Pediatric end-of-life: communication between patients, families, and healthcare providers

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Dedication

Thank you to my parents, Kevin and Dawn Rettig for supporting me and encouraging me through this entire journey. Thank you to Skyler, my brother, whose story of survival inspired both my chosen profession and this manuscript.
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Thank you to Walter Edinger, PhD, for all your patience, and dedication to my work. Thank you to Pamela Oatis, MD, for taking the time to educate me on pediatric end-of-life issues.
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In today’s society, death is easier to accept in the context of an elderly man or woman who has led a long and fulfilled life. However, when life ends so shortly after it begins, there are many issues that can be difficult to cope with and understand (Pierucci, Russell, Leuthner, 2001). In the last few decades there has been an explosive increase in technology and life-saving interventions, resulting in drastically decreased mortality rates in diseases that largely effect children, ranging from cancer to cystic fibrosis. Yet there are limits to what technology can do, and despite our best efforts, some patients will lose their personal fight with these diseases (Korones, 2007).

When dealing with the impending death of a child, parents, extended family members, and healthcare providers must function cohesively in order to deal with the ethical dilemmas and other tough decisions that may arise during the last moments, days, or months of a child’s life. Problems arise when there are differences between the patient’s family and healthcare workers regarding the end-of-life medical decisions and care, so effective communication is critical (Pierucci et al., 2001).

In order to discuss problems and reach decisions together, it is important to identify and overcome obstacles to initiating and maintaining the relationship between healthcare providers and the patient’s family. The purpose of this project is to review the current definitions, protocols, and guidelines of pediatric-palliative care; identify possible gaps in the literature regarding family-clinician relationships; and to build a frame-work for healthcare professionals to improve pediatric end-of-life communication with families.
Caregiver Education and Responsibilities

Healthcare providers must be able to shift from the delivery of medical intervention aimed at a cure, to end-of-life care that is initiated after medical therapies have been discontinued. When this decision is made, the goals of care shift to the relief of suffering (Kane & Hellsten, 2004). Healthcare providers caring for children who are critically ill need to be equipped with special knowledge and skills to help them handle this transition not only professionally, but compassionately. If this transition is handled inappropriately, there may be a long-lasting negative outcome for both the child and the family members involved in the process (Walden, Sudia-Robinson, & Carrier, 2001). Healthcare providers must understand that the family’s expectations, beliefs, and preferences regarding the medical care of their child will influence the family throughout the transition and the entire decision making process.

Education and training in end-of-life care is the first step in arming healthcare providers with the tools necessary to establish and maintain communication with family members of dying children. Information should be available to the medical staff concerning pain assessment, management, and other comfort measures available (Walden, et al., 2001).
Family Network and Stressors

In order to effectively communicate with family members, it is necessary for the healthcare team to understand what the family is experiencing. The admission of a child to the Intensive Care Unit for treatment is an emotional rollercoaster for the child, the family, and also the healthcare team involved in the child’s care (Shudy et al., 2007). There are often dramatic shifts in the child’s health from deterioration to possible recovery, and these events cause a great deal of stress on family members and affects their ability to cope with the situation and communicate effectively both within their family network, and also with healthcare providers (Shudy et al., 2006; Fuhrman & Zimmerman 2006).

Stress is defined by Kasper and Nyamathi as “circumstances that place physical or psychological demands on the individual and the overall emotional reactions experienced by the individual or family” (1988, p. 580). Miles and Carter identified and ranked stressors of family members by developing the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU) instrument. Similar studies using the PSS:PICU scale have indicated the number one stressor for parents is the role-reversal from provider, and protector to helpless bystander (1982). According to a qualitative study based on an anonymous parental questionnaire at three pediatric ICUs in Boston, Massachusetts, parents had a difficult time adjusting after relinquishing the role of primary caregiver and taking a “backseat” to the healthcare providers that have stepped in to provide the majority of care to the patient. Providers need to understand many parents’ feelings of helplessness, vulnerability, and frustration when they do not know how to help their child. Many parents feel they have lost the duty and privilege of protector and decision-maker, so it is necessary for the healthcare team to support the family members, and reaffirm the vital role they play in the child’s care (Meyer, Ritholz, Burns, & Truog, 2005).
Along with maintaining the parent-child relationship, other studies (e.g., Long, 2003; Huckabay & Tilem-Kessler, 1999) have stated that factors such as healthcare provider interaction, behavior, and communication become stronger predictors of parental/family stress as the duration of stay in the ICU increases. Healthcare providers need to be aware of the increasing impact of their actions, and communicate with others in a way to minimize this source of stress on the family members.
Ethical Dilemmas and Education

