

# Nursing interventions that facilitate end-of-life decision-making in pediatric oncology

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Lauren Baeringer  
*University of Central Florida*

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NURSING INTERVENTIONS THAT FACILITATE END-OF-LIFE DECISION-MAKING IN  
PEDIATRIC ONCOLOGY

by

LAUREN BAERINGER  
B.S.N. University of Central Florida, 2013

A dissertation submitted in partial fulfillment of the requirements  
for the Honors in the Major Program in Nursing  
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## **Abstract**

Nearly one-third of all pediatric oncology patients die from their disease, so nurses need to have an evidence-based standard of practice to guide their role in end-of-life decision-making. The purpose of this integrative review is to analyze current research on end-of-life decision-making within pediatric oncology to create a practice guideline for nurses working with this patient population. Eleven studies were examined to identify nursing interventions regarding the role of the nurse in end-of-life care, the role of the nurse in end-of-life decision-making, parent involvement in end-of-life decision-making, and child involvement in end-of-life decision-making, including the child's ability to participate in end-of-life decision-making. Based on the findings, the researcher identified several interventions that can be used by nurses to facilitate end-of-life discussion and decision-making that includes both parent and, when appropriate, the child.

## **Dedication**

For my family, especially my mother, who supported me throughout the writing process and have always encouraged me to go further than I thought possible.

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## **Introduction**

One to two children in every 10,000 in the United States will develop childhood cancer every year. For all childhood cancers combined, roughly 30 percent of children diagnosed will die from their disease (National Cancer Institute, 2008). This makes creating a guideline for facilitating pediatric patient inclusion in decision-making vital to providing full, comprehensive nursing care for these patients. Involving children in the decision-making process, especially the end-of-life decision-making process, can increase satisfaction with decisions made by all parties: the children, parents, and healthcare staff (Hinds, Oakes, Furman, Quargnenti, Olson, Foppiano, & Srivastava, 2001).

How involved the child is in the decision-making about their health care is especially important in the case of end-of-life decisions. Studies examining the factors that influence parental end-of-life decision-making indicate that the preference of their child plays a role in the decision parents make (Hallström & Elander, 2004; Hinds, et al., 2001; Hinds, Drew, Oakes, Fouladi, Spunt, Church, & Furman, 2005; Maurer, Hinds, Spunt, Furman, Kane & Baker, 2010).

The end-of-life process begins when treatments have not put the cancer into remission and the physician has deemed that cancer to be incurable (Klopfenstein, Hutchison, Clark, Young, & Ruymann, 2001). There are many factors that affect the different end-of-life choices, including but not limited to religious beliefs, patient preference, patient relationships with others, avoidance of adverse side effects, and prolongation of life (Hinds, et al., 2001; Hinds, et al, 2005; Maurer, et al., 2010). End-of-life decisions include decisions to withhold further treatment and

initiate palliative care, enter into a Phase I trial, or continue current treatments with a signed do not resuscitate order (DNR) (Hinds, et al., 2005).

The developmental and cognitive maturity of children with cancer may be different than that of healthy children. Children with chronic, life-threatening illnesses have a more complete understanding of their illness and the consequences of decisions related to their illness. Children with cancer also understand the possibility that they may die from their disease (Nitschke, Humphrey, Sexauer, Catron, Wunder, & Jay, 1982).

Parents and physicians may not want to include the dying child in end-of-life decision-making. This inclination of the family and healthcare team to protect the child can be detrimental to the child. This is where the nurse's role as the child's advocate is important. The relationship between the nurse, child, and family should be one based on trust and mutual respect for the nurse to be able to fully advocate for the child. The nurse can help create an environment where the child feels valued, respected, and included in decision-making at end-of-life (Whitty-Rogers, Alex, MacDonald, Gallant, & Austin, 2009).

Whitty-Rogers and colleagues (2009) found that parents who discussed death with their child dying of cancer did not regret it but parents who did not have that discussion with their child and felt their child was aware of their imminent death did have regrets. They concluded that nurses need to have a clear standard of care for promoting the autonomy and voice of the child especially during end-of-life. The researchers recommended that active involvement in decisions should not begin at the end-of-life, though it is essential during the end-of-life process.

## **Problem**

As a child with cancer nears the end-of-life, a component of the pediatric oncology nurse role is facilitation of end-of-life decisions and care. As such, there should be a standard for nurses on how to best support the end-of-life decision-making process for dying children and their families. Unfortunately, there is no guideline or standard for nurses to use to as a guide as to how to advocate for their pediatric patients at the end-of-life juncture (Hinds et al., 2001). The lack of an evidence-based process for how to approach the families of dying children makes it hard for nurses to advocate for those patients and their families effectively.

There is limited research on the decision-making process in pediatric end-of-life situations and there are few guidelines for how nurses should advocate for their patients in these situations. The question to be answered by this literature review is: what can the nurse do during the end-of-life decision-making process to involve the child and ease the burden on the family?

## **Purpose**

The purpose of this thesis is to identify nursing interventions that affect end-of-life decision-making by pediatric oncology patients. These interventions will include those that can positively affect the end-of-life decision-making process for patients and/or parents. These interventions will be integrated into an evidence-based protocol for nurses working with pediatric oncology patients during the end-of-life process. The thesis will also explore how to assess a patient's ability and readiness to participate in the end-of-life decision-making process.

