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## Perinatal and Pediatric Issues in Palliative and End-of-Life Care from the 2011 Summit on Compassionate Care

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### Abstract

More than 25,000 infants and children die in US hospitals annually; 86% occur in the NICU or PICU. Parents see the child's pain and suffering and, near the point of death, must decide whether to resuscitate, limit medical treatment and/or withdraw life support. Immediately after the death parents must decide whether to see and/or hold the infant/child, donate organs, agree to an autopsy, make funeral arrangements, and somehow maintain functioning. Few children and their families receive pediatric palliative care services, especially those from minority groups. Barriers to these programs include lack of services, difficulty identifying the dying point, discomfort in withholding or withdrawing treatments, communication problems, conflicts in care among providers and between parents and providers, and differences in cultural beliefs about end-of-life care. The 2011 NIH Summit on the Science of Compassion provided recommendations in family involvement, end-of-life care, communication, health care delivery, and transdisciplinary participation.

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Parents describe a child's death as the most devastating and difficult experience they have ever faced. All hopes, dreams and plans for the child's future are gone forever, and parents must deal with a sense of shock, numbness, pain and a feeling that a part of them has died. Parents see the child's pain and suffering before death; must make difficult decisions near the point of death including whether to resuscitate, limit medical treatment and/or withdraw life support; must make decisions after the death whether to see and/or hold the infant/child, to donate organs, agree to an autopsy, and make funeral arrangements; and must somehow maintain functioning to sustain themselves and the family. Much of this experience occurs in an ICU environment characterized by a mix of new and familiar people, unfamiliar machines and tubes, high noise levels, little privacy, loss of the parent caretaking role, and periods of separation from the infant or child during the dying process (Meert, Briller, Schim, Thurston, & Kabel, 2009). Memories of the experience in the ICU environment remain with parents for years after the child's death (Meert, Briller, Schim, & Thurston, 2008). For parents with a fetal demise or expected early perinatal loss, additional decisions include whether to be induced right away, to delay induction or wait for spontaneous labor, and choose where postpartum care should occur (Gold, Dalton, & Schwenk, 2007). Even when death is anticipated, parents may experience it as a surprise (Brooten, et al., in press). This paper is based on the Pediatric/Perinatal End-of-Life (EOL) issues breakout session

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held during the 2011 Summit, “The Science of Compassion,” hosted by the National Institute of Nursing Research. The purpose of this paper is to convey a brief summary of research on infant/child ICU death and parent experiences, needs, and responses used to stimulate discussion of perinatal and pediatric palliative/EOL care issues and to provide recommendations for future research and clinical practice generated by those attending this session.

## Methods

The 2011 Summit breakout session’s goals were to create a dialogue on various broad topic areas and to summarize key ideas, needs and gaps in Palliative and EOL care discussed by breakout session participants. For this session, “Pediatric/Perinatal EOL Issues,” the literature since 2000 was reviewed on broad issues and responses to infant/child ICU death, and palliative and EOL care in infants/children using Pubmed, CINAHL, and PsycInfo. Following a brief presentation of the literature on the broad issues, discussions from the breakout session participants were summarized and recommendations for research and clinical practice were provided.

## Family/Parent Needs and Responses

Over 53,000 infant and child deaths occur annually in the US (Heron, 2011); 48% in hospitals and 86% of those in neonatal (NICU) or pediatric (PICU) intensive care units (Ramnarayan, Craig, Petros, & Pierce, 2007). Some infants and children die after aggressive resuscitation efforts. Others are declared brain dead and life support is withdrawn, while for others death occurs after a decision to limit or withdraw life sustaining medical treatment (Meert, et al., 2009). A fetal or newborn death forces families to integrate the almost simultaneous experiences of birth and death (Gold, 2007). Some mothers are unable to deal with the double trauma of the baby being dead and having to deliver the baby’s body. One mother described herself as a “walking coffin” (Gold, et al., 2007). Following delivery, parents may not be able to choose where they receive postpartum care, whether in the postpartum unit with mothers whose babies are alive or elsewhere.

