Evidence-Based Neonatal Bereavement Care

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Neonatal intensive care encompasses not only the care of the acutely ill infant but also bereavement care for the parents and their families. Until now, bereavement care has been an intuitive response to a perceived need mainly based on Western cultural influences. Neonatal bereavement care encompasses the care given to infants and their parents from the time withdrawal of life support is considered until the parents have worked through their grief after the infant's death. This article explores research studies done in the past 10 years on neonatal bereavement care around the world. Only articles written in English were considered. Evidence-based care is supported by qualitative, descriptive studies of parents', physicians', and nurses' perceptions. The literature emphasizes the importance of communication, compassion, and trusting relationships, along with a good understanding of grief and bereavement issues. Follow-up care after the death is very important. Grief for multiple-birth losses is particularly complex. Little attention is given in the literature to the suitability of Euro-American bereavement practices for ethnic populations. More research is needed on the many aspects of neonatal bereavement care.

Keywords: Neonatal; Bereavement; Cultural; Care; Parents

In almost every society, men and women are encouraged to have children. Births are heralded with great celebration, and children are highly valued. Long before an infant is born, he or she is already a real person, one who is known, experienced, and loved. As the pregnancy advances, hopes and dreams of life with this child become part of daily living. Becoming a mother is one of the richest experiences a woman can have.

People do not expect babies to die. Because of the advances in modern technology and medical information, most women give birth to healthy children. It is a frightening experience when a baby is born early or, sick at birth. It is even more traumatic when it becomes clear that the infant will not survive. The death of a child is one of the most devastating and profound losses anyone can experience.[1]

Large amounts of money and highly qualified health care professionals are devoted to infants and their families in neonatal intensive care units. Neonatal intensive care encompasses not only the care of the acutely ill infant but also bereavement care of the parents and their families. Until now, bereavement care has largely been predicated on an intuitive response to a perceived need (p. F128).[2] To assess, justify, and improve bereavement care presently being instituted, evidence-based research must be considered. Clinical consensus must not be our only guide.

This article explores research studies done on neonatal bereavement care around the world. Most of the studies found were of the qualitative, descriptive kind with information gleaned by interviewing or surveying parents, physicians, and nurses. Cultural issues were of great interest, but most studies described Western bereavement practices only. The implications of the research discovered guide future neonatal bereavement care and research.

Parents' Perspectives

In Norway, Brinchmann and Vik[3] interviewed 35 parents to discover their perspectives of life-and-death decision making regarding their children. The parents emphasized that the physician's ability to communicate and to include them as decision-making partners was more important than the parents' right to an autonomous choice. The authors refer to the publication by Orfali[4] in which it is stated that French physicians do not ask parents' permission to withdraw care and that American neonatologists tend not to ask permission to continue. Orfali concludes that the French parents, whose physicians had the final say in what treatment would be offered, were more at peace than the American parents, who were asked to choose for their infant. Brinchmann and Vik[3] conclude that the Norwegian view is somewhere in the middle.

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An American pilot study of 6 cases, using tape-recorded interviews, was done with the purpose of describing decision making and the decision support needs of parents, physicians, and nurses regarding life support decisions made over time for extremely premature infants.[5] The results show that most parents wanted a model of shared decision making and perceived that they had this. Parents felt that physicians were the decision makers after the information had been given to them. (Interestingly, physicians felt that the parents were the decision makers.) Parents stressed the importance of encouragement and hope when being given bad news. They also emphasized that adequate nursing staff and literature to read on the subject was important. Parents differed in their desired level of involvement in decision making. However, they reported that it was helpful to have another family member or another health professional included when information was given to them.

A Swedish study by Lundqvist et al[6] examined 16 mothers' experiences and perceptions of the care given to them at neonatal clinics while facing the threat and the reality of losing their baby. When informed about their baby's incurable disease, the decision to start or withhold treatment was experienced as being left to the parents. These mothers did not want to be responsible for the decision, but after the physicians explained the pros and cons of treatment, the mothers were finally able to make the decision themselves. None of the mothers regretted their choice later.

