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Increasing Access To Evidence-Based Pediatric Palliative Care Through Continuing Education Of Nurses

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TITLE OF THE STUDY:
Increasing Access to Evidence-Based Pediatric Palliative Care through Continuing
Education of Nurses

Submitted to the Faculty
Yale University School of Nursing

In Partial Fulfillment
of the Requirements for the Degree
Doctor of Nursing Practice

Taryn J. Hamre

May 2017

This capstone is accepted in partial fulfillment of the requirements for the degree
Doctor of Nursing Practice.

A handwritten signature in black ink that reads "Ruth McCorkle". The signature is written in a cursive style with a large initial 'R'.

Ruth McCorkle, PhD, RN, FAAN

Date here March 26, 2017

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Signed: Taryn J. Hamre, FNP-BC, APRN, CPHON

March 26, 2017

Abstract

BACKGROUND

Each year approximately 42,000 children die and 400,000 children cope with chronic or life threatening illnesses in the U.S. Improved access to evidence based pediatric palliative care is essential to ease suffering, manage distressing symptoms and to improve quality of life.

METHODS

A literature review was conducted. A panel of national pediatric palliative care experts validated and rated educational subcategories identified in the review in accordance to relevance and importance.

RESULTS

The panel of experts rated 25 of 53 sub categories with a 0.78 percent agreement in both relevance and importance. Nine of those twenty-five sub categories had 100% agreement in relevance and importance among all the experts.

CONCLUSION

Providing nurses with education on general, evidence based pediatric palliative care skills, identified by an interdisciplinary team of experts in the field, is critical for expanding knowledge and access to palliative care to all children in need of such care.

Background

Palliative care evolved from the philosophy of hospice care to better address gaps in healthcare for seriously ill and dying children and adults. The goals of healing and curing intersect with the goals of easing suffering and improving quality of life. The World Health Organization (WHO, 2010) defines pediatric palliative care, as “active total care of the child’s body, mind, and spirit, and also involves giving support to the family; it begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.” As reported by the Institute of Medicine (IOM, 2002) this specialized care is essential not only for the children who survive, but also for those who ultimately die and for their families (Field & Behrman, 2003). Over the past few decades palliative care has been recognized as part of the total care of a child and his/her family (Waldman & Wolfe, 2013).

All children represent a medically underserved population. According to the Centers for Disease Control (2013), children 0-19 years old, accounted for 42,328 deaths in the United States (Osterman, 2015). Fifty-five percent of childhood deaths occurred in the infancy period (Friebert & Williams 2015). Nationally, the causes of death in children range from congenital malformations, chromosomal abnormalities, metabolic abnormalities, chronic medical conditions (neuromuscular disease), cardiac abnormalities, renal failure, diseases of the blood and malignancies to accidents, suicide and homicide (Korones, 2007). Seventy percent of children who die could be eligible for specialized end-of-life care (Jones, 2011).

In addition to the children who die each year, an estimated 400,000 children cope with life threatening conditions (Lugo & Hamilton, 2012). In 1997, researchers introduced evidence, that children who died, based on parental reports, suffered a great deal in their last month of life

(Wolfe et al., 2000). Since the centennial works of Wolfe and colleagues (2000), and the 2002 IOM report, much work has indicated that too often children with fatal or potentially life-threatening illnesses and their families fail to receive competent, compassionate, and consistent care that meets their physical, emotional and spiritual needs. In 2013, the American Academy of Pediatrics (AAP) published a policy statement to support palliative care and to provide guidelines and recommendations (Feudtner, Friebert, & Jewell, 2013). The AAP policy, along with recommendations from the National Quality Forum and the National Institutes of Health, further assert palliative care as a critical component of high quality medical care for children with advanced illness (Kang, Munson, Hwang, & Feudtner, 2014).

Ideally, all children's hospitals would have a multidisciplinary pediatric palliative care team available to assist clinicians, patients, and families with pain and symptom management, as well as supporting sensitive conversations surrounding goals of care. Moving toward this goal, the National Hospice and Palliative Care Organization (NHPCO, 2015) reported 69% of U.S. children's hospitals have established a palliative care team (Friebert & Williams, 2015). The challenge many children's hospitals face, even those with well established or developing palliative care teams, is that their time and funding are limited and they are unable to see all the patients that could benefit from their involvement. One potential way to increase access to pediatric palliative care is by educating the general pediatric nurse, working at the bedside on pediatric medical/surgical floors and in pediatric intensive care units. Nurses spend more time at the bedside than any other provider on the health care team. They build strong relationships with patients and their families, help to manage symptoms and advocate for patients' and their families wishes. Nurses can be our front line generalist palliative care providers and advocates for children who would benefit from such care.