This protocol can serve as a guideline for nurses to open up dialogue with patients and patient families regarding the child's participation in end-of-life decisions. It will also provide guidance as to when and how a pediatric oncology patient should be encouraged to participate in the end-of-life decision-making process. These guidelines will allow nurses to better support their patients and their patients' families as they make these decisions.

## Methods

The researcher analyzed the current research on end-of-life decision-making in pediatric oncology to determine the nursing interventions that impact child and family decision-making. Databases used to find research articles included CINAHL, MEDLINE, and Academic Search Premier. Databases were accessed electronically through the UCF library to find peer-reviewed articles, original studies, meta-analyses, literature reviews, and published dissertations. The bibliographies of published research studies and literature reviews were also searched to find studies related to the topic.

Specific inclusion and exclusion criteria for assessing whether or not the article should be used for this literature review were identified. To be included, articles were required to be written or translated into English. The nation of origin of the study did not have to be the United States, but any international articles were assessed to ensure that the perspective of the article regarding the death of a child was similar to that of the United States. Except for a seminal article published in 1982, articles used were published during or after the year 2000. The patient population of the studies included were ages 4-20 years. The children in the studies were required to be oncology patients. Ideally the studies and articles were about the pediatric patient decision-making process, however due to limited research on the subject, studies of parental decision-making were also included, but only as it pertained to pediatric oncology patients. To be included, the study needed to define parent as the person or people legally responsible for making medical decisions for the child. The end-of-life decisions addressed in the included articles were: adoption of a DNR, enrollment in a phase I clinical trial, and the cessation of disease-directed care and beginning terminal or palliative care.

Exclusion criteria were studies of pediatric oncology patients and their parents which were not about factors related to the decision-making process. Any studies that included pediatric oncology patients but focused on other illnesses as well were also excluded.

After the review of the literature, the researcher decided to include 2 studies that did not meet inclusion criteria as they examined decision-making in non-oncology patients. Another 3 studies were also kept despite not meeting the inclusion criteria as they examined ethical considerations of decision-making. The 5 studies were kept because there were limited studies specifically examining the child's perspective on decision-making in oncology. The studies kept examined the child's perspective or the ethical implications of discussing end-of-life with children with cancer and were used to derive nursing interventions.

The search terms used to search the databases were: pediatric\*, child\*, oncol\*, cancer\*, end-of-life, and palliat\*. Using those search terms, 35 articles were found. Articles were rejected primarily because they examined the decision made not the decision-making, or were not about children with cancer, the child's perspective on decision-making, or end-of-life decisions. After the articles were analyzed, the final number of articles used for the review of literature was nine.

## **Review of Literature**

### **Pediatric End-of-Life Decision-Making Studies**

Nitschke and colleagues (1982) examined a new protocol being used at Oklahoma Children's Memorial Hospital Oncology Service that included children in treatment related conferences and end-of-life decision-making. Forty-three children participated in the conferences. The researchers analyzed the children's understanding and ability to participate in the conferences and discussions. This research only studied the child's decision-making, not their parents. Nitschke and colleagues found that child involvement in decision-making conferences beginning at the time of diagnosis allowed children greater understanding and ability to participate, on some level, in end-of-life decision-making (1982).

P.S. Hinds and colleagues conducted the seminal research regarding pediatric end-of-life decision-making. Their 2001 study examined three qualitative studies on decision-making in pediatric oncology which focused parental and child, specifically adolescents, decision-making. The study samples included 95 parents and 10 adolescents, as well as 43 healthcare providers. The outcomes of the studies were compared and contrasted and then used to create a framework for evidence-based guidelines for end-of-life decision-making with adolescents. Hinds and colleagues created outlines for assisting parents and adolescents with end-of-life decision-making based on recommendations from professional associations and the outcomes found in the three studies analyzed (Hinds, et al., 2001).

Hinds and colleagues' 2005 study was a qualitative study that examined the decision-making process in parents and children by way of interviews with parents, children, and

physicians who were involved in making an oncology related end-of-life decision. The researchers interviewed 20 children, 18 parents, and 14 physicians about the end-of-life decision made, the options presented, what was considered when making the decision, and what helps them feel okay about the end-of-life decision. The answers to these questions were analyzed and coded. The study found that children and adolescents want to be involved in end-of-life decision-making and that parents also want to know their child's opinion. The children in the study considered their relationships with others and the implications of each end-of-life care option when making their decision (Hinds, et al., 2005).

Mauer and colleagues (2010) examined the decision-making of parents of children with cancer. The researchers interviewed 62 parents of 58 children about their reasoning for their decision, and what staff behaviors made the decision-making process easier for them. The study compared the motivations and concerns of parents who opted for enrollment in a phase I clinical trial and of parents who opted for palliative care with a DNR. This study did not examine the child's role in end-of-life decision-making. The research indicated that parents make their end-of-life decisions based primarily on the medical facts, quality of life implications, and their child's end-of-life care preference (Mauer, et al., 2010).