Parents need proximity and physical contact with their child both before and after their child’s death in the NICU/PICU. In a study by Meert and colleagues (2009), parents spoke of their need for physical proximity to their child including the need to touch, hold and be present throughout the dying process. Leaving the dying child’s bedside evoked parent feelings of abandonment. Parents’ ability to be present when an infant/child dies depends in part on the mode of death. When the decision to forego resuscitation and other aggressive life-prolonging interventions is made, parents generally are able to stay with their dying infant/child. In some NICUs and PICUs, parents also can stay during resuscitation efforts. Pector (2004) found that most parents of neonates preferred not to leave during resuscitation and wanted to hold their dying babies. Parents not present at the time of death appreciated a chance to hold the neonate’s body while it was still warm. MacDonald, Liben, Carnevale, and Cohen (2008) reported a mother stating that being present when her child was taken off life support and then wash her child’s body helped her accept that her child was “really dead.”

Parents are often encouraged to see or hold the dead infant/child. In their study of mothers who preferred not to hold or see their stillborn infant, Hughes, Turton, Hopper, and Evans (2002) found that mothers who held their babies had more symptoms of depression and post-traumatic stress disorder (PTSD) in a subsequent pregnancy and a disorganized attachment to that subsequent infant. Mothers who did not hold or see their stillborn infants had the best psychological and attachment outcomes in a subsequent pregnancy. Sloan,

Kirsh, and Mowbray (2008) found in the majority of studies that viewing the fetus after termination of a pregnancy for fetal anomaly and saying farewell assured parents of the anomaly, emphasized the reality of the loss, and helped the grief process. Some parents later regretted not seeing the fetus, while others did not.

Parents also need understandable information about their child's changing condition and treatment options (Brooten et al, in press). Sullivan and Monagle (2011) found parents valued an autopsy to validate why their child had died and to contribute to medical knowledge. Some parents experienced autopsy as a comfort. Others felt their grief was heightened. In other studies, parents did not receive follow-up information about the results or didn't know they could get autopsy results. Many parents found it difficult to go to the hospital for the results because it reminded them of their experiences (Gold, et al., 2007).

Making funeral arrangements can be emotionally and financially difficult for parents. Some studies report parents feeling the infant had been whisked away, they were unsure of what happened to their infant's body, and they had not been given a choice about a funeral (Gold, et al., 2007). Low-income parents reported needing to choose between a private and a "hospital" burial in a common burial site with no individual markers (Kavanaugh & Hershberger, 2005). They were unaware that funeral homes often perform infant services for free or that hospitals may have funds available for these services.

Parents need sensitivity and empathy, follow up contact, and information about counseling from health care providers. Parents expect health care providers to treat their child and the child's body with respect. Although parents felt support from critical care providers before the child's death, many felt that these providers discouraged continued contact after the death (Reilly, Huws, Hastings, & Vaughan, 2008). Staff members' absences at commemorative events after the child's death and lack of continued contact was perceived as hurtful by parents and families (MacDonald, et al., 2005).

Some parents need to talk about and maintain a connection to their child. Mothers were more likely to express their emotions and talk about their child and their loss, while fathers generally suppressed their emotional reactions to limit their outward show of grief (Aho, Tarkka, Astedt-Kurki, & Kaunonen, 2006) and to prevent hurting their partner (Kavanaugh & Hershberger, 2005). Reilly-Smorawski, Armstrong, and Catlin (2002) reported that mothers and fathers may find communication and relating to each other difficult, especially when they each blame themselves for the child's death and when their own pain is too great to support each other (Reilly, et al., 2008). Mothers and fathers with greater distress were more likely to attend support groups; fathers were more likely to use private counseling services (Murphy, Johnson, Lohan, & Tapper, 2002). In a cross-sectional study of 36 couples who lost a child (Kamm & Vandenberg, 2001), talking about their grief resulted in decreased grief over time for men. For women, talking about their grief was most helpful when the death was recent, but not after considerable time had passed. Laakso & Paunonen-Ilmonen (2002) found that some mothers reported a closer relationship and others reported a more troubled relationship with their spouses. These effects were permanent for some, temporary for others.

