Parent Involvement in End-of-Life Care and Decision Making in the Newborn Intensive Care Unit: An Integrative Review

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ABSTRACT

Survival rates for very preterm and critically ill infants are increasing, raising complex ethical issues for health-care providers and parents who face the challenge of making end-of-life decisions for newborns. The purpose of this integrative literature review was to evaluate parental involvement in end-of-life care and decision making for their infant in the newborn intensive care unit. Findings revealed that establishing good relationships and clear communication between health-care providers and parents builds trust and eases stress placed on parents making decisions about the care of their infant. Palliative care programs provide support for parents and facilitate their decision making. Parents can be educated about how to communicate with health-care providers. Educating nurses on how to provide end-of-life care may also help improve support for parents during this difficult time. Additional research is recommended to examine parents' needs during and after end-of-life care decisions for their newborn.

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An emergency cesarean surgery was performed at 27 weeks for the birth of a 700-gram infant with intrauterine growth retardation. After 11 months in the newborn intensive care unit and numerous medical procedures—a patent ductus arteriosus ligation, gastric tube placement, retinopathy of prematurity surgery, necrotizing enterocolitis repair, and a tracheotomy—the infant suffered cardiac and respiratory arrest. He was coded for 20 minutes and was stabilized. Following an MRI, the mother and father were informed the infant had lost almost all brain function and was being kept alive with the ventilator. After multiple conferences with health-care providers and the parents, a decision was made to remove all life-sustaining procedures from the infant. The infant lived for 14 hours. These were heartbreaking and agonizing hours for the parents and health-care providers, with everyone questioning end-of-life decisions. The parents specifically requested certain nurses to be at their side. The infant died in the arms of his mother.

Many ethical issues are generated concerning the provision and the withdrawal of treatment for extremely low birth weight or critically ill infants.

Hospital staff gave the family a bereavement box filled with their infant's hand molds, pictures, and clothing. The family also received information about counselors and support groups. The parents had a long road of grieving.

This scenario is not uncommon in the neonatal intensive care unit (NICU). It raises many questions about the procedures taking place in the NICU and the support and teaching parents receive. Many ethical issues are generated concerning the provision and the withdrawal of treatment for extremely low birth weight or critically ill infants.

Of the 130 million babies born every year worldwide, about 4 million die during the neonatal period (United Nations Children's Fund, 2007). Of those births, 15% are born premature, 5% of those premature infants are born weighing less than 2 pounds, and 75% of those infants will survive (Muraskas & Parsi, 2008). Globally, 450 newborns die every hour (Wallin, 2008). Most neonatal deaths in the United States are low birth weight and preterm infants (Mathews & MacDorman, 2006). Seventy-five percent of neonatal deaths occur in the first week, with the highest risk of death within the first 24 hours of life (Lawn et al., 2006). In 2004, more than 34% of all fetal deaths in the United States occurred between 20 and 23 weeks of gestation, and 50% occurred between 20 and 27 weeks (MacDorman, Munson, & Kimeyer, 2007). Rapid improvement in the health care of neonates has led to an increase in the survival rates of very preterm infants, also generally known as "micro preemies" (Arlettaz, Mieth, Bucher, Duc, & Fauchère, 2005). Survival of neonates born on the margin of viability has been continuously pushed back to younger and younger ages. Neonates as young as 25 weeks and as small as 750 grams are routinely being saved. However, survivors often have significant physical and mental impairments, including cerebral palsy, blindness, and learning disabilities (Robertson, 2004).

Before 1970, withholding treatment from infants born with diminished capacity for interaction or experience was rarely contested (Robertson, 2004). In 1984, the federal Child Abuse Amendment (CAA) became strongly protective of the rights and interests of the disabled and left little room for nontreatment decisions based on quality of life or the interests of parents. Whatever the extent of their disabilities, all children were to receive medical treatment unless they met narrow exceptions (Robertson, 2004; Sayeed, 2005). Resuscitating newborns born under 750 grams and before 25 weeks poses a major problem under the CAA. According to the CAA, all viable premature newborns must be treated even if they are likely to have severe physical and mental disabilities. To conform to the CAA, many neonatologists were likely to resuscitate premature newborns regardless of parental wishes (Robertson, 2004; Sayeed, 2005).

