

Establishing a Competency Protocol to Improve Pediatric Hospice Care in
Eastern North Carolina

By

Sharry Malpass

A Scholarly Project submitted to the faculty of
East Carolina University College of Nursing
in a partial fulfillment of the requirements for the degree of
Doctor of Nursing Practice

Greenville, NC

April 18, 2017

Abstract

The loss of a child can have overwhelming effects on families and caregivers. End of life care focuses on providing quality health care to both the child and family. Nurses are advocates that provide interventions and comfort to those in need. Nurses' attitude and knowledge can be contributory in improving patient outcomes. This project aimed to improve the comfort and knowledge of nurses caring for children in pediatric hospice care through the creation and use of an evidence-based competency protocol (also called clinical field guide). Knowledge and attitudes toward caring for pediatric hospice patients was explored among nurses in a focus group manner. A clinical field guide was developed based on evidence, an established adult hospice care guideline, and with input from the nurses in the focus groups. The participants were nurses employed in a home health and hospice agency. Outcomes of the project showed that nurses had an increased level of knowledge and comfort of caring for pediatric hospice patients with use of a clinical field guide. Participants expressed increased comfort knowing resources existed and were available for use.

Keywords: pediatric hospice care, guidelines, gaps in care

Approval Page

COMPETENCY PROCTOCOL

4

East Carolina University

College of Nursing Doctor of Nursing Practice

Final Project Approval

Student Name: Sharry Malpass

Project Title: Establishing a Competency Protocol to Improve Pediatric Hospice Care in Eastern North Carolina

Private Review Completed on 4/10/17

Public Presentation Completed on 4/13/17

Final Project/Final Paper Approval: 4/18/17

As the Chair of this student's Doctor of Nursing Practice Project Committee, I have reviewed and approved this student's project and final paper and agree that he/she has met the project expectations, including the DNP Essentials, and has completed the project.

DNP Committee Chair Signature: Donna W. Robar Date 4/18/2017

Acknowledgements

This project was possible through the encouragement and support of many individuals and I would like to express my sincere appreciation.

First, I would like to thank my committee chair, Professor Donna Roberson, who has provided much appreciated and treasured guidance as well as patience as I progressed through the program. She was a calm reassuring voice of reason when I was ready to “jump off the ledge.” She pushed me forward and made me think of the “who cares, so what”. I am grateful for the assurance she conveyed in my competence even when I was feeling hesitant and doubtful of pushing this project forward.

My committee member Gina Blackburn was a great resource with the process of finding what resources were available to me at the agency where project occurred and assisted me whenever I had questions. She always steered me in the right directions. Betsey Vera and Susan Sherrod were also great supporters of the project. Ms. Vera and Ms. Sherrod worked diligently covering my shifts at work when my project was too demanding. I can never thank the two of them enough. Dr. Tracey Bell, Dr. Ann King, and Dr. Dianne Marshburn were instrumental in the completion of this project by sharing their passion for teaching which made the project a success. Mr. Dan Bennett provided direction and guidance with statistical analysis of data.

Finally, I need to thank those closest to me, without whom this would not have been possible. My friends and colleagues: Brittany Canady, Debbie Orr, and Beth Ann Guevara who encouraged and supported me throughout the program. You all were my strength, my rocks and talked me from the ledge many times. My husband, Ryan and my family, who have been my sources of inspiration and motivation, I am grateful to be able to share this accomplishment with all of these remarkable people.

Table of Contents

Introduction and Background.....	10
Problem Statement.....	11
Needs Assessment.....	11-12
Population.....	12
Stakeholders.....	12
Organizational Assessment.....	12
Resources.....	13
Theoretical Underpinnings.....	14
Origin of Theory and Major Concepts.....	14-15
Feasibility of addressing the problem.....	16
Purpose.....	17
Review of Literature.....	17-21
Methodology.....	22
Design.....	22
Setting.....	22
Sample.....	23
Protection of Human Rights.....	23
Implementation.....	23-26
Instruments.....	24-25
Data Collection.....	26
Budget.....	26
Time.....	26
Data Analysis.....	26
Results.....	26-28
Discussion.....	28-31
Limitations.....	31
Recommendations.....	31-32
References.....	34-35
Appendices.....	36-80
Appendix A Literature Review Matrix.....	36-41

Appendix B Letter of Support.....	42
Appendix C IRB Approval	43
Appendix D Consent Form	44
Appendix E Email Invite to meetings.....	45
Appendix F Questionnaire.....	46
Appendix G Timeline.....	47-48
Appendix H Clinical Field Guide.....	49-80

List of Tables

Table 1 Agency SWOT assessment

Table 2 Focus group questions

Table 3 Project cost analysis

Table 4 Participants age

Table 5 Participants years of nursing experience

Establishing a Competency Protocol to improve Pediatric Hospice Care in
Eastern North Carolina

Introduction/Background

Advanced Practice Registered Nurses (APRN) must demonstrate the ability to recognize and respond to rapidly changing health care needs competently and efficiently. Changes in medicine and hospice care needs make it essential for the nurse to apply previously learned knowledge in new and challenging populations and health care settings, such as pediatric hospice. Research conducted by National Hospice and Palliative Care Association (NHPCA)(2013), showed that children's hospitals across the United States reported having a palliative care team in 69% of hospitals but only 30% of the programs offered home services to pediatric hospice patients. They also surveyed hospice agencies and 78% of responding hospices reported that they serve pediatric patients, but only 36.6% have a formal pediatric program in place (NHPCA, 2013). There are more than 500,000 pediatric patients in the United States with end of life issues or chronic conditions (Knapp et al., 2011). The focus of hospice care has shifted from the traditional serving older end of life patients to a more holistic hospice care serving those of all ages, requiring nurses to practice at a higher level of nursing.

Significance of Problem

Despite advancement in technology and health care, childhood cancer remains a leading cause of non-accidental death (Widger et al., 2016). APRNs are challenged to develop new educational strategies that facilitate learning and engage nurses in complex health care issues. Treatment and symptom management can leave a long lasting burden and cause disruption to the child and family (Widger et al., 2016). Home Health and Hospice (HHH) nurses must be prepared to assess complex situations and decide the most effective interventions and promptly

take action, for many pediatric hospices is scary and difficult to perform. HHH nurses at a local eastern North Carolina agency reported receiving little or no specific training in regards to pediatric hospice care (personal communication, n.d.). This absence created a need that could be filled by an APRN.

Problem Statement

Current guidelines and protocols are in place for adult end of life management at a local home health and hospice agency; however, none existed for pediatric patients, thus making it difficult for some visiting staff to provide optimal pediatric hospice care. In a local home health and hospice agency, staff verbalized the need for more guidance and tools to assist with caring for pediatric hospice patients. A competency protocol, a clinical field guide, for home health and hospice nurses promotes self-directed competency by allowing staff the ability to have a pediatric hospice guideline available at their fingertips. Including nurses in the creation of such a guideline offers opportunity for nurses to be proactive in policy and protocols development and self-management of profession. By using the created clinical field guide to provide patient care, and by application of theoretical concepts and skills, staff gained competency in pediatric hospice care with opportunities to reflect on the use of the clinical field guide at post-use focus groups. The clinical field guide included educational information to assist the visiting staff in pediatric hospice care such as assessment techniques, medication management, and strategies to support family members. It is critical that all nursing staff providing pediatric hospice care receive comprehensive education, guidance, and support to enhance competency in caring for children with chronic or end of life diseases. Furthermore, the protocol assisted nurses in building familiarity and trust in the clinical field guide, and strengthening relationships among staff leading to increased optimal care and bridged the gaps in education.

Needs Assessment

Population

The project site was a non-profit home health and hospice agency in eastern North Carolina offering home health, hospice, and private duty services. It employed over 400 professionals and operated seven clinical offices, an inpatient hospice center, and managed another inpatient hospice house. The population of this project was in home registered nurses providing care to patients less than 18 years of age with a hospice related diagnosis.

Stakeholders

Nursing staff and community members conveyed the need for a pediatric guideline or resources to the agency triage nurses on several occasions. The staff nurses felt there was a need for more educational guides on pediatric-specific information to assist them in the hospice care of pediatric patients. The agency had three triage nurses who served as the initial phone contact person for patients after hours. The triage nurses met over three separate meetings and discussed known concerns and needs within pediatric hospice population. The input was based on past concerns and needs raised by visiting staff nurses. A needs assessment was completed and identified the need for guidelines for medication and symptom management, and how to comfort and provide psychosocial support to family of dying children. (Triage Nurse, personal communication, October, 2015). Visiting staff need to be able to critically assess a situation and decide on an appropriate course of action. End of life care can be a long lasting and a potentially disruptive environment. Nurses need to be able to quickly find information and to be able to apply concepts in pediatric hospice care. The APRN is perfectly situated to lead the development of a clinical field guide that performs the role of resource for community pediatric hospice care nurses.

Organizational Assessment (SWOT)

The project agency had nine offices and two inpatient hospice houses. Of these, at least four offices had pediatric hospice patients in the last year. None of the offices utilized a pediatric protocol for hospice care. Most of the hospice information available was for adults and was not established for the pediatric population. The majority of the adult hospice information content was available online via the company intranet and taught in new employee orientation training. A Strengths, Weakness, Opportunities and Threats (SWOT) analysis of the agency may be found in Table 1.

Table 1. Agency SWOT assessment

Strengths	Weakness
<ul style="list-style-type: none"> • Open to educational opportunities • Mandatory new hire hospice training • Adult hospice manual and protocols available • Consulting Pharmacy • Consulting Pediatrician • Available management staff • Organized 	<ul style="list-style-type: none"> • Small population served • Limited staff to assist with development process • Time for research and development, focus meetings
Opportunities	Threats
<ul style="list-style-type: none"> • Development and growth of pediatric hospice care • Hands on learning guide • Self- directed learning • Independent • Network with other leaders and community members 	<ul style="list-style-type: none"> • Internet outages • Technical difficulties • Timing • Access to staff

Resources

Visiting nurses carry a car stock and nursing bag that includes items to complete a physical assessment such as: thermometer, pulse oximeter, stethoscope, and tape measure. Each office provided access to a pediatric scale and blood pressure cuff. All new hospice nurses were given a hospice guide with importance contact information and phone numbers. The Director of

Hospice is available during the day for questions and concerns and, after hours, the triage nurse/administrator is on call. Members of the consulting hospice pharmacy staff are available 24/7 for medication management questions.

Theoretical Underpinnings

Roger's diffusion of innovation was applied to this project innovation, Pediatric Hospice Clinical Field Guide. The visiting nursing staff positively perceived the innovation as of great importance and need. They expressed that a guide and available resources was imperative to providing quality pediatric hospice care. The acceptance of a new concept and implementing change can be challenging in an ever-evolving healthcare setting. Behaviors and perceptions are best influenced in science with change theories that are purposeful and well planned (Rogers, 2003). Nursing care is delivered based on best practice or evidence, which requires frequent updates and changes. Various forces will drive change and flow of new ideas or diffusion will be supported by workforce buy in, professional roles, patient satisfaction and quality of care. Diffusion of evidenced based research can be utilized and disseminated through innovation, which is a process of communicating in channels with members of certain social settings (Rogers, 2003). The innovation is the idea that is perceived as new. In Roger's diffusion of innovation, the rate of diffusion can be sped if the new innovation is positively perceived by the social group it is imperative that new innovation be implemented using evidenced based practice in healthcare.

Origin of Theory and Major Concepts

Research on the diffusion of innovation theory started in the 1950s (Rogers, 2003). The roots of the diffusion theory can be traced to the late 1800s in Europe when social science began to emerge (Rogers, 2003). The theory includes four parts: the innovation, the communication

channels, time, and the social system. The first element is the innovation and is an idea or practice that is perceived new to the area of implementation. Characteristics of innovation include: relative advantage, compatibility, complexity, trainability, and observability.

Intervention may occur if an innovation is changed or modified in the adoption phase.

The second element is the communications channels that describe how messages get from one individual to another. Mass channels are more effective within peer groups in getting new ideas adopted (Rogers, 2003).

