, even leaders, have different attitudes, strategies and time frames for finding their way around and about. Even those who were new to this project, and had years of experience in project management or health care had new discoveries and frustrations along their labyrinth journey. According to a seasoned participant, *getting a waiver was a monumental task. Another milestone was finding the code for the service and finding one that would fit. To create a new code required an exorbitant amount of time that had to go all the way to the federal level and whether you got it approved or not, still would remain a mystery.*

When exploring new paths there are always multiple questions and perhaps fears about the unknown. And yet, there are meanings to understand as well. It was no different with these “Leaders in Labyrinths” who expressed their thoughts and feelings about going on a path where others had not yet been, recounting their own personal story of overcoming barriers to pediatric palliative care services. *How will we do this? How will we be able to see our way through? How will we keep this going? How will we fund this? What are the right codes? How do we get this to work? What is the balance between ethics and the law? What’s the population? What’s the need?*

And as with most new explorations, the findings of this study reiterated that there is a need for “Labyrinth Leaders,” to continue to face the barriers to pediatric palliative care. The barriers identified by these leaders were: finance, access, advocacy, communication, change, and education.

### Connections with Quantitative Findings

#### Finance and Lack of Knowledge of Financial Sources as a Barrier

The issue of finance as a major barrier in the provision of pediatric palliative care programs was resounding as evidenced in each of the six interviews that were conducted with the CHI PACC directors. These barriers, according to the directors, included frustration with insurance companies with specific issues such as, not knowing which insurance plan reimbursed for what service, what the charges were, and whether or not these charges, or what part of the charges, would be reimbursed to the provider. And if the services would be reimbursed, at what percent? This financial barrier, according to the directors, often further impacted families in ways that many of them had to end up paying exorbitant amounts out-of-pocket to get the proper care for their child.

The quantitative part of this study identified finance as a barrier in two of the top three staff barriers that directors rated as the most severe barriers for staff to provide pediatric palliative care services. These financially related findings were (1) staff being unaware of community funds that may be accessible for palliative care, and (2) staff being unaware of foundation funds available within their organization that could be used for palliative care. This was interpreted to mean there were barriers with the staff's

knowledge of finance. It could be argued that if the staff were better educated about the different types of funding, in this case, community and foundation funds, then perhaps more financial resources could be made accessible to the child and family to receive either physical or psycho-social services that might not be covered by insurance plans. Further discovery in the quantitative portion of this study identified that the majority of services that were reimbursed were for physical care services versus psycho-social services. This study also revealed that there is a significant relationship between reimbursement for private insurance with perceived obstacles. Because finance was apparent in the findings from both phases of the study and evolved as one of the three themes, it will be addressed more in depth in the next section of this chapter under the heading of Making Change with Dollars and Sense.

#### Advocates for Access

Leaders are often in positions where it is necessary for them to promote, lead in favor of, support or urge by argument, and many times publicly recommend improvements for pediatric palliative care. This usually requires expert skill in the art of persuasion and influence as one participant demonstrated by the following: *We see that as our role [advocate]. We were successful in persuading the state government to add a mandated insurance benefit for hospice...to convince them that it can really work.* The work of this project team helped to provide more access to pediatric palliative care for children who otherwise were not receiving it.

Another participant emphasized the role of advocate in the following statements: *It is getting people to buy into the concept [of pediatric palliative care]..I think it is really*

*important to talk, to continually bring up the program at different times, in different venues, sell the program, talk about it and take advantage of those opportunities and not turn down speaking engagements.. blow your own horn [About the pediatric palliative care program].*

#### Access as a Barrier

Findings from this research as related to staff barriers indicated that one fourth to one third of respondents felt that nurse's unawareness of community and foundation funds created a severe barrier to children having access to pediatric palliative care services. Therefore, the nurse, as advocate for the child and his family, needs to become more knowledgeable about which services are, and which services are not, reimbursed by the family's insurance plan. The nurse can do this in collaboration with the case manager. This knowledge helps to guide the nurse advocate when treatment options are being discussed by the physician with the family. In addition, when the nurse knows what specific community, foundation and other philanthropic funds can be accessed for services for the child and family, she can negotiate for these funds and services (Armstrong-Dailey & Zarbock, 2001, p.96). This will not only increase the access to care, but also will help raise awareness of leaders in the community for where the funds are accessed. In time, a particular foundation could make pediatric palliative care their focus.

#### Communicators for Change

When "leaders" start to infiltrate territories, or turfs, of other people, they may find that they are not always welcomed with open arms. Many times this is due to their

differences and not their similarities. Perhaps those people whose turf is being invaded do not share the same philosophy, values or experiences of the leader, and often times may not want to know about any similarities with them. Usually it is a lack of knowledge and understanding that creates resistance. This is where the importance of communication plays a key role with the leader.

One director summarizes the importance of providing information in order to help another understand by the following: *At the end of the first year of the project the Medicaid agency who had the lead in the project at that time, brought in a researcher who did not have a whole lot of background in Palliative care or Hospice and so you know we implored all of the Hospices with experience to smother this guy with information...but different things can't happen if you hit a wall...he was picking up different trees in the forest and seeing the way out...after about 10-11 months we able to get the providers around the table and it just clicked...we started talking, we were communicating...we came together..he understood. We knew then we had hopped a big barrier.*

Communication also needs to be individualized by the leader to make sure that professional jargon, some, or all of which might not be understood by others, does not create additional barriers for moving the project forward. Sometimes a person in a position of power can test the patience of a “labyrinth leader” and appropriate communication methods may need to be adjusted, as the following demonstrates: *The new president was a very, very, very aggressive male...not knowing anything about our state...his naiveté and lack of experience was such that he thought all the children should*

*be put into a Hospice. He was coming from the very standpoint of just kind of taking over the world. It took patience but it also took aggressiveness to stand up for what needs to be done. I actually had to stand up to him verbally. I think that once he learned more he became more understanding...but once he crossed over the professional line and became more assertive, I would just become more assertive back...eventually we came to respect each other...he went out of office and we got a new replacement that really fixed everything nicely{laughter}.*

The participant emphasized the importance of communication and gave reference to “talking” more than ten times in the interview. *“I think it is just talking to them” ...It’s really important to talk ...we talk...we went from Division to Division in the [organization] talking about the program.”*

Another participant described the importance of knowing what needs to be changed in order to change it –in this case a licensing law. *You have to know the systems you are trying to change.* It is also implied that one needs to know what isn’t working right in the system, or in other words, what barriers are preventing the system from working smoothly. It is implied there is frustration associated with changing systems and peoples thought processes and the time involved to do this as is indicated in the phrase *that being diplomatic is important towards making these changes. We worked with our licensing agency trying to get them to change their mind set.* Here the participant alludes to the time and energy it took to educate, persuade and influence others on the facts regarding the services needed for children and their families. The emphasis was to

provide services at the time of diagnosis and throughout their life threatening illness, rather than just at the last six months of life as the law stated.

#### Communication and Change as Obstacles

Findings from the quantitative portion of this study support the findings from the qualitative portion in identifying communication and change as obstacles. For example, one of the top three items rated as a severe obstacle in providing pediatric palliative care was the reluctance of physicians to refer patients for palliative care. This is a communication issue and also one related to change since physicians are reluctant to talk about changing their practice from “curing” to “caring.” This could also be related to the fact that most medical curricula fail to provide medical students with the skills, knowledge and attitudes to care well for the dying (Ferrell & Coyle, 2001; Stephenson, 2000). From a qualitative perspective, the interviews with the directors of the CHI PACC projects reported communication as a barrier and so did the directors of pediatric palliative care programs in the quantitative study.

Results indicate that this lack of communication negatively impacts children and families and changes need to happen to turn this around. For instance, (a) staff need to be well informed about all funding sources so that children and families can access the care they need, (b) physicians need to be better informed about the differences in hospice and palliative care so that they will increase referrals for this service, and (c) families need to understand what is involved with palliative care so they can disassociate themselves with death and concentrate on quality and sacred time with their child. All of this requires excellent communication skills on the part of the communicator. Not only do health care

providers need to “walk the talk,” we need to do a better job of “talking the walk” and this includes doing it in the areas of education, practice, research and policy.