According to the American Academy of Pediatrics' Neonatal Resuscitation Program Steering Committee, the decision to withhold or discontinue health care may be considered by providers in conjunction with the parents acting in the best interests of the child (Sayeed, 2005). The federal CAA rules remove quality-of-life considerations and conflict with the best-interests paradigm advocated by the American Academy of Pediatrics Committee on the Fetus and Newborn (1995) and Neonatal Resuscitation Program (Sayeed, 2005).

Catlin (2005) found that physicians reported resuscitating all neonates and later deciding whether treatment exceeded the newborn's ability to benefit from treatment. It is more difficult to initiate treatment and then withdraw than to make an "up-front" decision to withhold treatment. Conflicts between families and health-care providers about whether to continue or withdraw life support for critically ill infants are not uncommon and often result from inadequate communication (Kopelman, 2006). Health-care professionals experience moral distress and frustration when, due to demands of families, they provide infants with treatment they feel is inappropriate. This action results in needless suffering in infants and the use of scarce and costly health-care resources (Engler et al., 2004; Hefferman & Heilig, 1999; Kopelman, 2006).

The emotional and financial burdens on the family are often underemphasized (McGettigan, J. Greenspan, Antunes, D. Greenspan, & Rubenstein, 1994). Parents are considered the primary decision makers for their children, based on our society's moral and legal traditions that uphold the family as the foundation of our values and beliefs (Stark & Thape, 1993). The decision to withdraw life support is very painful, leaving parents with feelings of loss, emptiness, guilt, anger, and pain. Health-care providers feel helpless and a sense of failure as the family mourns the loss of a child (Abe, Catlin, & Mihara, 2001). It is important for health-care professionals and families to engage in effective communication and mutual respect during this highly stressful, emotional period. There is growing recognition of the importance of palliative care for the dying infant and the family. Palliative care emphasizes quality of life while alleviating the symptoms of medical conditions and their treatments (Gale & Brooks, 2006; Sumner, Kavanaugh, & Moro, 2006).

It is important for health-care professionals and families to engage in effective communication and mutual respect during this highly stressful, emotional period.

An integrative review by Ward (2005) explored the ethical components to decisions made in the NICU regarding treatment plans or research enrollment. Ward focused on communication between parents and professionals. Due to rapidly changing standards for end-of-life care in the NICU, challenges to health-care providers caring for dying infants and their families are also changing. Moral and ethical issues related to decision making for infants born on the margin of viability are becoming more difficult. The purpose of the present integrative literature review was to evaluate parental involvement in end-of-life care and decision making for their infant in the NICU.

METHODS

An electronic search was done to identify studies that included end-of-life care given to dying infants and were published between 2000 and 2008 in the following databases: CINAHL, Alt Health Watch, Applied Science & Technology Abstracts, Health Source - Consumer Edition, Health Source: Nursing/Academic Edition, MEDLINE, PsycARTICLES, PsycCRITIQUES, PsycINFO, and The Cochrane Library. The search terms used were ''neonat* intensive care'' or ''intensive care;'' ''neonatal and comfort care,'' ''palliat* care,'' or ''end of life or terminal care''; and ''family involve*,'' or ''parent* decision making'' or ''parents or professional-family relations.'' The search was limited to data-based articles published in English. Additional relevant studies were reviewed based on an ancestral search. For inclusion in the critical review, infants in the selected studies must have been admitted to the NICU or pediatric intensive care unit.

RESULTS

The Table presents a description of the 10 studies in this literature review. Five of the studies explored parent involvement in decision making in end-of-life care for their infant (Abe et al., 2001; Arlettaz et al., 2005; McHaffie, Lyon, & Hume, 2001; Moseley et al., 2004; Streiner, Saigal, Burrows, Stoskopf, & Rosenbaum, 2001). Three of the studies explored the effects of palliative care and how it influences parents' perceptions and decision making for their infant (Carter & Guthrie, 2007; Lundqvist, Nilstun, & Dykes, 2003; Pierucci, Kirby, & Leuthner, 2001). The parental perception of withdrawing/withholding treatment was explored in two studies (Rini & Loriz, 2007; Wocial, 2000). One study was performed in Scotland (McHaffie et al., 2001); one study was performed in Sweden in multiple neonatal units (Lundqvist et al., 2003); one study was performed in Canada (Streiner et al., 2001); and one study was performed in Switzerland (Arlettaz et al., 2005). The remaining studies were conducted in the United States. All studies examined, in some way, parental involvement in end-of-life care of the infant.

