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PEDIATRIC PALLIATIVE/HOSPICE CARE IN THE UNITED STATES

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Abstract

The focus on pediatric palliative and hospice care has increased within the past five years. This field is designed to meet the unique needs of critically ill children and their families and includes physical, psychological, and spiritual care. Since working with children is very different than working with miniature adults, health-care workers must take great care to make certain the service provided is developmentally appropriate. The needs of those caring for critically ill children must also be acknowledged and addressed. While somewhat few in number, studies have been conducted that delineate the needs of those involved in palliative and hospice care for children.
Introduction

One of the few certainties in life is that, at one point, we are all going to die. However, since the life expectancy in the United States is 77.9 years, it is logical that most of us plan on living long and healthy lives (U.S. Department of Health and Human Services, 2004). When parents give birth to children, most are fortunate enough to see their children grow up and have children of their own. Sadly, this is not true for all parents. Close to 400,000 children in the Unites States spend each day living with a chronic and life-threatening illness. Each year, approximately 53,000 American children and infants (0-19 years of age) die. Of these 53,000 only about 50,000 receive hospice care and this care is usually only for a very brief period of time (Children’s International Project on Palliative/Hospice Services [ChiPPS], 2001). Palliative care provides relief from the symptoms of a disease or disorder without aiming to cure. According to the American Academy of Pediatrics (AAP), hospice is a package of palliative care services provided by physicians, nurses, and health-care professionals such as bereavement counselors, chaplains, and health aids. The goal of pediatric hospice is to help the child and family make decisions that improve the quality of life (as cited in Jennings, 2005). This literature reviews the needs of the family, the needs of health-care professions, and addresses the role of spirituality in regards to end-of-life care.

Needs of Health-Care Professionals

Providing care to children and families during the shift in phase towards palliative treatment was identified as the single most challenging part of working in pediatric oncology (De Graves & Aranda, 2005). Various studies were done that measured the hospital staff’s perceptions on their needs and roles in regards to providing quality pediatric palliative care. The
first exploratory study surveyed 446 staff and family members affiliated with Lucile Salter Packard Children’s Hospital in Stanford, California. Staff members reported feeling inexperienced, inadequate, and distressed in their communications with families regarding various aspects of palliative care. Staff members reported having inadequate emotional, psychological, and social support and expressed a need to debrief after a patient's death (Contro, Larson, Scofield, Sourkes, & Cohen, 2004).

Researchers in the University of Melbourne School of Nursing performed the second exploratory study. This study used group discussion and in-depth interviews to look at some of the overall challenges faced by health practitioners who initiate and provide palliative care to children with cancer. The aim of this study was to identify the issues that develop when it becomes apparent that the focus of treatment needs to shift from cure to comfort. The study participants were five registered nurses, six hematology/oncology consultants, and three hematology/oncology social workers. One finding was that healthcare professionals believe that they have an important role in fostering hope for children and their families. The stressful impact of uncertainty was also acknowledged. As the authors state:

There is a lack of certainty surrounding the outcomes of life-threatening treatments such as bone marrow transplantation and aggressive chemotherapy and, even if these prove successful, the threat of relapse remains (De Graves & Aranda, 2005, p. 136).

The authors also found that often the relationship between cure and palliative care treatment was not mutually exclusive and that the boundaries were blurred. The question asked by many healthcare professionals is how to start palliative care early while at the same time utilizing curative measures.
In Ireland, a study was conducted that examined the unique needs of pediatric hospice caregivers. Researchers studied doctors and nurses working in an adult hospice center that occasionally provided care to children. The research took place in St. Francis Hospice where 0.5% of the patients are children. They first reviewed the charts of child patients from 1997-2003. From the chart review they found that 20 children were cared for in this 5-year period. Of this 20, 17 children died at home and 2 were still living. They conducted a questionnaire survey and a focus group for all 20 of the adult trained medical and nursing staff that cared for children. They received 14 questionnaires back, a 70% response rate. They found that 60% of the staff believed they developed new skills but did not have the chance to maintain or extend their newly acquired skills. Also, 85% of the staff reported having concerns about calculating medication doses for children. They also reported that specific communication skills were needed to speak with children at different stages in development. The focus group consisted of 8 of these 14 participants. Some of the staff members questioned whether or not the care they provided was “good enough” and others felt their care was the “best available”. They stated that caring for children was not the same as caring for “small adults”, and they expressed concern regarding medication doses. The focus group said that there was increased stress with caring for terminally ill children, their parents, and siblings and additional resources were needed (O’Leary, Flynn, MacCallion, Walsh, & McQuian, 2006).

In the book *Hospice Care for Children*, Armstrong-Daily and Golzer (1993) offer 10 burnout avoidance strategies for health-care professionals working with terminally ill children (*see Table 1*). They emphasize the importance of an administration and supervisor that is understanding and involved, that health-care professionals be given respites throughout the day,
and that are given an appropriate time to grieve personal deaths. Additionally, they state that on-
going educational programs that include the topic of emotions be offered.