An American study, exploring 20 parents' perceptions of their experiences in the neonatal intensive care unit when faced with withdrawal, extracted data from open-ended interviews.[7] Wocial[7] discovered that having parents hold their infant had the ultimate effect of moving the decision-making process forward. The need for frequent updating and constant information was important as acceptance occurred once the critical nature of the situation became real. The showing of emotion, especially grief by the health care provider, was powerful in demonstrating caring, and when parents believed providers cared, then, it meant that they could be trusted. Trust in the provider influenced parents' belief in the information given. Therefore, parents were focused on gaining trust and the relationship they develop with health care providers rather than on the ethics of the situation.

Moro et al[8] reviewed current research (from 1996) on end-of-life care for neonates, from birth to 27 days of age. Ten articles were selected for review. They discovered that the use of palliative services was very low despite the number of deaths in neonatal intensive care units. Parents were involved in the decision to withhold or withdraw life support, but their level of involvement varied. Parents who felt involved tended to be more inclined to trust providers and were better able to consider limiting treatment. Factors that helped parents decide to withdraw treatment were visible deterioration, the possibility of experiencing pain, and clear information about the gravity of the baby's condition and prognosis. Most parents wanted to be a part of the dying process but were not always well prepared for it. The death often took longer than anticipated. It was also found that the use of pain medication in neonates was not consistent, particularly when ventilator support was removed. Medical chart documentation was often lacking, and therefore, it was difficult to know what really happened with regard to palliative care.

Gold[9] conducted a systematic review of 61 English language studies from 1966 to 2006, addressing fetal and early infant loss, and extracted information about interactions with health providers. Parents had mixed experiences with health providers but indicated that nurses tended to be more supportive than physicians. The most frequent criticism of caregivers was the lack of emotional support or frank insensitivity. Parents were most appreciative of demonstrated emotional support and attention paid to the physical needs of the mother and infant. Education on the grief process was appreciated. Consistent information on the baby's status and cause of death was deemed very important. Parents found that far too many care providers were uncomfortable with death and bereavement, and they remembered small acts of kindness and insensitive comments for years afterward. It was discovered that hospital bereavement programs can incorporate a variety of interventions, but few have been tested for efficacy. Regardless, Gold[9] recommends that all hospitals should provide ongoing training for staff on grief and bereavement issues.

A Swiss qualitative study reported in 2007 explored 19 parents' experiences after the unexpected death of a preterm infant to deepen understanding and enable more adequate support to be provided by professionals.[10] Interviewed parents stated how important it was to be provided with clear medical information. Parents indicated that, if possible, a neonatologist should be in contact with them before the birth of their infant. They should receive emotional support and be offered rituals when their infant has died, including pastoral and psychological support if they wished. Parents wanted to be contacted for a medical interview 3 months after death.

Gold et al[11] reviewed parent experiences with hospital care after perinatal death in an evaluation of more than 1100 American articles from 1966 to 2006. They discovered that 82% of parents considered seeing their infant after death as an essential bereavement option. It is common practice for hospitals to take photographs and provide memorabilia of the deceased infant as part of bereavement care, and this was associated with high parent satisfaction. Most parents wanted an autopsy but did not receive follow-up information regarding results.

Brosig et al[12] interviewed 19 families to identify factors important to parents in their infant's end-of-life care. They concluded that parents can effectively cope after the death of an infant, but there is still much that medical staff can do to improve the end-of-life care for infants and their families. Parents wanted honest information, to be involved in medical decision making, have a physician present throughout the dying process, and support from other hospital workers. Like Gold,[9] most parents had positive experiences with nurses and felt it was important for the staff to take care of them as well as their infant. They noted that palliative care services were underused for infants. Parents recommended participating in the child's care as much as possible. No parent reported a negative spiritual experience or turning away from his or her faith.