An integrative review of the literature is a form of research in which past research is systematically analyzed and summarized to generate new knowledge about the topic. The integrative literature review can be used to evaluate the strength of the scientific evidence, reveal gaps in current research, and identify the need for future research.

Parent Involvement in Decision Making in End-of-Life Care

In the NICU, parents are often faced with the immense, heartbreaking responsibility to decide to withdraw life-sustaining treatments for their infant. Similarly, health-care providers are confronted with the ethical dilemma to continue or withdraw care of critically ill neonates. These decisions are based on future quality of life, severity of handicaps, and projections of longevity and often reflect the values of parents and health-care providers (Moseley et al., 2004). Shared decision making between health-care providers and parents raises a number of troublesome issues. Health-care providers are challenged, knowing treatment can be continued but questioning if it should be continued. Parents face the challenge of comprehending the medical information provided to them and using the information to decide whether they should allow their child to live or die. From the parents' perspective, the situation is not necessarily about ethics but about making decisions in the best interests of their child (Wocial, 2000).

Streiner et al. (2001) found that 64% of parents agreed or strongly agreed that an attempt should be made to save all infants regardless of birth weight or

TABLE
Summary of Studies Reviewed

Authors	Study Design	Purpose	Sample	Findings
Abe, Catlin, & Mihara (2001)	Retrospective chart review	To examine the process of ventilator withdrawal, medication administration, parental participation in EOL decision making, and support of the family in the NICU.	18 infants died after ventilator withdrawal 15 parents participated in the decision to remove ventilator support (United States)	83% parents participated in decision; ventilator withdrawal due to quality of life and prognosis; parents present at death. Parents received support from each other and social worker. No documentation of emotional support given by nurses. Three charts documented withdrawal of treatment requested by parents. One chart documented parents' decision to forego palliative surgery and to allow their infant to die. 30% parents received support from clergy and family members. 60% of charts documented providing keepsakes for the parents.
Arlettaz, Mieth, Bucher, Duc, & Fauchère (2005)	Retrospective chart review	To evaluate how EOL decisions are made in the perinatal center. To analyze consistency of decisions made with the framework for structured ethical decision making.	199 neonatal deaths (Switzerland)	79% of EOL decisions made according to the ethical framework. 92% of cases involved the parents in the decision; in all cases but one, the parents agreed with the decision. In majority of cases, newborns died in the parents' arms.
Carter & Guthrie (2007)	Descriptive survey	To study the current documentation of NICU palliative EOL care.	26 surveys (United States)	Documentation of EOL care ranged from excellent to poor, with 100% on pain management to 54% on spiritual support. Staff and trainees reported greater awareness of issues important to EOL care.
Lundqvist, Nilstun, & Dykes (2003)	Descriptive survey	To examine neonatal practice before birth, at birth, and during dying/after death of neonate.	32 of 38 NICUs (Sweden)	76% parents visited NICU after prenatal diagnosis. 40% parents at risk for preterm birth visited a preterm neonate in the NICU and met the neonate's family. 54% offered consultation after parents informed of fetal impairment. Majority of units encouraged parents to touch and hold neonate and participate in discussions about medical treatment. Expected parents to be with dying neonate, collected neonatal mementoes, and did follow-up visit. 75% informed parents about withdrawal of treatment. 60% emphasized withdrawal treatment was physician's decision, but parents could wait for relatives to be present

