The Effects of Palliative Care Programs in the Pediatric Population

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Abstract

Although adult palliative care is a growing field in the healthcare industry, pediatric palliative care (PPC) is a relatively new service and area of research. Palliative care is a specific type of medical care that aims to improve the quality of life of patients and families by focusing on symptom and stress relief (“What Is Palliative Care?,” 2017). In the past, palliative care has confused with end-of-life care; however, palliative care is useful for patients of all ages facing a serious illness. Pediatric palliative care is family-centered, and the palliative care team uses closed communication to make sure the patients and families fully understand all of the options they have. This allows the family to make decisions that best align with their values and ideals (“What Is Pediatric Palliative Care?,” 2015). The purpose of this paper is to examine and study the current literature in order to determine the effects of palliative care in the pediatric population, including symptom management, psychosocial support, and care of the family. Furthermore, the paper will also discuss the University of Florida Comfort Shawl Project. This project allows participating students to witness the effects of palliative care and enhances their interpersonal, interdisciplinary, and communication skills.

Keywords: pediatrics, palliative care, end-of-life care, comfort shawl, family support
**Introduction**

The National Consensus Project for Quality Palliative Care states that “palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering” (Facts on Hospice, 2015). Furthermore, it focuses on all needs of the patient and family, including physical, emotional, psychosocial, and spiritual needs. Palliative care gives patients the power of autonomy by allowing them to make decisions that they feel may improve their quality of life. Increasing their sense of comfort and decreasing their burdensome symptoms through palliative care may help alleviate some of the hardship they are suffering from. The number of palliative care healthcare teams in the United States has increased throughout the years; however, the accessibility to these programs is still lacking. In fact, one third of hospitals in the United States do not offer palliative care services (Dumanovsky et al., 2015). The health care system should strive to implement more palliative care programs because they have been shown to have significant benefits for patients and families.

Moreover, there is a significant need for pediatric palliative care worldwide. The United Nations Children’s Fund (UNICEF), the International Children’s Palliative Care Network (ICPCN), and multiple national palliative care organizations conducted a cross-sectional analysis to estimate this global need for PPC. The analysis concluded that each year over 21 million children worldwide benefit from palliative care services (Connor, Downing, & Marston, 2017). Globally, most efforts to improve health in the pediatric population are aimed towards decreasing mortality, but little has been done to study and improve pediatric palliative care.

Many other areas of healthcare focus on one specific part of a person; for example, a psychiatrist focuses on the emotional and psychosocial aspects of their patients. On the contrary,
Palliative care focuses on all aspects of patient care, including physical, spiritual, psychosocial, etc. Pediatric palliative care helps support patients and families throughout the course of the illness (Facts on Hospice, 2015). Due to the wide range of patient ages in pediatrics, the pediatric palliative care team must be able to manage a plethora of diagnoses and disease courses while supplying developmentally appropriate care (Facts on Hospice, 2015).

This paper will focus on the need of palliative care in the pediatric population by evaluating the development and impact of this new field. The pediatric population is defined as neonates to children up to age 18. In this population, the palliative care team collaborates with both the child and their family members in order to provide the highest quality of care. According to the National Hospice and Palliative Care Organization, only 14.1% of medical care facilities that offer palliative care services have staff specialized in the field (Facts on Hospice, 2015). Unfortunately, there hasn’t been enough research conducted to study pediatric palliative care to fully understand the true effects that these programs have. Nonetheless, the majority of studies that have been done have shown that pediatric palliative care programs improve the quality of life for both patients and families.

Determining the prevalence of children who benefit from palliative care is very challenging for a multitude of reasons. One challenge to overcome is that there isn’t a clear, universal definition of which conditions warrant the need for palliative care in pediatric populations. For instance, it is clear that a child who is currently dying and suffering would benefit from palliative care. However, palliative care can also benefit children living with significant impairments who are not terminally ill (Institute of Medicine [IOM], 2015). Another issue is the difficulty of accurate prognosis for how long the children will live in various conditions. This makes it difficult to determine who would benefit the most by palliative care
services. Lastly, there is lack of data regarding this topic, which makes it challenging to determine the true advantages of these services (IOM, 2015). Thus, more research needs to be conducted in order to further our understanding and use of pediatric palliative care.

**Methods**

To begin my research, I chose a topic that I am passionate about and that inspires me. Furthermore, I am involved with the University of Florida College of Nursing Comfort Shawl Project, which focuses on palliative care. Thus, I decided to research the need for and effects of palliative care in the pediatric population. With the assistance of the reference librarian, we conducted a search of the PubMed database. We used the following MeSH terms and filters: pediatric,” “palliative care,” and “end of life care.” I sorted the results based on “best match” instead of “most recent.” In addition, I searched for articles from the year 2000 to the present. This search strategy revealed 100 articles.