A 2001 study examining the medical records of 146 children with cancer who died at a children's hospital focused on the variables impacting the end-of-life choices that were made. Klopfenstein and colleagues used the medical record to determine if and how age, diagnosis, length of last hospital admission, and duration of DNR orders had impacted the end-of-life decisions made, specifically the choice to use hospice services. They found the type of cancer

and the longer the last hospitalization was increased the chance of being recommended to hospice services. To improve end-of-life care for children with cancer, the researchers concluded that more comprehensive and complete documentation throughout the end-of-life process is required (Klopfenstein, et al., 2001).

### **Studies Related to Ethics in Pediatric End-of-Life Decision-Making**

While the mindset and abilities of parents and children involved in end-of-life decision-making process are important to understand, ethics is also important especially in dealing with the pediatric population. Hendrickson and McCorkle (2008) performed a dimensional analysis of 41 scholarly articles and 2 newspaper articles to examine the concept of “good death” in regards to children with cancer. They found 7 dimensions with individual attributes that are factors in the end-of-life process for child with cancer and their families. The dimensions include age-appropriate participation, personal style, quality of life, preparing for death, aspects of care, legacy, and impact on survivors (Hendrickson & McCorkle, 2008).

A 2006 qualitative study of decision-making in pediatric oncology sought to determine who has decisional authority in pediatric end-of-life decision-making. The researchers examined the role of parents, children, and clinicians in decision-making and the structure of medical decisions to create a model for making end-of-life decisions. They concluded that the model is not the same for every instance. The age, maturity, and experience of the child and parents determine who has the most authority to make end-of-life decisions for children (Whitney, Ethier, Frugé, Berg, McCollough, & Hockenberry, 2006).

Whitty-Rogers and colleagues (2009) performed a descriptive literature review using a relational ethics approach to examine the ethical issues involved when working with children during end-of-life decision-making. The researchers looked at ethics of trust and autonomy and the cognitive development of the children involved in end-of-life decision-making. The literature review also includes four case studies related to child involvement in end-of-life decision-making. The researchers concluded that giving the child a voice and promoting age-appropriate participation in end-of-life decision-making is the key role of the nurse caring for a child dying of cancer (Whitty-Rogers, et al., 2009).

### **Non-End-of-Life Pediatric Decision-Making Studies**

Studies related to pediatric involvement in decision-making and the decision-making process do not focus only on the end-of-life decision-making process. A 2002 Swedish study examining the role that children have in decision-making during hospitalization found that children can participate, in varying capacities, in decision-making. The researchers followed 24 children and their families during their first hour of arrival and at different points during hospitalization. Systematic notes were taken after each observation then analyzed, coded, and graded on a 5-point scale based on the interactions between the children and nursing staff. The researchers found that when the healthcare staff hurries through procedures and explanations, children are less likely to be involved in decision-making. However, if the healthcare staff works to develop a trusting relationship with the child and intentionally involve in the child in decision-making, the child is more likely to be included by their parents in decision-making (Runeson, Hallström, Elander, & Hermerén, 2002).

A 2004 follow-up study used the data obtained through non-participant observation from the 2002 Runeson and colleagues study to analysis and code the data regarding parent and child involvement in decision-making during hospitalization. Hallström & Elander found that parents and children were involved in making small decisions during hospitalization, but needed to be encouraged by staff the take the lead in decision-making (2004).

## **Discussion**

Based on this review of literature on end-of-life decision-making in children with cancer, six areas related to nursing care were identified. These are related to the nursing care importance, the role of the nurse in end-of-life care, the role of the nurse in end-of-life decision-making, parent involvement in end-of-life decision-making, children's ability to participate in end-of-life decision-making, and child involvement in end-of-life decision-making. Although none of the studies directly examined the role of the nurse, the foundation for a protocol for nurses in support of the child in end-of-life decision-making was inferred from the articles.

### **Nursing Care Importance**

Nursing care is an important aspect of end-of-life care for pediatric oncology patients. Children and their families develop an attachment to the nurses who care for them. Knowing and trusting the nursing staff caring for a child during the end-of-life process is important to the child and their parents (Hendrickson, et al., 2008). This trust is developed throughout the course of caring for a child and extends into the end-of-life process. When nurses allow the child to be involved in their care, even in small ways, it creates a trusting relationship between the nurse and the child (Runeson, et al., 2002). Trusting the nursing staff made hearing about end-of-life care options easier for parents (Hinds, et al., 2001; Hinds, et al., 2005).

The trust developed between nurse and child and nurse and family creates an environment for the nurse to empower the parents and child to be involved in decision-making by offering options without bias (Whitney, et al, 2006). The nurse can create an environment that allows for discussion and exploration of information presented (Hinds, et al., 2001; Whitty-

Rogers, et al., 2009). Throughout the discussion, the nurse provides information, answers questions, and helps to clarify the implications for the child with each care decision presented. Hinds and colleagues study found that 16 out of 19 parents felt that trust in the healthcare team's expertise and care as well as feeling supported in their decision-making role helped them during their decision-making process (2005).

### **Role of Nurse in End-of-Life Care**

**Continuity of care.** Continuity of care for children during the end-of-life process is more than consistency in who is providing care. It includes consistency of knowledge of the situation throughout the entire healthcare team (Hinds, et al., 2001). A 2008 dimensional analysis of end-of-life themes in pediatric oncology found that children list seeing the same faces throughout their care as the most important aspect of care (Hendrickson, et al.). Parents valued the smooth transmission of information from one healthcare team member to another. When parents had to repeat their situation or the end-of-life decision made to new people, it made the end-of-life process more difficult for them (Mauer et al., 2010). One example of consistency of knowledge valued by parents and children is having the entire healthcare team know the end-of-life terms the family uses to discuss the end-of-life options presented to them (Hinds, et al., 2001). When providing information to children and families having written materials to accompany verbal discussion can help to ensure that complete information is being passed from the nursing staff to the family (Hinds, et al., 2005).