#### Education and Leaders

One particular participant whose body language demonstrated pride and confidence in accomplishments with the PACC project had this to say. *..One of the problems that we face is children who are terminally ill and need to be cared for, or want to go home to be cared for in their hometown, may not have access to palliative care services, particularly agencies that are comfortable taking care of children who are dying. We were able to educate the care providers so that the child was able to die in her own home. I think just the education piece, overcoming the fear of taking care of terminally ill children, I think is a variable we were able to overcome.* This same participant discussed how the project was doing onsite education seminars and related that they were *targeting as many people as possible... because they [caregivers] want everything, they want to hear about everything, all of the aspects of pediatric palliative end of life care.*

Another leader shared this experience. *There were no specific templates [for education seminars] we just designed it ourselves. There is a lack of education on the part of nursing and medical staff on pediatric palliative end of life care. I have no training whatsoever and that is pretty much par for the course, ..so you kind of learn, just by on the job training.*

### Education as a Barrier

Again, both phases of the study support each other in the sense that the lack of education is a major barrier. For example, in the quantitative portion of this study, one of the top three staff barriers, as reported by directors of the pediatric palliative care programs, was that the lack of standardized competencies for staff was a severe barrier to provide pediatric palliative care. In this same phase of the study a severe obstacle to care was the physician's lack of referrals of children for palliative care –clearly another educational issue. From the qualitative phase of this study, the lack of education was mentioned multiple times by most of the participants as a barrier to care.

The bottom line is that there is a lack of education with the majority of health care professionals which negatively impacts the access, cost and quality of care that we provide to children and their families. Education efforts have begun with specialized programs about pediatric palliative care across the country. Some focus only on nurses, some on physicians, and others on social workers and not enough on the interdisciplinary approach. Education needs to be provided to all members of the health care team.

### Making Change with Dollars and Sense

The second theme, *Making Change with Dollars and Sense*, was evident from the interview transcripts and identified the lack of financial reimbursement for pediatric palliative care services as a major barrier. Many responses were in reply to the second question participants were asked, which was to share a story in their own words about a

time they felt good about the work they were doing with pediatric palliative care. It was interesting to hear, and then to read, that a lot of the directors' job satisfaction in working with pediatric palliative care came from being able to make changes happen, especially those that are related to money and common sense. Some of the leaders interviewed actually seemed to demonstrate a sense of thrill with the challenge to change systems that are not working the way they could and should. One particular director was totally animated when it came to talking about change. The face lit up, there was a grin from ear to ear, and a chest posture that was straight, rigid and had pride written all over it (Researcher's reflective notes). Words this director used to describe the changes which have occurred with this particular project were *neat, exciting, and fascinating!* *Now that it [the program] has become part of the [organizations] culture that is what is really exciting! It is just fascinating to watch the change.*

Passion and commitment for making changes to improve care for children with life threatening illnesses came through with another director when this director's face turned red and the arms left the side of the body and swung up into the air. *You can explain how much you can do with nothing using the Hospice approach...to convince them that it [Hospice] really works in dollars spent...*

Making sense and finding meaning to better understand why insurance policies do not provide the necessary coverage for dying children was a source of frustration and a challenge for another director. This director was trying to make a change to improve pediatric palliative care that made sense (and saved cents). *The hugest barrier issue is financial for Hospice and the family. We admitted a child who was with a managed care*

*third party payer who followed hospice guidelines so strictly that there would be no reimbursement. So, what we had to do financially was to provide core services free, supported by grants and foundations and use her commercial insurance for everything she needed at home. Within six months her [the dying child's] dad died and the insurance stopped.*

One director was very candid when talking about the PACC project and its relationship to funding. *One of the biggest issues I think in our state, and it is certainly the same in all capacities, is the cost of the program.* The director goes on to say. *a PACC program envisions that certain services will be reimbursed by the Medicaid program. In our state, just like all other states, you get absolutely no sympathy from the Medicaid program if you come to them and say, this is really important to do but it is going to cost you more money.*

*Because their marching orders are not to spend anymore, in fact to reduce what they spend. So I think it is very important to be able to couch what you do in such a way that you're cognizant of that and that in essence what you are proposing ultimately can save money. The biggest issues in our state with the PACC program are the cost, the control of the costs and who actually would have ultimate control of what is being spent and how that would play out as our program evolved.*

Bringing on a financial expert brought optimism to one director to help better understand the whole financial perspective. *So I think our state really got a hold of those data and having an actuary work with them [Medicaid] and then ultimately illustrate that*

*there is a good deal of potential for some cost savings in our state, was certainly I think, the biggest victory that we felt thus far in this whole process.*

Another director relayed how families know that health care and insurance systems “do not make sense” when it comes to providing care for their ill children. *But the home and community based waiver programs was kind of our foot in the door where the federal government realized that if they ({government}) pay for institutional care only people will stay there and it will be a lot more expensive. We talked to families and did focus groups and a number of families, who were not on Medicaid, in fact, said that it didn't make any sense. They said yes as long as we keep our child in the hospital it is fine [for payment of services], but if they go home then there is nothing [payment for in-home care].*

### Connections to Quantitative Findings

#### Finance as a Barrier

The qualitative results listed above support the quantitative findings which identified the two top staff barriers to provide pediatric palliative care as: 1) staff unaware of community funds that may be accessible for palliative care and 2) staff unaware of foundation funds available within their organization that could be used for palliative care. In addition, other apparent funding issues are the differences in the amount of reimbursements that are being provided for physical care services rather than for psycho-social services. The IOM recommended that “federal and state Medicaid agencies, pediatric organizations, and private insurers should cooperate to examine the appropriateness for reimbursing pediatric palliative and end-of-life care of diagnostic,

procedure, and other classification systems that were developed for reimbursement of adult services” (Field & Behrman, 2003). The lack of reimbursement for psycho-social services can have a negative impact on the access, cost and quality of care for pediatric patients who are dying and needs to be addressed in future research.

Other issues as related to finance that came out in this study in order to provide pediatric palliative care services were (a) the emphasis on neutral budgets for programs who provide pediatric palliative care, (b) the importance to decrease hospital costs, (c) the increase of care in the home to decrease psychological barriers for children and their families, and (d) the need for increased flexibility with health care plans, whether they are public or privately funded, to provide more options for children and their families.

Further, according to Dr. Lantos, Chief of General Pediatrics at the University of Chicago, our society needs to start thinking about using spreadsheets not only as financial documents, but as moral documents. Financial documents are only one indicator when looking at doing the right thing, at the right time and in the right way, which CHI PACC programs are trying to do (personal communication, March 4, 2004).

According to statements in the 1998 Survey of Hospice Care for Children, reimbursement and education were two issues identified as being needed to provide care [palliative] for children and their families (CHI, 1998). It is now 2004 and we are still striving towards these goals. Perhaps hopeful outcomes for these PACC programs is that the federal government will eventually understand that making changes to current health

care policies will ultimately improve pediatric palliative care, save tax payers “dollars and cents,” and make “sense.”

### We Are Just Soldiers

The title of this last theme, We are Just Soldiers, was actually taken from the transcriptions of one director who said, *The best line I ever heard from a Hospice director went something like, We are just soldiers, we are not the General. We go in and do the best we know to do and then somebody else controls the outcome as to whether people achieve an acceptable quality of life. I think hospice people are blessed with faith in themselves and because of the issues that they deal with, faith in some higher power, that they are just doing their part.*

Interestingly, although the transcripts never had any of the directors talking about how they were serving others, one of the definitions for the word soldier is “a person who serves in any cause” (Random House, 1984). The soldier theme resonated in the responses of the other directors who used similar language that is often prevalent in a military environment. Some of these words and phrases were: “being in the trenches,” “conflicts,” “marching orders,” “charging in,” “target,” “facing resistance,” and “survival,” “forging ahead,” “taking a stand,” “crossing over lines,” “overcoming obstacles,” and “mapping out the steps.” I interpreted this to mean that perhaps these leaders recognized they were on a mission into a foreign land (labyrinth) and were not familiar with the paths.