Practitioners also need a better understanding of the ethical aspects of pain assessment and management as this will play a vital role in the healthcare provider’s ability to communicate with other providers as well as the patient’s family. For example, one of the major concerns of clinical staff members is the use of opioids in pain management. When a child is administered opioids there is the deliberate effect of relieving pain, but also the possible unintentional effect of hastening death. Some healthcare providers may refuse to administer opioids if they feel they are somehow causing the patient’s death. Although this is an acceptable internal conflict, providers need to know that it is morally, legally, and ethically justified to administer opioids if the purpose is to relieve suffering, despite its unintended side effect. This concept is known as the Principle of Double Effect, and although it is difficult to understand and apply, healthcare workers need to be aware that the goal of end-of-life care is to relieve pain and suffering (Jacobs, 2005). This principle is just one of the major issues surrounding end-of-life care, but demonstrates the importance of healthcare provider education so they may better carry out their duties and obligations to the child and their family.

Another ethical dilemma faced by many providers is the withholding or withdrawing of life-sustaining medical treatment. Although the recommendations for when it is appropriate to forego life-sustaining treatment are widely accepted, it can still be a very emotional situation for providers and families, especially in the pediatric setting. While most agree that, ethically, there is no difference between withholding medical treatment and withdrawing medical treatment (Matzo & Sherman, 2001), healthcare providers and family members often find it harder to withdraw medical treatments because it feels like you are directly causing the death.
Withholding and withdrawing treatment can involve any life-sustaining treatment including antibiotics and ventilation. But one of the most controversial decisions is foregoing nutrition and hydration (Jacobs, 2005). According to Matzo and Sherman, there is “an emerging moral and legal consensus that concludes that artificial nutrition and hydration is a medical treatment that may be refused or withdrawn on the same grounds as any other medical intervention (2001, p. 157). Medical providers need to be aware of this legal and moral consensus in order to clarify possible questions among themselves, and/or with the patient’s family.
One of the most widespread misconceptions surrounding pediatric palliative care is that it should only be implemented after medical interventions have been discontinued. This misconception is bred from the former model of palliative care. In this former model, there was an abrupt line drawn between “curative” and “palliative care.” Only after curative care, which is aimed at prolonging life was abandoned, did the relief of suffering and palliative care begin. Healthcare providers need to be aware that this is no longer the standard of care, and realize that palliative care begins long before the decision to implement end-of-life care begins. The more current definition of pediatric palliative care is, “the relief of physical, social, emotional, and spiritual suffering in children and their families” (Korones, 2007, p. 46). Although the role of palliative therapy continues to increase as the roles of curative medical interventions decrease, it can and should be incorporated into the child’s care from the beginning (Korones).
Multidisciplinary Teamwork, Coordination, and Communication

To effectively relieve the suffering of patients, palliative care needs to be implemented using an integrated and multidisciplinary approach in order to effectively maintain communication with everyone involved. The medical literature often describes these complex units as “partnerships” between physicians, physician assistants, nurses, social workers, chaplains, family members, and any other team members involved in the patient’s care based on their disease and condition (Walden, Sudia-Robinson & Carrier, 2001).

According to the study by Miles and Carter, because the size of the team involved in the child’s care can seem to grow exponentially at times, family members have concerns with adequate communication between everyone involved. In order for family members to have confidence in the entire team, it is important to seek adequate care coordination and communication to minimize confusion (1982). Lack of adequate care coordination and communication will only add unnecessary stress to the family, forcing them to seek constant clarification of the plan of care, and adding to their already mounting anxiety. A simple suggestion for initiating and maintaining effective communication and care coordination is to “just ask.” Ask parents early on what their preferred style of communication is, how involved they would like to be in decision-making, and how often and when would they like to be updated on new information and changes in the therapeutic plans. This study suggests that most parents seek full disclosure of information by healthcare providers (Walden, et al., 2001; Miles & Carter). According to many family members, this type of open communication allows for better comprehension of the “big picture,” a firm sense of trust and honesty between healthcare providers and the family, and helps the parents feel more involved and informed in decision-making (Meyer, et al., 2005).
Along with full disclosure, families reported the need to hear information from a provider that they were familiar with and who had a good relationship with the family. Parents stressed the desire that these providers communicate honestly, yet compassionately (Contro, Larson, Scofield, Sourkes, & Cohen, 2004). Communicating in such a manner can help minimize any discrepancies between family expectations and the reality of the situation.