**Care regardless of decision.** During the end-of-life process, there are multiple options presented to the child and family regarding what end-of-life care will consist of for the child

(Whitty-Rogers, et al., 2009). The role of the nurse is to assure parents and children that the nursing staff will continue to care for the child throughout the end-of-life process (Hinds, et al., 2001). Parents and children need to be reminded that the nursing staff's role as caregiver will not change and that symptom relief will continue to be provided regardless of what decision is made, especially if the end-of-life care decision is not treatment-based (Hinds, et al., 2005; Mauer, et al., 2010). Hinds and colleagues 2005 study found that children wanted to know that they would not experience adverse effects related to their decision, including both treatment side effects and disease-related discomfort.

### **Role of Nurse in End-of-Life Decision-Making**

The role of the nurse in assisting children and their families through the end-of-life decision-making process is to provide information about the end-of-life options (Hinds, et al., 2005) without putting any pressure on the child or family to make the decision quickly (Klopfenstein, et al., 2001; Nitschke, et al., 1982). The role of the nurse is not to sway the decision being made, nor is it to judge the decision. Respecting the parents' and child's decision whether it be palliation or continued therapy is vital to maintaining the trusting relationship develop through the course of treatment (Hinds, et al., 2005; Mauer, et al., 2010; Whitty-Rogers, et al., 2009).

Making an end-of-life decision is difficult for families, particularly with pediatric patients. Nurses and other healthcare staff need to understand that children and families may take more time to process the information provided (Hinds, et al., 2005; Nitschke, et al., 1982). Parents and children need time away from the nursing and healthcare staff to discuss the end-of-

life options presented (Hinds, et al., 2001). Not only does this allow them privacy, it gives the child and parents more time to make the decision. (Runeson, et al., 2002). Parents are likely to go back and forth between several options before fully committing to an end-of-life care plan. Parents and children may not always feel the same about the decision they've made and prefer to be supported by the nursing staff throughout decision-making (Hinds, et al., 2001). When the decision-making process is not rushed, the child is more likely to be involved in making the decision (Runeson, et al., 2002).

Nurses and other healthcare team members need to deliberately involve children and parents in the decision-making process and not make assumptions or make decisions for them (Whitney, et al., 2006). Parent and child involvement in decision-making needs to be facilitated by their healthcare team. If all options and alternatives are not presented to parents and children, they may not know to ask questions or they do not know the right questions to ask (Runeson, et al., 2002). When involving the child and parents in decision-making, the nurse can discover specific needs of the child or family. This allows the nurse to better support the family by providing individualized support and information about available resources (Hinds, et al., 2001). Some parents want to attend parent support groups, some want assistance in funeral planning. Regardless of their concerns, the nurse is able to provide additional and individualized support for families having to make end-of-life decisions, including how to tell other family members about the end-of-life decision made (Mauer, et al., 2010; Hinds, et al., 2001).

## **Parent Involvement in End-of-Life Decision-Making**

Legally parents have the most responsibility for decisions during the end-of-life decision-making process. For each parent the decision-making process can be very different. The level of input that parents want from the nursing and healthcare staff and the amount of encouragement parents may need to fully participate in the decision-making process can vary greatly (Whitney, et al., 2006). Parents make their end-of-life decision based on the information provided by the nursing and healthcare staff (Hinds, et al., 2001). The research reviewed showed that parents frequently are concerned with their child's quality of life with each end-of-life care option (Hendrickson, et al., 2008; Mauer, et al., 2010; Whitney, et al., 2006). Some parents are concerned with ensuring their child participates in the decision-making process at an age-appropriate level (Hendrickson, et al., 2008). Others consider the medical facts related to their child and the treatments available, how others around them feel about the options presented, and they want to know their child's preference before making a decision (Mauer, et al., 2010).

When parents are able to involve their child in the decision-making process they can feel like they've provided more optimal care for their child (Hallström & Elander, 2004). In several studies, parents wanted to know their child's end-of-life care preference before they made the end-of-life decision (Hinds, et al., 2001; Hinds, et al., 2005; Mauer, et al., 2010). Parents felt more comfortable with the end-of-life decision made when they knew their child's preference (Hinds, et al., 2001). Knowing their child's end-of-life decision and being able to listen to their child's request provided comfort to parents (Whitty-Rogers, et al., 2009). Whitty-Rogers and colleagues also found that parents who had open end-of-life discussions with their child had no regrets when their child died, but parents who did not discuss end-of-life decisions with their

child regretted not being more open (2009). Hinds and colleagues found that parents liked to have the nursing and healthcare staff help them identify their child's end-of-life care preference. The same study found that 18 out of 19 parents wanted to know what their child's end-of-life decision was when making the final determination (Hinds, et al., 2005). Nurses are in an ideal position to influence child involvement in end-of-life decision-making (Whitty-Rogers, et al., 2009).