Palliative care in pediatrics shows promise in improving quality of life and prolongation of life (Friedrichsdorf, 2017). Of the children who die each year, 75% to 85% of deaths occur in the institutional setting (Harrington-Jacobs, Ferrell, Virani, & Malloy, 2009). Pediatric nurses, working in acute care settings, play a pivotal role. However, many do not fully appreciate the significance of pediatric palliative care, due to the lack of formal education (Jones-Schenk, 2016).

The need for palliative care education in nursing was first identified in the 1960's. Dr. Jeanne Quint Benoliel, recognized that increased medical treatments at the end-of-life decrease a patient's quality of life and can increase suffering (Quint & Strauss, 1964). Quint's research identified that care of the dying was not a part of nursing education. She concluded nurse educators were not equipped to teach students about this topic, and recommended content be added to nursing school curricula (Pace & Lunsford, 2011).

Guidelines for end-of-life care in nursing education were reported in 1997 by The American Association of Colleges of Nursing (AACN) (Pace & Lunsford, 2011). Two decades later, multiple professional health care organizations have continued to support the need for pediatric specific palliative care education. Most recently, the IOM (2015) recommended all educational institutions provide palliative care education: "all clinicians across disciplines and specialties who care for people with advanced illness should be competent in basic palliative care, including communication skills, interprofessional collaboration and symptom management" (Meghani & Hinds, 2015). Additionally, the American Nurses Association (ANA) and the Hospice and Palliative Nurses Association (HPNA) released *The Scope and Standards of Practice* in 2013, which encourages all nurses caring for patients with serious illness to utilize a palliative approach. Unfortunately, the topic continues to receive minimal focus in curricula

(Pesut et al., 2014).

In spite of the recommendations put forth, several barriers exist causing inconsistent palliative care and end-of-life education in undergraduate nursing programs especially in reference to pediatrics. High quality palliative and end-of-life education is often further challenged by the lack of time dedicated for continued staff education, shortage of nursing faculty with expertise in the area to teach curricula, and difficulty finding appropriate clinical settings (Pesut et al., 2014).

The lack of palliative care education in undergraduate nursing programs makes the need for strong continuing education in pediatric palliative care all the more critical. Although there are well known evidence-based national curricula for pediatric palliative care continuing education, such as End of Life Nursing Education Consortium (ELNEC) and the Education in Palliative and End of Life Care (EPEC), most general pediatric nurses working in hospital-based settings do not have the funds or opportunity to attend such trainings. The addition of palliative care continuing education, based on the top themes identified by our expert panel review, could be a reasonable way to provide this needed education and skill set.

White, Roczen, Coyne and Wiencek (2014), in a study, found palliative care continuing education to be inadequate. At the completion of their undergraduate training, nurses are not well prepared to care for patients at the end-of-life (Haut et al., 2012). Many nurses lack knowledge related to sensitive communication skills and pain management (Lugo & Hamilton, 2012; Wittenberg-Lyles, Goldsmith, & Ragan, 2011). In addition, nurses are uncomfortable discussing symptom burden and understanding the role of hospice (Ashley & Fasolino, 2016).

The combination of sparse pediatric palliative care education in nursing curricula, along with limited availability of pediatric palliative care continuing education opportunities, results in

a negative impact to the access of pediatric palliative care services. Ideally, nurses empowered with palliative care strategies can help to reduce the suffering of children and families (Foster, LaFond, Reggio, & Hinds, 2010). Palliative care can be provided at the bedside by nurses who are adequately prepared (Wallace, Halpern, Divya-Devi, & Zwerdling, 2015). The purpose of this project was to identify the most essential evidence-based pediatric palliative care content for a condensed continuing education program for pediatric nurses working in pediatric hospital settings. This is a critical first step toward our ultimate goal of increasing access to pediatric palliative care for patients and families.

