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The relationship between nurses' anxiety and attitude related to pediatric hospice

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The Relationship Between Nurses' Anxiety And Attitude

Related To Pediatric Hospice

by

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A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science
College of Nursing
University of South Florida

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The Relationship Between Nurses' Attitude and Anxiety
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ABSTRACT

To lose a child is a profoundly emotional experience. Even if it is not your own, the experience involves deeply held beliefs about death, the quality of death, ethics, and perhaps personal experience. Left unexplored, these beliefs and the anxiety they may produce, can become barriers to providing quality end-of-life care for children with life limiting conditions and their families. The purpose of this study was to explore the relationship between hospice nurses' attitudes toward providing pediatric hospice care and the level of anxiety they may experience related to pediatric hospice care. A self-administered questionnaire was completed by 30 hospice nurses. The 20-item state anxiety questionnaire from the State-Trait Anxiety Inventory was used to rate the nurses' level of anxiety related to pediatric hospice care. The nurses' attitudes toward pediatric hospice care were measured using a modified version of Attitudes About Care at the End of Life Among Clinicians Scale. State-anxiety refers to the reaction or process taking place at a given time and the level of intensity related to the situation. The possible range of scores was 20-80 with the higher score indicating greater levels of anxiety. The actual range was 20-65, with a mean of 35.9 (SD=12.1). The possible range of scores for the total attitude score was 12-60, with a higher score indicating a more positive attitude

toward pediatric hospice. The total attitude score had a mean of 31.0 (SD=5.2). Attitude was further divided into three attitude subscales: comfort in discussing pediatric hospice with parents, perceived benefit of pediatric hospice and attitude toward physician involvement in pediatric hospice. The possible range for each subscale was 4-20, again with higher scores indicating a positive attitude. The comfort subscale had a mean of 8.3 (SD=2.8). The benefit subscale had a mean of 9.3 (SD=2.5). The physician involvement subscale had a mean of 13.7 (SD=2.1). The results suggested the presence of some amount of anxiety experienced with pediatric hospice. The total score on the attitude portion of the survey indicated a generally positive attitude toward pediatric hospice in general. Additionally, the subscales of comfort in discussing pediatric hospice, the benefit of pediatric hospice and the attitude toward physician involvement demonstrated a positive attitude as well. While there was no significant relationship found between the total attitude score and anxiety or between the comfort and benefit subscales, there was a significant relationship ($p<.01$) found between the physician subscale and anxiety. This may indicate a desire for more physician involvement or the belief that physician involvement decreases anxiety. This study revealed self-knowledge and pediatric specific hospice training as areas for future research and education.

Chapter I

Introduction

A report from the Institute of Medicine (2003), *When Children Die*, states that approximately 55,000 children up to age 19 die in this country annually. However, less than 1% of the children who need hospice care receive it (Children's Hospice International, 2003). A study conducted by Children's Medical Services of Florida in 1999 (as cited by Children's Hospice International, 2005) stated that 50% of the hospice programs in Florida reported that the needs of terminally ill children were not addressed to their satisfaction. At that time, only 18 Florida hospice programs of the 36 surveyed provided a full hospice program for children. Nationally, on any given day, approximately 8,600 children could benefit from hospice care (Rushton, 2004).

It is unclear why the needs of terminally ill children are not achieved more adequately. In the researcher's clinical experience, the commonly stated reasons for lack of pediatric hospice are: economics, lack of a pediatric hospice model, parents' beliefs about hospice care, and nurses' attitudes toward providing hospice care to children. The Children's Hospice International *Program for All-Inclusive care for Children and Their Families* (CHI PACC) is beginning to address both the economic issues and the need for a pediatric model of end-of-life care. The beliefs of families as well as nurses' attitudes can be changed through education.

For hospice nurses to educate patients or their families, they must first educate themselves on the topic at hand. This education begins with identifying beliefs and attitudes regarding hospice care for children as well as any anxiety related to the hospice care experience. Children's Cancer Center in Tampa Florida holds a support group for parent's who have recently lost their children to cancer. During these meetings the

parents often share their hospice experiences with each other. Some shared that they were without hospice care altogether, others stated that their hospice experience was marred by the hospice nurses' poor attitude, lack of compassion, or emotional breakdown, and thankfully a few told of the supportive compassionate care they received from a hospice nurse. Clearly, the needs of the parents and their terminally ill children in this particular setting were not met.

Andersen, Seeharan, and Toce (2004) noted that most health care providers are not sufficiently trained to deal with death in the pediatric population. Nurses are trained to perform the tasks required of care regimens and how to operate medical devices, but little if any training involves nurses sorting out their personal beliefs and their attitudes toward death, particularly the death of a child. Many emotions come into play when nurses are faced with the potential death of a child. A nurses' inability to deal with those emotions might give the appearance of poor attitude or a lack of compassion. A nurse might become overwhelmed by those unchecked emotions and fail to support the patient and the patient's family. The anxiety produced when these factors are combined can become a barrier to providing pediatric hospice care.

Statement of the Problem

To lose a child is a profoundly emotional experience. Even if it is not your own, the experience involves deeply held values about death, the quality of death, ethics, and perhaps personal experience. Left unexplored, these beliefs and attitudes can become barriers to providing quality end-of-life care for children with life limiting conditions and their families. If the nurses' attitudes and beliefs are negative the nurse may also experience anxiety.

There are several areas of concern related to providing quality end-of-life care for children. Economic policies and appropriate models of care are not enough in and of themselves to bring about change. The correct model and the funds to support it are of little use if there are too few trained hospice nurses to provide the needed care. A

conscious effort must be made to change the attitudes and beliefs of nurses who care for terminally ill children (Rushton, 2004). That transformation begins with research into the underlying attitudes and anxieties that effect hospice nurses when faced with the care of a dying child.

Purpose

The purpose of this study was to identify the relationship between hospice nurses' attitude toward providing pediatric hospice care and the level of anxiety they experienced related to pediatric hospice care.