### **Children's Ability to Participate in End-of-Life Decision-Making**

Children can participate in decision-making even if they are not the main decision maker (Hallström & Elander, 2004). They are capable of being a part of and have a role in the decision-making process (Hinds, et al., 2001). Hinds and colleagues found that children in their 2005 study were able to make complex end-of-life decisions based on multiple factors. Children have a role in end-of-life decision-making and can participate at some level. Adolescents familiar with their condition may be able to make their own end-of-life decision (Whitney, et al., 2006). Whitney and colleagues concluded that mature adolescents were better able to make an end-of-life choice than their physician (2006).

With age, children become more competent at making their decisions or sharing that role with their parents. The amount of responsibility a child has for the decision made depends on their maturity, understanding, and willingness to participate in end-of-life decision-making (Whitney, et al., 2006). Nitschke and colleagues also concluded that age and intellectual capacity, as determined by the child's parents and familiar healthcare staff, must be considered when determining how large a role in end-of-life decision-making the child will have. They

found that children as young as 5 have participated in end-of-life decision-making at varying levels depending on development (1982). Runeson and colleagues concluded that decision-making was also influenced by the child's past experience with illness and their level of independence along with their stage of development (2002).

Nitschke and colleagues concluded that children with cancer have an emotional and conceptual development that exceeds their chronologic age in regards to their cancer (1982). Children with a history of cancer can understand the concept of death and the outcomes of the end-of-life decisions being made (Mauer, et al., 2010). Another study from 1982 also found that children can understand the concept of death and may even have an adult-like concept of death. Children as young as 5 can understand the final outcome of the end-of-life decision made. Those same children, if only receiving supportive care, can understand and tolerate their impending death (Nitschke, et al., 1982).

Hinds and colleagues 2005 study found that 18 out of 20 children were able to recall all the end-of-life options presented to them. The two who could not remember all the options had cancers of the brain and could only remember the decision they made. The same study found that children with terminal cancer think of their relationships with others in a way that is not developmentally expected. Nineteen of 20 children considered the other people in their life when making an end-of-life decision. Eleven of the 12 children who chose to participate in a phase I clinical trial or continue therapy in the study expressed a desire to help unknown people in the future. Parents of the children in the study also expressed this altruism for unknown children in

the future. This altruism is not shown in adult oncology patients who enter phase I clinical trials, it is only exhibited in the pediatric oncology population (Hinds, et al., 2005).

### **Child Involvement in End-of-Life Decision-Making**

Two studies found that if children were well informed of their condition from diagnosis on, children were more prepared and capable of participating in the decision-making process (Nitschke, et al., 1982; Whitty-Rogers, et al., 2009). Nitschke and colleagues concluded that informing children of their condition at the time of diagnosis created better understanding on the part of the child during end-of-life decision-making (1982). Whitty-Rogers and colleagues found that children who were told the truth of their condition throughout treatment were more able to understand and cope with the fact that treatment had not been successful (2009).

Not only do children have better understanding of their condition when they are well informed, but children want to be informed of their condition, their treatment plan, and how it's working (Hinds, et al., 2001). In regards to end-of-life, children want to be informed because they want the opportunity to say goodbye to their friends and family (Hendrickson, et al., 2008). Adolescents are open and willing to discuss their end-of-life preferences for care, if encouraged (Wiener, et al., 2008). Participating in the decision-making process helps children develop their sense of self (Hallström & Elander, 2004). When hospitalized children are involved in decision-making it increases their sense of control over the situation. When parents support the child's involvement in decision-making, the child is more likely to participate in the decision-making process (Runeson, et al., 2002).

Overall satisfaction with the end-of-life decision made among parents and children increased when the child's preference was known and respected (Hinds, et al., 2001). Hinds and colleagues 2005 study found that 18 out of 20 children felt good about the final decision made. The two children who did not feel good about their decision had decided to continue therapy because of their family's desires and not their own. The 18 children whose end-of-life decisions were respected did not have the same worries as the 2 whose decisions were not respected (Hinds, et al., 2005).

## **Recommendations for Practice**

Studies reviewed did not contain nursing interventions because they did not study nurses. Presented below are interventions deduced from articles supporting the child's participation and overall end-of-life decision-making. These are related to encouraging child involvement in end-of-life decision-making, answering questions honestly, assuring parents and children of continued care regardless of decisions made, providing adequate time for decision-making, effectively communicating with other members of the healthcare team, and supporting the decisions made by parents and children.

### **Encourage Child Involvement in End-of-Life Decision-Making**

The trusting relationship developed while caring for a child during treatment allows the nurse to encourage age-appropriate involvement in end-of-life decision-making. Children with cancer have a greater understanding of their disease and a greater understanding of death than a child of the same age who has not been chronically ill. Some children who have lived with a chronic illness may have an adult-like concept of death and can understand the finality of the decisions being made. This greater understanding allows them to contribute to the end-of-life care discussion, in some capacity even if they are not the final decision maker.

Children with cancer want to be informed about their condition. They have a desire to know what's happening and, with their greater understanding of death and dying, also have a desire to say goodbye to their loved ones. Parents of children with cancer also want to know what their child's end-of-life care preference is as well. Research has shown that when parents know their child's end-of-life decision they tend to follow through with that decision. When the

child's wishes are known and respected the overall satisfaction with the decision is increased. Involvement is vital to providing children some sense of control over the situation they are in.