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Authors	Study Design	Purpose	Sample	Findings
McHaffie, Lyon, & Hume (2001)	Descriptive qualitative	To explore parents' perceptions of treatment withdrawal/withholding.	108 parents of 62 neonates (Scotland)	56% of parents decided to stop treatment. Some parents wished they had taken responsibility. One parent felt guilt 3 months after the event. Factors that minimized doubt were full and honest information and concrete evidence of a poor prognosis.
Moseley et al. (2004)	Retrospective chart review	To determine if there are differences in choices made by African American and White parents' EOL decision-making.	38 infant charts (United States)	80% of White parents agreed to limit life-sustaining medical treatment compared to 62% African American parents.
Pierucci, Kirby, & Leuthner (2001)	Retrospective chart review	To describe EOL care for infants and analyze palliative care consultations.	196 infant deaths (United States)	13% of families had palliative care consultations, resulting in fewer medical procedures and more supportive services for infants/families.
Rini & Loriz (2007)	Descriptive qualitative	To determine presence and role of anticipatory mourning, and to describe parental themes.	11 parents sustained the death of a child during the child's hospitalization 8 of the children died in the PICU, and 2 died in the NICU (United States)	Unsupportive health-care team that was ill prepared to deal with the impending death of a child. Themes emerged: (1) giving information to parents; (2) impact of attitudes and actions of health-care professionals; (3) physical presence with the dying child; (4) location of the child's death; (5) issues of hospital policy, procedures, process, and rules; (6) existence of anticipatory mourning and its relationship with bereavement.
Streiner, Saigal, Burrows, Stoskopf, & Rosenbaum (2001)	Descriptive quantitative	To compare the attitudes of neonatologist, neonatal nurses, and the parents of ELBW infants toward saving infants of borderline viability and who should be involved in the decision-making process.	169 parents of ELBW infants 123 parents of term infants 98 neonatologists 99 neonatal nurses (Canada)	Physicians recommended all life-saving interventions at earlier gestation than nurses. 64% of parents agreed an attempt should be made to save all infants, compared to 6% of health-care professionals. Majority believed that parents should have the final say regarding treatment of infant. 63% of physicians and 75% of nurses cited economic costs related to caring for ELBW infants. 84% of health-care professionals agreed attitudes of parents were important and thought it unethical to save infants with potentially severe disabilities.

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Authors	Study Design	Purpose	Sample	Findings
Wocial (2000)	Descriptive qualitative	To explore parents' perception of their experiences in the NICU when faced with withholding/ withdrawing treatment from their infants.	20 parents whose infants received NICU treatment (United States)	Parents felt involved in the decision when clear, accurate, and timely exchange of information was given to them. Trust between parents and providers promoted confidence in parents about information received and the decision reached. Care of providers promoted trust in the parents.

Note. ELBW = extremely low birth weight; EOL = end of life; NICU = newborn intensive care unit; PICU = pediatric intensive care unit.

condition at birth, compared to only 6% of health-care providers. Reasons given included parental religious beliefs, belief in the sanctity of life, and the belief that infants should be given a chance to live because the outcome is uncertain. Daily NICU costs exceed $3,500 per infant; a prolonged stay commonly costs up to $1 million (Muraskas & Parsi, 2008). This expense does not include the cost to care for a child with severe disabilities after discharge from the hospital. In Streiner et al.'s (2001) study, health-care providers who did not believe all infants should be saved cited economic costs incurred upon society in having to care for these infants and lifelong stress imposed on the family due to potentially severe disabilities of their infant. The most appropriate decisions about care combine the professional expertise of health-care providers with the parents' values to determine the infant's best interests (Ward, 2005).

Streiner et al. (2001) found that an overwhelming majority of health-care providers in their study believed parents should have the final say in their infant's care. In other studies, participation of parents in the decision to stop life-sustaining support was between 75% and 92% (Abe et al., 2001; Arlettaz et al., 2005; Lundqvist et al., 2003). When parents felt they had personally made the decision about treatment, they described the physicians as guiding, supporting, or recommending a course of action. When parents believed the physicians had made the decision, the parents perceived them to be carefully listening to the parents' views as they assessed the option to continue or withdraw treatment (McHaffie et al., 2001).

There are situations, however, where the parents do not feel involved or supported in their decision to maintain treatment. In the study by Arlettaz et al. (2005), one set of parents did not agree with the physician to withdraw treatment right away because they were waiting for family members to arrive; however, treatment was withdrawn anyway. The parents were told it was for the best interest of the baby. In this situation, the parents had accepted the need to withdraw support; however, they disagreed with the physician on when it should take place. A few days after their infant's death, the parents showed understanding and accepted the physician's decision.

McHaffie et al. (2001) described parents in their study who begged the health-care staff to do all they could, with frequent replies from the staff implying treatment was futile. However, the consultant responsible for the baby believed that he had further discussed the issue with the parents, because it is the health-care provider's responsibility to ensure that parents understand the information given them.

Discrepancies were found among different ethnic groups as to whether the parents agreed to withhold treatment. Moseley et al. (2004) found 80% of families of White infants agreed to limit life-sustaining treatment, compared to 62% of families of African American infants. Being involved in decisions for their infant is extremely important to parents; however, not all parents want to make the ultimate decision for their infant's life or death.