Research Questions

1. What are the attitudes of nurses toward pediatric hospice care?
2. What is the level of anxiety of nurses providing pediatric hospice care?
3. Is there a significant relationship between attitude toward pediatric hospice care and anxiety in nurses caring for pediatric hospice patients?

Definition of Terms

The following questions guided this study:

1. Pediatric Hospice care - A philosophy of care, which addresses the physical, social, emotional, and spiritual needs of children and adolescents with life-threatening conditions and their families. (Children's Hospice International, 2005)
2. Palliative care - Intervention that focuses primarily on reduction or abatement of the physical and psychological symptoms of terminal illness. (Children's Hospice International, 2005)
3. End-of-life (EOL) care - Refers explicitly to the final weeks of life when death is imminent. (Ferrell & Coyle, 2002)
4. State Anxiety – Refers to a transitory emotional state characterized by subjective feelings of tension that may vary in intensity over time (Spielberger, 1983)
5. Attitude – behavior based on conscious or unconscious views developed through cumulative experience that influences behavior (Cramer, 2003)

Significance to Nursing

The purpose of this study was to explore the nature of the hospice nurses' attitudes toward hospice care for children and the anxiety experienced when asked to participate in pediatric hospice care. To provide quality care for dying children and their families requires a personalization of care and an attentiveness to patient and family values, wishes and cultural preferences; the art of nursing requires one to ask, listen, and respond (Feudtner, 2004). In order for hospice nurses to be attentive, to listen and to respond appropriately, they must first overcome any emotional barriers they might have including a less than positive attitude toward pediatric hospice or excessive anxiety. Identifying nurses' attitudes toward pediatric hospice will provide an additional focus for hospice nurse education and training. Determining the level of anxiety experienced by nurses providing hospice care to children will be helpful to educators in planning appropriate training for this population of nurses. This knowledge will assist in supporting the emotional health of the hospice nurses, allowing them to identify and address potential areas of anxiety and stress.

Chapter II

Review of Literature

This chapter reviews and summarizes some of the current empirical literature on the attitudes and perceptions of healthcare providers regarding pediatric hospice care. Due to the limited published research involving pediatric hospice care this review includes articles on the related subject of attitudes toward adult hospice care. This review also contains findings regarding health care professional's anxieties related to pediatric hospice care. Research on this topic and hospice care in general is primarily qualitative in nature, and includes descriptive studies, case studies, and scholarly non-research articles. The quantitative studies incorporate multiple variables; however for the purpose of this review only the findings related to anxiety and attitude are presented.

Case Studies

Rushton (2005) presents two case studies comparing two very different treatment models. The first model is perhaps the most common, with a focus on the disease and a cure at any cost attitude. The second model takes a more holistic view of the patient, treating the patient as a whole person rather than individual systems or symptoms.

The first case study involved an eleven-year-old boy, Jason, who was diagnosed with acute myelogenous leukemia (AML). He was treated first with chemotherapy and after a period of remission, he relapsed. The treatment team discussed options for further intervention with the family as well as the likelihood of survival. It was decided that Jason would undergo bone marrow transplant (BMT). Jason suffered several life-threatening complications and each time aggressive therapies were performed to prolong his life. Palliative care and hospice were not mentioned to the family. From the time of the first complication until his death Jason was ventilator dependant, heavily sedated and

unable to communicate. He died in the PICU and the family was distraught because they did not have an opportunity to say goodbye.

The second case study involved a twelve-year-old girl, Melinda, also diagnosed with AML. Melinda's treatment however was within an integrated holistic model of care including palliative care from the time of diagnosis. The palliative care team talked with the family and Melinda about the usual course of the disease, treatment options, the goals for treatment, symptom management, and pain management. The team provided physical, emotional, and spiritual support throughout the course of her illness. Like Jason, Melinda achieved remission after chemotherapy and later relapsed. They too made a decision to undergo BMT. The palliative care team again talked with the family and patient; this time regarding what matters most in Melinda's life according to both Melinda and her parents, their fears, and regarding at what point might the burden of treatment become too great. Before starting the transplant Melinda and her family made a video and some special mementos. Following the transplant Melinda developed graft-versus-host disease and despite aggressive support she continued to deteriorate. The team and the family later agreed that the quality of Melinda's remaining time took precedence over further treatment. The treating team weaned Melinda from sedation and removed her from ventilation. Melinda was able to interact with her family briefly and then died peacefully with her family around her.

Comparing these two cases clearly demonstrates the benefits of a holistic palliative care approach for the patient and the patient's family. Rushton (2005) also describes the nursing attitudes needed to provide quality care at the end of a child's life and the foundation of that care requiring attunement and presence. According to Rushton, attunement is based on self-awareness, which begins with understanding the influence of one's experiences and responses. She described presence as requiring the healthcare professional to deepen self-knowledge in order to let go of the desire to control the uncontrollable. Attitudes are developed through experiences and as responses to those

experiences. Clearly recognizing and addressing those attitudes is part of cultivating self-awareness. It would seem to follow that an increased self-awareness would produce a more positive attitude and thereby decrease anxiety. Rushton considers the challenge to be making peace with conflict, not eliminating it and views the challenge as an opportunity to change.

In another case study, Rushton (2004) addressed attitudes and beliefs surrounding the ethical issues of pediatric palliative care. This case is about David who was born prematurely at 24 weeks gestation and over the course of his 30-month life was hospitalized six times for a total of more than 45 weeks. With each hospitalization David's condition worsened and significant developmental delays became more apparent. Each time the parents insisted on aggressive treatment. The treatment team made every effort to help his parents understand the trajectory of David's condition and the consequences of the decisions they would need to make.

While trying to do the best thing for David, the members of the care team struggled with their own grief and ethical beliefs. The team members had developed particular attitudes regarding discontinuing life-prolonging treatments, based on their years of experience. The anxiety in this instance was related to the inability of the team members to do what they believed was the right thing for their patient. The ethical conflict between the parents and the treatment team became more apparent as the team reiterated its recommendation that the family limit life-prolonging interventions.