One director gave examples of how resourceful somebody on a new mission needed to be especially when they don't know what to do. *I think you need to be resourceful, and I think you need to delegate to different people with more expertise than yourself to work on some aspects of the program. You have to be able to wear a lot of different hats and realize it's not just the financing thing but the changing, also educating and taking care of this population. I think you have to be willing to tolerate setbacks and know that it is going to take time for change. I think the other thing is just having some concept of grant writing and financing and doing budgets...it is a learning process.*

One of the directors interviewed would most likely support the saying that "patience is a virtue." This director responded, with absolutely no hesitation, that *the key word is patience*, when asked to describe the qualities it took for somebody in the role of a director. In fact, the director mentioned the word "patience" multiple times in a very short time frame. *I think that it is very easy to get frustrated and to kind of throw up your hands and I think that particularly, in a very large agency, you have to find a way to kind to narrow your time frame and your time horizon, so that you are not frustrated when things don't seem to happen quickly, because they don't happen quickly.* I wondered whether this could have been a battle cry?

*In order for someone to survive in a role like this, one has to be comfortable in being flexible, that's the key.* The response here implies that the position of director is one full of challenges and stresses, where there is little constancy. This is reflected in the turnover of patients that are cared for and the different needs of these individual patients and their families. Flexibility plays a role in dealing with the diversity of patients and

their individual values; self, family and staff expectations and experiences; religious and cultural beliefs. The ability to be open and adaptable to change, according to the personal needs of the patient, also implies a non-judgmental approach to situations.

This then leads to issues of ethical principles such as respect for human dignity and the right to self determination. What works for one may be unacceptable to another, so flexibility would be key in trying to understand the meanings behind people's decisions and helping them to implement those decisions. Part of her statement...*for someone to survive...* implies a quality of persistence or stick-to-it-ness in overcoming challenges. It implies an ability to step back, to be "*reflective,*" to review events and outcomes, to learn from them. It led me to think that perhaps this director is on a journey of self improvement both personally and professionally and is carefully evaluating actions and reactions. The participant also believed that additional qualities for a PACC director are: *a high energy level, the ability to be open and honest and the ability to charge in and at things when needed.*" Like a soldier, this implies that a director (leader) also needs to be able to take action and make decisions whenever and wherever situations arise requiring leadership and communication skills.

One could assume that the director would also have to be a risk taker and advocate when the participant states "*charge in and at things when needed.*" Working with patients and families who are dealing with end-of-life issues can be emotionally draining, so the ability for directors to "*have a high energy level*" would be important. The director's role requires the ability to be present, to be there physically and emotionally, and in order to serve the needs of patients, their families and the staff that

care for them. A low energy level could lead one not “*to survive in this role*” and could ultimately end up causing harm to one’s own health and thus lead to lesser quality of care for patients and families.

### Connection to Quantitative Findings

#### Top Three Perceived Obstacles

The title of this theme denotes the “battle” that advocates for pediatric palliative care are encountering as indicated in the findings from the quantitative study. The findings of the top three perceived obstacles to the delivery of pediatric palliative care as reported by directors of pediatric palliative care programs were 1) the association of hospice or palliative care with death, 2) physicians reluctance to make referrals for pediatric palliative care, and 3) the family’s reluctance to accept palliative care.

The next section will focus on “The Battle of the Obstacles” where each of the identified obstacles will be discussed as three individual “battles” that need a strategy in order to be won, that is, to move the pediatric palliative care movement forward.

### The Battle of the Obstacles

#### Battle # 1: The Association of Hospice or Palliative Care with Death

This is a tough battle to overcome since patients, families and many health care professionals do not understand the difference between hospice and palliative care. The association of death with the word “hospice” has alienated professionals from making referrals to this service often because they themselves have problems with thinking about

their own mortality. Efforts are underway to somehow change this association, but I believe until all the “soldiers” understand what palliative care means, and that would mean a change in societal thinking about death, it will be a very long, hard climb to overcome this enemy.

#### Battle # 2: Physicians Reluctance to Make Referrals for Pediatric Palliative Care

Traditional medicine has embraced the philosophy that the role of physicians is “to cure” and to do whatever it takes to prolong life. This philosophy is slowly beginning to change as economics, culture, demographics and technology change. Yes, life can be prolonged, but at what emotional and financial cost to patients and their families? The loyalty and trust that were once unquestionable towards physicians has changed over the years. People are no longer accepting a doctor’s word as that of a God. Enlightened physicians know this and are beginning to understand that many people are more interested in the quality of their lives, rather than the prolongation of their lives.

Pediatric palliative care physician leaders, although currently few in number, are working hard to educate their colleagues about the difference in hospice and palliative care. This can be seen in the recent number of articles and seminars focusing on pediatric palliative care yet will be an ongoing battle until there are more “troops” engaged in the same fight. It is also reflected in guidelines recently established by the American Academy of Pediatrics which address palliative care.

#### Battle # 3: The Family’s Reluctance to Accept Palliative Care

Is one ever able to accept the death of one’s child? For many, accepting palliative care is giving up hope, the only thing a parent has left as they watch and pray for a

miracle. This battle is one that will take exceptional leadership skills as health care providers use their knowledge and skills to introduce families to this model of care. Education efforts are on the rise to teach health care professionals how to do this and hopefully a difference will be made one family at a time. This is another battle that will be a long, drawn out one until families better understand that they have a choice in which battles they choose in order to end the war.

#### “FACE”ing the Barriers

I created the acronym, FACE, to simplify memorization and to relate it to leadership of palliative care for future writing purposes. I chose this particular term because it would remind me of what the leaders who were paving the way for pediatric palliative care were doing. That is, directors who “FACE” barriers and obstacles as they strive to improve palliative care for children on a daily basis in their roles. Further, the acronym “FACE” seemed to be appropriate because it could also be linked to the issues found in my literature review and to the findings from Phase I, the quantitative portion of this study. For instance, findings from the literature identified finance, access, communication and education (FACE) as important issues in pediatric palliative care.

Results of the quantitative portion of this study reinforced the literature review findings. The two top staff barriers that were reported as the most severe barriers in providing pediatric palliative care were related to finance (F); staff not being aware of community or foundation funds which could be used to supplement services for children that might not be provided by the child’s insurance provider. Access (A) to palliative care was identified as an obstacle since respondents reported that families were often reluctant

to accept this type of care for their child. The “A” could also be used to designate the importance of the role of advocates to promote the need for pediatric palliative care as discussed by participants during the qualitative phase of this study.

Communication, the “C” in the FACE acronym, was another identified obstacle in the quantitative study because physicians are reluctant to make referrals for pediatric palliative care. This stems from a communication problem with many physicians who find it difficult to approach the subject of death with parents of a dying child. Physicians were taught to cure, and when it is clear that a cure is not in the prognosis for a child, there is often a break down in communications. The final part of the FACE acronym, “E,” is also linked with Phase I of this study. The third top staff barrier identified as most severe was the lack of standardized competencies for staff to provide palliative care. Linking all of the issues together, from the literature review, the quantitative portion of this study and the qualitative portion of this study, I believed that each, and all of them, are critical issues that we as a society need to “FACE.”

#### Integration with Theoretical Framework

The framework chosen for this study was the Longest Model of the Public Policymaking Process in the United States (Longest, 1998). This model is comprised of three phases: policy formulation, policy implementation and policy modification and is aligned with recommendations from the IOM report. The report recommended "that public and private insurers should restructure hospice benefits for children" and "should modify policies restricting benefits for other palliative services related to a child's life-threatening medical condition" (Field & Behrman, 2003). Policies have already been

formulated for regulating reimbursement issues by Medicaid, Medicare, and some private health care plans, and are now under scrutiny since their implementation is not meeting the needs of health consumers, specifically children needing palliative care and that is for children with insurance coverage. It is assumed that if children have insurance they will have access to pediatric palliative care. Unfortunately, often this is not the case. And what about those children who are uninsured? About 8.5 million children—or 11.6 percent of those under age 18—are uninsured and may or may not qualify for Medicaid benefits.