Time is the third element in diffusion. It is comprised of three areas: the innovation-diffusion process, the innovativeness and the rate of adoption. In the innovation-diffusion process, one must conceptualize knowledge, persuasion, decision, implementation, and confirmation. This leads to the adoption or rejection of use of the innovation. Innovativeness is the degree to which members adopt the idea earlier. In social systems classifications of adopters include: innovators, early adopters, early majority, late majority, and laggards. The last section of time is rate of adoption, which means the relative speed of the innovation being adopted (Rogers, 2003).

The final element is social system and is the unit or members engaged in problem solving or accomplishing a common goal. Within a social system you have those that are opinion leadership who have the ability to informally influence others in attitudes and behaviors. A change agent can attempt to influence the client's innovation or decisions. An aide is also a less than fully professional change agent who contacts clients and influence decisions. Finally the social system that has been influenced will adopt or reject an innovation based on changes and influence of the innovation (Rogers, 2003).

Roger's theory is best summarized by identifying the three areas that include awareness,

interest-evaluation-trial phases, and adoption of the innovation. Bringing awareness to pediatric hospice educational needs to a local home health and hospice agency was identified by the triage nurses and visiting staff that have cared for pediatric hospice patients over the last year.

The problem was that there was no standardized protocol available for staff to use when providing pediatric hospice care and this deficit caused lack of comfort on the part of nurses. Some staff members were motivated to change and wanted to use a protocol. Resources were identified and a protocol was created by modifying existing adult hospice resources and with input from the staff. As described in the second phase of Rogers's theory, the staff members were interested in the development of a protocol and eager to put it use. Focus groups were held to gather input from staff in the process of creating evidence based protocols for pediatric hospice care. The clinical field guide was introduced to staff and made available for visiting staff nurses use. After two months use, a post-focus group was held to evaluate the use of the guide and determine how well the protocol performed. The post-meeting served as a way to determine if modifications were needed for further use.

Feasibility of Addressing the Problem

The time was right for the implementation of a pediatric hospice clinical field guide in the project agency due to the increase in pediatric hospice cases. The agency had six patients in the preceding six months and that was an increase from the previous six months. As parents and caregivers dealt with chronic illnesses and end of life care, significant barriers to providing care were identified by triage nurses filtering calls and assisting visiting nurses in management of care. As found in a recent study by Widger et al. (2016), family centered care and symptom management was not always practiced at the fullest due to lack of proper training. There was sufficient time for the clinical field guide to be implemented and evaluated within the project

timeline. The biggest obstacle to the project was time of the visiting nursing staff and their involvement in the project. The nurses were invited to participate in the project as volunteered with no additional time and pay by the organization. The pre and post focus meetings were held during regular scheduled weekly meetings. The project was conducted by a Doctor of Nursing Practice (DNP) student at no additional cost to the organization.

The agency fully supported the project and encouraged nurses to participate in this quality improvement project. The use of already scheduled time for meetings allowed for ease and participation by staff nurses in the project.

Purpose

The purpose of this quality improvement project was to establish a competency protocol in pediatric end of life care in a local home health agency in Eastern North Carolina with the creation of an evidence-based clinical field guide for pediatric hospice care. The clinical question examined if collaborating with the nurses and utilizing the evidence to develop a pediatric hospice clinical field guide would increase the nurse's level of knowledge of caring for pediatric hospice patients and build competency.

The aim of this project was to create and implement a pediatric hospice competency (clinical field guide) protocol using evidenced based practice as a foundation with focus meetings as a way to collaborate, fill knowledge gaps, while increasing perceived level of competence of pediatric hospice care. The DNP student hoped that the field guide would serve as a tool to identify resources and improve quality of care, increase nursing knowledge and proficiency in caring for pediatric hospice patients.

Literature Review and Current Practice

A review of the literature was conducted using the key words: nursing guidelines and

hospice using Pub Med/Med Line including full text, journal publications, human population, and articles dated from 2010 to present to ensure current articles were reviewed. When combined search keywords nursing guidelines and hospice, 61 articles were identified. The search was expanded to include pediatrics and elicited five articles. Another search with impact of nursing care, comfort levels and practice guidelines produced 15 more articles. After a review of retrieved articles for associated evidence based practice that focused on guidelines, management of end of life pediatric patients and ways to implement into practice, 18 articles were identified to be of significance to the quality improvement project. The literature review matrix identifies articles that were of major benefit to development of project and guideline (See Appendix A). This literature review is divided into the following section: pediatric hospice care, gaps in care, guidelines, and competency protocols. Gaps in nursing care and management in pediatric hospice vary among palliative and hospice care programs.

Pediatric Hospice Care

For the purpose of this project, the NHPCA (2015) defines pediatric hospice care as, “a philosophy and an organized method for delivering competent, compassionate, and consistent care to children with chronic, complex and/or life-threatening conditions, as well as their families”(p. 2). Patients are considered pediatric for this group between the ages of two and 21 (NHPCA, 2015).

Tracking pediatric hospice cases is difficult for many different reasons. Statistics on this branch of care are sparse because of the variety of resources, lack of agencies providing services and underuse (Crozier & Hancock, 2012). Children are also difficult to track due to fact they are frequently changing services from different health care providers or agencies (NHPCA, 2015). The lack of pediatric referrals may hinder developing competent staff. Additionally, parents

often do not want to end aggressive care (Varela et al., 2012). The lack of a standard guideline or protocol to define and offer services, as well as decreased access to well-established services, also makes pediatric hospice care hard to track. In a study by Bassah, Seymour, and Cox (2014), “while qualified nurses report they not received adequate palliative care education, newly graduated nurses report a lack of competence and confidence to care for patients and their families in palliative care situations” (p.2). Another issue identified was the vast variety of age differences in pediatric cases that make it hard to categorize disease and death rates (NHPCA, 2015). Despite barriers, there is a growing concern for the numbers of pediatric hospice patients in the United States who are not receiving the care they need (NHPCA, 2015). The number of children with life-limited medical problems accounts for over 50,000 a year that die and more than 500,000 that need to be served (Varela et al., 2012).

Gaps in Care

Children comprise a medically underserved population with barriers to utilization of care including nurse- physician education, payment reimbursement, and difficulty with providers understanding palliative and hospice care (Jones, 2011). Due to reimbursement issues with pediatric hospice, it is difficult to find agencies that can service pediatrics (NHPCA, 2015). Expansion is needed with access to care and provider education related to pediatric hospice care to ensure delivery of optimal quality care. In a retrospective study by Kaye et al. (2015), an analysis showed that when programs were implemented to educate staff on chronic and life threatening illnesses, there was a decrease in length of hospital stays and readmissions. It seems reasonable to conclude education could also reduce care problems in home care.

Access to properly trained staff and accessible equipment remains an issue as well. In a study conducted in North Carolina by Varela et al. (2012), there was a perceived lack of pediatric

trained staff, professionals available to consult on pediatrics, and difficulty with the complexity of pediatric care needs. Collaboration between health care providers was identified to increase knowledge and implement protocols into practice (Jones, 2011). Education of health care team on best practices of physical assessment, medication management and fostering psychosocial relationships can support hospice patient. Nurses often report finding it difficult to talk to families concerning death and dying but feel competent in managing pain symptoms (Feudtner et al., 2006). It is critical that health care providers that work with children with chronic illnesses received across the board instruction on knowledge and skills to support comprehensive positive outcomes (Widger et al., 2016).

Guidelines and Protocols

There is very little research available on pediatric hospice guidelines. One must remember that children are not adults and that they need protocols and guidelines that are specific to their population and disease management (Levine et al., 2013). While many descriptive reports speak to the benefits of earlier integration of palliative care in pediatric and adolescent oncology, currently there is a lack of data to support care (Weaver et al., 2014). To assist health care providers in utilizing evidence based practice for pediatric patients, agencies need guidelines or protocols that support palliative care or hospice services. Barriers exist in using evidence based practice to create clinical guidelines. A recent study found that various barriers and reasons exist and will often impede creation and use of guidelines (Gifford, Graham, & Davies, 2013). Identified perceived nursing barriers in this study included a lack of knowledge or skill, no reason to change, lack of comfort and confidence, perceived lack of time, and little expectation that changes will make a difference. Agencies must work beyond these barriers to ensure intervention strategies support quality improvement and care.

Many important advances have occurred in pediatric oncology practice. Utilization of standards or protocols aimed at medical interventions assist health care providers in managing physical complications caused by cancer and other chronic illnesses (Weaver et al., 2014). Guidelines that focus on nursing education for pediatric chronic diseases and health care needs are encouraged with hopes to bridge gaps in care. As agencies assess the need for programs and service availability, guidelines can assist with staffing and program needs (NHPCA, 2013). Researchers found that if cancer pain guidelines, clinical pathways, and expert consultations were utilized, staff were more likely to adopt and use those in clinical practice (Phillips, 2015). Clinical pathways apply evidenced based team management plans that include different innovations, therapies, objectives, and goals that are useful in a certain population (Phillips, 2015). In a recent quality improvement project conducted by Lozman, Belcher and Sloand (2013), evaluation of guidelines for Papanicolau test in clinical practice following an educational session found that, although providers did not always use clinical guidelines in practice for different reasons, they did benefit from the focused discussion meetings held before and after the project implementation. Competencies that are focused on one population and are specific can increase knowledge in health care providers (Klick et al., 2014).

Guidelines are based on published evidence and should increase the strength of tools that are utilized in home health settings (Langemo et al., 2015). Nursing interventions that increase nursing, family and patient knowledge in cancer and other chronic diseases can help improve overall outcomes (Kaye et al., 2015). Interventions can reduce emotional and psychological stress will promote healing when education is offered to patients and family in terminal and chronic disease processes (Ryan, Bernhard, & Fahlberg, 2015). Guidelines have been shown to be an effective way to increase staff knowledge and improve outcomes (Weaver et al., 2014). In

a quality improvement project by Saunders (2015), best practice evidence from national guidelines was used as sources for clinical interventions to assist nurses in pain management. The results of the project showed that translation of best evidence from guidelines into a usable form improved quality and consistency of care delivery achieving more consistent and equitable integration of guidelines into clinical practice. The lack of standard guidelines may result in inconsistent access and management of pediatric patients and families. Having no standard guidelines can ultimately prevent access to care in rural areas. Standards of care need to be established for the pediatric hospice population.

Methodology

Design

Health care is shifting from in-patient acute setting to community based care (Kaye et al., 2015). In home hospice care is an effective holistic way to manage pain and other distressing symptoms in the course of a chronic or life threatening disease (World Health Organization, 2016). Hospice nurses are not only expected to have the knowledge and skills to take care of patients, but they must act at a higher level of nursing care in an advanced role using protocols by applying complex concepts while managing chronic pediatric illnesses. Furthermore, APRNs in home health and hospice can serve as leaders in the implementation of new guidelines and updated care practices.

This project used a descriptive survey method design approach using pre and post focus groups with nursing staff at a local home health and hospice company. The participants were asked via survey about their comfort and perceived experience of caring for pediatric patients. Focus groups provided time for nurses to voice concerns and to solicit suggestions to improve care of pediatric hospice patients.

Focus group meetings prior to the intervention were a good way to include nurses in the project development. In a study by Weiner et al. (2016), small focus group discussions and lectures were common and effective ways to train staff on palliative care models. Staff were offered the time to share any feelings and offer input in regards to educational needs in 30 minute focus meetings. Participants were encouraged to provide additional evidenced based resources to guideline. Participation increased the nurses' stake in the project. In this project, nursing staff were excited to have teaching materials that were easy to read and use when providing pediatric hospice care (B. Suggs, personal communication, n.d.).

The clinical field guide was created after meeting with nurses and establishing needed protocols. Existing adult protocols were modified for use with the pediatric population based on evidence. Furthermore, requests by the nurses resulted in the inclusion of information on medications, assessment techniques and methods of communication with parents and children. Participating nurses sent additional evidenced based resources that they felt needed to be included in the guideline. Recommendations for the clinical field guide also came from a consulting pharmacist with considerations for best practice for medication in pediatric patients. The final guideline was sent to hospice director and clinical managers for approval and circulation.