David's parents finally agreed to a DNR order, but continued to resist the idea of hospice because they believed that would mean giving up on their son. The team members' ability to share their positive attitudes and experiences about the holistic and supportive focus of hospice care allowed the parents to come to terms with David's inevitable death. Identifying and discussing the attitudes of the family and those of the team members decreased anxiety on both sides. David's parents took him home and

effort was made to ensure his comfort. He then spent his last few days in his parent's arms.

Hinds, Oakes, Hicks, and Anghelescu (2005) reported on a case study involving a six-year-old boy with leukemia. The family was struggling with two opposing issues: the desire to be what they considered good parents by limiting their son's suffering and the desire to interact with him as long as possible. Sufficient pain relief caused their son to be greatly sedated, so the family requested pain medication be limited. As noted in previous case studies, the focus of care was not only palliative support for the patient but also support for the family. Supporting the family's wishes in this case caused the staff to suffer, because they would have preferred to reduce the patient's pain. The staff also experienced grief during the course of care and in anticipation of their patient's death.

This study, like the previous ones, points out the dilemmas that can arise as a result of conflicting ethical beliefs. Again the attitudes of the team members were based on years of positive experience, experience that the parents do not have. There were increased anxiety levels on both sides due to the staff's goal of pain relief and the parent's goal of interacting with their son as long as possible. According to Hinds et al. (2005), prolonged unresolved conflicts can emotionally debilitate clinicians and affect their commitment to providing patient care. Grieving affects staff emotionally as well and has additional physical, mental, and spiritual repercussions. If these conflicts are not addressed a healthcare provider could develop compassion fatigue. Hinds et al. described compassion fatigue as similar to grief with symptoms including lower frustration tolerance, dread of care-giving, diminished sense of purpose, depression and loss of hope, diminished capacity to listen and communicate, and loss of confidence. Education regarding these intense feelings and attitudes enables nurses to identify and address issues as they arise thereby decreasing the possibility of long term adverse effects.

Quantitative Research

Vejlgaard and Addington-Hall (2005) conducted a cross-sectional retrospective survey of Danish doctors and nurses regarding attitudes and issues related to palliative care. The survey was constructed from other questionnaires and studies identified from a literature review. Three hundred forty seven nurses and doctors working in a Viborg county hospital, home care, and related services responded to the survey. The responses were compared using chi square statistics and chi square for trend.

One of the questions posed by Vejlgaard and Addington-Hall (2005) was, “Dealing with a dying patient makes one aware of one’s own feelings regarding death” (p.122). Ninety-seven percent of nurses and eighty percent of doctors agreed with this statement. Another question related to attitude was, “I reflect a lot upon existential matters (thoughts about the meaning of life and death)” (p.122). Ninety percent of nurses and sixty-three percent of doctors agreed with this statement. Again this question and the majority response, demonstrates the profundity of feelings and attitudes addressed by nurses in a palliative care setting.

In addition to revealing the nature of the feelings experienced by nurses, Vejlgaard and Addington-Hall (2005) also posed the question, “It is primarily the task of the nurse to deal with patients’ reactions to death” (p.122). Fifty-nine percent of nurses agreed with this statement. So, not only are nurses dealing with their own feelings toward death, they shoulder the majority of the burden of dealing with the patients’ reactions as well. This study gives clear direction for the areas that could be included in nursing training to better prepare nurses for dealing with their attitudes toward death and the anxiety produced when working with dying patients.

Sahler et al. (2000) gathered a group of physicians together for the purpose of identifying opportunities for, and barriers to, medical education about end-of-life care in the pediatric setting. One of the barriers identified by the group was the simple fact that in the county where this study was conducted, relatively few children die, which limits

the exposure health professionals have to the intense emotions associated with the death of a child. If not dealt with, feelings of anxiety and negative attitudes related to pediatric death, may cause physicians and nurses to react by pulling away both emotionally and physically. Helping nurses while in training to recognize and consider the affects of these emotions through self-reflection would increase professional satisfaction and quality of the relationship with the patient and their family.

Another barrier discovered by Sahler et al. (2000) was the difference between curative and palliative care in congenital disease. With congenital disease a child may live many years without the possibility of cure. As time passes, the focus of care may change from life-prolonging to comfort measures and back again several times during the child's life. If palliative care is considered part of the care paradigm from the time of diagnosis, the transition from one focus to the next is done gradually and intuitively, thus decreasing the psychological and emotional burden.

An additional barrier discovered by Sahler et al. (2000), also relating to attitude, is the caregiver's response in EOL care. While death is expected to provoke an emotional response, the death of a child can bring feelings of powerlessness, unfairness, and personal vulnerability (Sahler, 2000). In this country there is an expectation that children will grow to adulthood and become the foundation for the next generation. The possibility of this hope not coming to fruition produces great anxiety.

Cramer, McCorkle, Cherlin, Johnson-Hurzeler, and Bradley (2003) conducted a study of 180 nurses in order to describe the characteristics, attitudes, and communications of nurses regarding hospice and caring for terminally ill patients. A cross-sectional design was used and data was collected from self-report questionnaires. Thirty nurses were randomly selected from each of six randomly selected Connecticut hospitals n=180.

Cramer and colleagues (2003) included staff nurses employed at least 6 months prior to the study and assigned to the cardiac, pulmonary, or oncology units. The sample was primarily female (94.8%) and white (94.2%). The inquiry was based on the belief that the

potential influences on nurses' practice include both fixed and modifiable characteristics. Three fixed and three modifiable areas were identified. Three modifiable domains pertaining to attitude were studied. Responses to a set of statements about the care of terminally ill patients and hospice were used to assess attitudes toward hospice via a Likert type scale. The three attitudinal scores had a possible range of 12 to 60. Higher scores indicated a more positive attitude toward discussion of hospice, the benefit of hospice and perception of physician responsibility in hospice care. The original instrument, from which these attitudinal items were derived, was tested in a pilot study in which the instrument showed good test-retest validity and good construct validity. The outcomes and independent variables were assessed using *t* tests. Multiple logistic regression was used to analyze a separate final model for each of the three modifiable domains. The researchers found that the modifiable characteristics of self-knowledge, hospice training, and attitude had a positive association ($p < .05$) in the nurses' comfort in discussing hospice and its benefits with hospice patients and their families.