Methods

The identification of the most essential evidence-based pediatric palliative care education content for pediatric hospital-based bedside nurses was conducted from June 2016 through October 2016. As a first step, a literature review was conducted to identify pediatric specific palliative care continuing education programs, guidelines and recommendations. Search terms used included *palliative care*, *end of life*, *pediatric*, *education*, *nurse*, *nursing*, and *nursing education*. The search was narrowed to include results in English and those published between 2005-2016. Exclusion criteria included resources not in English and those published before 2005. Search engines included OVID, SCOPUS, CINAHL and Google. Additionally through this search, one article in particular was found to contain valuable perspective on categories essential to pediatric palliative care education (Wiener, et al., 2015). Once programs, guidelines and recommendations were identified, a matrix was constructed and only those currently active were extracted and thoroughly reviewed. The matrix consisted of broad palliative care categories that were bolded and listed in title rows (i.e. Introduction, Communications, etc.). Under each major palliative care category column various sub-categories were listed below in subsequent rows.

The project team then reviewed the matrix and provided insight to refine the total content into ten major categories, each with sub-categories.

A national panel of pediatric palliative care experts was sought to validate and rate the categories on the matrix, according to relevance and importance to developing a continuing education program aimed toward the general bedside pediatric nurse, working in a pediatric hospital setting. A seven member expert panel agreed to rate the sub-categories found in the initial step (Lazenby, Dixon, Coviello & McCorkle, 2014). Care was taken to identify experts from a combination of advanced practice registered nurses and physicians working in the field in order to obtain diverse perspectives. Experts were chosen from across the nation based on their presence in the literature, reputation in the field, and agreement to participate.

The initial matrix was used to develop a rating form for the experts to use in rating relevance and importance of the sub-category content. A comment box was provided next to each subcategory on the rating form, for panelists to clarify responses, if desired. A letter was sent to each expert panel member with an explanation of how to rate the items on the rating form, scoring for relevance and importance. In addition, the experts were asked to return the rating form within two to four weeks. The percentage of agreement for the sub-categories was calculated and those with 78% or greater agreement were further evaluated (Polit, Beck, & Owen, 2007). Institutional review board approval was not necessary as it was a literature review done to design a condensed continuing educational program for hospital based (acute care) pediatric registered nurses, using national experts to validate the content.

Results

The review of current pediatric palliative care educational programs, guidelines,

recommendations and objectives revealed ten major categories. These included: introduction to pediatric palliative care, perinatal/neonatal palliative care, communication in pediatric palliative care, ethical/legal considerations, cultural/spiritual sensitivity, pain management, symptom management, loss/grief/bereavement, care of the dying child/family and models of excellence in pediatric palliative care. There were a total of 53 sub-categories divided among the 10 major categories. The panel of pediatric palliative care experts rated 25 of 53 sub-categories with a 0.78 percent agreement in both relevance and importance (see Table 1). Nine of those twenty-five sub-categories had 100% agreement in relevance and importance among all the experts.

Sub-categories with perfect agreement were: defining the difference between palliative and hospice care; implementing strategies for effective communication; assessing/identifying/planning goals of care; supporting religious/spiritual beliefs; promoting self-care for professionals; identifying pain, symptom management and communication needed in the final hours; educating the family on the dying process; supporting professional development on palliative care skills; and promoting practice-based learning and improvement strategies. The 100% agreement of the interdisciplinary panel in these areas highlights several themes essential to the continuing education needs of the general pediatric nurse working in the pediatric hospital setting.

Additionally, there were 19 sub-categories that experts had 100% agreement on relevance, but with varying agreement on importance. These sub-categories fell across all major category sections.

Discussion

Pediatric palliative care allows children to live as well as possible for as long as possible. It can be provided concurrently with curative treatments to ease suffering, manage symptoms, control pain, advocate for patients/families and to support the patient's primary team in achieving the patient's and family's goals of care while promoting quality of life. Without access to healthcare providers who are knowledgeable and skilled in generalized pediatric palliative care, children living with chronic or life-threatening illnesses are faced with the potential of unnecessary suffering and diminished quality of life.