Family members were also more likely to have a positive response to staff members who were open, kind, and compassionate (Melnyk, 1995). Although many practitioners find it necessary to be able to detach from repeated emotional and stressful medical situations, questionnaires show that practitioners who seemed approachable, caring, and “real” were received well by most families, which resulted in a trusting relationship. Providers who seemed detached or aloof were perceived as apathetic and cold, and did not earn the respect and trust of family members (Shudy et al., 2006). Because personalities and attitudes can help or hinder communication, it is necessary for healthcare providers to behave in a manner that lets the family know you truly care about the situation, and this is not just your job (Contro, et al.).

Even when caregivers effectively communicate with family members, problems can occur. As in any partnership, questions can arise when one partner makes a decision that affects the other partners. For example, in our society, it is assumed that parents know what is best for their children, and based on that assumption, parents are given a wide reign over decision-making by other parts of the multidisciplinary team. Most of the time parents agree with the provider’s recommendation, but not always. Encouraging the parents to have in-depth family discussions both alone, and with healthcare team members is a good way for parents to have a complete understanding of what they believe is best for the child, and recognize any areas of concern or disagreement between family members. Incorporating the family into
interdisciplinary meetings is a way to prevent disagreements from permanently harming the clinician-patient-family relationship, and these meetings can foster cooperation and effective communication, two things necessary for effective shared decision-making (Jacobs, 2005).

Although many situations can be resolved peacefully, sometimes the situation grows more complex and difficult. When this conflict arises, it may be necessary for healthcare providers to refrain from engaging in power struggles, and arguing right verses wrong. Team members should carry out the family’s wishes and desires whenever possible, but the ultimate goal is the best interest of the patient (Walden, et al., 2001; American Academy of Pediatrics, 2000a).

When the conflict over what is in the best interest of the patient cannot be resolved, medical professionals should request assistance from the hospital’s ethics committee (Jacobs).
How to Effectively Communicate when Sharing Bad News

In any pediatric end-of-life situation, if a practitioner is providing full disclosure and being honest with the family, he or she will inevitably be faced with the daunting task of sharing bad news. Sharing bad news both honestly and compassionately with family members is not an innate ability, but it is a learned skill, like much of what we learn in our healthcare experience (Korones, 2007). In a family and staff survey conducted at the Lucile Salter Packard Children’s Hospital at Stanford, 68% of families interviewed believed a careless or insensitive remark had been made at some point in time by a healthcare professional (Contro, et al., 2004). Although telling such difficult news is a learned skill, there is little room for error, because even one isolated event of a breakdown in communication or a poor choice of words can leave lasting emotional scars in family members (Korones, 2007). Guidelines have been established to assist in telling bad news, and Buckman has described a helpful six-step protocol, as seen in Table 1 (1992).
Communicating with Children who are Dying

Communicating with children who are dying can be one of the most daunting tasks a healthcare provider may encounter. In the staff survey at Lucile Salter Packard Children’s Hospital, 40% of attending physicians, 71% of residents, 43% of nurses, and 58% of other staff felt inexperienced in communicating with dying patients (Contro, et. al., 2004). It is important for providers to realize that most children realize they are dying without being told (Korones, 2007; Waechter, 1971). If family members and healthcare providers avoid telling the child what he or she is experiencing, the child will most likely feel isolated, afraid and alone.

In order to effectively communicate with the child, the multidisciplinary team must be aware of the child’s “concept of death,” because their views follow a predictable, changing pattern as they grow older, which has been outlined by the American Academy of Pediatrics (2000b). From birth to the age of 2, infants and toddlers have no cognitive understanding of death, and they view it as abandonment, or separation. From the ages of 2-6, children see death as a form of punishment, which is reversible. From the ages of 6-11, children are able to develop concrete reasoning, identifying cause-and-effect relationships, with a gradual awareness of the finality and irreversibility of death. Finally, over the age of 11, children are able to use abstract reasoning, and become fully aware that death is irreversible and inevitable. Although there is a documented pattern, one must also take into account that each child is different, and views of life and death are widely variable from one child to another. Medical professionals should take all of these variables into consideration when approaching a child and discussing end-of-life matters.
Understanding Different Spiritual Beliefs, Religions, and Cultural Practices

The American Academy of Pediatrics (2000a) recognizes that spirituality plays a vital role in pediatric palliative care. Furthermore, in order to emphasize the importance of spiritual care, the Joint Commission on Accreditation of Healthcare Organizations mandates that an assessment based on the spiritual needs of the family be made to any child receiving pediatric end-of-life care (Robinson, Thiel, Backus, & Meyer, 2005).