McHaffie et al. (2001) found that 56% of the parents in their study felt they had taken responsibility for the decision to withdraw treatment. Reflecting back 3 months after their decision, 83% believed the decision had been made by the right person. The parents who had doubts about their decision cited their inability to assess the situation knowledgeably and the lack of concrete evidence of a poor prognosis. Leaving the decision strictly to the parents may leave them with a lifelong burden of guilt. Parents feel they have made the right decision if they see deterioration in their infant, acknowledge the prospect of suffering, receive clear information about the condition of their infant, and accept a poor prognosis (McHaffie et al., 2001; Rini & Loriz, 2007; Wocial, 2000).

An extremely premature infant or an asphyxiated term infant has a ''clinical honeymoon'' that usually ends by the third day of life (Muraskas & Parsi, 2008, p. 656). A ''clinical honeymoon'' refers to infants who are stable, with minimal need for respiratory assistance and medications. It is important for parents to understand this condition as they make decisions for their child's care. Detailed information explaining an infant's prognosis is critical in helping parents prepare for the death of their child. A study in Switzerland found the decision to withhold treatment is generally not based on the probability of survival but on the probability of survival without severe disabilities (Arlettaz et al., 2005). Rini and Loriz (2007) found that 64% of the parents in their study would have done things differently had they known that the death of their child was imminent. Good communication between the health-care provider and the parents is essential when making end-of-life decisions (McHaffie et al., 2001). If parents perceive the health-care providers as caring, they are more likely to trust the information given to them about their infant (Rini & Loriz, 2007; Wocial, 2000). To be involved in decisions, parents need consistent updates on their infant's status and care. In the NICU, parents receive updates on the phone, at the bedside, and in care consultations with health-care providers.

Palliative Care and Decision Making

Neonatal palliative care includes bereavement support for the family after the infant's death but begins with care for the living infant (Gale & Brooks, 2006). In the NICU, palliative care conferences take place before the infant's birth, during the infant's stay in the NICU, and after the infant's death. Lundqvist et al. (2003) found that in 40% of the units they studied, parents were invited to visit the NICU after ultrasound findings indicated the fetus was suffering from severe disease. Parents at risk of preterm birth were invited to see a preterm infant and to meet the family of the infant.

Palliative care conferences assist parents in making decisions about treatments their infant may receive (Carter & Guthrie, 2007; Gale & Brooks, 2006; Pierucci et al., 2001). Pierucci et al. (2001) noted that, in their study, the NICU infants whose parents had palliative care consultations had fewer resuscitation attempts and more withholding of mechanical ventilation and cardiac medications than infants whose parents did not have consultations. Fewer blood draws, central lines, endotracheal tubes, and feeding tubes were used when parents participated in a palliative care conference. Pierucci et al.'s (2001) findings suggest palliative care conferences result in fewer treatments for the infant and better support for the parents.

Parents are often encouraged or expected to be at the bedside of their infant at the time of withdrawal of life-sustaining treatment. In several studies, parents were encouraged to touch and hold their infant and, in the majority of cases, the infant died in the parents' arms (Abe et al., 2001; Carter & Guthrie, 2007; Lundqvist et al., 2003; Pierucci et al., 2001). Rini and Loriz (2007) reported all the parents in their study expressed a similar sentiment: Being physically present and able to participate in the care of their infant was extremely important in the experience of anticipatory mourning. Active participation in the care of their infant fostered a sense of control and facilitated preparation for the event of death. In some studies, bereavement support was engaged more often in NICUs where palliative care standards were used; however, specific documentation of the types of emotional support given by physicians and nurses to the parents was lacking (Abe et al., 2001; Carter & Guthrie, 2007; Pierucci et al., 2001). In some cases, mementoes of the infant, such as hair, armbands, hand molds, pictures, and hats, were collected and provided to the parents to assist with bereavement (Abe et al., 2001; Carter & Guthrie, 2007; Lundqvist et al., 2003; Pierucci et al., 2001).