A study by Andersen, Seecharan, and Toce (2004) researched the perceptions of nurses and physicians regarding quality of death for their pediatric patients. The study was conducted in a faith based tertiary children's hospital in Missouri where the participants worked as part of the palliative care team. Self-administered surveys were mailed to seventy-one physician/nurse pairs identified as the primary care providers for the same child. The surveys consisted of closed-ended questions regarding the quality of care in the areas of pain, physical, psychosocial, and spiritual support, as well as provider perceptions. The questions were derived from provider focus group feedback. Analysis comparing nurse and physician responses was performed using simple chi square in dichotomous and nominal categories and chi square for trend statistics.

Anderson, Seecharan, and Toce (2004) noted that both nurses and physicians in the categories of anticipatory guidance, symptom and pain management, and quality of death reported a high level of agreement. Nurses and physicians believed that a quality

experience during the dying process was achieved if these needs were met. A difference was noted in the roles of nurses and physicians however. Nurses were more likely to talk with the family about sibling, psychosocial, and religious issues, while physicians were more likely to talk with families about decision-making. Based on these results, regardless of the role the provider plays it appears that there is a positive association between a palliative care approach and positive nurse and physician attitudes regarding the quality of death. When healthcare professionals can feel positive about their ability to provide a quality death for a patient, the anxiety level is decreased.

To determine the core competencies and educational needs for EOL care, White, Coyne, and Patel (2001) conducted a survey of nurses belonging to the Oncology Nurses Society in Georgia, Virginia, Washington, and Wisconsin. The researchers developed and mailed a descriptive survey containing open-ended questions to 2,334 nurses and received 760 responses. Nearly all of the respondents reported that EOL care was part of their practice and that continuing education was important. Despite the reported importance of continuing education, one third of those surveyed stated that they had less than two hours of continuing education in the previous two-year period. Among the top rated core competencies were: how to talk to patients and families about dying, pain control, comfort measures, palliative treatments, and dealing with personal feelings. This study points out the perceived need among hospice nurses that feelings or attitudes are a critical topic of education.

Amery and Lapwood (2004) utilized a descriptive quantitative study and qualitative survey to identify and explore the educational needs of children's hospice doctors in England. They developed a self-administered questionnaire from an analysis of existing children's palliative care literature. In addition to the survey they also asked the participants to keep a preformatted educational diary. All doctors caring for pediatric hospice patients (n=55) were approached, and 35 responded. The surveys were designed

to assess the doctors perceived educational needs and the diaries were to be used in practice to identify unmet educational needs.

Amery and Lapwood (2004) found a discrepancy between the educational needs derived from the surveys and the needs described in the diaries. The questionnaires revealed that the doctors most wanted education in clinical areas such as symptom control. The diaries however, revealed that education in areas of higher order, such as personal coping strategies and communication was of most importance. Statistical analysis was not reported.

Amery and Lapwood (2004) found that the participants felt significant personal burden when working dying children, the particular concerns were the ability to handle their own emotions, their sense of isolation, and the crucial need to find peer support. The researchers believe that the diaries reflect the actual learning needs of the learner in their day-to-day practice as opposed to the learner's perceived learning needs (Amery and Lapwood, 2004). The participants in this study imply a need to decrease anxiety through support and a means of dealing with the emotions common to pediatric hospice.

With the purpose of improving care for dying patients Bradley, et al (2000) conducted a study to develop and test an easy to use instrument for measuring the attitudes of clinicians working with terminally ill patients. After a review of the current literature and interviews with both nurses and physicians three attitudinal constructs were identified; professional responsibility in caring for dying patients, efficacy of hospice and communication about dying. From those constructs, 25 items were developed to measure the constructs qualitatively. The items were then tested, unclear items were eliminated and additional items were added, resulting in a 12 item Likert type scale. The 12 item scale was then tested for validity and reliability and shown to have good test-retest validity and good construct validity for all twelve items combined was reported at 0.86.

Bradley, et al (2000), stated that because clinicians are such an essential part of the patient care decisions made at the end of life, their attitudes are also essential to directing

that care. One of the reported weaknesses of this study however, was that the clinicians participating in the study were caring for a more elderly population and that clinicians caring for children might have a very different set of attitudes.

Summary

Throughout the literature there is a consistent theme of how attitude affects the disposition of the nurse, the quality of care, the ability to communicate and even the quality of the child's death. Though not always stated directly, there is a sense of underlying anxiety produced by a less than positive attitude. The majority of attitudes and beliefs held by health professionals seem to be based on personal rather than work experiences, and most nurses stated that they felt inadequately trained to deal with the issues surrounding death, especially the death of a child. Further complicating the problem is the difficulty or inability to identify and express particular attitudes. Another area of concern noted in this brief review was the challenge of resolving conflicts between nursing staff and parents with opposing attitudes and the anxiety these situations produce. While key attitudes regarding pediatric hospice care and the anxieties experienced have been documented to some degree, what is lacking is a clearly stated connection between those attitudes and the level of anxiety. It is possible that a more positive attitude might help to decrease the level of anxiety.

Chapter III

Methods

The methods of research are presented in this chapter, including a description of the participants, the instruments of measurement and the variables studied. The procedures for data collection and method of analysis also are included.

Sample

A convenience sample of registered nurses currently working at Lifepath Hospice and Palliative Care was used to obtain an appropriate number of participants. The criteria for inclusion were (a) registered nurse providing hospice care; (b) ability to read and write in English. The sample size was estimated using power analytic techniques. With $r = .30$ and an alpha of $.05$, it was determined that a sample size of 83 was needed to achieve a power of $.80$.

Instruments

The State-Trait Anxiety Inventory (Spielberger, 1983) was used to rate the nurses' level of anxiety related to pediatric hospice care. Nurses' attitudes were measured using a modified version of Attitudes About Care at the End of Life Among Clinicians (Bradley et al., 2000). Permission to use these instruments was obtained (Appendix A and B).