In spite of this mandate, it is typical that the spiritual needs of patients and their families are overlooked. According to Koenig (2004), a recent survey of 476 physicians in several healthcare centers showed that 85% of those surveyed believed all physicians should be aware of a patient’s religious and spiritual beliefs. Although most physicians believed that understanding spirituality in clinical practice was vital, only 31% thought it necessary to ask parents about their beliefs and practices in outpatient settings, and only 39% found it necessary in inpatient settings (Monroe et al., 2003). Furthermore, it has been reported that a mere 10% actually ask family members about their beliefs (Chibnall & Brooks, 2001).

Many health care providers are not familiar with the range of religions, cultures and beliefs in caring for patients at the end of life. In order to prevent miscommunication and misunderstanding, providers should be familiar with different spiritual views, and understand that religious practice and prayer are among the most common ways that patients and their families cope with an illness (Koenig, 2004).

Yet, there are several barriers that often prevent these conversations from taking place such as lack of time and training, unfamiliarity with the subject and lack of interest. In order to incorporate spirituality in a pediatric patient’s care, it is important for healthcare providers to be able to elicit an accurate “picture” of both the patient’s and the family’s beliefs. According to
Koenig, “it is probably most appropriate to obtain a spiritual history when the physician is collecting comprehensive information, such as when taking a complete history on a new patient, or when a patient is admitted to the hospital” (2004, p. 2881). Although it is important to obtain a spiritual history, it is also important to realize that some patients and their families are not religious and will not be incorporating matters of spirituality into their child’s treatment. In order to prevent conflict and barriers against trust and communication, providers must not force a spiritual history on those who are not religious.

Healthcare providers need to be aware that parental spiritual beliefs, religion, and cultural background may play an integral role in their views towards end-of-life, decision-making, and overall outlook on the medical situations (Robinson, et al., 2005). Effective communication requires an understanding of where the parents and the patient are coming from as they face this critical point in their lives.
Pediatric Palliative Care Consultations: A Useful Tool to Aide in Communication

Many hospitals now offer pediatric palliative care consultations, and these consultations can serve as a way to maintain and improve communication among team members and the patient’s family. At the Children’s Hospital of Wisconsin, their pediatric palliative care consultation team works directly with the existing medical team and the patient’s family. They help by providing emotional support, making recommendations concerning the child’s environment, medical interventions, and advance-directive planning. In a study conducted by the above hospital, infants who had received consultations had decreased use of central lines, feeding tubes, and x-rays. The study also suggests that nurses and physicians tended to document parental emotional needs if a pediatric palliative care consultation had taken place. Those who received a palliative care consultation were also more likely to receive chaplain and social service consultations (Pierucci, et al., 2001). Given the above information, it is appropriate to suggest that pediatric palliative care consultations help to promote communication from everyone involved in the care, clarification on certain ethical issues, and encourage support from other services necessary to ensure the overall well-being of the patient and family.

Although pediatric palliative care consultations are useful, there is confusion among providers on when to implement such services. A pediatric palliative consultation is not needed in every pediatric case, but it is important to recognize situations in which one would be beneficial. Korones provides a helpful list to assist healthcare providers in recognizing such situations:

“1) pain and other symptoms that do not respond to standard measures, 2) clarification of goals and limits of therapy for a chronically ill child, 3) end-of-life decision making, 4)
support of critically ill child’s family, 5) support of staff, and 6) bereavement.” (2007, p. 55).