I reviewed the journal abstracts to further focus my search and ultimately selected thirteen peer reviewed journal articles that were most relevant to the purpose of my literature review. Additionally, I included six palliative care websites and reports that were pertinent to the topic of the paper. In the following section, I will present the findings related to the effects of palliative care in the pediatric population, and the impact of palliative care on symptom management, psychosocial support, and care of the family.

**Results**

According to the Institute of Medicine, approximately 45,000 children die each year in the United States (IOM, 2015). The most common cause of death in this population is trauma and other external causes. Over the past twenty years, interdisciplinary palliative care has expanded rapidly and pediatric palliative care has emerged as a subspecialty. Palliative care in
the pediatric population has been shown to have beneficial effects on both the patient and the family (Friebert & Williams, 2015). Three major effects found in the literature were symptom management, psychosocial and emotional support, and care of the family.

**Symptom Management**

Symptom management and relief is one of the primary goals of palliative care, in both pediatric and adult populations (“What Is Palliative Care?,” 2017). Pediatric palliative care requires healthcare providers to have a thorough knowledge of pain and symptom management (Feudtner & Nathanson, 2014). If healthcare providers are educated and properly implement palliative care measures, the patient is more likely to have their symptoms managed or temporarily relieved (Gelband, 2001). One study examined children who were diagnosed with cancer. Over 100 parents were interviewed after their child had died, and 89% stated that their child suffered significantly from their symptoms, with 27% endorsing that attempts to manage symptoms were unsuccessful (Mandac & Battista, 2014). When both the parents and physician have a good understanding of the situation, results may include greater patient satisfaction, enhanced symptom management and patient comfort, and improved use of hospice care (Vern-Gross et al., 2015).

Pediatric palliative care focuses on trying to improve the quality of life by identifying and alleviating both physical and psychosocial symptoms (Siden, Chavoshi, Harvey, Parker, & Miller, 2014). Managing the burdensome symptoms of the patient is a vital part of palliative care because people feel better mentally when they feel better physically. In serious illness, aggressive management of symptoms can relieve stress and lead to better outcomes for the patient and family (Mandac & Battista, 2014). Knowing that many parents do not believe their child’s symptoms were successfully controlled, palliative care strategies should be employed to
address and manage patient suffering (Mandac & Battista, 2014). The American Academy of Pediatrics encourages for an interdisciplinary approach to proficient and compassionate care that provides palliative care services from the time of diagnosis throughout the course of illness (Weaver et al., 2015).

Providing quality care to a patient suffering from a chronic illness or debilitating disease begins by identifying, managing, and alleviating symptoms. The symptoms should be controlled from the time of diagnosis until the end of life by integrating palliative care and disease-directed approach to care (Mandac & Battista, 2014). However, symptom management should not make the patient’s quality of life decline. For instance, the physician should aim to limit troublesome medical interventions as these may cause further stress and anxiety on the patient and family (Keele, Keenan, Sheetz, & Bratton, 2013). Controlling and alleviating the symptoms whenever possible may help improve quality of life for the patient, and it is a crucial aspect of pediatric palliative care.

**Psychosocial and Emotional Support**

Supporting the patient through their physical pain and symptoms is noticeably a crucial part of palliative care, but the literature suggests that psychosocial and emotional support is also a key aspect in improving quality of life (Weaver et al., 2016). Being ill and uncertain about the future can be very stressful and upsetting for both the child and family. Depending on the age of the patient, many children express fear and worry about leaving their family behind. To help support the patient’s emotional and psychosocial needs, the palliative care team may arrange mental health services (Weaver et al., 2016). Allowing the patient to participate in activities whenever possible is another beneficial way to support their psychosocial needs. For instance, providing art, music, and play therapy can be positive and constructive ways to spend their time.
in the hospital (Siden, Chavoshi, Harvey, Parker, & Miller, 2014). Moreover, all parts of palliative care are intertwined and connected. For instance, if the child’s pain and symptoms are uncontrolled, their anxiety may increase. This can add even more stress and burden to both the patient and parents. Therefore, it’s imperative for the healthcare team to focus on all aspects of palliative care, including both physical and emotional needs.