Setting

The project took place at an eastern North Carolina non-profit home health and hospice agency that served over 15 counties. The agency's acceptance of the project was further exemplified by their motto "to serve those in need" (see Appendix B). There was physical space at each agency office for meetings with staff to discuss and conduct the elements of the project.

Sample

The participants of this study included a convenience sample of visiting nursing staff that provide care for pediatric hospice patients in a rural home health setting. The sample size for this project consisted of 18 in home staff registered nurses working in a home health and hospice agency in Eastern North Carolina who participated in both planned the pre and post focus group meetings. The inclusion criteria included visiting nursing staff registered nurses that provided direct patient care. Exclusion criteria included nurses who were providing in-patient hospice care and those that do not provide direct patient care.

Protection of Human Subjects

The project was deemed exempt by the University and Medical Center Institutional Review Board at East Carolina University (UMCIRB) in May of 2016 (see Appendix C). The non-profit agency supporting the project did not require institutional review board (IRB) approval as they deemed the work as a quality improvement project. Participants were given an informed consent attached to the Demographic Information and Nursing Perception Evaluation Survey in caring for Pediatric Hospice Patient (see Appendix D). Confidentiality was maintained by storing the signed consents in a locked private office. The participants were asked not to write any information that would identify them on the questionnaire.

Implementation of project

The project leader met with the agency management team to collaborate on the project. The participants were notified of focus group meetings at least two weeks in advance of scheduled meetings. The meetings were announced via email, inviting all visiting nursing staff to participate in focus meetings and project (see Appendix E). The meetings were held after the normally scheduled interdisciplinary meetings that were held every 14 days in each office. A focus meeting was held in each of the nine offices over a span of two months. All visiting nurses

were invited to participate in meetings. Each focus meeting had at least five participants.

Demographic information was collected by survey to include: age, gender, race, ethnicity, and the number of years with company, number of years of experience as a nurse, level of education and location of practice.

The pediatric hospice competency protocol (clinical field guide) project was implemented in July of 2016. Initially based on the evidence and with additions from discussions at the focus meetings, clinical guidelines were prepared and organized in an electronic form for staff to use. The clinical field guide was created by using current policies and procedures within the agency, as well as evidence based resources obtained from pharmacy staff, durable medical equipment providers, and support staff as well as nursing staff. Additionally, a literature review on pediatric medication, physical assessment, and psychological needs was conducted and pertinent evidenced based practice guidelines were included based on input from nurses in pre focus meetings. Nursing staff participated in sharing evidenced based practice resources that would be beneficial for quality pediatric care with the project leader. All of the resources were combined and placed in an electronic guide by the project leader. The guideline in electronic form was made available to staff after all pre focus meetings were held and approved by hospice director and clinical managers. The clinical field guide was used at least two months and, at that time, a post implementation focus meeting was held to obtain feedback from staff on the guide and recommendations for future revisions obtained.

Instruments

A ten item demographic information and nursing perception evaluation survey in caring for pediatric hospice patient was given to participants to collect demographic information including participant's age, gender, years of experience as a nurse, education level and clinical

office location (see appendix F). The survey also included five items measuring comfort level in pediatric hospice nursing skills and experience. The survey was only accessible for each participant at the pre focus group meeting and at the post focus group meeting. The project leader discussed pediatric hospice best practice and utilized small group discussion group to engage participants in discussion of best practice and hospice education needs. Table 2 represents open-ended questions utilized during focus meetings to engage nurse input in meetings.

Table 2. Focus group questions

<i>Pre-Focus Group Questions</i>	<i>Post- Focus Group Questions</i>
How many of you have cared for pediatric hospice patients? Did you feel comfortable?	For those of you that have used the pediatric clinical field guide, what are your thoughts?
What are barriers or concerns you have in managing pediatric hospice patients?	What other resources or information is needed to assist you in caring for pediatric patients?
Do you have concerns with managing medications in pediatric hospice patients?	
Are there any issues or equipment needed in order to perform a complete pediatric physical assessment?	
How do you feel when you have to discuss end of life issues with patient or family members?	
What resources do you feel are not available in home hospice that hinders your ability to care for patients?	

Responses were analyzed to determine needs of the participant and to gain insight needed to create and refine the pediatric clinical field guide.

Data Collection

Data was collected at focus group meetings prior to and after the intervention. The group sizes varied depending on each office. Post focus meetings were held at all offices. There was

good participation at both pre- and post-meetings with 18 participants providing input in the project.

Budget

The budget for this project had few expenses but included cost of project copies given to participants and mileage to the sites (Table 3). The greatest expense was in time and travel for the elements of the project, but those expenses were critical to the implementation.

Table 3. Project cost analysis

Cost	Price
Gas (\$0.54/mile, 982 miles)	\$530.28
Copies (0.02/each,	\$6
Total Cost	\$536.28

Timeline

The project spanned over 14 months (See Appendix G).

Data Analysis

Data collected was analyzed using Microsoft Office Excel TM Spreadsheet to include descriptive statistics as well as inferential statistics. The focus group qualitative data were reviewed and incorporated at the beginning of the project into the clinical field guide.

Demographic data were compiled for description.

Results

Exploring the demographics of the participants, the ages ranged from 23 to 56 years (Table 4). All of the participants were female.

Table 4. Age of participants

Age	Frequency	Percent
18-22	0	0
23-27	2	11
28-35	5	28

36-45	3	17
46-55	5	28
>56	3	17

All participants lived in eastern North Carolina and worked in one of seven offices within the company. The highest educational degree held by participants was a bachelor's degree 17% (n=3) participants. The other participants held associate nursing degrees that were 83% (n=15) participants. Years of practice are represented in Table 5.

Table 5. Years of nursing experience

Years of Experience	Frequency	Percent
<3	1	6
3-5	3	17
5-10	3	17
10-15	1	6
15-20	2	11
>20	8	44

As a way of determining the usefulness of the clinical field guide, the statistical analysis of survey data was completed and revealed that nurses in the project had some improved comfort in caring for end of life pediatric hospice patients. A paired t test of same means was conducted to compare the mean of nurses who felt comfortable in providing medication management to pediatric hospice patients. Participants were asked to score responses of "1" for very comfortable, "2" somewhat comfortable, "3" neither comfortable nor uncomfortable, "4" somewhat uncomfortable, "5" very uncomfortable on pre and post focus group questionnaires. A lower the score on the questionnaire indicated high comfort or positive attitudes toward pediatric hospice care. A standard $p < 0.05$ significance level was accepted; however, there was not a significant difference in pre and post implementation scores ($p = 0.158$).

Participants were asked if the use of the pediatric guidelines assisted them in feeling more comfortable in caring for pediatric hospice patient. An analysis of pre and post intervention

means was statistically significant ($p=0.0002$). An interesting finding, only ten of the participants reviewed or used the clinical field guide ($n=18$). Some stated they had not had any pediatric patients during the project timeline or had missed information regarding the availability of the guidelines. Lastly participants in the project were asked if they felt comfortable in discussing aspects of pediatric end of life care resulting in a statistically significant difference ($p= 0.043$).

The use of the clinical field guide aimed to improve the nurse's confidence and knowledge in care. By integrating the clinical field guide into practice, nurses developed a deeper understanding of concepts and management techniques needed when caring for pediatric hospice. This project addressed the lack of clinical pediatric guidelines and boosted the nurse's knowledge and perceived experience in caring for pediatric hospice patients.

Discussion

This project investigated the feasibility of an evidence based clinical field guide for pediatric hospice care (see Appendix H). Furthermore, the project examined how collaborating with the nurses and utilizing the evidence to develop pediatric hospice clinical field guide increased the nurse's level of comfort and experience of caring for pediatric hospice patients and served to fill educational gaps. Only two of the five concepts measured showed a statistically significant difference in attitudes of care for pediatric patients. Although not statistically significant, there was certainly clinical significance based on comments from the participants. The nurses were more aware of their feelings regarding pediatric hospice care as expressed:

"I will never feel totally comfortable in caring for a dying child;"

"I don't know how I will ever feel comfortable in talking with parents of dying child:"

"Being able to participate in the creation of a guide, allows me to be involved and more accountable in quality of care that is being provided."

“I don’t think there is an education that I can receive that will make me feel comfortable;”

“It is reassuring to know that I always have someone here to call if I am unsure.”

“Having resources and a guide available, makes me feels more comfortable in my job”

These attitudes identified areas of opportunities for more educational services to nurses, but showed that guidelines and available resources do make a difference in perceived experience and care of patients. First, if nurses have available resources on hand that discuss hospice concepts and how to manage pediatric patients, nurses should feel more comfortable in providing care. With support of an APRN, support resources would be available as in this setting for visiting nursing staff. Other valued resources included after-hours triage nurse and an administrator on call that answered questions of staff. The pharmacy was a tremendous resource and support nurses. For example, a created a tool kit for medication administration for patients based on weight would offer resources when needing to make changes to current medications. The participants appreciated the availability of resources and felt more comfortable knowing resources existed.

Based on post-implementation feedback, the clinical field guide will need modifications to further improve content and more resources for staff. More information is needed to improve education and the APRN can be crucial to assisting with future modifications. While nurses felt gaps in care and resources improved with guideline, it also made them more aware of more educational needs. More education and support are needed to improve attitudes toward pediatric hospice care and in order to allow nurses to feel a sense of competence.

Participants of the project initially noted that they were unsure of policies and procedures related to pediatric hospice within the agency. Some nurses expressed a lack of knowledge of

resources that were currently available. From the focus meetings, discussions indicated the nurses did not feel capable of caring for pediatric patients and did not know what to say to parents. Upon completion of the project and use of the guideline, participants expressed feelings of increased competency in caring for pediatric patients knowing resources existed and staff available to assist them.

Despite low use of the guidelines, there was statistical significance that the guide increased comfort in pediatric hospice care. Perhaps knowing the guide was available improved a sense of security. Within pediatric hospice training, it would be helpful to include the types and location of resources. The nurses felt that the ability to provide better quality of care for this special population was increased due to having guidelines to follow. Participants expressed feeling more competent in providing quality care despite not being totally comfortable at times with pediatric care.

When evaluating the clinical field guide within the theoretical model of Rogers Diffusion of Innovation, one must first consider the innovation itself. The guide was a resource built from evidence based practice and was a new tool to the agency. The staff had the ability and education to use complex resources. Staff willingness to adopt and use the clinical field guide was instrumental in the success of improving comfort and increasing ability to discuss aspects of care. Another consideration was the high level of staff communication with each other.

One of the last elements in the theoretical model is adoption or rejection of use. Participants may choose to be innovators and early adopters while some may choose to not participate or use due to varies reasons (Rogers, 2003). The clinical field guide was not adopted for use due to the need for areas of modification. The hope is that future interest in improving pediatric hospice outcomes will include modification and use of a clinical field guide within the

agency. There is a great need for further research to improve pediatric policies and resources. This project did not study the perceptions of the patient and family and such information could be beneficial in improving patient outcomes. Further studies could also study the attitudes and comfort of staff caring for pediatric hospice patients as a whole.

Limitations

Limitations for this project included the low numbers of pediatric hospice patients. A huge barrier that occurred during the project implementation was that a major natural disaster occurred in the state causing several of the offices to have major structural damage causing meeting cancellations. Scheduling of post focus meetings were also delayed due to the natural disaster.

Another limitation for the project was staff composition. Some staff nurses were newly hired or contracted while others were not available due to vacation or staffing reasons.

Implication for Practice

Coaching nurses to care for dying pediatric patients and their families signifies a need and challenge for hospice agencies. Studies have identified that nurse have concerns about death and caring for pediatric patients. Caring for dying children can be a very emotional and intimidating experience. The emotional distress that comes with caring for the dying patient can be exacerbated by nurse's experience and education related to the end of life experience. Coaching and educating nurses early in training can change attitudes, fears, and experiences working with end of life issues. Guidelines and educational resources are an effective approach for tackling end of life concerns and improving the quality of life care in pediatric patients.