Needs of Family

A retrospective study reviewed the medical records of 145 patients who died of cancer between January 2000 and June 2001 at St. Jude Children’s Research Center in Memphis. The intent was to evaluate the effectiveness of the institution’s palliative care initiative. This study looked at the cause of death, CPR/DNR status prior to death, length of end of life care prior to death, sibling counseling/bereavement counseling after death and patient family preferences regarding the death experience.

It was observed that progressive disease occurred 2-15 times more often than other diseases and in 48.3% of the cases a DNR order was present. Also, the amount of end-of-life care received by patients varied depending upon their diagnosis. Patients with Leukemia averaged the least number of days (11) whereas patients with brain tumors averaged the most days (29). Sibling counseling was documented in 16% of the cases and bereavement follow-up was documented in about 50% of the cases. Furthermore, patient preferences regarding the death experience were documented in 44.1% of the cases for children over 6 years of age. Most patients expressed their preference 8 to over 365 days prior to their death. Parent preference was documented in 73.9% of the cases and was expressed a median of 32 days before death. These findings show that patient and parent preferences regarding the death experience can be solicited and documented and that a more standardized approach to documenting bereavement care is necessary. Furthermore, they suggest that a relationship exists between diagnosis, cause of death, and place of death (Bradshaw, Hinds, Lensing, Gatuso & Razzouk, 2005).
Needs of Children and Siblings

A dying child has better symptom control when they have an emotionally supportive environment (Armstrong-Daily et al., 1993). In a freestanding hospice program in Canada, Canuck Place, an evaluative study was conducted to obtain the child’s perspective of the care they were given. The study consisted of 2 phases. In the first phase, 50 individuals from 18 randomly selected families were interviewed. The participants were 4 ill children, 10 siblings, and 36 parents. The children were usually interviewed in their room and the interview questions were adapted for the children’s developmental level. When needed, the researcher would present other children’s experiences to help draw out less verbal children. The interview results were entered into a computer program for analysis. The second phase was made up of a questionnaire that was mailed off to 144 families who had used the facility during its first 30 months. They received responses from 70 families, which included 26 ill children and 41 siblings. The questions asked children/siblings for responses to 18 activity and facility features.

Researchers found that the overall feature endorsement was 89.9% from critically ill children and 89.1% from their siblings. The features that were rated highest among the critically ill children were features such as the hot tub, school room, own room w/own TV and VCR and special events that were offered. The lowest responses went to the Snoezlin Room, a room designed to provide multi-sensory experiences, and the Volcano Room that is designed to release emotional and physical energy. Siblings gave the highest ratings to special events that are usually held off-site and out-of-town. 70% noted how unusual it was to get special attention. Both ill children and siblings mentioned that more activities were needed for teens and older children (Davies, Collins, Steele, Cook; et al, 2005).
An exploratory study of social workers perspectives was conducted to identify what they believe are the psychosocial needs of pediatric patients and their families at the end of life. The data was gathered from the 131 respondents to a survey that consisted of both quantitative and qualitative questions. The two highest rated needs for both children and adolescents were pain control/symptom management and the ability to talk freely about feelings and fears. However the next highest need for children was consistent caregivers and for adolescence was control over treatment decisions and choice of where to die. For families, the highest needs were pain control/symptom management, access to complete medical information, and the ability to talk freely about fears and feelings (Jones, 2006).

Needs of Parents

One of the most difficult challenges to parents is the threat of the death of a child (Armstrong-Daily & Goltzer, 1993). The next two studies address the needs of parents of critically ill children. The first study is a descriptive study that looks specifically at the experiences of the fathers and their bereavement. The study took place in Southern California. The participants were 9 fathers whose children had died between 12 and 36 months prior. Most of the fathers were Caucasian, 1 was African and 1 was “American”. All fathers were married to the mothers of the deceased child and their ages ranged from 34-39 years. Their children ranged in ages from 3 months to 14 years when they died. The fathers were interviewed in person and the interviews lasted from 1-3 hours.

The researchers stated that one father related his experience to living in the shadow of a dragon and other fathers agreed with this view. This battle was made up of three areas: the battle with uncertainty, the battle with responsibility and the battle with everyday disruption. The fathers felt the need to be strong for their families and saw themselves as the protector, although
some of them felt ambivalent of this role. The fathers had many positive things to say about some physicians and nurses but criticized some as being insensitive. According to this study, fathers often get their information from their wives so it is recommended that health-care professionals communicate to mothers in simple language so they can better pass information on to fathers and the fathers can be prepared to contribute to decision-making (Davies et al., 2004).

The next study was designed to pinpoint parents prioritize and to receive recommendations for improving end-of-life care to children. 3 hospitals participated in this study, Children’s Hospital Boston, Massachusetts General Hospital, and Tufts New England Hospital. Anonymous questionnaires were mailed to 96 parents whose children had died 12 to 45 months prior. 2 questionnaires were mailed to each home. They received 56 completed questionnaires, 36 from mothers and 20 from fathers. The mean age was 42.3 years with a SD of 8.4 years.