## Parent Health

Research finds effects of a child's death on the physical and mental health of parents. A study of bereaved parents (N=21,062) in Denmark revealed higher mortality rates (Li, Precht, Mortensen, & Olsen, 2003) and greater risk of psychiatric hospitalization (Li, Laursen, Precht, Olsen, & Mortensen, 2005), cancer (Li, Johansen, Hansen & Olsen, 2002), and type 2 diabetes (Olsen, Li, & Precht, 2005) for mothers than fathers. Li and colleagues (2005) found that fathers are more prone to heavy alcohol use. Mothers' risk of first time

psychiatric hospitalization was highest in the first year and remained elevated for 5 years or more after the child's death. Fathers had a similar pattern but with fewer events. Parents who lost their only child had the highest risk of psychiatric hospitalization. Research by Fang and colleagues (2011) on more than 100,000 parents indicates that parents who have lost a child are at higher risk for cancers associated with human papilloma virus (HPV) infection such as cervical cancer. Higher risk ratios for most cancers, including liver and stomach cancers, were observed within 5 years after child loss. These findings support the hypothesis that severe life stressors, such as child loss, raise the risk for several, chiefly HPV-related, cancers.

### Parent Grief

Although both parents suffer greatly from their child's death, mothers often experience greater grief, depression, trauma symptoms, and PTSD (Jind, Elklit, & Christiansen, 2010; Li, et al., 2005) and for a longer time than fathers (Sirkiä, Saarinen-Pihkala, & Hovi, 2000). Meert and team (2011) reported that parents' complicated grief symptoms were high 6 months after their child's PICU death, decreased between 6 and 18 months, but persisted for some time. Parents after a child's traumatic death and those with greater grief avoidance experienced greater improvement in grief scores. Biologic parents and those who were characterized as more responsive caregivers experienced less improvement in their grief scores. Older age of the deceased child and presence of other children in the home at the time of the death were related to longer recovery time (Sirkiä, et al., 2000). Parents of children with disabilities experience grief at the time of diagnosis and again when the child dies. Fathers reported that they grieved differently, but not less, than their wives and had a decrease in the intensity of their grief over time (Wood & Milo, 2001).

### Parent Personal Growth

For some people, traumatic events precipitate personal growth. Feigelman, Jordan and Gorman (2009) found that nearly two thirds of their study's 462 parents who lost children to suicide 5 or more years earlier had higher than average personal growth scores. Parents whose child died following a terminal illness reported being changed by their children and their legacies (children's qualities, concern for family, belief in an afterlife) and felt inspired to live their lives differently (Foster, et al., 2009). Bereaved White parents who were married had significantly greater appreciation of life than parents who were not married (Polatinsky & Esprey, 2000). Hogan and Schmidt (2002) found that bereaved parents with less grief and greater social support reported greater personal growth. Thus, grief may have transformational potential, with people feeling changed by the loss and becoming more compassionate, caring, and help-giving.

In summary, parents need proximity to their dying child in the NICU/PICU, information on the child's condition and treatment options, support for the decisions made, and stress reduction. Knowledge gaps center on the best ways to address these needs. Research is needed to identify and address barriers to providing proximity to the dying child in the NICU/PICU and having parents remain during resuscitation. Although research repeatedly has identified parent and family information needs when a loved one is in the ICU, new strategies are still needed to improve what, how, and when information is provided so parents and family members can understand and use that information. Strategies to maximize support for parents' decisions about their child's care before and after death and minimize the display of dissension among health care providers are needed. Critical care procedures and infrastructure also are needed to help parents express their grief and ensure continuing contact from NICU/PICU health care providers after the infant's or child's death.