Despite limitations, the results of this project informed means to improve care resources for nurses in pediatric hospice care. The project showed that there was an increased perceived

level of competence in caring for pediatric patients knowing the field guide and resources existed. The field guide filled some knowledge gaps and increased comfort level in discussing aspects of pediatric end of life care as demonstrated by pre and post surveys conducted at focus meetings. More research to improve pediatric assessment as well as medication administration is needed. The creation of evidence based tools to assist with choosing appropriate sizes of catheters, intravenous catheters and syringes were requested.

The findings from the project identified as lack of education and preparation in communication skills, grief, and loss management. Additional classes and educational services would be helpful in order to show positive attitude changes when caring for pediatric hospice patients. Further projects could be done utilizing a larger sample and geographical area. Also more time with staff that would allow for an improved created clinical field guide should offer more nurse buy-in to innovation and improve ownership of the guidelines. Encouraging APRNs to continue work on translating evidence to practice can only improve patient outcomes. The use of the Pediatric Hospice Clinical Field Guide improves quality of care, increases nursing knowledge and proficiency in caring for pediatric hospice patients.

References

- Bassah, N., Seymour, J., & Cox, K. (2014). A modified systemic review of research evidence about education for pre-registration nurses in palliative care, *BMC Palliative Care*, *13*(56). doi: 10.1186/1472-684X-13-56
- Crozier, F. & Hancock, L.E. (2012). Pediatric palliative care: beyond the end of life, *Pediatric Nursing*, *38*(4), 198-203.
- Feudtner, C., Santucci, G., Feinstein, J.A., Snyder, C.R., Rourke, M.T., & Kang, T.I. (2006). Hopeful thinking and level of comfort regarding providing pediatric palliative care: a survey of hospital nurses, *Pediatrics*, *119*(1), 186-192. doi:10.1542/peds.2006-1048
- Gifford, W. A., Graham, I. D., & Davies, B. L. (2013). Multi-level barriers analysis to promote guideline based nursing care: A leadership strategy from home health care. *Journal of Nursing Management*, *21*(5), 762-770. doi:10.1111/jonm.12129
- Kaye, E. C., Rubenstein, J., Levine, D., Baker, J.N., Dabbs, D., Friebert, S.E. (2015). Pediatric palliative care in the community. *A Cancer Journal for Clinicians*, *65*(4), 315-333. doi:10.3322/caac.21280
- Klick, J.C., Friebert, S., Hutton, N., Osenga, K., Pituch, K.J., Vesel, T., ...Morrison, L.J. (2014). Developing competencies for pediatric hospice and palliative medicine. *Pediatrics*, *134*(6), 1670-1677. doi: 10.1542/peds.2014-0748
- Knapp, C. A., Madden, V., Wang, H., Kassing, K., Curtis, C., Sloyer, P., & Shenkman, E. A. (2011). Pediatric nurses' attitudes toward hospice and pediatric palliative care. *Pediatric Nursing*, *37*(3), 121-6.
- Jones, B.W. (2011). The need for increased access to pediatric hospice and palliative care, *Dimension Critical Care Nurse*, *30*(50), 231-235. doi:10.1097/DCC.0b013e3182276ded

- Langemo, D., Haesler, E., Naylor, W., Tippet, A., & Young, T. (2015). Evidence-based guidelines for pressure ulcer management at the end of life. *International Journal of Palliative Nursing, 21*(5), 225-232.
- Levine, D., Lam, C.G., Cunningham, M.J., Remke, S., Chrastek, J., Klick, J.,... Baker, J.N. (2013). Best practice for pediatric palliative cancer care: a primer for clinical providers. *The Journal of Supportive Oncology, 11*, 114-125. doi:10.12788/j.suonc.0012
- Lozman, R. L., Belcher, A., & Sloand, E. (2013). Does a 30-min quality improvement clinical practice meeting reviewing the recommended papanicolaou test guidelines for adolescents improve provider adherence to guidelines in a pediatric primary care office? *Journal of the American Association of Nurse Practitioners, 25*(11), 584-587.
doi:10.1111/1745-7599.12019
- National Hospice and Palliative Care Organization (2015). Pediatric facts and figures. Retrieved from http://www.nhpco.org/sites/default/files/public/quality/Pediatric_Facts-Figures.pdf
- Phillips, J.L. (2015) Australian survey of current practice and guideline use in adult cancer pain assessment and management: the community nurse perspective. *Collegian (Royal College of Nursing, Australia), 22*(10), 33-41.
- Saunders, H. (2015). Translating knowledge into best practice care bundles: A pragmatic strategy for EBP implementation via moving post procedural pain management nursing guidelines into clinical practice. *Journal of Clinical Nursing, 24*(13-14), 2035-2051.
doi:10.1111/jocn.12812
- Rogers, E.M. (2003). *Diffusion of Innovation* (5th ed.). New York, New York: Free Press.
- Ryan, A., Bernhard, H. & Fahlberg, H. (2015). Best practice for prenatal palliative care. *Nursing, 2015, 45*(10), 14-15. doi: 10.1097/01.NURSE.0000471422.49754.9b.

Varela, A.M., Deal, A.M., Hanson, L.C., Blatt, J., Gold, S., & Dellon, E.P. (2012). Barriers to hospice for children as perceived by hospice organizations in North Carolina, *American Journal of Hospice and Palliative Medicine*, 29(3), 171-176.

doi:10.1177/1049909111412580

Weaver, M. S., Heinze, K.E., Bell, C. J., Wiener, L., Garee, A.M., Kelly, K.P., ...Hinds, P.S. (2014). Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review. *Palliative Medicine*, 30(3):212-23. doi: 10.1177/0269216315583446.

Widger, K., Friedrichsdorf, S., Wolfe, J., Liben, S., Pole, J. D., Bouffet, E., & Rapoport, A. (2016). Protocol: Evaluating the impact of a nation-wide train-the-trainer educational initiative to enhance the quality of palliative care for children with cancer. *BMC Palliative Care*, 15, 12. doi:10.1186/s12904-016-0085-8

Wiener, L., Weaver, M. S., Bell, C. J., & Sansom-Daly, U. M. (2015). Threading the cloak: palliative care education for care providers of adolescents and young adults with cancer. *Clinical Oncology in Adolescents and Young Adults*, 5, 1–18.

doi:10.2147/COAYA.S49176

World Health Organization (2016). Cancer. Retrieved from

<http://www.who.int/cancer/palliative/definition/en>

Appendix A

Literature Review Matrix

Title	Authors	Details	Significance
Development of an in-home standardized end-of-life treatment program for pediatric patients dying of brain tumors	Arland, L.C., Hendricks-Ferguson, V.L., Pearson, J., Foreman, N.K., & Madden J.R.	Journal for Specialists in Pediatric Nursing, 2013, 144–157, doi: 10.1111/jspn.12024	An EOL program may improve symptom management and decrease required hospital admissions – did not use
A modified systemic review of research evidence about education for pre-registration nurses in palliative care	Bassah, N., Seymour, J., & Cox, K.	BMC Palliative Care, 2014, 13(56). doi: 10.1186/1472-684X-13-56	Education is reported as effective in improving students’ attitudes towards care of the dying.
Pediatric palliative care: beyond the end of life	Crozier, F. & Hancock, L.E.	Pediatric Nursing, 2012, 38(4), 198-203.	Focuses on quality of life and symptom management, pain, GI discomfort, seizures, fever, dyspnea
Hopeful thinking and level of comfort regarding providing pediatric palliative care: a survey of hospital nurses	Feudtner, C., Santucci, G., Feinstein, J.A., Snyder, C.R., Rouke, M.T., & Kang, T.I.	Pediatrics, /peds.2006-10482006, 119 (1), 186-192. doi:10.1542	Nurses’ level of hope is associated with their self-reported comfort and competence regarding palliative care.
Multi-level barriers analysis to promote	Gifford, W. A., Graham, I. D., & Davies, B. L.	Journal of Nursing Management, 2013, 21(5), 762-770. doi:10.1111/jonm.12129	Barriers Assessment Taxonomy provides

<p>guideline based nursing care: A leadership strategy from home health care.</p>			<p>framework for nursing to understand the complexity of barriers that exist, assist in choosing intervention strategies to support improved quality care and patient outcomes.</p>
<p>Pediatric palliative care in the community.</p>	<p>Kaye, E. C., Rubenstein, J., Levine, D., Baker, J.N., Dabbs, D., Friebert, S.E.</p>	<p>A Cancer Journal for Clinicians, 2015, 65(4), 315-333. doi:10.3322/caac.21280</p>	<p>Early integration of Palliative care model at home Uses shared decision making, facilitate seamless handoffs of care, ease the end of life for children who die at home</p>
<p>Developing competencies for pediatric hospice and palliative medicine</p>	<p>Klick, J.C., Friebert, S., Hutton, N., Osenga, K., Pituch, K.J., Vesel, T., ...Morrison, L.J.</p>	<p>Pediatrics, 2014, 134 (6), 1670-1677. doi: 10.1542/peds.2014-0748</p>	<p>Pediatric HPM should be integrated into training. Provide framework for emerging innovations</p>
<p>Pediatric nurses' attitudes toward hospice and pediatric palliative care.</p>	<p>Knapp, C. A., Madden, V., Wang, H., Kassing, K., Curtis, C., Sloyer, P., & Shenkman, E. A.</p>	<p>Pediatric Nursing, 2011, 37(3), 121-6.</p>	<p>Results suggest that prior training could alter nurses' attitudes, which might subsequently lead to increased improved outcomes</p>
<p>The need for increased access to pediatric</p>	<p>Jones, B.W.</p>	<p>Dimension Critical Care Nurse, 2011, 30(50), 231-235. doi:10.1097/DCC.0b013e3182276ded</p>	<p>Discusses barriers and strategies to pediatric hospice</p>

<p>hospice and palliative care,</p>			<p>discusses concurrent care laws</p>
<p>Evidence-based guidelines for pressure ulcer management at the end of life.</p>	<p>Langemo, D., Haesler, E., Naylor, W., Tippett, A., & Young, T.</p>	<p>International Journal of Palliative Nursing, 2015, 21(5), 225-232.</p>	<p>Discusses wound and risk assessment, prevention and care for pressure ulcers for the palliative care patient and the recommendations given in the palliative care</p>
<p>Best practice for pediatric palliative cancer care: a primer for clinical providers.</p>	<p>Levine, D., Lam, C.G., Cunningham, M.J., Remke, S., Chrastek, J.,Klick, J.,...Baker, J.N.</p>	<p>The Journal of Supportive Oncology, 2013,11, 114-125.doi:10.12788/j.suonc.0012</p>	<p>Focused on the principles of best practice in the provision of palliative care for children and adolescents with cancer: pain and symptom management caring for and interacting with parents and adolescents and delivering concurrent disease-directed care</p>
<p>Does a 30-min quality improvement clinical practice meeting reviewing the recommended papanicolaou test guidelines for adolescents improve</p>	<p>Lozman, R. L., Belcher, A., & Sloand, E.</p>	<p>Journal of the American Association of Nurse Practitioners, 2013, 25(11), 584-587. doi:10.1111/1745-7599.12019</p>	<p>Focused, in-office educational interventions via clinical practice meetings may be an effective way of discussing recommended guidelines to improve provider adherence. meeting in a</p>

<p>provider adherence to guidelines in a pediatric primary care office?</p>			<p>pediatric primary care office. This was on HPV and not hospice related, still relevant information on guidelines</p>
<p>Australian survey of current practice and guideline use in adult cancer pain assessment and management: the community nurse perspective.</p>	<p>Phillips, J.L.</p>	<p>Collegian (Royal College of Nursing, Australia), 2015, 22(10), 33-41.</p>	<p>A clinical pathway gives guidance on evidence-based practice may ensure patients with cancer pain have access to best available care.</p>
<p>Translating knowledge into best practice care bundles: A pragmatic strategy for EBP implementation via moving post procedural pain management nursing guidelines into clinical practice.</p>	<p>Saunders, H.</p>	<p>Journal of Clinical Nursing, 2015, 24(13-14), 2035-2051. doi:10.1111/jocn.12812</p>	<p>Best evidence practice placed into guidelines as usable forms or bundles adapted to the local setting may increase implementation and uptake of guidelines and improve quality and consistency of care delivery</p>
<p>Best practice for prenatal palliative care.</p>	<p>Ryan, A., Bernhard, H. & Fahlberg, H.</p>	<p>Nursing, 2015, 45(10), 14-15. doi: 10.1097/01.NURSE.0000471422.49754.9b.</p>	<p>Tips/guidelines support families experiencing perinatal loss, implement these best practices for perinatal palliative care</p>