State Trait Anxiety Inventory

Anxiety was measured using the state anxiety portion of State-Trait Anxiety Inventory (STAI), a widely used measure of anxiety (Spielberger, 1985). The 20-item inventory consists of 10 anxiety-present items and 10 anxiety-absent items. Participants responded to each of the items on a four point summated rating scale, with options ranging from (1) not at all to (4) very much. Summing the responses provided a state

anxiety score ranging from 20 to 80 with the higher scores indicating a higher state of anxiety. The state and trait portions of the STAI have well established psychometric properties, with an internal consistency coefficient [alpha] reported as 0.89-0.94. This form can be seen in Appendix C.

Attitudes About Care at the End of Life Among Clinicians

The Attitudes About Care at the End of Life Among Clinicians (Bradley et al., 2000) instrument was modified to reflect attitudes related to a pediatric population rather than the adult population for which it was originally designed. The original instrument was a 12-item survey designed to assess three attitudinal constructs. The first concept refers to one's level of comfort in discussing hospice with the parents of a terminally ill child. The second concept involves views regarding what roles and responsibilities medical professionals have in caring for terminally ill children. The third concept refers to the degree to which one believes hospice is beneficial compared to conventional medical care. Participants respond to each of the items on a five point summated rating scale, with options ranging from (1) strongly agree to (4) strongly disagree. Summing the responses provides a picture of the nurse's attitudes toward hospice care with higher scores indicating a more positive view. The original instrument, from which these items were derived, was tested in a pilot study (Bradley et al., 2000) and showed good test-retest validity and good construct validity for all twelve items combined was reported at 0.86. This form can be seen in Appendix D.

Demographic Data Form

Demographic information on each participant was collected using a demographic data form. This form included: age, gender, years of hospice nursing experience, number of years in nursing, pediatric hospice experience, ethnicity, highest level of nursing education and amount of any of training in pediatric hospice. This form can be seen in Appendix E.

Procedures

Approval was obtained from the bioethics committee at Lifepath Hospice and Palliative Care as well as the University of South Florida Institutional Review Board (Appendix F and G). A description of the study was provided during several team meetings at the hospice offices. Nurses were invited to participate and questions were answered. Consent was implied if the participants completed the survey and to protect privacy the surveys were filled out anonymously. The study survey was distributed during several staff meetings, completed independently and returned immediately upon completion.

Data Analysis

Demographic data were analyzed using frequencies, percentages, means, and standard deviations. Means and standard deviations were calculated for research questions one and two. And finally, Pearson's correlation was used to analyze research question number three.

1. What is the level of anxiety of nurses providing pediatric hospice care?
2. What are the attitudes of nurses toward pediatric hospice care?
3. Is there a significant relationship between attitude toward pediatric hospice care and anxiety in nurses caring for pediatric hospice patients?

Chapter IV

Results, Discussion, and Conclusion

This chapter presents the results of the study. The study's strengths and weaknesses are discussed, as well as its implications for nursing. Suggestions for future research and for overcoming this study's limitations are also discussed.

Results

Sample

Thirty surveys were distributed to nurses working at a local hospice during several staff meetings. All of the surveys were returned completed. The surveys were completed anonymously in an effort to achieve the most accurate information.

The majority of respondents were white females over the age of 45 (Table 1). Nearly sixty-seven percent of the respondents had been working in hospice for greater than one year, however only 27% were currently working with pediatric patients. Eighty percent of the respondents had greater than ten years of nursing experience (Table 2).

Table 1. Age and Gender of Sample

	n	Mean	SD	Frequency	Percentage
Age	30	46.6	8.5		
Gender	30				
Female				27	90
Male				3	10

Anxiety

The state anxiety portion of the STAI was used to measure the first research question regarding the level of anxiety nurses experience when providing pediatric

hospice care. The participants were instructed to answer each of the twenty questions in relation to how they feel when working with pediatric hospice patients. State-anxiety refers to the reaction or process taking place at a given time and its level of intensity, in this case when involved with pediatric hospice care (Spielberger, 1983). The possible range of scores is 20-80 with the higher score indicating greater levels of anxiety. The actual range was 20-65, with a mean of 35.9, a standard deviation of 12.1 and a median anxiety score of 35.0 (Table 3).

Table 2. Description of Sample Demographics

	n	Mean	SD	Frequency	Percentage
Years of Nursing Experience	30	2.7	.70		
Education Level	30				
LPN				3	10.0
Diploma				1	3.3
ASN				13	43.3
BSN				8	26.7
MSN				5	16.7
Hospice Experience	30				
< 1yr				10	33.3
1-5 yr				12	40.0
>5 yr				8	26.7
Pediatric Hospice Experience	30				
In Past				16	53.3
Presently				8	26.7
Training	30				
Yes				8	26.7
CEU only				7	23.3
Ethnicity	30				
White				23	76.7
Black				4	13.3
Hispanic				3	10.0

Attitude

The second research question addressed the attitudes of nurses toward pediatric hospice care and was measured using the *The Attitudes About Care at the End of Life Among Clinicians* questionnaire (Bradley et al., 2000). This instrument measured overall attitude and breaks attitude into three subscales of attitude using a 12-item questionnaire with 4 questions for each subscale. The possible range of scores for the total attitude score is 12-60, with a higher score indicating a more positive attitude toward pediatric hospice. The total attitude score had a mean of 31.0, a standard deviation of 5.2 and a median attitude score of 32.0 (Table3).

The range for each subscale was 4-20, again with higher scores indicating a positive attitude. The first subscale measures the level of comfort in discussing hospice and hospice related issues with the parents of a terminally ill child. The mean for this subscale was 8.3, the standard deviation 2.8 and the median was 8.0. The second subscale measures the views of nurses regarding the roles and responsibilities of medical professionals caring of terminally ill children, specifically physician involvement. A higher score in this case indicates that nurses feel positively about physician involvement. This subscale had a mean of 13.7, a standard deviation of 2.1 and a median of 13.0. The final subscale measures the perceived benefit of hospice verses conventional medical care. A higher score indicated the nurses believe hospice is more beneficial than conventional medical care in meeting the needs of terminally ill children and their parents. The mean for the benefit subscale was 9.3, with a standard deviation of 2.5 and a median score of 9.0 (Table 3).