This framework helped to guide the study in that the researcher recognized that current policies were outdated and not designed for children and require modification. For example, Medicare hospice benefits were designed for adults and yet some Medicaid and private health insurance plans, still follow the Medicare policies where hospice care is only provided if a doctor certifies that death will occur in six months or less (Field & Behrman, 2003). Further, previous health care policies were developed that promote and pay for advanced technology to prolong life, but do not provide palliative care for the child with a life-threatening illness at the time of diagnosis, which is now recommended. For instance, many insurance policies will pay for blood transfusions, but not for services provided by a child life specialist, who could help the dying child work through his fears.

The issues with outdated policies and restrictions that limit pediatric palliative care were confirmed by the findings of this study. According to interviews with the directors, states, other than the ones with designated CHI PACC programs who have waivers to work around the reimbursement system, still have to adhere to outdated

policies such as those that require children to forgo curative treatment in order to receive palliative care. For example, directors of the CHI PACC programs discussed their frustration with outdated policies that limited the care children could receive prior to the implementation of the waivers that bypassed those policies. These same policies limited access to care for children as well because they could not legally be given the care they needed because of eligibility requirements. Too often it is the issues of outdated health care policies that prohibit quality care. The CHI PACC programs are working to resolve these issues and demonstrate to Congress that changes in policies will improve pediatric palliative care, for the better. For all of those children who are dying in other states that do not have CHI PACC demonstration programs, parents and health care professionals are fighting on their behalf to advocate, to change the policies that impeded care.

Problems with access, cost and quality issues have arisen and a "window of opportunity" has opened where further research on reimbursement issues can help to inform and influence this health policy agenda through analysis.

Advocators for pediatric palliative care have reached the politicians and action has begun at the federal level for legislative change. For instance, there are now two bills in process addressing pediatric palliative care. One in the House of Representatives called the Pediatric Palliative Care Act (H.R. 3127) and one in the Senate, The Children's Compassionate Care Act (S.1629). The Pediatric Palliative Care Act (PPCA) was introduced by Congresswoman, Deborah Pryce (R-Ohio) and addresses the needs of children with life-threatening illnesses, especially for palliative care. This bill proposes to: increase training, increase funding for research, expand current pediatric palliative

care programs, increase the number of professionals with pediatric palliative care training and provide demonstration projects. The Children's Compassionate Care Act (S -1629) was introduced by Senator Mike DeWine (R-Ohio) and basically incorporates the same principles as the Pediatric Palliative Care Act. Ultimately, we have begun to see the Longest Model in action as health care advocates and policymakers are attempting to "modify" policies and make them work for children, as demonstrated in the two proposed bills above.

#### Limitations

This study had a number of limitations which included: 1) a very small sample size, 2) a low response rate, 3) deficits in some data areas, 4) possible confusion with terminology and 5) confusion with questionable level of data on the survey form. To begin with, the targeted population was 160 administrators/directors/coordinators of pediatric palliative care programs, but was quickly reduced to an accessible population of 130 because of the return of un-opened surveys. Of these "known" pediatric palliative care programs identified as the convenience sample, only 37 ultimately responded with a completed survey, and some of these had deficits in their data. It has been reported among colleagues who work in associations related to pediatric palliative care that approximately 30% of pediatric palliative care programs per year do not remain viable. When surveys are sent out, it appears that one out of three programs appear to have closed each year. This may or may not have contributed to the survey's low response rate of 28%.

Perhaps another limitation was some confusion with the terminology on the questionnaire or specifically with the term “palliative.” Some of the respondents seemed to be unclear of the philosophy of palliative care, even though they claimed to be employed by a hospice organization. For instance, one particular respondent wrote on the survey form that “they were from hospice programs but didn’t do “palliative care.” This clearly demonstrated a disconnect with some health care providers and yet an opportunity for much further exploration and education regarding how palliative care is the center of hospice care. Further, there may have been questions or unclear interpretations of and by respondents when answering questions on the staff barrier and obstacle scales. The staff barrier scale asked respondents to check off on a scale with words that described staff barriers as “not a barrier,” “somewhat of a barrier,” and a “severe barrier.” Similarly, and probably somewhat confusing, the obstacle scale asked respondents to rate obstacles on a scale of 0-4, but using similar language, such as “not an obstacle,” “somewhat of an obstacle.” It could be argued that perhaps the terminology of “barrier versus obstacle” could have confused respondents, even though the staff barrier addressed staff issues while the obstacles addressed family, physician and organizational related issues.

In addition, since respondents were asked to estimate the percentage of children funded by insurance, Medicaid or donations, they may have interpreted that it was limited to individual children versus an aggregate of child services funded by the various mechanisms. This question was a limitation because it is very difficult to access this information and most directors, because of their busy schedules, do not take the

necessary time to verify these numbers because they already have too much work to do and it is a time consuming task. Although the survey question limits the total number to 100%, some might have interpreted that it meant the total would exceed 100% if the child were covered by more than one service. Also, this question did not address those children who were not provided services as a lack of funding from any of these three sources, so rewording of the question would be recommended for future research. This confusion might have hampered the response to this variable. The problem should be eliminated in future research.

#### Implications for Education

There has been clear evidence from the literature in addition to the findings from this study that point to the need for improved education in pediatric palliative care. Ferrell, Virani, and Grant (1999) conducted a review of 50 nursing textbooks for end-of-life content and discovered that only 2% of the overall content was related to end-of-life care, and much of that information was not accurate. The 1997 IOM report on improving end-of-life care also cited major deficits in professional education. This report recommended that changes in undergraduate, graduate, and continuing education programs be made so that practitioners would obtain the knowledge, skills, and attitudes to care for dying patients (Ferrell & Coyle, 2001).

Although changes in nursing curricula have been taking place over the last few years to make these adjustments, large gaps remain. For instance, one of the findings in this study was that “the lack of standardized competencies for staff to provide care” was identified as a severe barrier as reported by directors of pediatric palliative care programs.

This demonstrates the lack of awareness of some administrators and practitioners of what is available to assist health care professionals as they care for the dying. In 1995, the American Association of the Colleges of Nursing conducted a round table of expert nurses and other health care professionals to discuss end-of-life care.

The outcome of that event was "A Peaceful Death" document that outlines 15 competencies for nurses to provide high quality end-of-life care (AACN, 1997).

Although this document was not specific to the pediatric population, the competencies are transferable to any age, yet many nurses are unaware of its existence.

Further, palliative care curricula for nurses, physicians, social workers, and interdisciplinary teams have evolved over the last few years. The methodologies used for these curricula vary, and range from three day national training conferences, to hourly seminars, to videos, self-study programs, and simulated clinical exercises to help guide the learner. The content of these curricula are similar in that they provide information on the following: palliative care, pain and symptom management, communication, cultural considerations, ethical and legal issues and care at the time of death.

For instance, the Johns Hopkins Leadership Institute for End-of-Life Care uses professional actors, to help nursing participants enrolled in the institute, to practice advocating for palliative care programs. The nurse participants prepare their own script "to sell" or advocate for a palliative care program at their institution. They role play with the actors, who assume roles of Chief Executive Officers (CEO), Chief Nurse Executives (CNE), and Vice Presidents of Finance (VPF). This role playing teaches the nurse participants successful strategies and effective techniques to inform, influence, and

persuade the decision makers to consider implementation of some form of palliative care within their individual organizations.

Education programs for pediatric palliative care need to have strong, united voices to promote the “care versus cure” model of care. All of these programs, in addition to the basics, should emphasize the importance of psycho-social issues, the links of care with spirituality, the importance of being “present” with the child and family during these “sacred moments” (Hutton, 2002). Perhaps in time, families of children who are dying may be more willing to accept palliative care, provided by compassionate, caring nurses as a final gift for their child.

#### Implications for Practice

Nurses have long been known for their abilities to provide compassionate care. Yet when it comes to the competencies needed for providing pediatric palliative compassionate care, nurses (and physicians) can not practice what they do not know. This is why it is imperative that end-of-life care be ingrained into all nursing and medical curricula, so that when the practitioners get out of the classroom and into the clinical setting, they know how best to help the child and family. Their increased knowledge will influence clinical outcomes so that children and families will have greater satisfaction with the care they are provided whether it is as an inpatient, an outpatient, or in the home.