Parents' Perceptions of Withdrawing Treatment

In the reviewed studies, parents described the attitudes and actions of hospital staff members as having a profound and lasting effect on their experience surrounding the loss of their child (Rini & Loriz, 2007; Wocial, 2000). One parent stated, ''These are the last memories, sometimes the only memories that we are going to have of our children'' (Rini & Loriz, 2007, p. 276). The parents remembered the people who were with them during the extremely difficult and emotionally stressful time of their child's death. If the parents perceived the hospital staff as compassionate, sensitive, and intuitive to the parents' needs, they recalled the experience in a favorable manner. If the parents perceived that staff was negative, routine, and callous, they reported that the staff's behavior negatively affected their mourning process (Rini & Loriz, 2007).

Parents identified nurses as central figures in helping them assume parental roles (Wocial, 2000). Interventions that assisted parents to feel involved were encouraging the parents to hold the infant, encouraging parents to help with routine cares, and talking to parents about the infant as a person, not the infant's medical condition. Having parents hold their infant had the ultimate effect of moving forward the decision to withhold treatment.

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To learn more about the Footprints palliative care program at SSM Cardinal Glennon Children's Medical Center, visit www.footprintsatglennon.org

Many parents suggested having a health-care professional who is trained in end-of-life care to describe in detail what the death experience was going to look, feel, and be like (Rini & Loriz, 2007). Staff members who were knowledgeable in end-of-life care facilitated parents' bereavement after the death of their child.

DISCUSSION

Implications for Clinical Practice

Health-care providers must establish a strong relationship with parents of infants in the NICU. This relationship is built on good communication and trust (Ward, 2005). When health-care providers show compassion and manifest caring behaviors for the infant, parents are more likely to trust the information given them. Trust allows parents to move forward with decisions about care for their infant, feeling confident that they are making the right choice (McHaffie et al., 2001; Rini & Loriz, 2007; Wocial, 2000). To assist parents with their decision, palliative care conferences are helpful in educating parents about the condition and expected outcome of their infant.

Palliative care "incorporates symptoms management for the infant, and emotional, psychosocial, and spiritual support for the infant and family members" (Kenner & McSkimming, 2006, p. 960). Studies reviewed show that palliative care assists parents throughout their experience in the loss of their child. Because many infants die prior to birth or in the neonatal period, health-care providers are encouraged to integrate palliative care into pregnancy and the immediate newborn period, which is "the antithesis of what most of us expect to provide to newborns. Yet it is a vital part of her [the mother's] neonatal skills" (Kenner & McSkimming, 2006, p. 962). Families may have a limited amount of time with their infant; prenatal palliative care emphasizes the importance of planning for the experience of losing an infant (Sumner et al., 2006). Palliative care conferences can be held prenatally and throughout the infant's stay in the NICU. Early introduction of palliative care may ease transition for families from curative to palliative modes of treatment (Romesberg, 2007). Himelstein (2006) recommended palliative care programs be child-focused, family-oriented, and relationship-centered. Pain and nonpain symptoms management must be addressed, as well as support for siblings. Siblings may feel abandoned while parental/family attention focuses on the ill infant.

An exemplary palliative care program is the "Footprints Program" implemented at SSM Cardinal Glennon Children's Medical Center in St. Louis, Missouri. The mission of the Footprints Program is to help children and their families to live well along their journey, regardless of the site of care. The NICU and the Footprints team allow families to make positive memories of their child's life. The Footprints Program organizes a team of physicians, nurses, and chaplains to meet with parents and make plans for the infant. If the parents want to take the infant home, the team will facilitate what is needed to fulfill the parents' decision. The Footprints staff contacts all the care providers who will be involved in the infant's care after the infant is home (e.g., home health and emergency medical services). The local police department is notified of the infant's illness and that the infant is not expected to live. The Footprints team stays connected with the family through follow-up phone conversations during the infant's life and after death. The example of the Footprints Program, and the positive outcomes of palliative care reported in the research, may encourage health-care providers to establish a palliative care program in their NICU.

The Palliative and End of Life Task Force at St. Jude Children's Research Hospital is another example of a palliative care program implemented for the care of infants and children. The task force involves parents in the decision-making process from the moment they arrive at St. Jude Hospital. Palliative care at St. Jude begins from the moment of diagnosis until the patient is cured or until end of life. The goal is to alleviate pain and suffering. The St. Jude Palliative Care Initiative (2005) offers an organized method to address the spiritual, physical, and emotional aspects of the child and family. Currently, a global movement is underway toward the implementation of palliative care for newborns and children, which is a new care concept in many countries (Callister, 2007).