Relationship Between Anxiety and Attitude

Pearson's correlation was used to analyze the third research question exploring the relationship between attitude toward pediatric hospice care and anxiety in nurses caring for pediatric hospice patients. There was no significant relationship found between the total attitude score and the total anxiety score, or the comfort and benefit subscales as

correlated with the total anxiety score. There was, however, a significant relationship ($p<.01$) in the physician involvement subscale as compared with the total anxiety score (Table 4).

Table 3. Attitude and Anxiety Scores

	n	Possible Range	Actual Range	Mean	SD	Median
Attitude Total	30	12 – 60	21 – 45	31.0	5.2	32.0
Anxiety Total	30	20 -80	20 - 65	35.9	12.1	35.0
Subscales						
Comfort	30	4 - 20	4 - 15	8.3	2.8	8.0
Physician	30	4 - 20	11 - 20	13.7	2.1	13.0
Benefit	30	4 - 20	4 - 15	9.0	2.5	9.0

Table 4. Attitude and Anxiety Correlations

	n	<i>r</i>	<i>P</i>
Attitude Total Score	30	.159	NS ^a
Comfort Subscale	30	.053	NS ^a
Physician Subscale	30	.481	.007
Benefit Subscale	30	-.131	NS ^a
Anxiety Total Score	30	.159	NS ^a

^a NS = Not significant

Discussion

Sample

This survey was limited to one hospice with a small sample size of only 30 participants and therefore the findings may not reflect the total population of hospice nurses. Ninety percent of the participants were female, 76.7% were white and almost

60% were over the age of 45, making this a fairly homogenous group. Another weakness may be the fact that such a large number (73%) of the participants were not currently working with pediatric hospice patients. Future studies should be more diverse and have a larger sample size.

The line between the other weaknesses and the strengths of the sample are not as clear. Well over half (66.7%) of the participants had been working in hospice for more than one year, with 26.7% of those having more than five years of hospice employment. As a weakness this may create a positive bias toward hospice and a decrease in overall anxiety. However this may also be considered a strength because the participants were speaking from experience not conjecture. Similar arguments can be made of the nurse participant's overall nursing experience. Ninety-three percent of them had greater than 5 years of experience, 80% of those had more than 10 years of experience. In light of these limitations the results are nonetheless food for thought.

Anxiety

The results reveal a disparity between the respondents' self-rated anxiety level and the anecdotal information that prompted the study. Conversations with both nurses and the parents of terminally ill children prior to the study indicated a very high level of anxiety related to pediatric hospice. Scores below fifty on the STAI indicate a lower level of anxiety. The mean score was 35.9 indicating a trend toward low to moderate levels of anxiety, with one participant scoring a very high 65. A larger sample size may have given a better picture of the actual anxiety level experienced by most hospice nurses. There may be other reasons for the discrepancy between the researcher's clinical experience and the outcome of the study. Since the survey was given during a staff meeting, the participants may not have been able to place themselves in the appropriate mindset, thus minimizing the anxiety level they might experience in the pediatric hospice setting. In addition, in order to avoid bias, the investigator administering the survey did not give instructions that would have led the participants in any way. Participant self-bias may

have played a role as well. Despite assurances that the results were completely anonymous, the participants may have attached a negative connotation to high levels of anxiety and therefore scored themselves lower to appear more positive.

Attitude

The total score on the attitude portion of the survey indicated a generally positive attitude toward pediatric hospice in general, with lower scores indicating a more positive attitude and a mid-point score of 44 dividing positive attitude from the more negative. The mean score was 31. The subscales of comfort in discussing pediatric hospice, the benefit of pediatric hospice and the attitude toward physician involvement had a smaller range of 4 to 20 possible. The attitude toward the benefit of pediatric hospice scored comfortably on the positive side with a mean of 9.0 as did the comfort subscale with a mean of 8.3. The physician involvement subscale is scored in reverse significance with higher scores indicating a more positive attitude toward physician involvement, so with a mean of 13.6 this subscale again demonstrated that the nurses in the sample had a positive attitude related to physician involvement. While the overall attitude toward pediatric hospice was expected to be positive, particularly toward the benefits of pediatric hospice, the attitude toward comfort in discussing hospice with the parents of terminally ill children was anticipated to be more negative, based again on the previous experience of the researcher. Perhaps the participant nurses were considering their comfort level in discussing hospice in general, rather than specifically pediatric hospice.

Relationship Between Anxiety and Attitude

While there was no significant relationship found between the total attitude score and anxiety or between the comfort and benefit subscales, there was a significant relationship found between the physician subscale and anxiety. Given the positive attitude scores in total as well as in the comfort and benefit subscales, it would seem to follow that the anxiety level would be lower. This assumes that a more positive attitude would positively affect (lower) the nurse's level of anxiety. The cause of the significant

relationship ($p < .01$) between attitude toward physician involvement and level of anxiety is unclear. Perhaps the nurses in this sample desire more physician involvement than they currently have. Since most of the nurses in this study did experience some level of anxiety related to pediatric hospice they may view physician involvement as a way to help decrease anxiety.

This study revealed implications for hospice nurse training related to attitude and anxiety. Nurses cannot be trained to change their attitude or ignore their anxiety, but they can be given the skills needed to help them identify and deal with their attitudes toward death and the anxiety produced when working with dying patients, particularly terminally ill children. Cramer and colleagues (2003) found that self-knowledge, hospice training and attitude had a positive association with nurses' comfort in discussing hospice and its benefits. In a country where relatively few children die, experience alone is not enough for nurses to gain insight into their attitudes toward the death of a child. Therefore, techniques for gaining self-knowledge could be one of the skills taught during training.

Fifty-nine percent of the nurses in the Vejlgard and Addington-Hall (2005) study believed that nurses shoulder the majority of the burden when dealing with the patients' reactions to death. The patients' reaction coupled with the nurses' personal attitudes and anxiety can become overwhelming. If not identified and dealt with, these attitudes and anxiety may cause nurses to react by pulling away both emotionally and physically. This further emphasizes the need for self-knowledge at the time of training, so that pediatric hospice nurses are from the time of their first assignment, able to perform the physical tasks required while emotionally supporting the dying child and the child's parents.