**Care of the Family**

Additionally, the literature shows that it is crucial to support and care for the family as well as the patient (Jones, Contro, & Koch, 2014). The stress involved with having an ill and potentially dying child can be extremely overwhelming and burdensome for parents and other family members, including siblings and grandparents. Many parents expressed how they struggled watching their child suffer and how they found it difficult to stay strong for their child (Weaver et al., 2016). Moreover, they often describe feelings of loneliness and isolation. Siblings and other family members also carry these burdens and feel overwhelmed by the situation (Weaver et al., 2016). Thus, healthcare providers need to be there for the family to support them throughout the entire process. Healthcare providers can adopt many therapeutic skills to benefit the family, such as empathy, respecting the parent’s knowledge of the child, allowing hope, and willingness to be questioned (Jones, Contro, & Koch, 2014). One study found that up to 44% of parents were diagnosed with post-traumatic stress after their child was diagnosed with cancer (Mandac & Battista, 2014); therefore, it is paramount to assess the needs of parents involved in their child’s health care and in the decision making process. Caring for the patient as well as the family can help improve the quality of life for all parties involved.

Palliative care programs have been shown to benefit the patient’s physical, psychosocial, and emotional needs. Although the patient is considered the first priority, parents and family
members also need support. Furthermore, parents and family need continued emotional support even when the child has died. If the health care team doesn’t follow up with the family, the parents feel like there is a lack of closure and like they have been emotionally abandoned support (Jones, Contro, & Koch, 2014. However, when the parents are continuously supported and contacted by the health care team, they feel a sense of comfort. In fact, the standard of care for pediatric palliative care actually incorporates and emphasizes bereavement and grief support (Jones, Contro, & Koch, 2014). Not only is it important to include the patient and their parents in discussions and integrate them both into the health care plan, but it is also important to be aware of the needs of the patient’s siblings. It is crucial to keep both the patient and family as comfortable and happy as possible. In fact, physicians and other healthcare providers are ethically bound to care for both the patient and their family (Jones, Contro, & Koch, 2014).

Discussion

The purpose of this literature review was to investigate the benefits and effects of palliative care in the pediatric population. A simple yet accurate way to describe palliative care is “to cure when possible, to comfort always” (Feudtner & Nathanson, 2014). Although more research needs to be done to further explore this topic, the results from previous research indicates that pediatric palliative care is not implemented enough, both in the United States and worldwide.

The three main effects that were found in this literature review include symptom management and relief, psychosocial and emotional support, and care of the family. By relieving and managing symptoms, patients and families are more likely to have an improved quality of life. Controlling and alleviating some, if not all, of their symptoms may also decrease their stress and anxiety levels (Weaver et al., 2016). The children that need palliative care not only have
physical symptoms, but also emotional and psychosocial symptoms that need to be managed. Moreover, their parents and family have needs that need to be met or addressed by the interdisciplinary pediatric palliative care team.

One issue with palliative care is that many healthcare providers are not properly educated, so they focus only on the physical needs rather than the emotional needs. It is crucial to support the patient’s psychosocial and emotional needs as well as their physical needs. Additionally, the family needs to be supported by the palliative care healthcare team as well. The stress and burden that comes from knowing your child is very ill and may be nearing death is quite overwhelming for parents and other family members, such as siblings. They need support and guidance throughout the process in order to make the situation as bearable as it possibly can be. Each of these aspects of palliative care are extremely important in regards to providing the highest quality of care to the patient and family. Further research needs to be conducted in order to further understand pediatric palliative care, which in turn will hopefully encourage the implementation of these programs around the nation and the globe.

In addition, education is a key aspect in palliative care. In fact, in 2003, the Institute of Medicine recommended specialized training for pediatric palliative care, creation of interdisciplinary standards directly related to pediatric palliative care, and improvements in research to better the quality of care for patients and families (Feudtner et al., 2013). It is crucial to thoroughly educate physicians and other health care providers about palliative care and the best ways to improve quality of care for their patients because having a good understanding and knowledge of the topic will aid them in providing the highest quality of care to their patients (Gelband, 2001). Parents often believe that their children’s symptoms are better managed when the healthcare team had specialized palliative care training (Mandac & Battista, 2014). It is also
very important for the physician and the other members of the healthcare team to have a positive relationship with the patient and the parents. Building a strong rapport and having a trusting, open relationship with the patient and their family can lead to better health outcomes (Eichner et al., 2012). On the contrary, when parents and patients feel as though the physician isn’t considering their opinions, the family may feel threatened, which may inhibit their ability to have an open, trusting relationship with the healthcare team (Jones, Contro, & Koch, 2014). People want to feel safe, especially in times of distress, so having a strong personal connection can encourage the healthcare provider to provide support and comfort.