Factors Associated With Favorable Attitudes Toward End-of-Life Planning	Ruff,H., Jacobs,R.J., Fernandez, M.I, Bowen, G.S., & Gerber, H.	American Journal of Hospice & Palliative Medicine, 2011 28(3) 176-1822011 doi: 10.1177/1049909110382770	Not helpful. Article was on end of life planning with attitudes associated with death.
Children’s nurse education—what is important to the service user?	Summers, K.	British Journal of Nursing, 2013, Vol 22, No 13	Did not use - service user involvement of a children with palliative care curriculum development
Barriers to hospice for children as perceived by hospice organizations in North Carolina	Varela, A.M., Deal, A.M., Hanson, L.C., Blatt, J., Gold, S., & Dellon, E.P.	American Journal of Hospice and Palliative Medicine, 2012, 29(3), 171-176. doi:10.1177/1049909111412580	Training of pediatric hospice may improve access to hospice services for children
Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review.	Weaver, M. S., Heinze, K.E., Bell, C. J., Wiener, L., Garee, A.M., Kelly, K.P., ...Hinds, P.S.	Palliative Medicine, 2014,30(3):212-23. doi: 10.1177/0269216315583446	Standardized approach to psychosocial support for staff and resources required to achieve optimal care.
Protocol: Evaluating the impact of a nation-wide train-the-trainer educational initiative to enhance the quality of palliative care for children with cancer.	Widger, K., Friedrichsdorf, S., Wolfe, J., Liben, S., Pole, J. D., Bouffet, E, & Rapoport, A.	BMC Palliative Care, 2016, 15, 12. doi:10.1186/s12904-016-0085-8	Train the trainer model: identified gaps in care provided to children with cancer lack of education for health care professionals perceptions of bereaved parents who describe

			suboptimal care.
Threading the cloak: palliative care education for care providers of adolescents and young adults with cancer.	Wiener, L., Weaver, M. S., Bell, C. J., & Sansom-Daly, U. M.	Clinical Oncology in Adolescents and Young Adults, 2015, 5, 1–18. doi:10.2147/COAYA.S49176	Educational issues for provider training are addressed palliative care cancer and guidance is also provided on ways to support quality of life as end of life nears.

Appendix B
Letter of Support



April 5, 2016

To Whom It May Concern

We at 3HC – Home Health and Hospice Care, Inc. have reviewed Sharry Malpass' DNP Scholarly Project title "Establishing a Competency Protocol to Improve Pediatric Hospice Care in Eastern North Carolina". Sharry Malpass has organizational support and approval to conduct his/her project within our Institution. We understand that for Sharry Malpass to achieve completion of the DNP program, a public presentation and manuscript submission related to the scholarly project will be required by the University.

Our organization has deemed this project as improvement initiative and requiring institutional IRB review.

Thank you,

Jennifer Whitley, Vice President of Clinical Services

Appendix C

Institutional Approval



EAST CAROLINA UNIVERSITY

Office of Research Integrity and Compliance (ORIC)
 University & Medical Center Institutional Review Board (UMCIRB)
 Brody Medical Sciences Building, 4N-70 • 600 Moyer Boulevard • Greenville, NC 27834
 Office 252-744-2914 • Fax 252-744-2284 • www.ecu.edu/irb

TO: Sharry Malpass, ECU College of Nursing, DNP Program

FROM: Office for Research Integrity & Compliance (ORIC)

DATE: June 6, 2016

RE: Doctor of Nursing Practice (DNP) Project

TITLE: Establishing a Competency Protocol to Improve Pediatric Hospice Care in Eastern North Carolina

This activity has undergone review on 6/6/2016 by the ORIC. A Doctor of Nursing Practice candidate is planning a quality improvement project to fill educational gaps in pediatric end of life care in a local home health agency in Eastern North Carolina. The goal is to improve nurses comfort level when serving this population and increase quality patient outcomes.

This activity is deemed outside of UMCIRB jurisdiction because it does not meet the current federal descriptions for human subject research. Therefore, this activity does not require UMCIRB approval. Contact the office if there are any changes to the activity that may require additional UMCIRB review or before conducting any human research activities

Relevant Definitions for Human Subject Research:

- *Research* means a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge. Activities which meet this definition constitute research for purposes of this policy, whether or not they are conducted or supported under a program which is considered research for other purposes. For example, some demonstration and service programs may include research activities
- *Human subject* means a living individual about whom an investigator (whether professional or student) conducting research obtains:
 - (1) Data through intervention or interaction with the individual, or
 - (2) Identifiable private information.

The UMCIRB applies 45 CFR 46, Subparts A-D, to all research reviewed by the UMCIRB regardless of the funding source. 21 CFR 50 and 21 CFR 56 are applied to all research studies under the Food and Drug Administration regulation. The UMCIRB follows applicable International Conference on Harmonisation Good Clinical Practice guidelines.

Appendix D
Consent Form

I am a student in the Doctor of Nursing Practice program at East Carolina University, Greenville, North Carolina. As part of my program, I am working on a quality improvement project filling educational gaps in pediatric end of life care. I am particularly interested in collaborating with the nurses and utilizing the evidence to develop pediatric hospice guidelines to see if there is an increase the nurse's level of comfort and perception of caring for pediatric hospice patients by filling educational gaps. Should you choose to participate in this study, you will be asked to complete a short questionnaire survey that has five demographic questions and 5 Likert questions about caring for dying pediatric patients. The survey and use of guideline will be required during this project as well as attending a pre focus and post focus group meeting. The questionnaire should only take about 10 minutes to complete. Do not include any information on the questionnaire that would identify you. You may withdraw at any time from this project. There will be no risk to you or compensation given for taking participating in this study. The benefits of this study will help identify future guidelines and tools to assist staff in caring for pediatric hospice patients. If you choose to participate, the completion of the questionnaire will imply you are consenting to participate in the project. After completion of the study, results will be made available to participants. Thank you for your participation in this study.

Sharry Malpass MSN, RN

Telephone # 910-214-9561

Doctor of Nursing Practice Student East Carolina University

Appendix E

Email Invite for Participants

Good Morning Visiting Nursing Staff,

I am a student in the Doctor of Nursing Practice program at East Carolina University, Greenville, North Carolina. As part of my program, I am working on a quality improvement project filling educational gaps in pediatric end of life care within your organization. I am particularly interested in collaborating with the nurses and utilizing the evidence to develop pediatric hospice guidelines to see if there is an increase the nurse's level of comfort and perception of caring for pediatric hospice patients by filling educational gaps. I invite you to participate in this quality improvement initiative and project. Should you choose to participate in this study, you will be asked to complete a short questionnaire survey that has five demographic questions and 5 Likert questions about caring for dying pediatric patients. The survey and use of guideline will be required during this project as well as attending a pre focus and post focus group meeting. The first required meeting will be held after your next scheduled ITC meeting and should not take more than 30 minutes. When pediatric guidelines have been created and ready for use, you will be notified of availability at your locate office. You will be notified at least two week in advance of the final focus group meeting. Thank you for your participation in this study.

Sharry Malpass MSN, RN

Telephone # 910-214-9561

Doctor of Nursing Practice Student East Carolina University

Appendix F
Questionnaire

Demographic Information and

Nursing Perception Evaluation Survey in caring for Pediatric Hospice Patient

1. What is your age group?(1)___18-22 years (2) ___23-27 years (3)___28-35 years (4)___36-45 years (5) ___ 46-55 years (6)___ 56 years and older
2. What gender do you identify with? (1)___male (2) ___ female
3. How many years of nursing experience do you have?
(1)___<3, (2) ___3-5(3) ___5-10 (4) ____, 10-15, (5) ___15-20, (6) ___20 +
4. What is the highest nursing degree obtained?
(1)___LPN, (2) ___ADN, (3) ___BSN, (4) ___MSN, (5) ___DNP/PHD
5. Which clinical office are you employed in?
(1)___Clinton/Fayetteville, (2) ___Goldsboro, (3) ___Greenville, (4) ___Kinston, (5) ___Pollocksville (6) ___Smithfield/Raleigh, (7) ___Wilson
6. Do you feel comfortable in providing medication management to pediatric hospice patients? (1) ___Very comfortable, (2) ___Somewhat comfortable, (3) ___Neither comfortable or uncomfortable, (4) ___somewhat uncomfortable, (5) ___very uncomfortable
7. Do you feel comfortable in to performing a physical assessment on a pediatric hospice patient? (1) ___Very comfortable, (2) ___Somewhat comfortable, (3) ___Neither comfortable or uncomfortable, (4) ___somewhat uncomfortable, (5) ___very uncomfortable
8. Do you feel comfortable in discussing end of life care with pediatric patients and families? (1) ___Very comfortable, (2) ___Somewhat comfortable, (3) ___Neither comfortable or uncomfortable, (4) ___somewhat uncomfortable, (5) ___very uncomfortable
9. Did the use of the pediatric guideline assist you in feeling more comfortable in caring for pediatric hospice patients? (1) ___Very comfortable, (2) ___Somewhat comfortable, (3) ___Neither comfortable or uncomfortable, (4) ___somewhat uncomfortable, (5) ___very uncomfortable
10. Do you feel comfortable in discussing aspects of pediatric end of life care? (1) ___Very comfortable, (2) ___Somewhat comfortable, (3) ___Neither comfortable or uncomfortable, (4) ___somewhat uncomfortable, (5) ___very uncomfortable

Appendix G
Timeline

January 2016	February 2016	March 2016
<ul style="list-style-type: none"> • Saba introduction to scholarly practicum 1 • Explore project topic • Review the literature for topic of interest • Talk with Director of Hospice at local agency for topic interest and concerns 	<ul style="list-style-type: none"> • Review the literature for topic of interest • Define project topic • Meet with VP of clinical services at local agency to discuss potential project topic and use of agency • Submit proposal of topic of interest • Attend DNP Intensive 9-10 • Establish Project committee • Establish how the project will be implemented • Spoke with potential chair committee members about project 	<ul style="list-style-type: none"> • Review the literature for topic of interest • Work on guideline development • Meet with Director of Hospice • Meet with Senior Hospice Director • Continue Project committee development • Submit Scholarly project timeline • Submit abstract • Submit Citi module certificate of completion • Search for survey to use to measure confidence level of staff
April 2016	May 2016	June 2016
<ul style="list-style-type: none"> • Review the literature for topic of interest • Work on guideline development • Meet with hospice director/committee as needed • Complete rough draft of paper • Compete final draft of paper 	<ul style="list-style-type: none"> • Review the literature for topic of interest • Meet with hospice director/committee as needed • Create guideline • Create tools, consents for project 	<ul style="list-style-type: none"> • Review the literature for topic of interest • Attend DNP intensive 14-16 • Submit project for IRB approval at ECU •
July 2016	August 2016	September 2016
<ul style="list-style-type: none"> • Review the literature for topic of interest 	<ul style="list-style-type: none"> • Review the literature for topic of interest 	<ul style="list-style-type: none"> • Review the literature for topic of interest

<ul style="list-style-type: none"> • Submit paper presenting full project • Hold Pre-intervention focus group meetings for nurses at local home health agency • Administer pre intervention survey 	<ul style="list-style-type: none"> • Hold Pre-intervention focus group meetings for nurses at local home health agency • Administer pre intervention survey • Finalize Educational intervention based on feedback of focus groups 	<ul style="list-style-type: none"> • Attend DNP intensives • Hold Pre-Intervention focus meeting • Administer pre-intervention survey • Place Clinical field guide into use within agency
October 2016	November 2016	December 2016
<ul style="list-style-type: none"> • Review the literature for topic of interest • Schedule Post focus group meetings 	<ul style="list-style-type: none"> • Review the literature for topic of interest • Hold Post-intervention focus group meetings for nurses at local home health agency • Administer post intervention survey • Data retrieval 	<ul style="list-style-type: none"> • Submit formal paper that includes implementation and evaluation • Continue Data evaluation • Hold Post intervention group meetings.
January 2017	February 2017	March 2017
<ul style="list-style-type: none"> • Review the literature for topic of interest • Continue to evaluate data and finalize project 	<ul style="list-style-type: none"> • Review the literature for topic of interest • Attend DNP intensives 	<ul style="list-style-type: none"> • Rough draft paper of entire project • Revision to paper
April 2017	May 2017	
<ul style="list-style-type: none"> Revision for paper Complete final paper for project Present Poster Presentation 	<ul style="list-style-type: none"> Submit manuscript to Journal of Hospice and Palliative care for publication Disseminate project information 	

Appendix H
Clinical Field Guide

Pediatric Hospice

Clinical Field Guide



This pediatric hospice clinical field guide was created as a quality improvement initiative by Sharry Malpass MSN, RN, Doctor of Nursing Practice Student at East Carolina University. It is the hope of the creator that the field guide will be used to bridge the educational gaps and barriers in providing pediatric hospice care in Eastern North Carolina. I hope that by collaborating with others and utilizing evidence based practice to develop pediatric hospice skills that nurses will utilize the guide and have an increase in level of comfort and perception of caring for pediatric hospice patients.