The need for training in general was revealed in the demographic data. An overwhelming majority (73.3%) of the participants in this survey had received no training in pediatric hospice at all. Further research into specific educational needs of pediatric hospice nurses is indicated, with the results used to develop a model for pediatric hospice training. This study did not compare the lack of pediatric hospice training to the nurses'

level of anxiety. Additional research into this area would provide more support for pediatric specific hospice training.

There were limitations to the study instruments. The conflicts described in the case studies presented in the literature review could not be addressed with this attitude measure. Developing a tool to measure the significance of those conflicts and their effect on anxiety would enhance future studies. The anxiety instrument, although very reliable as a measure of state-anxiety, may not have given an accurate picture of the level of anxiety related to specific pediatric hospice situations. A tool containing both the aspect of pediatric hospice being measured and the corresponding level of anxiety might give a more accurate result. Increasing the sample size and including several hospice organizations would help to overcome some of this study's limitations as well.

Conclusion

The results of the study demonstrated a generally positive attitude toward pediatric hospice including the specific areas of comfort in discussing pediatric hospice, the benefits of pediatric hospice and the attitude toward physician involvement in pediatric hospice. Some level of anxiety was indicated by the nurses in the study, although most scored themselves on the lower end of the anxiety scale. The disparity between the respondents' stated level of anxiety and the anecdotal findings of the researcher might be rectified with a stronger study. Unfortunately, not enough information was gained to develop a teaching tool directly from these results. However, the study does give some direction for future research and the development of more specific methods of measure.

Future Research

Future research into the issue of nursing anxiety and attitude toward caring for pediatric hospice patients should:

- Include larger samples from multiple hospices,
- Include a more diverse sample,
- Be conducted immediately prior to performing pediatric hospice care,

- Compare nurses' level of pediatric hospice training to level of anxiety,
- Work toward developing a tool that is specific to the anxiety-producing aspects of pediatric hospice

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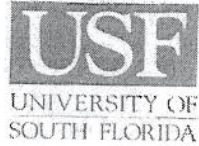
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Appendices

Appendix A: Letter of Permission to Use the STAI



March 22, 2006

Ms. Teresa Hoover
329 County Line Rd. E.
Lutz, FL 33549

Dear Ms. Hoover:

In response to your recent request, I am very pleased to give you permission to reproduce and use the State-Trait Anxiety Inventory (STAI) for your Masters Thesis research, entitled:

**The Relationship Between Nurses' Attitudes and Anxiety Related to
Pediatric Hospice Care**

It is my understanding that your research will be carried out at:

Life Path Hospice & Palliative Care, Inc.

This permission is contingent on your agreement to share your research findings with us. I look forward to receiving further details about your procedures and the results of your study as such information becomes available.

Best wishes on your research project.

Sincerely,

A handwritten signature in dark ink, appearing to read "Charles D. Spielberger".

Charles D. Spielberger, Ph.D., ABPP
Distinguished Research Professor of Psychology
Director, Center for Research in Behavioral
Medicine and Health Psychology
Phone (813) 974-2342; Fax (813) 974-4617

DEPARTMENT OF PSYCHOLOGY • COLLEGE OF ARTS AND SCIENCES
University of South Florida • 4202 E. Fowler Avenue, PC104118G • Tampa, Florida 33620-7200
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Appendix B: Letter of Permission to Use the Attitude Scale

Hoover, Teresa

From: Hoover, Teresa **Sent:** Thu 11/17/2005 4:14 PM
To: Elizabeth H. Bradley
Cc:
Subject: RE: attitudes toward hospice scale
Attachments:

Thank you very much. Would you like a copy of the paper when I'm finished?

Teresa

-----Original Message-----

From: Elizabeth H. Bradley [mailto:Elizabeth.Bradley@yale.edu]
Sent: Tue 11/15/2005 2:36 PM
To: Hoover, Teresa
Subject: Re: attitudes toward hospice scale

Sure -- feel free to use it and cite in any paper/publication you use it for.

Betsy

Quoting "Hoover, Teresa" <tehoover@hsc.usf.edu>:

>

> Dear Dr. Bradley,

>

> My name is Teresa Hoover, I am pursuing a Master's in Nursing at the
> University of South Florida. My thesis topic is on the relationship between
> nurses' attitudes and anxiety level related to pediatric hospice care. I
> would appreciate your permission to use the scale that you developed to
> measure attitudes related to hospice care. Additionally I would request your
> permission to modify it to fit a pediatric population. Please advise on how
> to proceed.

>

> Thank you for your consideration,

>

> Teresa Hoover

>

> tehoover@hsc.usf.edu

> 813-949-0780

Elizabeth H. Bradley, PhD
Associate Professor
Director, Health Management Program
tel 203.785.2937

SELF-EVALUATION QUESTIONNAIRE STAI Form Y-1

Please provide the following information:

Name _____ Date _____ S _____

Age _____ Gender (Circle) M F T _____

DIRECTIONS:

A number of statements which people have used to describe themselves are given below. Read each statement and then blacken the appropriate circle to the right of the statement to indicate how you feel *right now*, that is, *at this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

VERY MUCH SO
MODERATELY SO
SOMEWHAT
NOT AT ALL

- 1. I feel calm 1 2 3 4
- 2. I feel secure 1 2 3 4
- 3. I am tense 1 2 3 4
- 4. I feel strained 1 2 3 4
- 5. I feel at ease 1 2 3 4
- 6. I feel upset 1 2 3 4
- 7. I am presently worrying over possible misfortunes 1 2 3 4
- 8. I feel satisfied 1 2 3 4
- 9. I feel frightened 1 2 3 4
- 10. I feel comfortable 1 2 3 4
- 11. I feel self-confident 1 2 3 4
- 12. I feel nervous 1 2 3 4
- 13. I am jittery 1 2 3 4
- 14. I feel indecisive 1 2 3 4
- 15. I am relaxed 1 2 3 4
- 16. I feel content 1 2 3 4
- 17. I am worried 1 2 3 4
- 18. I feel confused 1 2 3 4
- 19. I feel steady 1 2 3 4
- 20. I feel pleasant 1 2 3 4