## Palliative and EOL Care Issues

Palliative care is viewed by some as always having been part of the care of children. For others, pediatric palliative care is still in its infancy. Palliative care includes any intervention that focuses on relieving suffering, slowing disease progression and improving quality of life at any stage of the disease (Klick & Hauer, 2010). Others define palliative care as health services with a focus on relieving physical and mental suffering of terminally ill patients and their families (Beckstrand, et al., 2010). With children, integrating palliative with curative care can be difficult since the uncertain prognosis of a seriously ill child makes it difficult to predict progression of the child's disease (Vats & Reynolds, 2006). Because of this difficulty, the mandated life expectancy of 6 months or less required by some programs restricts palliative or hospice care to less than 1% of all dying children in the US (Kane, Barber, Jordan, Tichenor, & Camp, 2000). A study by Feudtner and team (2011) of 6 hospital-based pediatric palliative care programs in the US and Canada indicated that most of the pediatric patients were alive for more than 1 year after initiation of palliative care. In addition, many programs lack staff with expertise in caring for children.

In 2000, the Committee on Bioethics and the Committee on Hospital care of the American Academy of Pediatrics recommended that integrated palliative care services be made available to all children with a life threatening or terminal condition (Brosig, Pierucci, Kupst, & Leuthner, 2007). Others suggested that palliative care services be extended to the perinatal period if the fetus is at risk of dying (Sumner, Kavanaugh, & Moro, 2006). Despite these recommendations, studies show that palliative care services for infants and children remain underutilized (Rodgers, et al., 2011).

Critical care providers often view palliative care as an alternative to the aggressive, curative-focused ICU care. As a result, providers in the NICU and PICU often wait to implement palliative care until they believe there is no hope for the child's survival (Docherty, Miles, & Brandon, 2007). The result is inadequate symptom management for dying children (Meyer, Burns, Griffith, & Truog, 2002). Research of Solomon, Sellers, and Heller (2005) found that when clinicians give inadequate pain medication, they do so most often out of fear of hastening a child's death. For infants who received palliative care services, fewer medical procedures were performed and more supportive services were provided to infants and their families (Pierucci, Kirby, & Leuthner, 2001). The transition from curative to palliative care is more difficult if the ICU team must transfer responsibility to a palliative care team not in the ICU (Docherty, et al., 2007). Cultural beliefs on EOL care can also play a part.

## Cultural and/or Religious Issues

According to the National Hospice and Palliative Care Organization (2012), currently more White Americans receive palliative and hospice care compared to Black and Hispanic Americans. A recent study by Feudtner and team (2011) of 6 hospital based pediatric palliative care programs in the US and Canada indicated that 70% of recipients were White and 8% Hispanic. Bullock (2011) found philosophical differences between White and Black adults in EOL care. Whites were more likely to plan for their EOL care, to discuss the plan with their physician, and to rely on the health care team's recommendations. Whites tend toward individual decision making while Hispanic Americans and African Americans prefer decision making as a family. Blacks in Bullock's study (2011) were more likely to disregard planning for EOL care believing it would not make a difference. Blacks verbalized mistrust of physicians and preferred to have their families with them or to speak on their behalf in meetings with health care providers.

Although Blacks and Whites in Bullock's study (2011) rated themselves as somewhat or very religious, Blacks were more likely to talk about God's will, being God-fearing, and



believing in a higher power and miracles. While mistrust of health care providers led Black participants to prefer aggressive treatment in life-threatening situations, they also saw hospice and palliative care as “giving up” and being inconsistent with their religious beliefs. These beliefs help to explain disparities in withdrawing or withholding life-sustaining medical treatment by Blacks and Whites. In a study by Mosley, Church, Hempel, Yuan, Goold, and Freed (2004), 80% of parents of White infants compared to 62% of parents of Black infants agreed to such limitations in care. In a study of 35 PICUs in the US, decisions on limitations in EOL care were also seen less frequently for Black children (Lee, Tieves, & Scanlon, 2010). In a study of withholding or withdrawing life sustaining treatments in a PICU in Spain, the level of parent involvement in the decision to limit treatment was high (Launes, Cambra, Jordan & Palomeque, 2011). Parents may also fear that “do not resuscitate” (DNR) orders will reduce the level and quality of their child’s medical care. Research by Baker and team (2010) found that of the interventions children received at the time of the DNR order, 66.7% to 99.3% were continued following the DNR order.