The practice of palliative care improves clinical outcomes. This is achieved when practitioners are formally educated and learn how to relieve suffering and pain with proper pain management. Palliative care is achieved when health care providers involve

the child and family in the plan of care, so that families are involved in the difficult decisions that affect their lives. It is achieved when health practitioners learn that their being present, often in silence, is enough for many families as they sort their way through a grave period in their lives.

The resurrection of end-of-life education programs has enlightened the health care field. In fact, palliative care is becoming recognized as a new and upcoming specialty in nursing and medicine. It has recently received national certification status, in spite of the small numbers of nurses and physicians who are dedicated to this specialty. These dedicated health practitioners are laying the groundwork for future followers and have found that they have a lot of challenges before them. For instance, for palliative care to become more accepted in practice, practitioners need to change the way they think about it. The emphasis needs to be taken off its association with death, and put on care, and quality of life. The philosophy and culture for implementing palliative care needs to change within the organization. It needs to be based on it being the right thing to do for all the people involved; children and their families, the health care providers, the organization, the community, and society. Practitioners need to remember to ask themselves, "If this were my child, what would I want the care team to do?" The answer to this question then is to remember to do for others as we would have them do for us.

#### Implications for Research

Because pediatric palliative care is in its infancy stage, with very limited research, opportunities abound for researchers to advance the knowledge in this field. According to Toce and Anderson (2004), further research is needed in the areas of data collection,

evaluation and research. Some of these areas include appropriate models of care for inpatient and community palliative care; appropriate tools for the assessment of quality of life, quality of care and hospice care and decision making. Heida Huskamp, an economist at Harvard, recommends research to document the variations of coverage and reimbursement policies across payers, to identify how patients access costs in different settings, whether as inpatient, outpatient or home, and to identify how the distribution of hospice costs and the development of simulation models that can be used to estimate costs (H. Huskamp, personal communication, November 6, 2003).

This investigator supports the research recommendations of the 2003 IOM report and other previous researchers in order to improve the care to children who are dying and face life threatening illnesses. It is imperative that future research includes both quantitative and qualitative studies that will (a) continue to investigate financial and regulatory issues as related to pediatric palliative care, (b) identify methods for improving communication among health care providers and families about palliative care, (c) assess and evaluate the effectiveness of staff competencies for pediatric palliative care, (d) assess community and health care organizations criteria for using foundation funds for palliative care services, and (e) explore physicians' reluctance to make referrals for palliative care. This investigator believes that research on financing pediatric palliative care is critical to the development of appropriate policies that will fit the needs of children.

### Implications for Policy

One size does not fit all. Children are not little adults. The current policies that reimburse for palliative care were designed for adults and do not address the needs for children with life-threatening conditions. Further, these policies were developed with mostly the insured population in mind. They do not help the 8.5 million children who are uninsured, nor the 4.3 million children who are eligible for Medicaid and State Children's Health Insurance Plans (SCHIP), but are not enrolled. More than 25,000 children are expected to die annually due to life-threatening conditions and may not have access to the palliative care services they need due to inadequate funding mechanisms, legal restrictions, complicated reimbursement systems and Medicaid programs, which in some states, do not cover hospice care. Therefore, the implications are that policies need to be formulated or modified, at the federal level to meet the needs of these children. Policies can be modified now and should include: the expansion of the hospice benefit beyond the six month patient limitation, improve reimbursement for continuous care from the time of diagnosis, change regulations to make services provided at home reimbursable versus hospitalization, increase reimbursements for psycho-social services.

Two legislative bills are in process to address this concern, namely the Pediatric Palliative Care Act (H.R. 3127) and the Compassionate Children's Act (S. 1629). Additional hope on the horizon is the January, 2004 IOM report: *Insuring America's Health: Principles and Recommendation*, which proposed universal health coverage for all Americans. This report recommends health care coverage that is "universal, continuous, affordable and sustainable for society" and recommends that "these

principles be used to assess the merits of current proposals and to design future strategies that would provide coverage for everyone” (Kellerman, 2004, p.155).

As Dr. Steffie Woolhandler, co-founder of Physicians for a National Health Program stated, “radical surgery to cure our failing health insurance system is sorely needed” (Laurier, 2004). Nurses can play a major role as first assistants in this surgical procedure by advocating, educating, and encouraging legislators to excise outdated federal health care policies.

#### National Efforts to Improve Policy Reform for Pediatric Palliative Care

A national effort to improve pediatric palliative care is in its infancy stage of development. Multiple initiatives, besides CHI are working to address the needs for children with life threatening illnesses, and just like children, they are continuing to grow. Some of these initiatives are as follows:

- The Americans for Better Care of the Dying (ABCD) whose goal is to make change happen through their work with the public, policymakers and health care professionals and to build momentum for reform for the improvement of end-of-life care. More information may be obtained from their website at [www.abcd-caring.org](http://www.abcd-caring.org).
- The Center to Advance Palliative Care (CAPC) is a national initiative supported by Robert Wood Johnson Foundation, with direction and technical assistance provided by the Mount Sinai School of Medicine (NY). CAPC provides professionals with the training, tools, and technical assistance necessary to start and sustain successful palliative

care programs. CAPC sponsors regular regional and national meetings designed to provide a core curriculum for programs in the planning or early stages of development. More information may be obtained from their website at [www.capc.org](http://www.capc.org).

- Children's International Project on Palliative/Hospice Services (ChIPPS) is a project out of the National Hospice and Palliative Care Organization (NHPCO), located in Alexandria, VA. Its goal is to increase the quality of end-of-life care for families by advancing the science and practice of palliative care for both adults and children. In addition, ChIPPS has a Pediatric Advanced Illness Coordinated Care (PAICC) model whose purpose is to improve communications with families of children with life-threatening illness and to coordinate care. The model uses a PAICC trained nurse or social worker to facilitate communication among the providers and parents, emphasizing counseling, education, advocacy for a coordinated system of care. More information may be obtained from their website at [www.chionline.org](http://www.chionline.org).

- The Initiative for Pediatric Palliative Care (IPPC) which is working diligently with children's hospitals, general hospitals with pediatric units, and in other health care settings that serve gravely ill children, to ignite quality improvement efforts and to improve the competency of clinicians (Solomon et al; 2002). More information may be obtained from their website at [www.ippc.org](http://www.ippc.org).

- Last Acts is a campaign coalition of consumer and professional organizations focused on improving end-of-life care through better pain management and overall palliative care. This organization just merged with Partners for Caring and is now called

Last Acts Partnerships. More information may be obtained from their website at [www.lastacts.org](http://www.lastacts.org).

- The National Alliance for Children with Life-Threatening Conditions (NACWLTC) is an initiative that was a response to the 2002 IOM report on pediatric palliative care. This alliance was formed to give a unified voice of all stakeholders, including parents, to help create change for children with life-threatening illnesses. More information may be obtained from their website at [www.nacwltc.org](http://www.nacwltc.org).
- Partnership for Caring is a non-profit organization that collaborates with other organizations and individuals to improve care of the dying. It provides state and specific living wills, medical powers of attorney and has a end-of-life crisis hotline and information center. More information may be obtained from their website at [www.partnershipsforcaring.org](http://www.partnershipsforcaring.org).

## Conclusion

This study used a sequential mixed methods design to explore and better understand the barriers to pediatric palliative care programs and their relationships to funding. A self report instrument and semi-structured interviews provided the data, which were then analyzed using SPSS and the van Manen method for thematic analysis, respectively. The top three staff items that were reported as barriers to deliver pediatric palliative care were, (1) staff were unaware of community funds that may be accessible for palliative care, (2) staff were unaware of community funds that were available within their organization that could be used for palliative care, and (3) the lack of standardized competencies for staff to provide pediatric palliative care.

The top three obstacles reported as being the most severe in providing pediatric palliative care were (1) the association of hospice or palliative care with death, (2) the physicians' reluctance to make referrals for pediatric palliative care, and (3) the family's reluctance to accept palliative care. Other key findings included that the majority of pediatric palliative care services are reimbursed for physical services versus psycho-social services and that there is a statistically significant relationship between reimbursement for private insurance with perceived obstacles ( $r = -.449$ ,  $p < .05$ ), but no relationship between Medicaid and obstacles ( $r = .001$ , NS) or donations and obstacles ( $r = .341$ , NS).