Facilitating child involvement in end-of-life decision-making is a vital aspect of the nursing role when caring for children with cancer. The nurse should advocate for child involvement and encourage the parents to discuss the end-of-life options with their child, as is appropriate for their child's age and development. Assessing age, maturity, and cognitive development are necessary to determining how large a role the child is capable of taking in the decision-making process, but Nitschke and colleagues (1982) research has discovered that children as young as 5 are able to participate in decision-making on some level. Educating parents on their child's ability to process and understand the information is part of encouraging child involvement. Hinds and colleagues (2005) research found that 94% of parents in their study (18 out of 19) want to know their child's end-of-life preference before making a decision.

### **Answer Questions Openly and Honestly**

Once end-of-life care options have been presented, the nurse should answer any questions the child or parents may have about those options. Parents and children may not understand the physical implications for each end-of-life care options. The nurse should describe how the child is likely to respond to each option including the child's physical appearance, ability to communicate, and their energy level. The options should be explained to the child and parents without bias towards any particular course of treatment. When caring for children with cancer making end-of-life care decisions, the nurse should understand that there are many ways forward

from this point and the family should have all the information presented clearly in order to make their decision.

The parents and child may not have questions right after hearing about the end-of-life care options available. There should be written materials to provide to the child and parents after the discussion with the healthcare team. The child and parents may think of questions to ask later when they have had more time to think about the options. The nurse should ask for any questions about the end-of-life care options whenever interacting with the child and parents to try to ensure that questions will be asked and answered. The family may have specific questions about end-of-life care plans or general questions about what happens once a decision is made. The child or parents may ask the nurse what his or her opinion is. The child or parents working together, not the nurse, must make the end-of-life care decision. The role of the nurse is to support the decision-making process and to answer questions about the end-of-life care options presented.

### **Assure Parents and Child that Care Continues Regardless of Decision Made**

A common thread throughout the research was the concern from parents that if they decided not to continue treatment that their child will stop receiving care. It is important to reassure parents and children that if they chose to stop treating their disease the nurses and healthcare team will continue to treat the symptoms. The nurse needs to explain that a palliative care plan is designed to treat the pain, discomfort, or uncomfortable symptoms related to cancer. Expressing to the parents and child that the staff does not consider palliation giving up and that the child will continue to receive quality care and pain management is an important nursing intervention. There are treatment based end-of-life care options and palliative based end-of-life

care options and both types are valid options for parents and children to choose from. Parents and children making end-of-life care decisions need to understand that care will continue to be provided regardless of the decision made.

### **Provide Adequate Time for Decision-Making**

The parents and child will need to consider the end-of-life care options and their implications away from the nursing and healthcare team. Nurses and other members of the healthcare team should not rush or put pressure on the child or parents to make their decision. This is a complex, multi-faceted decision with very serious implications for the child and parents. Rushing the decision-making process may not benefit the child. Hallström and Elander (2004) found that when decisions are not hurried children are more likely to be included in the decision-making process. Parents may also fluctuate on how they feel about the decision they've made. The nurse should be supportive throughout the decision-making process, answer questions, and give the parents and child time to make their decision.

### **Effectively Communicate With Other Healthcare Team Members**

During the decision-making process and after a decision has been made it is important that the healthcare team caring for the child knows what is happening in regards to the end-of-life decision. It is very stressful for parents and children to continually repeat the end-of-life decision they've made or to have to describe why they haven't been able to decide yet. Not only does the healthcare team need to be aware of where the child and parents are in the decision-making process, they also need to know the terminology the child and parents are using to describe various end-of-life care options or even the decision itself. Interdisciplinary

communication, as well as nurse-to-nurse communication needs to be as efficient and effective as possible. Communication is not directly related to increasing the participation of the child, but it does support decision-making involvement.

The documentation of what was discussed with whom should be easily accessible by all members of the healthcare team and needs to be available in different places. Most hospitals have electronic medical records (EMR) where most of the charting is done, but there are still paper charts as well. The terminology used by a family and what stage they are in the decision-making process needs to be documented in both places and easily found, if not the first page seen. During shift change or rounds communication about the child and parents' decision needs to be discussed before talking with the family. Proper report and proper documentation allows every healthcare team member caring for the child to understand and be involved with, on some level, the end-of-life care decision.

### **Support the End-of-Life Decision Made**

Once the parents and child have made their end-of-life decision, the nurse needs to support the decision and continue to care for the child in accord with their plan of care. The nurse should answer any questions that the parents or child may still have about end-of-life care, but it is not the role of the nurse to judge the decision of the parent or child. When discussing the end-of-life decision made, it is important that the nurse uses non-judgmental tone and phrasing. Continued questioning from the nurse and other healthcare team members will only make the end-of-life decision-making process more difficult for the child and parents. Unless there are serious ethical or professional concerns from the nurse, the end-of-life decision made by the

family was based on information from the healthcare team about current medical facts and the descriptions and explanations of the end-of-life care options and should be respected.

## **Recommendations for Education**

For nurses to implement these interventions into practice, nurses need to be provided with the information. Nurses should be provided with written guidelines to refer to when interacting with children and families making end-of-life decisions. The nurses will need education on how to use the guidelines provided and how to effectively collaborate with other healthcare providers during the end-of-life process.