**Project Narrative**

The Comfort Shawl Project at the University of Florida allows participating students to have a firsthand experience with palliative care in which their interpersonal and interdisciplinary skills are enhanced. The program is led by Dr. Toni Glover, and each year, honors students and community service volunteers work with Dr. Glover to knit shawls and gift them to patients at UF Health Shands. Fortunately, students are also given the occasional opportunity to gift shawls to patients at Haven Hospice E.T. York Care Center. The goals of the project include providing handmade shawls to patients receiving palliative care at UF Health Shands, providing UF nursing students an experimental immersion in palliative care, and fostering an intergenerational exchange between nursing students and elderly Comfort Shawl volunteers.

The students meet with Dr. Glover throughout the year to discuss how the program is progressing and which activities we would like to participate in throughout the year. Moreover, the students create a schedule and attend the UF Health Shands interdisciplinary palliative care team weekly meetings to discuss and learn about the patients they are going to gift to; the team varies weekly but usually consists of a physician, a nurse practitioner, a physician assistant, a
social worker, a chaplain, and an employee from Haven Hospice. We then retrieve the amount of shawls that we need and visit different units at the hospital to gift the shawls to a variety of patients. The patients that receive shawls are anywhere from newborns to centenarians. There are over one hundred volunteers involved with the project, including nursing students and Gainesville community volunteer members. The project has grown significantly since its inception in 2014, and over 500 shawls have been given thus far.

The students involved in the Comfort Shawl Project participate in a variety of activities related to palliative care throughout the year. This year, we visited the Haven Hospice E.T. York Care Center. We were given a tour of the facility and discussed the premise behind it, and we were fortunate enough to gift shawls to a few of the patients there. We also visited Oak Hammock, which is a retirement community located in Gainesville, Florida. Many of the volunteers that donate handmade shawls to the Comfort Shawl Project reside in this community, so we visited the facility to meet these inspiring women and tour the facility. Interacting with these women allows us to create and foster intergenerational relationships. We also visited Prairie Creek Conservation Cemetery, a natural burial ground and cemetery located in Gainesville, Florida. Additionally, the students participated in Death Over Dinner in which we met as a group along with Dr. Glover and student facilitators to have discussions about death and advance care planning. We talked about different aspects of death, including what we want to do in the future when we die. Each of the places we visit and activities we participate in are related to palliative care, death, and dying.

Moreover, the program has recently included a research component. After gifting, students write three words related to the experience with that each patient. When the gifting process is complete, the students write reflections about the experience, including how it made
them feel and the impact they felt the shawl had on the patient and family. Furthermore, if deemed appropriate, the students may give the patient and/or family members a link to take a survey. If completed, this survey provides insight to how the comfort shawl project has impacted the lives of patients and families. The results gathered from this survey can provide better understanding of how palliative care programs affect patients and improve their quality of life.

Overall, this project runs quite smoothly, with little challenges to overcome. However, there were a few challenges that arose during my experience with the Comfort Shawl Project. The primary issue that we had to overcome was creating the gifting schedule. The interdisciplinary team meets every morning at 8:30am, which doesn’t always coincide with the students’ class and personal schedules. Fortunately, we overcame this issue by creating a google document that allows us to continuously edit the gifting schedule based on our personal agendas. Since there are nine students involved and only two or three need to gift each week, it wasn’t too difficult deciding which days worked best for everyone.

Unfortunately, many nursing programs do not emphasize the topics of death, dying, and palliative care in the curriculum. Thus, many of the students involved in this project weren’t fully aware of these topics and weren’t sure how to deal with them. Being a part of this project has made the students more aware of death and palliative care. It has given us first-hand experiences related to patients nearing the end of life or in great need of symptom relief. I hope that more palliative care research is conducted, especially in the pediatric population, because I feel like it can be very powerful and beneficial aspect of healthcare.

The Comfort Shawl Project has immersed me in the palliative care aspect of healthcare. It has allowed me to grow as a person and as a nurse by encouraging me to be a leader. Furthermore, I have become much more confident in terms of my interpersonal and
interdisciplinary skills. During my time in the Comfort Shawls Project, I have been able to gift shawls to a plethora of patients whose ages vary across the lifespan, including pediatric patients. Gifting to pediatric patients has opened my eyes and furthered my desire to work as a pediatric registered nurse. In a few years, I hope to attend a DNP program to become a pediatric nurse practitioner, both in the acute and primary settings. This project has inspired me to always be an advocate for my patient and to always provide the highest quality of care. I hope that throughout my time as a registered nurse and nurse practitioner, I will be able to learn, grow, and continue my education, and I would like to one day be able to educate others about the importance of palliative care.
References