The three themes that emerged from the interpreted transcripts were Leaders and Labyrinths, Making Change with Dollars and Sense, and We Are Just Soldiers. Each of

these themes were directly linked to the quantitative findings and strengthened the credibility of the results of each.

The significance of this research is that it is believed to be one of a few studies to explore the barriers of pediatric palliative care programs and their relationships to funding. In addition, prior to this study, we did not know, nor understand, the experiences of the six directors of the CHI PACC programs who encountered these barriers as they were trying to make changes to improve pediatric palliative care. We now know that many of the barrier and obstacle findings support previous research, and that further research is needed. We now know that the implications of this study overlap for education, practice, research and policy. We now know that it is time for legislators, administrators, and regulators to FACE the barriers (finance, access and advocacy, communication and education) to pediatric palliative care. It is time for nurses, to take a leadership role to advocate for changes in health care policy that support improvements for children needing palliative care.

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**APPENDIX A: HUMAN SUBJECTS REVIEW BOARD APPROVAL**

Office of Sponsored Programs  
Compliance Office

TO: Veronica Feeg, CNHS

FROM: Ann T. McGuigan, Director, Office of Sponsored Programs

DATE: January 12, 2003

PROJECT TITLE: Pediatric Pallative Care Survey on Reimbursement Issues

Cc: Maureen McLaughlin, CNHS

The Office of Sponsored Programs reviewed your human subjects research form and found that your project is not research involving human subjects because you are not collecting private identifiable information regarding the subjects. Instead, you will be obtaining information about the facility, where the subject is employed. You are not obtaining data as described in the Common Rule, the Federal regulation for the protection of human subjects. Therefore, based on the GMU human subjects policy, the GMU Human Subjects Review Board will not review your project and no further action to comply with the GMU human subjects policy is required of you at this time. However, if you modify your project to include research activities, you are required to request and receive approval from the human subjects review board prior to conducting the research activities.

You may contact Ann McGuigan at [REDACTED] if you have any questions or need clarification. Thank you for your patience while the Office of Sponsored Programs reviewed your paperwork to make this determination.

**APPENDIX B: INFORMED CONSENT**

## APPENDIX B: INFORMED CONSENT

### Barriers to Pediatric Palliative Care

#### RESEARCH PROCEDURES

The purpose of this research study, **“An Exploratory Study of Barriers to Pediatric Palliative Care Programs and Their Relationships to Funding”** is to identify and discuss strategies that directors of CHI PACC Programs are using in the present and intend to use in the future to address the barriers to pediatric palliative care programs and their relationships to funding. This study is being done by Maureen McLaughlin, a nursing doctoral candidate at George Mason University, Fairfax, Virginia. If you agree to participate, you will be interviewed by Maureen McLaughlin. For your convenience, the interview will take place at the Radisson Hotel in Old Town Alexandria, Virginia during September 14 -17 while you are attending the CHI 15<sup>th</sup> World Congress. Should you not be attending this conference, an alternative method of interview can be arranged such as a phone interview on a day and time of your choosing.

In this interview you will be asked about what your program is doing to address the barriers to pediatric palliative care programs and their relationships to funding. This interview should take approximately 30-60 minutes; however, the interview can be discontinued at any point during the interview as you deem necessary. The interview will be audiotaped and then transcribed. A copy of the transcription will be sent to you at which time you will be asked to read and verify that the transcription is accurate. Only the interviewer will be able to identify you by a marked code she will use on the

interview tape. All audiotapes will be kept for three years and locked in the home of the researcher.

#### RISKS

There are no foreseeable risks or discomforts for participation in the research study.

#### BENEFITS

There are no benefits to you as a participant other than to further research pediatric palliative care.

#### CONFIDENTIALITY

Only the interviewer will be able to identify you by a marked code she will use on the interview tape. All audiotapes will be kept for three years and locked in the home of the researcher. The tapes will be destroyed at the end of the study. Results of this study may be published, but you will not be identified from any excerpts used in this interview.

#### PARTICIPATION

Your participation in this research study is voluntary, and you may withdraw from the study at any time and for any reason. If you decide not to participate or if you withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled.

There are no costs to you or any other party for participating in this study.

#### CONTACT

This study is being conducted as part of the doctoral requirements at George Mason University. Should you have any questions or wish to report a research related problem, please feel free to contact the researcher, Maureen McLaughlin at [REDACTED] or her dissertation chair Dr. Veronica Feeg at [REDACTED]. You may contact the Office of

Sponsored Programs at George Mason University at [REDACTED] if you have questions or comments regarding your rights as a participant in the research. This project has been reviewed according to the guidelines of the Human Subjects Review Board at George Mason University.

***I have read this consent form and agree to participate in this study.***

---

Signature of Person being interviewed

**APPENDIX C: PEDIATRIC PALLIATIVE CARE SURVEY ON  
REIMBURSEMENT ISSUES**

**APPENDIX C: PEDIATRIC PALLIATIVE CARE SURVEY ON  
REIMBURSEMENT ISSUES**

The purpose of this survey is to identify reimbursement issues, and other barriers, and how they relate to a programs ability to deliver pediatric palliative care services. For this survey, pediatric palliative care is defined as “the total active care of pediatric patients whose disease is not responsive to curative treatment.” This survey should take about 5-10 minutes to complete. Which of the following barriers to pediatric palliative care delivery exists in your organization? Please “check off” in the appropriate box.

STAFF BARRIER SCALE	N/A	Not a barrier	Somewhat of barrier	Severe barrier
1. Staff is not familiar with different types of services covered by insurance plans, Medicaid or private donations.				
2. Staff is not aggressive in trying to access coverage for services not provided by insurance plans, Medicaid or private donations.				
3. Staff is unaware of foundation funds available within the organization for palliative care.				
4. Staff is unaware of community funds that may be accessible for palliative care.				
5. Staff is not educated or trained on how to provide palliative care for pediatric patients.				
6. Lack of standardized competencies for staff to provide palliative care.				

### OBSTACLE SCALE

Please rate each of the following obstacles to the degree to which you feel they interfere with the delivery of pediatric palliative services in your organization. 0 = N/A; 1 = Is not an obstacle; 2 = Is somewhat of an obstacle; 3 = Moderately interferes and 4 = Is a severe obstacle to services.

#### OBSTACLE SCALE

Obstacles	0	1	2	3	4
a) Absence of an advance directive for the child					
b) Lack of family making child's care preference known to others					
b) Lack of clarity by staff regarding child/family's preferences for care					
d) Lack of physician's familiarity with the availability of palliative care					
e) Physicians' reluctance to make referral for palliative care					
f) Family reluctance to accept palliative care					
g) Association of hospice or palliative care with death					
h) Perception by family that palliative care means giving up hope					
i) Lack of understanding by the family of the severity and/or irreversibility of their child's illness					
j) Lack of institutional support or providing palliative care					

### SERVICES SCALE I - INPATIENT

For each service listed below, please “check off” all sources of funding or reimbursement for inpatient pediatric palliative care services by insurance plans, Medicaid, or private donations in your present organization.

### SERVICES SCALE I - INPATIENT

Services Reimbursed for Inpatient Services	Insurance Plans	Medicaid Medicare	Private Donation
1. Child Life Specialist			
2. Counseling by physician (for child/family)			
3. Counseling by non-physician (for child/family).			
4. Palliative care team consults			
5. Diagnostic procedures			
6. Equipment			
7. Grief/bereavement support			
8. I.V. therapy			
9. Medication for pain/symptom management			
10. Nursing care by an R.N.			
11. Occupational/speech therapy			
12. Physical therapy			
13. Complimentary/alternative therapy			

### SERVICES SCALE II – Outpatient

For each service listed below, please “check off” all sources of funding or reimbursement for outpatient pediatric palliative care services by insurance plans, Medicaid, or private donations in your organization.