Nurses should not be expected to effectively use the guidelines until they are more familiar with the end-of-life process. Nurses' should be taught that despite the culture of hope that exists in pediatric healthcare, when working in pediatric oncology they will likely lose patients. Nurses' emotions and responses vary greatly when working with children who are dying. Group debriefing sessions to discuss the impact that losing a patient, especially a young patient, would benefit nurses and allow them to better implement the interventions presented.

## **Recommendations for Research**

Research to replicate and expand upon existing research with more focus on the child and the outcomes for the family would provide useful. In particular, a replication of the 2005 Hinds and colleagues study should occur with more focus on the child perspective at the end-of-life. Research that directly focuses on the role of the nurse during end-of-life decision-making would be useful for finding nursing interventions related to end-of-life decision-making. Studies examining specific nursing interventions also need to occur to assess the effectiveness of current and future guidelines. Studies that examine the impact of having protocols to guide the nurse in their support of the child and parents when decisions are made are needed.

## **Limitations**

There is limited research on the child perspective in end-of-life decision-making. The focus of most current research is on the parents' and physicians' end-of-life decision-making process. There is no research directly researching the nursing role in end-of-life decision-making.

## **Conclusions**

The nurse has an important role in end-of-life care decision-making. There are six interventions identified that can guide the nurse when caring for children dying of cancer. These include encouraging child involvement in decision-making, answering questions, assuring parents and children of continued nursing care regardless of the decision made, providing time for decision-making, communicating with other healthcare team members, and supporting the end-of-life decision made. More research is required on the pediatric oncology patient's end-of-life concerns and decision-making process.

## **Appendix: Table of Evidence**

<b>Study</b>	<b>Sample/Study Design</b>	<b>Findings: Parents</b>	<b>Findings: Children</b>	<b>Findings: Nurses</b>
Hallstrom, Elander. <i>J Clin Nurs.</i> 2004; 13: 367-375	24 children & their parents  Qualitative study	- When they involve their children in decision making, parents feel like they are part of a team and provide more optimal care during hospitalization	- Can participate in the decision making process, even if not main decision maker - Having a voice in decision making helps develop the child's sense of self	- Developing a trusting relationship with the child can create an environment that allows greater participation from the child in decision-making
Hendrickson, McCorkle <i>J Ped Oncol Nurs.</i> 2008; 25(3): 127-138	Dimensional analysis of 41 scholarly articles, 2 newspaper articles	- Concerned for patient's QOL - Concerned with having age-appropriate participation - Grief counseling after death can be helpful	- Want to say goodbye to friends and family - Can become attached to nurse - Continuity of care is very important	- Nurse help with advanced care planning so patient knows what to expect - Continuity of care should be important when planning care
Hinds, Oakes, Furman, et al. <i>Cancer Nurs.</i> 2001; 24: 122-136	Literature review of 3 qualitative studies	- Made decision based on information provided by the healthcare team - Trust of staff was important - Wanted to know child's preference regarding decision; helped them make final determination (gave them comfort in the decision) - May fluctuate on how they feel about EOL decision	- Wanted to be well-informed - Are capable of being a part of the decision - The overall satisfaction with the decision increased when the patient's preference was known and followed	- Important to provide information and answer patient questions - All members of the healthcare team should know the decision and what EOL terms are being used - Include more than 1 healthcare team member in the EOL discussion - Emphasize staff's commit to caring for patient at all times

		<ul style="list-style-type: none"> <li>- May need help figuring out how to discuss this decision with other family members</li> <li>- Need private time to discuss options</li> </ul>		<ul style="list-style-type: none"> <li>- Describe implications of each EOL option</li> <li>- Provide information about supportive resources</li> </ul>
<p>Hinds, Drew, Oakes, et al. <i>J Clin Oncol.</i> 2005; 23: 9146-9154</p>	<p>20 children (10 years or older) 19 parents</p> <p>Qualitative study</p>	<ul style="list-style-type: none"> <li>- Liked when staff helped them identify their and their child's preferences</li> <li>- 18/19 wanted to do what child preferred</li> <li>- 16/19 trusted staff and felt supported (not judged) by them</li> <li>- Influenced by patient/child perspective</li> </ul>	<ul style="list-style-type: none"> <li>- Most patients (18/20) able to recall all options given</li> <li>- Most patients felt good about decision made (2 did not – doing trial for others)</li> <li>- P1 trial patients expressed desire to help others in future by being in trial (altruism) – people unknown to them</li> <li>* Not developmentally expected*</li> <li>- 19/20 thought of their relationship to others to make decision</li> <li>- Patients in study able to make complex decision based on multiple factors</li> </ul>	<ul style="list-style-type: none"> <li>- Provide written information as well as verbal instruction</li> <li>- Answer questions, give patient and family time to think about and process information</li> <li>- Give support, state will be there for patient throughout treatment decision or non-treatment decision</li> <li>- Do not try to sway decision</li> <li>- Respect the decision made</li> <li>- Do not give up on patient or family</li> <li>- Consult with others on health care team and outside resources</li> </ul>
<p>Klopfenstein, Hutchison, Clark, et al. <i>J Ped Hemato/Oncol.</i> 2001; 23: 481-486</p>	<p>95 children (patients)</p> <p>Quantitative study (medical record review)</p>	None	None	<ul style="list-style-type: none"> <li>- Complete documentation is required to find where improvement is needed</li> <li>- Present all options and allow the family to decide without pressure from staff</li> </ul>