Knowing what pediatric palliative care is, when to ask for a consultation, and what its benefits are can help insure multidisciplinary teamwork, and at the same time maintain good communication and trust with a child and their family.
Provider Surveys: Concerns

Health care providers at Lucile Salter Packard Children’s Hospital were asked in what areas of pediatric end-of-life care did they feel inexperienced. Results showed that there were four main areas of concern for healthcare professionals: communicating with dying patients, communicating with patients’ families, discussing transition to palliative care only, and discussing “do not resuscitate” status. These feelings of inadequacy spanned the entire breadth of the healthcare team from attending physicians, to residents, to nurses, and other medical staff. This survey demonstrated that if care providers feel inexperienced and lack sufficient training in handling these sensitive, end-of-life issues, they are more likely to doubt their own expertise and are more susceptible to feelings of inadequacy, or distress. It is suggested that these feelings of inexperience and self-doubt may play a role in negative experiences with sharing bad news, so education and training is absolutely necessary to minimize these types of long-lasting, painful interactions (Contro, et al., 2004).
Conclusion

Death in the pediatric population is a complex and emotional situation for all involved: the child, parents, other family members, and healthcare providers. Due to the intense nature of the situation, it is the job of healthcare professionals to be aware of how to effectively communicate with family members and other healthcare providers. Caregiver education is the first step, and providers must be aware of the ethical dilemmas and moral standards that are accepted, and know how to implement these accepted practices. With education, caregivers will better understand the family network, realize the vital role they play in the situation, and identify common family stressors that may result in barriers to communication between family members and the healthcare team. Providers must know the definition of palliative care and understand how it is introduced and implemented. They must acknowledge that establishing a multidisciplinary team is the ideal way to approach pediatric end-of-life and the necessity of maintaining constant communication in order to prevent confusion between the team and family members. The healthcare team should also be aware of any pediatric palliative consultation services available to them and know when it is appropriate to request such services. Providers need to understand the importance of being both compassionate, yet honest when sharing bad news, and learn the necessary tools to effectively communicate with a dying child and their family. Finally, although these situations can be confusing, devastating, and immensely emotion-provoking, healthcare providers who are properly equipped with knowledge, good communication skills, and compassion, can remove any unnecessary pain and suffering to both the patient and their family members in their final moments together.
References


Table 1

*Guidelines for Sharing Bad News*

| Step 1 | Sit closest to those who are most directly involved in the care of the child  
|        | Make sure all cell phones and pagers are turned off  
|        | Take as much time as necessary and do not appear to be rushed |
| Step 2 | Determine what the family and child already know about the situation |
| Step 3 | Determine what the family and child want to know about the current situation |
| Step 4 | Share the information according to the previous two responses |
| Step 5 | Allow for long silences  
|        | Give the family time to think  
|        | Respond to all of their questions and concerns |
| Step 6 | Discuss the plans for follow-up (how often and with whom) |
Appendix

Quick Reference for Healthcare Providers

1. Understand the complexity of pediatric end-of-life situations
   a. Palliative Care Definition
      i. The relief of physical, social, emotional, and spiritual suffering in children and their families.

2. Understand concepts and guidelines of current ethical dilemmas
   a. Principle of Double Effect
      i. Opioid use is morally accepted, even though it may cause the unintended side effect of hastening death, because the goal is relief of suffering
   b. Witholding vs. Withdrawing Medical Treatment
      i. Ethically, there is no difference between withholding medical treatment and withdrawing medical treatment.

3. Identify and acknowledge common family stressors
   a. “Just ask.”

4. Establish a relationship that allows the family to have confidence in you
   a. Choose your words carefully
   b. Most parents questioned felt the need for information to be shared honestly, but yet compassionately.
   c. Maximize parental involvement and input as much as possible

5. Establish a multidisciplinary team to deal with these stressors
   a. Utilize people and resources provided by your hospital
b. Plan regular meetings in order to maintain effective communication.

Implementing these steps, and promoting clear communication between clinical staff and family members will help the family effectively cope with the situation.
Abstract

Death in the pediatric population is a complex and emotion-provoking situation. There are numerous individuals involved including the child, parents, other family members, and the entire healthcare team made up of physicians, physician assistants, nurses, clergy, etc. Communication between these individuals plays a vital role in minimizing confusion and stress and maximizing positive interactions. This manuscript provides a detailed description of how to establish and maintain effective communication between those involved through caregiver education on common ethical dilemmas, the ability to identify family stressors, the development of a multidisciplinary team, and knowing when to initiate palliative care. A “Quick Reference for Healthcare Providers” is also provided as a useful tool to help clarify this complex situation for healthcare providers.