### SERVICES SCALE II – Outpatient

Services Reimbursed for Outpatient Services	Insurance Plans	Medicaid Medicare	Private Donations
1. Child Life Specialist			
2. Counseling by physician (for child/family)			
3. Counseling by non-physician (for child/family)			
4. Palliative care team consults			
5. Diagnostic procedures			
6. Equipment			
7. Grief/bereavement support			
8. I.V. therapy			
9. Medication for pain/symptom mgt.			
10. Nursing care by an R.N.			
11. Occupational/speech therapy			
12. Physical therapy			
13. Complimentary/alternative therapy			

### SERVICES SCALE III – Home Care Services

For each service listed below, please “check off” all sources of funding or reimbursement for home care pediatric palliative care services by insurance plans, Medicaid, or private donations in your organization.

#### SERVICES SCALE III – Home Care Services

Services Reimbursed for Home Care Services	Insurance Plans	Medicaid/Medicare	Private Donations
1. Child Life Specialist			
2. Counseling by physician (for child/family)			
3. Counseling by non-physician (for child/family)			
4. Palliative care team consults			
5. Diagnostic procedures			
6. Equipment			
7. Grief/bereavement support			
8. I.V. therapy			
9. Medication for pain/symptom management			
10. Nursing care by an R.N.			
11. Occupational/speech therapy			
12. Physical therapy			
13. Complimentary/alternative therapy			

Please estimate what per cent of children (total 100%) in your palliative care unit are covered by:

Private health insurance such as HMO's \_\_\_\_\_

Medicaid (public) \_\_\_\_\_

Private donations (donated funds by individuals or groups) \_\_\_\_\_

Total: 100%

Thank you for completing this survey. If you would like to receive the results of this survey, please provide the following information. Questions, comments? Please call

Maureen McLaughlin at [REDACTED] or e-mail at: [REDACTED]

Name: \_\_\_\_\_

Title: \_\_\_\_\_

Organization: \_\_\_\_\_

Address: (work) \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_

Zip: \_\_\_\_\_

Phone: \_\_\_\_\_ E-mail: \_\_\_\_\_ Fax: \_\_\_\_\_

**APPENDIX D: STAFF BARRIER SCALE**

**APPENDIX D: STAFF BARRIER SCALE**

<b>STAFF BARRIER SCALE</b>	<b>N/A</b>	<b>Not a barrier</b>	<b>Somewhat of barrier</b>	<b>Severe barrier</b>
1. Staff is not familiar with different types of services covered by insurance plans, Medicaid or private donations.				
2. Staff is not aggressive in trying to access coverage for services not provided by insurance plans, Medicaid or private donations.				
3. Staff is unaware of foundation funds available within the organization for palliative care.				
4. Staff is unaware of community funds that may be accessible for palliative care.				
5. Staff is not educated or trained on how to provide palliative care for pediatric patients.				
6. Lack of standardized competencies for staff to provide palliative care.				

**APPENDIX E: PERCEIVED OBSTACLES SCALE**

**APPENDIX E: PERCEIVED OBSTACLES SCALE**

OBSTACLE SCALE	0	1	2	3	4
a) Absence of an advance directive for the child					
b) Lack of family making child's care preference known to others					
c) Lack of clarity by staff regarding child/family's preferences for care					
d) Lack of physician's familiarity with the availability of palliative care					
e) Physician's reluctance to make referral for palliative care					
f) Family reluctance to accept palliative care					
g) Association of hospice or palliative care with death					
h) Perception by family that palliative care means giving up hope					
i) Lack of understanding by the family of the severity and/or irreversibility of their child's illness					
j) Lack of institutional support or providing palliative care					

**APPENDIX F: SERVICES SCALE I – INPATIENT**

**APPENDIX F: SERVICES SCALE I – INPATIENT**

Services Reimbursed for Inpatient Services	Insurance Plans	Medicaid Medicare	Private Donations
1. Child Life Specialist			
2. Counseling by physician (for child/family)			
3. Counseling by non-physician (for child/family)			
4. Palliative care team consults			
5. Diagnostic procedures			
6. Equipment			
7. Grief/bereavement support			
8. I.V. therapy			
9. Medication for pain/symptom management			
10. Nursing care by an R.N.			
11. Occupational./speech therapy			
12. Physical therapy			
13. Complimentary/alternative therapy			

**APPENDIX G: SERVICES SCALE II – OUTPATIENT**

**APPENDIX G: SERVICES SCALE II – OUTPATIENT**

Services Reimbursed for Outpatient Services	Insurance Plans	Medicaid Medicare	Private Donations
1. Child Life Specialist			
2. Counseling by physician (for child/family)			
3. Counseling by non-physician (for child/family)			
4. Palliative care team consults			
5. Diagnostic procedures			
6. Equipment			
7. Grief/bereavement support			
8. I.V. therapy			
9. Medication for pain/symptom mgt.			
10. Nursing care by an R.N.			
11. Occupational/speech therapy			
12. Physical therapy			
13. Complimentary/alternative therapy			

**APPENDIX H: SERVICES SCALE III – HOME CARE**

**APPENDIX H: SERVICES SCALE III – HOME CARE**

Services Reimbursed for Home Care	Insurance Plans	Medicaid Medicare	Private Donation
1. Child Life Specialist			
2. Counseling by physician (for child/family)			
3. Counseling by non-physician (for child/family)			
4. Palliative care team consults			
5. Diagnostic procedures			
6. Equipment			
7. Grief/bereavement support			
8. I.V. therapy			
9. Medication for pain/symptom management			
10. Nursing care by an R.N.			
11. Occupational/speech therapy			
12. Physical therapy			
13. Complimentary/alternative therapy			

**APPENDIX I: LETTER TO PEDIATRIC ADVISORY BOARD MEMBERS**

**APPENDIX I: LETTER TO PEDIATRIC ADVISORY BOARD MEMBERS**

November 24, 2002

Dear Pediatric ELNEC Advisory Board Member,

It was fortunate for me to meet you this past summer at the Pediatric ELNEC training course in Chapel Hill, NC, and to observe first hand the knowledge that you contributed to the discussions on pediatric end-of-life care. Recognizing your expertise in this field, I would therefore like to invite you to be one of the “**expert reviewers**” for a survey form I have developed as part of an independent research study. The survey form is entitled: **Pediatric Palliative Care Survey on Reimbursement Issues** and is comprised of five questions. I need experts like you to review this form and provide constructive feedback so I can make it a quality tool that covers the issues in ways that will be easily understood by the persons who will eventually complete it, as part of a formal research study.

The purpose of this non-experimental, descriptive and correlational study is to identify frequencies and proportions of programs that identify reimbursement barriers, their relationship to funding sources, and their overall ratings of barriers to deliver pediatric palliative care. This study is being done as part of my doctoral coursework, under the direction of Dr. Veronica Feeg, Coordinator of the PhD Nursing Program, at George Mason University in Fairfax, Virginia.

There are no costs associated with being an “expert reviewer” of this survey other than the time it will take you to review the questions and provide written or verbal feedback.

There are no known risks involved. The benefits however, will be that you will have

contributed (again!!) to the knowledge regarding the barriers to the provision of pediatric palliative care which may ultimately help to change and improve health care policy for children in the future. For your convenience, a postage-paid return envelope has been included to return the survey, which in order to finalize the form in a timely manner, is due back **by December 12, 2002**. (If you are no longer working with palliative care issues, I would greatly appreciate you passing this on to another colleague.)

Please feel free to call me at [REDACTED] or e-mail me at [REDACTED] or Dr. Veronica Feeg at [REDACTED] regarding any questions or comments you may have about this survey. If you would like a copy of the summary of the results of this study please let us know. Thank you for your time and willingness to help improve pediatric palliative care.