## Communication Issues

Communication between providers and parents during and after the child’s death is essential but can be problematic during periods of high stress, especially where there are language differences between parents and providers. Parents are stressed by NICU/PICU environments, seeing their dying child in pain, frightened, and not being able to communicate with the child. For other parents, the stressor is an impending preterm birth and premature infant. In one study of impending preterm birth, anxiety levels for one third of mothers were very high and the concordance of recall of medical information between parents and providers was poor (Zupancic, et al., 2002). In another study, parent anxiety was high following the child’s PICU admission but parents seemed to understand their child’s medical issues within the first 24 hours (Needle, O’Riordan & Smith, 2009). Much depends on the amount, level and method of providing the information.

Minority and non-English speaking families often have cultural expectations and nuanced understandings of language that, if not understood and addressed, can interfere with effective care. Davies, Contro, Larson, and Widger (2010) reported that Mexican- and Chinese-American parents who received no information described more anger, distress and sadness during their child’s illness than parents who received adequate information, understood the implications, had questions answered and emotions acknowledged. Hispanic families report more difficulty than non-Hispanic families in understanding non-Hispanic physicians, regardless of language (Doty & Ives, 2002). Ramirez (2003) found physicians ignore more comments from Spanish speakers than English speakers. Members of minority cultures may also be passive with authority figures and fearful in medical situations (Levetown, 2008). In a study by Beckstrand, Rawle, Callister, and Mandelco (2010), pediatric nurses identified language as an important barrier to providing EOL care.

## Health Care Delivery System

Whether infants and children receive palliative and EOL care also centers on the discomfort that health care providers have with death and dying, decision making about aggressive treatment and ending life support, and identifying the dying point. The discomfort health care providers have with death and dying is well documented (Robertson, Aldridge & Curley, 2011). Contro, Larson, Scofield, Sourkes, and Cohen (2004) found that providers reported feeling unprepared to deal with pain and symptom management. In a study of 190 PICU health care providers, most indicated that they had only a moderate level of comfort and confidence in providing palliative care, especially with psychosocial care. Nurses and physicians with 8 or more years of practice had a higher level of comfort (Jones <http://>

[www.ncbi.nlm.nih.gov/pubmed?term=%22Jones%20BL%22%5BAuthor%5D](http://www.ncbi.nlm.nih.gov/pubmed?term=%22Jones%20BL%22%5BAuthor%5D), Sampson, Greathouse, Legett, Higerson, & Christie, 2007). A study by Knapp and colleagues (2011) found that both having prior training in palliative care and being employed in a site with such a program increased pediatric nurses' positive attitudes toward palliative and hospice care. Solomon and team (2005) found that nurses were more than 20 times as worried about saving children who "should not be saved" as about giving up too soon. One nurse in a study on EOL care commented "we are trapped between technology and reality" (Beckstrand, et al., 2010). Docherty et al. (2007) found that ICU nurses were concerned they were becoming too involved with the family when providing palliative care and that this might affect their ability to be objective and provide quality care. Others report that nurses bond with children and their families and experience both moral and emotional distress when a child is dying (Kaplan, 2000). A number of studies indicate that providers felt unsupported as they cared for dying children (Contro, et al., 2004).