Nurses play a key role in supporting the parents during their infant's end-of-life care in the NICU (Wocial, 2000). According to Fegran, Fagermoen, and Helseth (2008), partnerships between parents and nurses in the NICU develop in three phases: acute critical phase, stabilizing phase, and discharge phase. The stabilizing phase is the most difficult because parents need a trusting relationship established with their primary nurses. During this stage, nurses purposely withdraw from the parents to facilitate the parents' independence as caretakers. It is important for parents and nurses to acknowledge the need for detachment to facilitate closing the parent-nurse relationship.

As the parents in Rini and Loriz's (2007) study suggested, it is helpful if NICU nurses have received end-of-life education to properly support families of infants they are caring for. Because NICU nurses are likely to care for a critically ill or dying infant, education on how best to teach parents about the care their infant is receiving and/or end-of-life education may be considered as part of orientation for all NICU nurses. This education would increase the nurse's comfort level when faced with the challenge of caring for a dying infant and providing palliative and end-of-life care. According to a recent study, NICU nurses recommend an inclusive team approach, including the parents, when caring for terminally ill neonates who may have a do-not-resuscitate order (Bellini & Damato, 2009).

Implications for Childbirth Education

Ward (2005) found the perceptions of appropriate communication differ between parents and health-care providers in the NICU setting. This difference may leave parents with regret about decisions they did not believe they influenced or fully understood. Educating expectant parents on how to communicate with their infant's health-care provider may facilitate more confident decision making for the parents. If parents can learn to identify and voice their concerns, misunderstandings, and beliefs, health-care providers can provide information to the parents based on the infant's status and the parents' needs. Couples with a high-risk pregnancy would greatly benefit from education about the NICU and what to expect if their child is hospitalized in the unit.

Implications for Further Research

Moseley et al. (2004) found a discrepancy between White and African American parents' decisions to withhold life-sustaining treatment for their infant, which indicates a need for further studies with participants of more diverse backgrounds. Additional studies are warranted to properly assess the needs of populations that represent diversity in ethnicity, ethical outlooks, income level, education level, and age of parents.

McHaffie et al. (2001) found some parents experience guilt over their decision to withdraw treatment. Rapid progression of neonatal resuscitation and the increasing complexity of the ethical dilemmas to treat infants with very low birth weight have made decision making difficult for parents and health-care providers. The decision to withhold or withdraw treatment raises questions about quality of life and economic costs to society. Studies to evaluate guilt felt by parents after the death of their infant are needed to prevent or assist parents with their feelings of guilt or regret. McHaffie et al. (2001) also found that some parents want to be the primary decision maker for their infant, while other parents prefer to leave the decisions to the health-care providers. Further studies that examine parents' decision-making preferences may assist health-care providers to identify and properly support parents' needs in decision making.

Results from some of the reviewed studies suggest detailed documentation for emotional support given to parents by nurses and physicians in the NICU may be lacking (Abe et al., 2001; Carter & Guthrie, 2007; Pierucci et al., 2001). Because emotional support for parents is a key component of NICU care, future studies that examine documentation of the specific types of emotional support provided by NICU staff may give more insight into the benefits and costs of providing emotional support. Additionally, further studies on end-of-life education for NICU staff and the benefits versus costs for NICUs to provide this education for NICU staff are warranted.

CONCLUSION

As advances in technology preserve the lives of very low birth weight and critically ill newborn infants in the NICU, ethical dilemmas regarding treatment become more complex. Parents need to be closely involved in the care and decision-making process

If parents can learn to identify and voice their concerns, health-care providers can provide information based on the infant's status and the parents' needs.

associated with their infant. Health-care providers must provide parents with accurate information to help them make decisions about the treatments for their infant. To bolster parents' confidence in the information they receive, a relationship of trust must be built between them and the health-care provider. The parents' trust is based on good communication and the belief that the health-care provider truly cares about their infant. The experience in the NICU is extremely difficult and stressful for parents, and support throughout their infant's stay is imperative.

Study findings demonstrate palliative care and end-of-life programs established in the NICU improve parental support throughout the entire course of their infant's care and facilitate parents' decision making. Support from the NICU staff is important as parents face many challenges during the difficult time of facing end-of-life care decisions. Nurses also play a vital supportive role to parents caring for their infant in the NICU and are a key component in the parents' grieving process when end-of-life decisions are made. It is important for NICUs to consider establishing a palliative care program in their unit and to provide nurses with end-of-life education.

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