Sincerely yours,

Maureen McLaughlin, MS, RN

Nursing Doctoral Student at George Mason University

Enclosures: Survey Form and postage-paid return envelope

**APPENDIX J: CONTENT VALIDITY FORM**

### APPENDIX J: CONTENT VALIDITY FORM

#### Evaluation Form for Testing the Content Validity of the Instrument “Pediatric Palliative Care Survey on Reimbursement Issues”

Name: \_\_\_\_\_ Degree: \_\_\_\_\_

Job Title: \_\_\_\_\_ Date: \_\_\_\_\_

#	Criteria for Validity	Yes	No	Comments
1.	Are the questions clear and easy to understand?			
2.	Are the questions an appropriate length?			
3.	Are the questions in an appropriate order?			
4.	Are the questions comprehensive?			
5.	Are the numbers of questions sufficient?			
6.	Are the questions relevant to reimbursement issues?			
7.	Are the questions relevant to pediatric palliative care?			
8.	Are the questions relevant to the purpose of the study?			
9.	Do any questions reflect a bias?			
10.	Is the survey an appropriate length?			

Other Comments:

\_\_\_\_\_  
Thanks.

**APPENDIX K: COVER LETTER TO PEDIATRIC COLLELAGUES**

**APPENDIX K: COVER LETTER TO PEDIATRIC COLLELAGUES**

November 24, 2002

Dear Pediatric Palliative Care Colleague,

You have been identified by another professional colleague as one who would be interested and willing to complete a short survey associated with pediatric palliative care. Therefore, I'm hoping you will assist with this study by completing the enclosed survey entitled **Pediatric Palliative Care Survey on Reimbursement Issues**.

The purpose of this non-experimental, descriptive and correlational study is to identify frequencies and proportions of programs that identify reimbursement barriers, their relationship to funding sources, and their overall ratings of barriers to deliver pediatric palliative care. This study is being done as part of my doctoral coursework, under the direction of Dr. Veronica Feeg, Coordinator of the PhD Nursing Program, at George Mason University in Fairfax, Virginia.

There are no costs associated with this survey other than the five-to-ten minutes of your time it will take to complete the form. There are no known risks involved. The benefits however, will be that you will have contributed to the knowledge regarding the barriers to the provision of pediatric palliative care which may ultimately help to change and improve health care policy for children in the future.

For your convenience, a postage-paid return envelope has been included to return the survey, which in order to analyze the data in a timely manner, is due back **by December**

12, 2002. (If you are no longer working with palliative care issues, I would greatly appreciate you passing this on to another colleague.)

Please feel free to contact me at [REDACTED] or e-mail [REDACTED] or Dr. Veronica Feeg at [REDACTED] regarding any questions or comments you may have about this survey. If you would like a copy of the summary of the results of the study please let us know. Thank you for your time and willingness to help improve pediatric palliative care.

Sincerely yours,

Maureen McLaughlin, MS, RN

Nursing Doctoral Student at George Mason University

Enclosures: Survey Form and postage-paid return envelope

**APPENDIX L: INVITATIONAL LETTER TO CHI PACC DIRECTORS**

**APPENDIX L: INVITATIONAL LETTER TO CHI PACC DIRECTORS**

Dear \_\_\_\_\_,

This letter is to invite you to be a participant in an upcoming qualitative study, "An Exploratory Study of Barriers to Pediatric Palliative Care Programs and Their Relationships to Funding". This study is being done to fulfill requirements for my doctoral degree in nursing at George Mason University in Fairfax, Virginia. You were identified as a possible participant in this study because you are a director of a CHI PACC demonstration project and may be attending the CHI 15<sup>th</sup> World Congress to be held on September 14 -17, 2003 in Alexandria, Virginia. The purpose of this study is to identify and discuss strategies that directors of CHI PACC demonstration programs are doing to address the barriers to pediatric palliative care programs. If you agree to participate, you will be interviewed at the Radisson Hotel in Old Town Alexandria, while you are attending the CHI 15<sup>th</sup> World Congress. Should you not be attending this conference, a phone interview will be arranged on a day and time of your choosing. In this interview you will be asked about your demonstration program and what is currently being done, and what it anticipates it will have to do in the future, to address the barriers to pediatric palliative care. This interview should take approximately 30-60 minutes; however, the interview can be discontinued at any point during the interview as you deem necessary. The interview will be audiotaped and then transcribed. A copy of the transcription will be sent to you at which time you will be asked to read and verify that the transcription is accurate. Only the interviewer will be able to identify you by a

marked code she will use on the interview tape. All audiotapes will be locked in the home of the researcher for three years . The tapes will be destroyed at the end of the study.

Your participation in this research study is voluntary, and you may withdraw from the study at any time and for any reason. If you decide not to participate or if you withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled. There are no costs to you or any other party for participating in this study. There are no foreseeable risks or discomforts for participation in this research study. There are no benefits to you as a participant other than to further the research of pediatric palliative care. This study is being conducted as part of the doctoral requirements at George Mason University. Should you have any questions or wish to report a research related problem, please feel free to contact the researcher, Maureen McLaughlin at [REDACTED] or her dissertation chair Dr. Veronica Feeg at [REDACTED]. You may contact the Office of Sponsored Programs at George Mason University at [REDACTED] if you have questions or comments regarding your rights as a participant in the research. This project has been reviewed according to the guidelines of the Human Subjects Review Board at George Mason University. If you are willing to participate in this study please contact me by September 5, 2003. I can be reached at [REDACTED] or at [REDACTED]. Thank you.

Maureen McLaughlin, MS, RN

**APPENDIX M: HUMAN SUBJECTS REVIEW BOARD APPROVAL  
FOR PHASE II OF STUDY**



**APPENDIX N: INTERVIEW GUIDE**

## APPENDIX N: INTERVIEW GUIDE

### INTERVIEW GUIDE

Prior to beginning the interview, the researcher will exchange social pleasantries to help put the study participant at ease. The researcher will offer and provide liquid refreshments (coffee, soda, water). The researcher will engage in friendly conversation for a few minutes to create a relaxing atmosphere and to help put the participant at ease. Next the researcher will review the purpose of the study and the informed consent form with the study participant. Following an oral overview and allowing enough time for the participant to read the informed consent, the researcher will then ask the study participant if he/she has any questions. Questions will be clarified by the researcher and then the study participant will be asked by the researcher to sign the consent form. Following signature of the informed consent by the study participant, the researcher will begin the interview process.

#### Prompt Questions:

1. Would you tell me, in your own words, about a specific time when you were able to overcome some barrier to pediatric palliative care services?
2. Can you share a story, in your own words, about a particular time you felt good about the work you are doing to make a difference in the provision of pediatric palliative care services?
3. Can you describe, in your own words, the qualities you think it takes for someone like yourself, to overcome barriers in order to

provide pediatric palliative care services?

Sub Questions:

1. Would you please describe your experience with the reimbursement of services for pediatric palliative care?
2. Would you explain how it differs between the types of insurance funding and donations?
3. Would you please share your experience of how the reimbursement of services may influence the barriers to the delivery of pediatric palliative care services?
4. Would you please share your experiences regarding any relationships between reimbursements of services for pediatric palliative care and where the services are delivered?
5. How would you describe the relationships, if any, between reimbursements of services for pediatric palliative care and the services delivered as an inpatient?
6. How would you describe any relationships between reimbursements of services for pediatric palliative care and the services delivered as an outpatient?
7. How would you describe any relationships between reimbursements of services for pediatric palliative care and the services delivered while in the home?
8. Would you please tell me about any experiences you have had in relationships to financial and educational barriers that influence the reimbursement of services for pediatric palliative services?
9. How would you describe the relationship between the staffs' knowledge with reimbursement issues and the delivery of pediatric palliative care services?

10. Would you please discuss how staff education and training influence the barriers to the delivery of pediatric palliative care services?

## CURRICULUM VITAE

Maureen Kirkpatrick McLaughlin was born in Johnstown, Pennsylvania. She is one of five children born to Joseph and Sarah Kirkpatrick. She began her health related career as an operating room technician and went on to receive a diploma of nursing at St. Francis Hospital School of Nursing in Pittsburgh, PA. She earned her Bachelor of Science Degree in Professional Arts at St. Joseph's College in Windham, Maine and a Master of Science Degree in Organizational Effectiveness at Marymount University, Arlington, VA. Her career in the health care field has included multiple leadership positions at the local, state and national levels. She is married to James M. McLaughlin and is the proud mother of three sons, Matthew, Sean, and Aaron.