Some clinicians believe that parent input in life support choices should be limited so that the sole deciding authority does not rest with parents, concerned that parents will feel ultimately responsible. Parents, however, may feel such choices are theirs alone (McHaffie, Laing, Parker, & McMillian, 2001). In studies of limitation or withdrawal of treatment with neonates (Abe, Catlin, & Mihara, 2001) and children (Meert, et al., 2009), parents were involved in making the decision to withdraw or withhold treatment in the majority of cases. Pector (2004), studying bereaved parents of multiple gestation (twins, triplets, etc.) neonates, reported that most decisions on life support were made collaboratively with the physician. In a study by Meyer, et al. (2002) of 56 families, nearly half of the parents reported having thought about withdrawal of life support, but 90% indicated that the physician had initiated the discussion. Parents cited their child's pain and quality of life and the low probability of their child's condition improving as important to their decision to limit or withdraw treatment. Garros, Rosychuk, and Cox (2003) reported that 51.4% of families agreed with withdrawing or limiting life-sustaining treatment in the first formal meeting with physicians; 17.6% agreed at their second formal meeting, but 28% needed three or more meetings until they agreed, raising questions about the family's true role in making the decision. Meyer et al. (2002) found high agreement between spouses with the decision to withdraw life support, but 52% of parents reported their families disagreed with the decision. In retrospect, nearly 25% of families reported they would have made decisions differently.

Whether infants and children receive palliative/EOL care also centers on identifying the dying point. In these situations there is a need for agreement among providers and between providers and parents that a child has reached the dying point. Disagreement among health care providers involved in the child's ICU care results in confusion and distress (Brooten, et al., in press), with some providers continuing aggressive treatment (Beckstrand, et al., 2010). With very preterm infants, physicians may recommend early life-saving interventions more than nurses resulting in conflict among caregivers (Streiner, Saigal, Burrows, Stoskopf, & Rosenbaum, 2001). In one study, parents witnessed disagreements among clinicians about ending life support and 18% of parents encountered criticism from the health care staff on their decisions on ending life support (Pector, 2004).

In summary palliative and EOL care for children and their families is underutilized. Potential solutions include increasing the number of staff with expertise in caring for children near death, integrating palliative care with critical care for all children with life-limiting conditions or fetuses at risk of dying, and nurses and physicians trained in communication skills and comfortable with EOL care, and those who understand and respect racial/ethnic differences in EOL decisions. Attitudes of health care providers, researchers,

and IRB members often present a huge barrier to conducting research about children and their families in this area.

## Recommendations for Future Research and Practice

Recommendations on future palliative/EOL care research and practice emanated from discussions by those who attended the Pediatric/Perinatal EOL Issues breakout session. They are not meant to be an exhaustive synthesis of all research areas or to represent specific Summit recommendations from NINR and its sponsors.

- Families. Palliative and EOL care for children and parents must include proximity to the dying child, information on the child's changing condition and contact with staff after the death. Such care has to intimately involve parents' and families' beliefs, problems, resources, and culture as the context for care decisions. Parents at an ICU bedside are frequently challenged when their decisions are not consistent with those of health care providers. Perhaps remembering that parents are ultimately responsible for their children and will live with the decisions and the child's EOL experience for the rest of their lives would put these issues into proper perspective.
- Palliative and EOL care. Strategies are needed to integrate the philosophies of palliative care and intensive care. Joint clinical management by the critical care team and the palliative care team early in the infant's or child's ICU course would provide better management of children's pain and other distressing symptoms and decrease their suffering during critical illness. This would also provide important resources for parents and other family members to better cope with the infant's/child's deteriorating condition.
- Communication. Developing and testing interventions to improve health care providers' communication and listening skills are critical. Those found to be effective need rapid transfer to practice. Special attention is needed for parents in the US whose primary language is not English. Studies of parent involvement in EOL decisions imply a discussion and consideration of options by both parents and health care providers. However, holding multiple meetings until the parents agree with the providers (Garros, et al., 2003) may mean that providers are not truly considering the parents' views.
- Health care delivery system. Education of health care providers in better communication skills and earlier integration of palliative care in the ICU is only one part of the picture. Studies are needed to identify the infrastructure and resources health care providers need to be able to support improved communication with parents and continue contact after the death. In addition, having staff prepared to provide hospice and palliative care for children and better reimbursement for this care would likely increase the availability of services.
- Transdisciplinarity. Discussions of the issues in forums including scholars and clinicians from disciplines not traditionally considered health disciplines (e.g. Anthropology, Family Studies, Sociology) would provide a much richer understanding, a broader perspective, and a wider range of options to address the issues.

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