This guide was created using evidence based nursing practice and 3HC approved policies.

Purpose of Hospice

To provide holistic support and care for patients and their families in the final phase of a terminal disease.

Hospice Definition

Hospice is a physician-directed interdisciplinary program of supportive services for terminally ill patients and their families. The Hospice team is a group of staff members who focus the patient plan of care on the physical, psychosocial, emotional and spiritual needs of the patient, family, and/or caregiver(s). The team is composed of physicians, nurses, certified nursing assistants, pharmacists, social workers, chaplains and specially trained volunteers.

Hospice Philosophy

Hospice affirms life and regards dying as a normal process. Hospice neither hastens nor postpones death. Hospice believes that through personalized interdisciplinary services and a caring community, patients and families can attain the necessary preparation for a death that is satisfactory to them.

Pediatric Hospice Care

Pediatric hospice care is both a philosophy and an organized method for delivering competent, compassionate and consistent care to children with chronic, complex and/or life-threatening conditions and their families. Pediatric hospice care is limited to people 21 years old or younger. Care is enhanced to focus on improving quality of life, minimizing suffering, optimizing function and providing opportunities for personal and spiritual growth. Active and compassionate hospice care is planned through collaborative efforts with inter-professional team members, family and caregivers and provided when disease-modifying therapies are no longer effective and comfort measures are of the utmost importance (National Hospice and Palliative

Care Organization, 2012).

It is critical that a holistic approach to management of pain and other distressing symptoms, together with psychosocial, cultural and religious beliefs, and spiritual care be implemented into nursing practice.

How is Pediatric Hospice different from Adult Hospice?

Consider the following when providing care for pediatric patients:

- trajectories of illness
- effective pain/symptom management interventions
- clinical models of care delivery,
- funding mechanisms
- research paradigms
- educational initiatives
- communication strategies
- ethical concerns
- staffing ratios and management

(NHPC), 2012)

*******Please note that Pediatric Hospice patients are taken on a case by case basis. Each case is reviewed by clinical management team for appropriateness and feasibility that care can be provided for child, utilizing management knowledge of hospice practice, consultation with consulting pediatrician and consulting hospice Pharmacy Company.**

Admission of Patients

1. Hospice referrals shall be accepted from the physician, patient, family, friends, clergy, or health professionals. All referrals must be assessed by the Medical Director/Hospice Physician in concert with the patient's attending physician for appropriateness of admission. Services are available without discrimination related to age, race, sex, religion, national origin, economic status or handicap.
2. Hospice will accept patients referred for services in accordance with the following considerations/criteria:
 - a. The patient resides in a county that Hospice serves.
 - b. The patient and family/caregiver(s), and attending physician, understand the Hospice philosophy, elect Hospice care and agree to work cooperatively with the Hospice team.
 - c. The designated primary caregiver agrees to accept the responsibility for 24-hour availability if patient is not capable or safe to stay alone or care for self, and acts as the family coordinator of care. In some situations, a patient may be accepted when there is no primary caregiver as long as the patient is safe and able to care for themselves. However, this must be approved by the Hospice Team.
 - d. The illness is in the terminal stages with limited life expectancy - six months or less if the disease takes its normal course.
 - e. The attending physician agrees to continue medical management of the patient's illness, act within the Hospice philosophy and become a member of the Hospice team.
 - f. Recommendation of the Hospice Physician in consultation with or with input from the patient's attending physician.
 - g. Hospice has adequate and suitable personnel and resources to provide services required

by the patient/family.

- h. Physical facilities in the patient's home are adequate for the patient's care.
- i. The home environment is safe.
- j. The patient is receiving care that is reasonable and necessary for the palliation or management of the terminal illness and related conditions. Chemotherapy and radiation are generally not appropriate for Hospice. Based on the recommendation of 3HC Hospice Team and the Hospice Physician, Trachea may be considered palliative for an esophageal cancer patient who does not have a tracheostomy. Blood transfusions may be given based on symptoms patient is exhibiting, but not on lab values. Chemotherapy and radiation are given for symptom management on an individual basis. (An ECOG score above 2 is usually not a candidate for chemo/radiation unless approved based on specific symptoms). Approval is to be obtained from the Hospice Director. The Hospice Director will document approval via ITC note after consulting the Hospice Physician and ProCare.
- k. Generally, patients shall not receive TPN or PEN while receiving Hospice services.
- l. Patients may have Pleurx Catheter Kits.
- m. Patients receiving nutrition by tube feed will be accepted for Hospice services and covered by Hospice if the tube feeding is for patient's recognition of thirst and hunger and relative to hospice diagnosis. If feedings are not related to hospice diagnosis or if patient is not tolerating feedings, the hospice Team discusses, and generally will not cover under the hospice benefit.
- n. Non-routine medications prescribed by an attending physician that are said to be palliative must be approved by 3HC's Hospice Physician and Hospice Team.
- o. For Medicare/Medicaid patients entering 3rd benefit period or later, a face-to-face visit

by the Hospice Nurse Practitioner or physician is required to determine hospice eligibility.

3. Hospice reserves the right not to admit a patient who does not meet one or more of these admission criteria. Before decision NOT to admit, nurse shall contact the Director of Home Hospice Services who will also involve the hospice physician PRIOR to NOT admitting the patient. If the patient is not admitted to Hospice, every effort shall be made to provide support and to refer the patient to other appropriate community resources.

a. The Hospice Physician must consider at least the following when making a decision that the patient is terminally ill:

i. Diagnosis of the terminal condition of the patient

ii. Other secondary diagnoses/co-morbidities whether related or unrelated to the terminal condition.

iii. Clinical aspects of the patient's condition/skilled need or burden of illness that support the prognosis based on his/her review of the medical record or by examination of the patient.

(This information may be obtained indirectly through the hospice nurse/IDG team)

4. Before patients are accepted as a transfer from another hospice agency:

a. A current physician statement that the patient meets hospice admission criteria (including six months or less to live) must be received. This may include current diagnostic tests.

b. The 3HC Hospice Physician must accept this prognosis.

c. The patient/family must have arrangements made for a local physician to assume care prior to transfer. If applicable, the 3HC Hospice Physician or FNP may temporarily maintain this responsibility until the Primary Care Physician is found.

d. For Medicare/Medicaid patients entering 3rd benefit period or later, a face-to-face visit by the Hospice Nurse Practitioner or Physician is required to determine hospice eligibility.

- e. Obtain a copy of Hospice Election Statement and copy of current plan of care.
- 5. Patients accepted shall sign a Hospice Election Statement form (HOS.007), thereby agreeing to Hospice services. If the patient is not able to sign, the form may be signed by the individual having legal guardianship or applicable power of attorney, or a family member, who will be the primary caregiver and actively participate in the hospice plan of care.

***** Please note that Pediatric hospice patients different in regulations in North Carolina under concurrent care guidelines than adults and may be able to have some aggressive treatment measures and be hospice. Always consult with Director of Hospice first when procedures that you may think are aggressive.**

Initial and Comprehensive Assessment of the Patient

1. 3HC shall conduct and document in writing, a patient-specific comprehensive assessment that identifies the patient's skilled need for hospice care and services, and including physical, psychosocial, emotional, and spiritual care.
2. This assessment includes all areas of hospice care related to the palliation and management of the terminal illness and related conditions.
3. The initial assessment consists of an evaluation of the patient's physical, psychosocial, and emotional status relative to the terminal illness and related conditions to determine the patient's immediate care and support skilled needs.
4. The comprehensive assessment must identify the physical, psychosocial, emotional, and spiritual needs related to the terminal illness and related conditions that must be addressed in order to promote the patient's well-being, comfort, and dignity throughout the dying process. This will be captured by the completion of the Social Work Psychosocial Assessment, Spiritual Assessment, Pre-Bereavement Assessment, and Rehab Evaluation, if applicable, as well as nursing initial assessment which includes a pain and nutritional assessment. This includes a thorough evaluation of the caregiver's and family's willingness and capability to care for the patient. The following must be documented in the comprehensive assessment:
 - a. The nature and primary condition/diagnosis causing admission to include objective data and subjective complaints.
 - b. Complications and risk factors that affect care planning, including:
 - i. Secondary conditions (related)
 - ii. Co-morbid conditions (not related)
 - iii. Issues that affect care planning

- iv. How the primary caregiver's age and health status impact caregiving.
- c. Skilled need
- d. Functional status, including the patient's ADL status, and ability to understand and participate in his or her own care.
- e. Imminence of death.
- f. Severity of symptoms.
- g. Burden of illness.
- h. Medication profile: This includes all of the patient's prescription and over-the-counter drugs, herbal remedies and other alternative treatments that could affect drug therapy. This includes, but is not limited to, the effectiveness of drug therapy, drug side-effects, actual or potential drug interactions, duplicate drug therapy, drug therapy associated with lab monitoring.
- i. Bereavement: an initial bereavement assessment of the needs of the patient's family and other individuals focusing on the social, spiritual, and cultural factors that may impact their ability to cope with the patient's death. Information obtained from the initial bereavement assessment must be incorporated into the plan of care and considered in the bereavement care plan.
- j. Other referrals: The need for referrals and further evaluation by appropriate health professionals such as Physical Therapy, Occupational Therapy, and Speech Therapy.
 - i. If related, referral should be approved and coordinated by IDG, included in Plan of Care and palliative in nature.
 - ii. If unrelated, share information and coordinate care with non-hospice providers to ensure the Plan of Care is appropriate and identify "care gaps" and the party responsible for filling them.

5. The Hospice IDG, in consultation with the individual's attending physician (if any) must complete the comprehensive assessment no later than five (5) calendar days after the election of hospice care (or start of care date). This includes all assessments by all disciplines that are identified to meet the patient's or caregiver's needs.
6. The comprehensive assessment must be updated by the Hospice IDG (in collaboration with the individual's attending physician, if any) and will consider changes that have taken place since the initial assessment.
7. The updated comprehensive assessment shall include information on the patient's progress toward desired outcomes, as well as a reassessment of the patient's response to care. The assessment update will be accomplished as frequently as the condition of the patient requires, but no less frequently than every 15 days.
8. The comprehensive assessment must include data elements such as PPS, FAST (if Alzheimer's disease), and labs, if applicable, and BMI that allow for measurement of outcomes. Such measurements/skilled need shall be documented for all patients as applicable based on diagnosis. The data elements shall take into consideration aspects of care relative to hospice and palliation.
9. The data elements are an integral part of the comprehensive assessment, must be documented in a systematic and retrievable way to be used in individual patient care planning.