<p>Mauer, Hinds, Spunt et al. <i>J Clin Oncol.</i> 2010; 28: 3292-3298</p>	<p>62 parents; 58 children  Qualitative study</p>	<p>Made decisions based on:  <ul style="list-style-type: none"> <li>- Concerns about QOL</li> <li>- Need to continue therapy</li> <li>- Do what's best for child</li> <li>- Medical facts</li> <li>- Patient's legacy</li> <li>- Agreement of others</li> <li>- Patient wishes</li> </ul> </p>	<ul style="list-style-type: none"> <li>- Can understand concept of death &amp; outcome of EOL decisions</li> </ul>	<ul style="list-style-type: none"> <li>- Support patient throughout end-of-life process</li> <li>- Don't make family repeat unnecessarily between healthcare providers</li> <li>- Refer to support groups</li> <li>- Provide private space</li> <li>- Respect need for continued therapy</li> </ul>
<p>Nitschke, Humphrey, Sexauer, et al. <i>J Peds,</i> 1982; 101: 471-476</p>	<p>36 parent/child/physician end-of-life conferences  Qualitative study</p>	<ul style="list-style-type: none"> <li>- May need several days to make end-of-life decision</li> </ul>	<ul style="list-style-type: none"> <li>- Involvement in decision-making depends on age and intellectual capacity</li> <li>- Children 5 and older have been involved at varying levels in EOL decisions</li> <li>- Children as young as 5 were able to comprehend the finality of their decision</li> <li>- Children should be informed of their disease at the time of diagnosis</li> <li>- Emotional &amp; conceptual development exceed their chronological age in children with cancer</li> <li>- Likely have a adult like concept of death</li> <li>- Children receiving only supportive care were able to tolerate their impending death</li> </ul>	<ul style="list-style-type: none"> <li>- Do not expect to have a decision right away</li> </ul>

<p>Runeson, Hallstrom, Elander, Hermeren. <i>Nurs Ethics</i>. 2002; 9: 583-598</p>	<p>24 children</p> <p>Patient's rated participation on a 5 point scale</p> <p>Qualitative study</p> <p>Not oncology specific</p>	<ul style="list-style-type: none"> <li>- Child participation increased when parents supported children &amp; explained difficult situations to them</li> <li>- If not alternatives are presented, parents don't know to ask about alternatives</li> </ul>	<ul style="list-style-type: none"> <li>- Involvement increases the sense of control they have over the situation</li> <li>- Participation determined based on: developmental stage, past experience of illness, level of independence, fears, family, and the health professionals involved</li> </ul>	<ul style="list-style-type: none"> <li>- Increased child involvement when staff created a trusting relationship with child</li> <li>- Should treat the child as a valid partner whose opinion is valued and considered</li> <li>- Child more likely to be included if staff did not rush procedure or decision</li> <li>- Nurse role to facilitate family participation in decision-making process</li> </ul>
<p>Whitney, Ethier, Fruge, et al. <i>J Clin Oncol</i>. 2006; 24: 160-165</p>	<p>Ethical model of pediatric oncologic decision-making</p>	<ul style="list-style-type: none"> <li>- As child ages, parents share more decisional authority with child</li> <li>- Parents have the most claim on decision during end-of-life</li> <li>- Decision reliant on current QOL and rigors and additional anticancer therapy</li> <li>- Parents have different decision-making processes</li> </ul>	<ul style="list-style-type: none"> <li>- Adolescents familiar with condition may be able to make own decisions</li> <li>- Assent = child involved to the fullest extent of their developmental capacity</li> <li>- Child's maturity, understanding, and participation "pivotal" factor in allocating authority for decision-making</li> <li>- Increased experience/time with illness increases share of family decisional authority</li> <li>- "A mature adolescent...is better positioned than the clinician to make this [EOL] choice."</li> </ul>	<ul style="list-style-type: none"> <li>- Should include parents and children in decision-making</li> <li>- Provide information and empower to make reasoned decisions</li> <li>- Opinion most wanted by family when there is a likelihood for cure</li> </ul>

<p>Whitty-Rogers, MacDonald, et al. <i>Nurs Ethics</i>, 2009; 24: 160-165</p>	<p>Descriptive literature review</p>	<ul style="list-style-type: none"> <li>- Parents who were open with end-of-life discussions with their children had no regrets</li> <li>- Parents who did not have end-of-life discussions, had regrets about not being more open</li> <li>- Need to consider children's autonomy in decision-making when taking the lead</li> <li>- Parents feel comfort in knowing they listened to their child's request</li> </ul>	<ul style="list-style-type: none"> <li>- Have the capacity to understand and should be told the truth about their condition</li> <li>- Being honest and open with children instills hope and provides support</li> </ul>	<ul style="list-style-type: none"> <li>- Healthcare staff assist parents by answering questions to determine "child's best interest"</li> <li>- Important to understand there is more than 1 way forward</li> <li>- Parental decisions should be respected unless there is evidence it is not in the best interest of the child</li> <li>- Nurses are in an ideal position to support end-of-life decision-making</li> </ul>
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