These researchers found 6 parental priorities for end-of-life care. Parents wanted to hear the truth and to be presented with the “big picture” whenever possible. Many parents felt overwhelmed by the number of people they had to speak with and wanted to speak with only a few professionals, although there were other parents who really liked hearing multiple perspectives. Parents wanted the staff members to express genuine kindness and compassion in their words and actions. Parents asked that the integrity of the parent-child relationship be preserved. Specifically, parents wanted to be listened to, included in the decision-making process, and to be given private time with their child. The final priority was the importance of faith and the integration of spirituality (Meyer, Ritholz, Burns, & Truog, 2006).
End-of-Life Decision

At Miami Children’s Hospital a retrospective study was done to investigate factors that effect end-of-life decisions. The medical records of 236 pediatric patients of children who had died from January 1999 through December 2001 were reviewed. They collected data from the neonatal intensive care unit, pediatric intensive care unit, cardiovascular intensive care unit, and medical surgery and oncology units. They documented whether or not there was an end-of-life care discussion and compared the data with various factors to determine those that effected the end-of-life discussion.

The researchers found a positive relationship between end-of-life discussions and the use of opioid analgesics and sedatives. They also found that the presence of spiritual support was associated with starting an end of life discussion as well as with a greater use of opioid analgesic and sedatives towards the last 24 hours of life. The presence of a chronic illness and the higher number of failed organs were found to be factors that increased the likelihood of an end-of-life discussion (Tan, Totapally, Torbati & Wolfsdorf, 2006).

Freyer discusses special considerations that need to be taken into account when caring for a dying adolescent (2004). The legal age of consent is 18 years old in the United States. However, adolescents facing their end-of-life often show great insight and maturity well beyond their years. Many believe that adolescents 14 years or older have the cognitive abilities to make binding medical decisions for themselves but there is ongoing debate as to their ability to make such decisions. While adolescents end-of-life decision making legal status is presently evolving, Freyer notes:

The insightfulness of adolescents and children dying of chronic illness can compel responsible adults to support their autonomy in end-of-life decisions,
irrespective of what legal status the minor may have in a particular local (p. 384).

Role of Spirituality

The process of dying can lead to a spiritual crisis for the parents and/or child that can manifest physically. Quality spiritual support at this time can improve symptom control (Armstrong-Daily et al., 1993). Since 73% of the respondents in Meyer’s study included a religious theme in their answers, a second study was conducted using the results from these questionnaires. This study focused on parent’s views on the role of spirituality and the clinical applications of spirituality in end-of-life care. They found 4 explicit spiritual themes. Several parents stated that prayer was the most important coping mechanism they had during the last days of their child’s lives. Secondly, many parents stated that they would offer suggestions such as “put your faith in God” and “Trust in God” to other parents in a similar situation. Next, access to and care from their own community clergy and hospital chaplains was stated as important. Finally, some parents spoke of a belief that the parent-child relationship transcends death. The researchers suggest that doctors and nurses integrate spiritual consideration into their care for the families (Robinson, Thiel, Backus, & Meyer, 2006).

Conclusion

Pediatric end-of-life care encompasses the physical, emotional, and spiritual aspects of dying children and their families. Research has shown that health-care professionals caring for these children have unique needs that must be recognized and provided for to avoid burnout. Both parents and children provide vital information as to how health-care professionals can continuously improve the quality of treatment they offer and relieve as much stress as possible from the families. The importance of acknowledging spiritual matters while providing pediatric hospice care was also documented in recent studies.
Table 1

10 Strategies to Avoid Burnout

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<tr>
<td>1</td>
<td>The health care facility must accommodate death work and reflect a quiet, active, and</td>
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<td>caring environment.</td>
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<td>2</td>
<td>The administration must be supportive of the program, the needs of terminally ill</td>
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<td>children and their families, and the importance of staff.</td>
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<td>3</td>
<td>Directors and supervisors must be role models for those professionals undertaking</td>
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<td>and commencing work with the terminally ill and dying.</td>
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<td>4</td>
<td>Supervisors must demonstrate an ability and willingness to be involved.</td>
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<td>5</td>
<td>Health-care professionals who desire to work with the terminally ill and dying must</td>
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<td>be able and willing to engage in a learning and developmental process.</td>
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<td>6</td>
<td>All health-care professionals on a service unit must be aware of the needs of dying</td>
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<td>children, their families, themselves, and other members of the staff.</td>
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<td>7</td>
<td>Health-care professionals who experience personal death must be given appropriate</td>
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<td>time to adjust to these deaths and do their own griefwork.</td>
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<td>8</td>
<td>All health-care professionals will require respite from the daily burden of working</td>
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<td>with the dying child and family.</td>
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<td>9</td>
<td>Institutions must acknowledge that working with dying patients and their families is a</td>
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<td>traumatic experience of varying degrees for health-care professionals.</td>
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<td>10</td>
<td>Educational programs must be continuous and ongoing with the topic of emotional</td>
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<td>involvement included in the curriculum.</td>
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REFERENCES