Pediatric Physical Assessment Guidance**Cultural Competency**

Respect family dynamics, beliefs, and communication style of different cultures

Determine beliefs of patients and families regarding illness and appropriate health care

Avoid criticism of non-harmful folk beliefs or folk remedies

Allow all family and support group visits and interactions with the patient that do not jeopardize health care

Be sensitive to implications of body language and personal space

Ask permission before touching and examining the child

Have hospice papers and information in native language

Obtain interpreter service when needed

Be aware of specific customs and preference of groups who use the health care services (for example: Gender, eye contact, response to pain, beliefs about illness, and body language)

General Guidelines to Communication with and Assessment of a Child

Collecting Subjective Data

Sit at the child's eye level when talking to the child or parent

Assess pertinent health history

Assess social history

Collecting Objective Data

Approach the child near eye level, sit when possible

Examine the child where he feels comfortable

Speak in soft, calm voice

Explain procedures

Allow the parent or child to handle equipment if able

Use play when possible

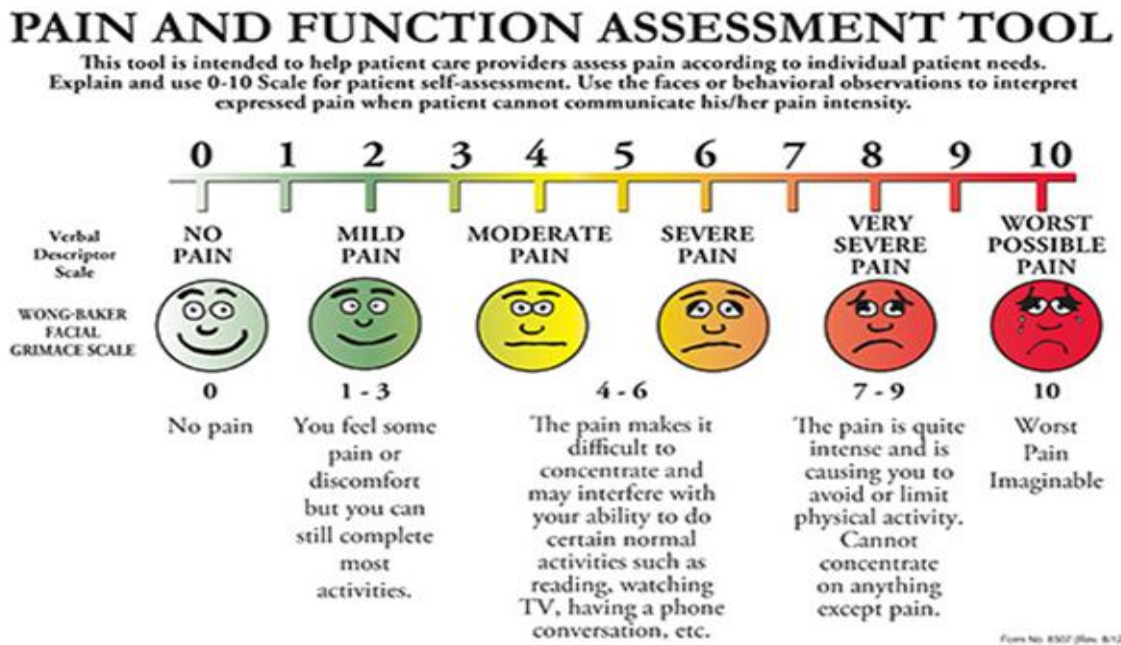
Allow choices when possible

Praise for all efforts

Assessment

Assess vital signs- Elevated temperature may indicate sepsis or end of life, decrease pulse- end of life near, elevated pulse or BP may indicate pain or restlessness

Assess pain- you can use the verbal descriptor scale or Wong-baker grimace scale.



(Cedars-sinai.edu)

Assess Alertness

Glasgow Coma Scale for Infants and Toddlers

Description	Score
Eye Opening	
Spontaneous	4
To sounds and speech	3
To pain	2
None	1
Verbal response- infant	

Smiles, interacts, follows objects	5
Cries, consolable	4
Cries, inconsistently consolable	3
Cries, inconsolable	2
No response	1
Verbal Responses- Toddler	
Interacts appropriately	5
Interacts but confused	4
Moans, uses inappropriate words	3
Incomprehensible sounds	2
No response	1
Best Motor Response	
Obeys command to move body part	6
Localized pain	5
Tries to remove painful stimuli	4
Flexes arm in response to pain	3
Extends arm in response to pain	2
No response	1

Assess reflexes- increased reflexes may be seen in seizures

Assess skin, hair, nails- observe for redness, broken areas, and lesions- skin recoils slowly or tents when lightly pinched may indicate dehydration

Assess head, ears, eyes, nose, and mouth- white coating on tongue or in mouth may indicate thrush, redness and exudate to throat may indicate viral or bacterial infection

Assess Neck- lymph nodes that are non-tender and non-mobile may be linked to underlying tumor

Assess Cardiovascular/ Respiratory/Chest

1. Observe for patency of airway- gurgling or adventitious breath sounds may indicate

partial obstruction of airway

2. Listen-

A. Respirations quiet

1. Audible wheezing may indicate bronchospasms, bronchiolitis or foreign body
2. Expiratory grunt may indicate increase in effort to keep alveolar expanded

B. No purse lip breathing

1. Older children may purse lip during expiration to keep airway open for a longer period

C. No Stridor

1. Acute inspiratory stridor- crowing sound is a sign of upper airway obstruction- croupy
2. Chronic inspiratory stridor can be related to congenital abnormalities such as collapse of laryngeal soft tissue collapse
3. Expiratory Stridor – sign of obstruction in lower trachea
4. Biphasic stridor- can indicate swelling in trachea area
5. Drooling may indicate airway obstruction
6. Restlessness is an EARLY sign of air hunger

D. Smokey smell to breath may indicate smoke inhalation

3. Breathing-

A. Observe rate, rhythm, and effort

1. Irregular rate or apnea may indicate airway obstruction, pain, or neurologic Abnormality

2. Note that periodic breathing can be normal in young infants
3. Soft tissue retractions, head bobbing, or flaring of the nostrils indicate increased working of breathing, retractions may be seen in the intercostal, sub costal, suprasternal, substernal and supraclavicular spaces.
4. Shallow respirations may indicate fatigue and need to ventilation assist.

B. Auscultate lungs in all lobes

1. Bronchial sounds are loud and high pitched heard in upper anterior chest
2. Broncho vesicular sounds are softer tubular sounds heard in anterior central chest and between scapulas's posteriorly
3. Vesicular are soft blowing sound heard in peripheral lungs
- a. Adventitious sounds may indicate foreign body, or mucus in airway

Rales- crackling sound common with pneumonia

Rhonchi- coarse sounds, may clear with coughing

Wheezing- whistling sound common in asthma or bronchiolitis

C. Observe activity and feeding

1. In infants with decreased oxygenation, you may see that children are not able to play or even eat
2. Older children may lean forward like a tripod position if they are short of breath.

4. Circulation

A. Normally you will have a regular rhythm and rate and no murmur is heard.

1. Murmurs indicate turbulent blood flow or movement of blood under increased pressure.

B. Pulses in all extremities should be brisk and have brisk capillary refill.

C. Observe oxygen saturation- less than 95% indicated decreased oxygenation

Assess abdomen- distention may indicate obstruction, heart failure, internal bleeding, or gastrointestinal infection, visible peristalsis may indicate obstruction, pyloric stenosis is indicated by olive shaped mass in upper abdomen, hyperactive bowels may indicate infection or obstruction, palpable masses may indicate cancer tumor. Palpate liver- liver more than 2 cm below right costal margin may indicate heart failure, hepatitis, biliary atresia. Palpate spleen- if palpable may indicate mono or sickle cell anemia.

Assess Musculoskeletal- Limited movement and mottling may occur in end of life as circulation decreases.

Assess Elimination- Pale stool- indicate liver pathology, black or tarry- may indicate bleeding internally

Ways to Communicate with Family and Patient

- Beware of volume-loud vs soft pitch of voice
- Beware of Non-Verbal Behavior – Posture, Facial expressions, Gestures, Movement
- Be an Active Listener
- Be available and remain silent if needed, allow time for family and patient to vent when needed
- Look for signals that the child is ready to talk, they may ask questions or bring up the subject.
- Be aware when the child or parent no longer is interested in talking. They may change the subject or look away.
- Look for "teachable moments"—such as death of a pet or a character in a book or a movie.
- Use simple, direct language that children can understand. For example, use the words death and dying, rather than misleading or confusing terms such as “passing away” or “going to sleep.”
- Reassure children that he or she will not be alone. Children need reassurance that their parents will be with them to love and support
- Reassure children that pain and suffering goes away after death
- Remind your child of the special things and memories will always be there for parents and friends.
- Discuss family's religious or spiritual beliefs about death and what happens after death.
- Encourage parents to give child "permission" to die, if you believe that will help. Many children feel guilty about leaving parents behind (Cancer.net, 2015).

Equipment Guidance

DME (Durable Medical Equipment)

New Patients: Monday through Friday during business hours

Once a Hospice referral has been received by the Central Intake Department, they shall consult with the patient/family regarding any durable medical equipment (DME) needs and order any DME for the patient based on the diagnosis and referral information provided. If approval of any DME is needed, Central Intake will contact the Director of Home Hospice Services prior to ordering.

Existing Patient: Monday-Friday during business hours

The Hospice Patient/Family Coordinator shall notify the Hospice Clinical Secretary, II of any additional DME needed after admission. If approval is needed, the Hospice Clinical Secretary II will contact the Director of Home Hospice Services. Once approved, the Hospice Clinical Secretary II will then order the equipment through the DME Company.

After-Hours and On Weekends

The Intake Nurse, Triage Nurse, Administrator On-Call, or RN will order DME for new admissions.

Emergency Closet

Each office will have access to nasal cannula, suction kit, humidifiers, and face masks on emergency need basis. If supplies are used, the Hospice Clinical Secretary II should be notified so supplies can be tracked and restocked.

Use and Maintenance of Equipment and Supplies:

1. The hospice must ensure that manufacturer recommendations for performing routine and preventive maintenance on durable medical equipment are followed. The equipment must be safe and work as intended for use in the patient's environment. Where a manufacturer recommendation for a piece of equipment does not exist, the hospice must ensure that repair and routine maintenance policies are developed. The hospice may use persons under contract to ensure the maintenance and repair of durable medical equipment.
2. The hospice must ensure that the patient, where appropriate, as well as the family and/or other caregiver(s), receive instruction in the safe use of durable medical equipment and supplies. The hospice may use persons under contract to ensure patient and family instruction. The patient, family, and/or caregiver must be able to demonstrate the appropriate use of durable medical equipment to the satisfaction of the hospice staff. On SOC, this is documented under the DME section of the Hospice Comprehensive Assessment. If DME is delivered after SOC, then documentation should be in the Routine Visit Note.
3. Hospices may only contract for durable medical equipment services with a durable medical equipment supplier that meets the Medicare DMEPOS Supplier Quality and Accreditation Standards at 42 CFR §424.57

PROCEDURE:

1. DME will be ordered through Respracare for Goldsboro, Kinston, Greenville, Maysville, Wilson and Family Medical for Clinton and Smithfield.
2. Family Medical:
 - a. Website: www.familymedsupply.com
 - b. No login or password needed.

c. Click printable referral, enter patient information (name, address, phone number, DOB).

Scroll down to comments. Enter in comments what is needed (ex., patient expired, d/c etc., on what date, patient needs hospital bed, gel mattress, etc.)

d. Click Submit.

3. Respracare

a. No website or login or password needed.

b. Call in orders: 1-800-394-5483 or,

c. E-mail orders to Respracare staff.

Medication Guidance

Home Hospice Standing Orders

POLICY:

1. Standing orders shall be initiated after notifying Hospice physician of admission.
2. Prior to the initiation of standing orders, the medications shall be checked against the patient's listed allergies.
3. Standing orders shall be sent to the Hospice physician for signature.
4. The standing order medications shall be added to the med profile once order completed in McKesson.