Appendix D: Attitudes About Care at the End of Life Scale

		Strongly Agree				Strongly Disagree
1.)	Most parents want their child's doctor to determine what care is best for the child.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
2.)	Telling the child and the family members that the child is dying is difficult for me.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
3.)	I think it is essential for the parents of a dying child to be told of the child's prognosis.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
4.)	Many terminally ill children who should receive hospice care <i>do not</i> receive hospice care.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
5.)	Many children would benefit if hospice care was initiated earlier in the course of their illness.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
6.)	Physicians do not have a role in hospice care.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
7.)	When hospice care is first discussed with the parents of a terminally ill child the parents often lose hope.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
8.)	Most of the child's symptoms, such as pain, shortness of breath, and nausea are not controlled any better with hospice care than with conventional care.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
9.)	Hospice care generally meets the needs of the parents better than conventional care.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
10.)	An interdisciplinary team approach can interfere with hospice care.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

Appendix D (Continued)

- 11.) I feel knowledgeable enough to discuss hospice care with the terminally ill child and their parents. 1 2 3 4 5
- 12.) I would like to work closely with a palliative care team if one existed within the acute care setting. 1 2 3 4 5

Appendix E: Demographics Form

Demographic Data Form

Participant age: _____

Gender: F M

Years of hospice employment: _____

Years of nursing experience: _____

Have you ever worked with pediatric hospice: Y N

Do you currently work with pediatric hospice patients: Y N

Have you had training in pediatric hospice care: Y N If so, what type? CEU

Other _____

Ethnicity: White ___ Black ___ Hispanic ___
Asian ___ Other ___

Highest level of nursing education:

Diploma ASN BSN MSN

Appendix F: Letter of Approval From Lifepath Hospice

04/17/2006 17:42 FAX 813 984 2488

LIFEPATH HOSPICE

001




DATE: 4/17/2006
TO: Teresa Hoover,
College of Nursing
USF
Tampa, FL 33620-6600
smcmilla@hsc.usf.edu; P: 974-9188 Fax: 974-7903
FROM: Sehwan Kim, Ph.D.
Director of Research
Lifepath Hospice and Palliative Care, Inc.
Phone 813/357-5667; Email: klm@lifepath-hospice.org
RE: RESEARCH PROPOSAL REVIEWED: APPROVAL

Dr. Susan McMillan:

The proposal submitted by Teresa Hoover entitled, "The Relationship between Nurses' Attitude and Anxiety Related to Pediatric Hospice Care" has been reviewed by the Research Review Panel members of the Lifepath Hospice and Palliative Care (LH). We have reviewed the research protocol and data collection methods. Since LP nurses are requested to participate in the survey, the RRP requests that you provide Informed Consent Form to the nurses before collecting raw data from them. In this survey, there are no individual identifiers. Accordingly, your application is exempt from a review on human subjects by LHPC. However, several research guidelines are attached with this letter of APPROVAL. These are additional conditions are set by LH. It is understood that the PI follow through the following provisions:

1. The PI to provide Informed Consent Forms to the nurses who participate in the survey.
2. A written Final Report is submitted to the Director of Research at LH within six months following the proposed survey.

We look forward to working with you on this important area of research in pediatric hospice care.


Sehwan Kim, Ph.D.
Director of Research

Date: 4/17/06

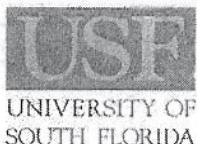
State City Center
3725 Upper Creek Drive
Riverton, FL 33573
813.634.7621

Tampa
3010 W. Azcoke Street
Tampa, FL 33609
813.877.2200

Temple Terrace
11150 N. 54th Street
Temple Terrace, FL 33617
813.988.7650

Corporate: 12975 Killebrew Pkwy, Suite 100, Temple Terrace, FL 33657 813.871.8111

Appendix G: Letter of Approval From USF IRB



April 21, 2006

Teresa Hoover
329 County Line Rd. E.
Lutz, FL 33549

RE: Exempt Certification for Application for Exemption
IRB#: 104617
Title: *The Relationship Between Nurses' Attitudes and Anxiety Related to Pediatric Hospice Care*

Dear Ms. Hoover:

On April 21, 2006, the Institutional Review Board (IRB) determined that your Application for Exemption **MEETS FEDERAL EXEMPTION CRITERIA TWO (2)**. It is your responsibility to ensure that this research is conducted in a manner consistent with the ethical principles outlined in the Belmont Report and in compliance with USF IRB policies and procedures.

Please note that changes to this protocol may disqualify it from exempt status. It is your responsibility to notify the IRB prior to implementing any changes.

The Division of Research Compliance will hold your exemption application for a period of five years from the date of this letter or until a Final Review Report is received. If you wish to continue this protocol beyond the five-year exempt certification period, you will need to submit an Exemption Certification Request form at least 30 days before this exempt certification expires. The IRB will send you a reminder notice prior to expiration of the certification; therefore, it is important that you keep your contact information current. Should you complete this study prior to the end of the five-year period, you must submit an Application for Final Review.

Please reference the above IRB protocol number in all correspondence to the IRB or the Division of Research Compliance. In addition, we have enclosed an Institutional Review Board (IRB) Quick Reference Guide providing guidelines and resources to assist you in meeting your responsibilities when conducting human subjects research. Please read this guide carefully.

DIVISION OF RESEARCH COMPLIANCE
University of South Florida • 12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-5618

Appendix G.(Continued)

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to the Human Research Protections Program. If you have any questions regarding this matter, please call 813-974-9343.

Sincerely,



Paul G. Stiles, J.D., Ph.D.
USF Institutional Review Board

Enclosures: IRB Quick Reference Guide

Cc: Angie Reagan, USF IRB Professional Staff
Dr. Susan McMillan
Tricia Holje

IA-EC-05-01