A reasonable approach to increasing access to pediatric palliative care is through evidence-based continuing education of the pediatric nurse working at the bedside on the medical/surgical floors and pediatric intensive care units in children's hospitals. If there were no limits on time or funding for pediatric palliative care education, ideally nurses would receive continuing education on all major categories and sub-categories included in our findings. The ratings of the multidisciplinary expert panel offer insight as to the most relevant and important pediatric palliative care skills for bedside nurses who aspire to be generalist providers of palliative care for children, despite barriers to such care.

The categories that ranked highest among the experts for relevance related to: identifying what palliative care is; various communication skills; cultural and spiritual sensitivity; pain and symptom management; care of the dying child and their family; the importance of self-care; support for professional development; and increased access to pediatric palliative care. In written comments experts shared that communication is an essential skill needed to help nurses' approach, speak with, and listen to patients and families. One advanced practice registered nurse (APRN) expert stated that, "the ability to communicate effectively is the backbone to providing good palliative care." A physician expert shared that as providers we "often find that when

‘aligned’ with the family, which can only happen once we’ve appreciated their values and beliefs, is when fruitful conversations can begin to take place.” Finally, registered nurses possess the skills to assess and manage symptoms of patients; however, further education needs to be provided concerning the process and timing of when to contact a palliative care team for additional support. A second APRN expressed receiving education on pain management is important to ease provider comfort, which can help patients. She commented “when nurses are uncomfortable with medications and treatments the patient care may not be optimal.”

Several areas were rated with lesser relevance and importance. Perinatal and neonatal palliative care was an area experts felt was critical to those nurses working in neonatal intensive care units and newborn nurseries but may not be essential to all nurses working in children’s hospitals. Experts felt ethical and legal categories could be taught in an overview type of presentation if there was time and felt that palliative care teams could assist with this material. Additionally, experts rated the loss, grief and bereavement section lower than others, noting that it was important but not essential to bedside nurses. A few of the panelists provided a clarifying statement, stating that although bedside nurses could benefit from anticipatory grief training, the nurses are not often providers of bereavement support outside of the hospital setting.

Implications

The pediatric palliative expert panel utilized in this project, further supports the need for professional development on palliative care skills and practiced-based learning. Hospitals are challenged to meet a multitude of continuing education needs. The results of this project can assist hospital-based nursing education teams to focus first on the pediatric palliative care categories that were rated most relevant and important, so that every nurse caring for children

with life threatening or chronic illness will become more knowledgeable in these areas. A variety of learning opportunities can be provided to address the needs of these adult learners without the burden of excessive cost to the hospital.

As a future pilot program, we plan to implement the recommended continuing education program in one children's hospital here in the U.S. To begin, we will advise planning a one-hour in-person session, to present an overview of pediatric palliative care, and describe what makes this care unique from hospice care. Next, we suggest presenting education concerning symptom management, as well as cultural, spiritual and religious content through brief web-based videos or an activity that nurses can access when they have time from work or home via the Internet. We will consider using some of the ELNEC materials taught by staff whom have attended the ELNEC train the trainer pediatric palliative care education program. Regarding enhancing palliative care communication behaviors, we believe these skills, according to the evidence, are best learned through practice. We suggest providing 1-hour simulated sessions to give nurses with an opportunity to learn more about communication strategies while also providing them with a safe place to practice. Finally, we received consistent feedback from the expert panel to include information concerning clinician self-care. For this area we recommend utilizing a flipped classroom approach. For example, the pediatric nurses would be provided with recent journal articles and handouts specific to caregiver fatigue and tips for self-care. Then, during a follow up in-person meeting, the nurses could spend an hour discussing ways to implement whatever strategy they felt could work for them while sharing these ideas with the group. We will consider creating a video containing brief interview segments, asking seasoned nurses what they find to be their most helpful self-care activity. The video could then be shared with staff nurses. To assess staff nurse learning post this educational intervention, nurse researchers will

develop a pretest and posttest survey, as well as require a written reflection to evaluate the program outcomes.

Conclusion

Increased access to pediatric palliative care is needed. Many infants and children facing life threatening or chronic medical conditions can benefit from reduced suffering, pain and symptom management, improved communication and increased quality of life. Providing nurses with general pediatric palliative care education of the most essential evidence-based skills identified by an interdisciplinary team of experts in the field is critical for expanding knowledge and access to palliative care to all children in need of such care.

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