PROCEDURE:

1. May use the following medications as ordered for comfort and symptom control.
2. May crush medications or use liquid medications PRN based on nurse's assessment of patients ability to swallow.
3. Use SL route for patients who may not be able to swallow tablets. Place a small amount of medication under tongue or inside cheek.
4. May use gastrostomy tube for crushed or liquid medications if available.
5. May use the PR route for patient who cannot swallow and cannot tolerate the SL route.

****** Please consult with Attending Physician, Hospice Physician, 3HC company consulting pediatrician, or Procare pharmacy for medication management of acute symptoms for Pediatric proper dosing and management.**

The following is a recommended Medications From Pro Care Pharmacy for acute symptoms:

Emergency Kit Medications Based on Patient's Mass in Kilograms (kg)

Conversion of pounds to kg: pounds/2.2 = kg

10 kg = 22 pounds

20 kg = 44 pounds

40 kg = 88 pounds

Kit for patients weighing < 10 kg

Morphine sulfate liquid 10 mg/5ml (2 mg/ml)

Dose: 0.2 -0.5 mg/kg/dose

Lorazepam liquid 2 mg/ml

Dose: 0.05-0.1 mg/kg

Dexamethasone solution 1 mg/ml

Doses: cerebral edema: load 1-2 mg/kg then 0.25-0.4 mg/kg qid for 5 days then taper for 5 days, then discontinue

Anti-inflammatory: 0.04-0.2 mg/kg bid

Chemotherapy-induced nausea: 0.3 mg/kg prior to chemotherapy

Glycopyrrolate liquid solution 1mg/5ml

Doses:Nausea related to opioids: 0.1 mg/kg q 4-6 hours

Terminal secretions that distress family: 0.02-0.1 mg/kg q 4-6 hours

Tylenol Suppository 80 mg and 120 mg

Dose: 15 mg/kg q 4-6 hours, maximum 120 mg/kg/day

Kit for patients weighing 10 to 40 kg

Morphine sulfate liquid 20 mg/5ml (4 mg/ml)

Dose: 0.2 -0.5 mg/kg/dose

Lorazepam liquid 2 mg/ml

Dose: 0.05-0.1 mg/kg

Dexamethasone solution 1 mg/ml

Doses: cerebral edema: load 1-2 mg/kg then 0.25-0.4 mg/kg qid for 5 days then taper for 5 days, then discontinue

Anti-inflammatory: 0.04-0.2 mg/kg bid

Chemotherapy-induced nausea: 0.3 mg/kg prior to chemotherapy

Glycopyrrolate liquid solution 1 mg/5ml

Doses: Nausea related to opioids: 0.1 mg/kg q 4-6 hours

Terminal secretions that distress family: 0.02-0.1 mg/kg q 4-6 hours

Tylenol Suppository 120 mg, 325 mg

Dose: 15 mg/kg q 4-6 hours, maximum 120 mg/kg/day or 4000 mg/day

Kit for patients weighing > 40 kg

Morphine sulfate liquid 20 mg/ml

Dose: 0.2 -0.5 mg/kg/dose

Lorazepam liquid 2 mg/ml

Dose: 0.05-0.1 mg/kg maximum 4 mg per dose

Dexamethasone solution 1 mg/ml

Doses:

Cerebral edema: load 1-2 mg/kg then 0.25-0.4 mg/kg qid for 5 days then taper for 5 days, then

discontinue

Anti-inflammatory: 0.04-0.2 mg/kg bid

Chemotherapy-induced nausea: 0.3 mg/kg prior to chemotherapy

Glycopyrrolate 2 mg tablets

Doses: Nausea related to opioids: 0.1 mg/kg q 4-6 hours

Terminal secretions that distress family: 0.02-0.1 mg/kg q 4-6 hours

Atropine 1% ophthalmic solution

Dose for terminal secretions that distress family: 1-2 drops q 2 hours prn

Tylenol Suppository 325 mg, 650 mg

Dose: 15 mg/kg q 4-6 hours, maximum 120mg/kg/day or 4000mg/day

Hospice Discharge

Discharge:

1. 3HC can discharge a patient for the following reasons:
 - a. If the patient is determined to no longer be terminally ill with a life expectancy of six months or less.
 - b. If the patient moves out of the 3HC's geographically defined service area or transfers to another hospice.
 - c. If the patient enters a non-contracted nursing home or hospital and all options have been pursued, but:
 - 1) a contract is not obtainable,
 - 2) the patient chooses not to transfer to a facility with which 3HC has a contract.
 - 3) the patient chooses not to transfer to a hospice with which the SNF has a contract. 3HC shall contact the fiscal intermediary to document that all options have been pursued.
 - d. Non-Compliance: The patient does not comply with the plan of care as set forth at start of care (ex., consistently missing established appointments with hospice staff or caregiver refusing to follow plan of care).
2. Discharge summaries are to be completed by Skilled Nursing/Social Worker within one week of the date of discharge. (SN Summary describes SN/HHA services that were provided. SW Summary describes Chaplain/Volunteer services that were provide).

Discharge of a Patient That No Longer Meets Hospice Prognosis Criteria of 6 Months or Less

1. If there is an indication that discharge of a patient is necessary or advisable, the Interdisciplinary Team will discuss the circumstances. The Hospice Director of Inpatient Facility, Patient/Family Coordinator or Director of Home Hospice Services, must contact the Medical Director or physician designee, to discuss possible discharge and obtain a verbal order to discharge the patient.
2. When possible, the patient/family shall be involved in planning for discharge and given verbal notice at least one week prior to discharge. A member of the IDG Team shall inform the patient/family, explain the reason for discharge, and provide any necessary family counseling, patient education, or other services by the members of the IDG, and notify the attending physician to obtain the verbal order, before the patient is discharged. Verbal discharge instructions shall be given as applicable. Deliver the Medicare Non-Coverage form if appropriate no less than 2 days and no more than 7 days prior to discharge. (See GEN.077 Medicare Non-Coverage Generic Hospice Form 8.14).
3. When needed, appropriate referral of the patient/family to other community resources shall be made with the approval of the patient/family and attending physician.
4. The designated IDG Team member is responsible for notifying the primary physician of discharge and completing discharge summary and discharge from agency.

Discharge for Cause

1. If the safety of the patient, other persons in the patient's home, or 3HC's staff is compromised, 3HC will make every effort to resolve these problems satisfactorily before considering discharge as an option. If the patient's (or other person(s) in the home) behavior is disruptive, abusive or uncooperative to the extent that delivery of care, or the ability of the hospice to operate effectively, is seriously impaired, 3HC will advise the patient that a discharge

for cause is being considered and is not due to the patient's use of necessary hospice services.

2. The patient's attending physician shall be consulted before discharge and his or her review and decision documented on the discharge note.
3. The IDG team is notified to discuss the discharge in detail and to ensure all appropriate measures have been taken and documented.
4. All efforts by 3HC to resolve the problem shall be documented in detail in the patient's clinical record, to include any referrals to community resources (APS, etc.).
5. A discharge order shall be obtained from the Hospice Medical Director/physician designee.
6. A detailed discharge summary shall be completed.
7. The Hospice Clinical Secretary II shall be notified of "discharge for cause". The Secretary will enter into system appropriate discharge information including code for discharge for cause to prompt billing to use the H2 code.

Discharged For Reason Other Than Death

1. If the care of a patient is transferred to another Medicare/Medicaid certified facility, 3HC shall forward to the receiving facility
 - a. The patient's clinical record, if requested.
2. If a patient revokes the election of hospice care, or is discharged from hospice in accordance with § 418.104(e), 3HC shall forward to the patient's attending physician:
 - a. The patient's clinical record, including discharge information as requested.
3. Discharge information may include:
 - a. A summary of the patient's stay, including treatments, symptoms and pain management.
 - b. The patient's current plan of care.
 - c. The patient's latest physician orders.
 - d. Any other documentation that will assist in post-discharge continuity of care or that is requested by the attending physician or receiving facility.

Discharged Because of Death

1. When death occurs, the attending physician and IDG Team shall be notified as soon as possible, within 24 hours.
2. The Hospice Nurse shall complete Discharge Death Note in detail upon patient's death. (A Discharge Summary is not completed on Hospice patients who expire.)

Contacts

For pediatric hospice related concerns during the day Monday- Friday 8-5, call you supervisor or director of hospice.

From 5-11pm Monday thru Friday and Saturday and Sunday 7 am- 7 pm, call the office, ask answering service to contact triage nurse who will call you back

From 11pm-8am Monday thru Friday and Saturday and Sunday 7pm-7 am, call the office, ask answering service to have administrator on call contact you, she will call you back.

References

- 3HC (2015). Hospice Purpose, Definition, Governing Body, and Philosophy. Retrieved from
3hc.org
- 3HC (2105). Policy and Procedure: Admission of Patient. Retrieved from www.3hc.org
- 3HC (2015). Policy and Procedure: DME Instructions; Retrieved from www.3hc.org
- 3HC (2015). Policy and Procedure. Home Health Hospice Standing Orders. Retrieved from
www.3hc.org
- 3HC (2015).Policy and Procedure: Hospice Discharge. Retrieved from www.3hc.org
- 3HC (2015). Policy and Procedure: Initial and Comprehensive Assessment of Patient. Retrieved
from www.3hc.org
- Cancer.net (2015). Caring for a terminally ill child: a guide for parents. Retrieved from
[http://www.cancer.net/navigating-cancer-care/advanced-cancer/caring-terminally-ill-
child-guide-parents](http://www.cancer.net/navigating-cancer-care/advanced-cancer/caring-terminally-ill-child-guide-parents)
- Cedars-sinai.edu (2015). Pain Assessment Chart. Retrieved from
https://images.search.yahoo.com/images/view;_ylt=AwrTcXjNqENXyT8AIWEunIIQ;_ylu=X3oDMTIydW1laWhqBHNIYwNzcgRzbGsDaW1nBG9pZANm
- Crozier, F. & Hancock, L.E. (2012). Pediatric palliative care: beyond the end of life, *Pediatric Nursing*, 38(4), 198-203.
- Feudtner, C., Santucci, G., Feinstein, J.A., Snyder, C.R., Rouke, M.T., & Kang, T.I. (2006). Hopeful thinking and level of comfort regarding providing pediatric palliative care: a survey of hospital nurses, *Pediatrics*, 119(1), 186-192.doi:10.1542/peds.2006-1048.
- Langemo, D., Haesler, E., Naylor, W., Tippet, A., & Young, T. (2015). Evidence-based guidelines for pressure ulcer management at the end of life. *International Journal of*

- Palliative Nursing, 21(5), 225-232. Retrieved from <http://jw3mh2cm6n.search.serialssolutions.com.jproxy.lib.ecu.edu/?V=1.0&sid=PubMed:LinkOut&pmid=26107544>
- Levine, D., Lam, C.G., Cunningham, M.J., Remke, S., Chrastek, J., Klick, J.,... Baker, J.N.(2013). Best practice for pediatric palliative cancer care: a primer for clinical providers. *The Journal of Supportive Oncology*, 11, 114-125. doi:10.12788/j.suponc.0012
- National Hospice and Palliative Care Organization (2012). *Pediatric Concurrent Care*. Retrieved from http://www.nhpco.org/sites/default/files/public/ChiPPS/Continuum_Briefing.pdf
- Phillips, J.L. (2015) Australian survey of current practice and guideline use in adult cancer pain assessment and management: the community nurse perspective. *Collegian (Royal College of Nursing, Australia)*, 22(10), 33-41. Retrieved from <http://www.ncbi.nlm.nih.gov.jproxy.lib.ecu.edu/pubmed/26285407>
- Ryan, A., Bernhard, H. & Fahlberg, H. (2015). Best practice for prenatal palliative care. *Nursing*, 201, 45(10):14-5. doi: 10.1097/01.NURSE.0000471422.49754.9b.
- Weaver, M. S., Heinze, K.E., Bell, C. J., Wiener, L., Garee, A.M., Kelly, K.P., ... Hinds, P.S. (2014). Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review. *Palliative Medicine*, 30(3):212-23. doi: 10.1177/0269216315583446.

