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## Breaking bad news and the importance of compassionate palliative care of the infant

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## Breaking bad news and the importance of compassionate palliative care of the infant

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### Abstract

Bad news to parents regarding their infant is information that negatively impacts the parent's feelings and view of the present and/or future. It is implemented in situations with feelings of no hope or those that induce a threat to a parent's mental and physical well-being. The term is difficult to define as it is based on parent's subjective feelings. However, it is important to be aware of the impact of bad news as it can cause severe anguish and stress on the parent's emotional stability. The style of delivering bad news has a significant impact on the physician/parent relationship and the satisfaction of the family upon the healthcare team and palliative care system. In the case of an inevitable death of an infant, the implementation of palliative care follows the delivery of bad news. The strategy of palliative care and the philosophy of communication between the healthcare provider and family unit leave a lasting impression on the parents regarding the care of their infant. Clinicians should strive to educate themselves regarding the art of breaking bad news as well as the approach to palliative care to minimize the suffering and grief of the family in their time of sorrow.

### Keywords

Compassionate palliative care, breaking bad news, SPIKES

Working in the Neonatal Intensive Care Unit (NICU) requires a physician determined to help society's smallest and most vulnerable members. Modern medicine and technological advances have given us the ability to create great success stories and give infants a chance at life. However, the NICU is also a place of heartache and despair, as some babies never get the chance to leave the Unit. As physicians, it is our privilege and responsibility to provide care to the best of our ability and to stand strong as leaders and communicators when faced with the inevitability of bad outcomes. While medical management remains the core of training, delivering bad news and end of life issues are equally integral to a NICU physician's practice. The style of delivering bad news has a significant impact on the physician-parent relationship and leaves a lasting impression on the parents regarding the care of their infant. This article strives to educate clinicians regarding the art of breaking bad news, as well as the approach to palliative care to minimize the suffering and grief of the family in this trying and vulnerable situation.

We share a story, not uncommon to those working in the NICU, and demonstrate how compassionate communication of bad news and establishment of palliative care can ease the transition from life to death for the infant and those caring for him or her. The patient in

this case was born via Caesarean section to a 17-year-old G1P1 with Evan's Syndrome and HELLP syndrome. APGAR scores were poor, 4/7 at 1 and 5 minutes respectively. He was intubated in the delivery room and given surfactant. After intubation, the neonate was admitted to the NICU with multiple metabolic derangements including hyperglycemia, hypernatremia, hyperchloremia, hypocalcemia, hyperphosphatemia, and metabolic acidosis. The patient's NICU course was wrought with medical complications including grade IV intraventricular hemorrhage, mechanical ventilation dependent respiratory distress syndrome, pulmonary interstitial emphysema, hypotension, renal failure, anemia of prematurity, hyperbilirubinemia, thrombocytopenia, and suspected sepsis. With the multitude of problems, it was evident that this infant faced a very poor prognosis, and this had to be communicated to the parents. Unfortunately, an unfavorable outcome in a newborn is something all pediatric physicians will inevitably experience. The first step in addressing a poor prognosis in a newborn is to be aware of an infant's life-limiting circumstances, the timing of which varies from diagnosis after conception, after delivery, and after efforts are made for the infant in the NICU and diagnosis is established. The next step in care is communication of said diagnosis with the family or "breaking bad news."

We established open communication with the parents regarding their child's health status and potential prognosis upon the patient's admission to the NICU, which allowed for easier transition and ability to follow the child's progress. The duty of the healthcare providers is to educate the parents to anticipate possible complications and reassure that they will not be left in the dark. When the patient's condition began to worsen, we immediately held the discussion with the parents, providing full transparency into their child's unfortunate progression. We ensured that both parents were present to hear the news, as well as other involved family members, at their discretion. The conversation took place in a small private room away from the noises and distractions of beeping monitors and crying infants that could trigger a strong emotional response in the parents. Interruptions were minimized and full attention was given to the family during the conversation. Team members directly involved and highly invested in the infant's care were present, including the physician leader, resident, and nurse. Critical aspects of the conversation included addressing basic information needs, immediate medical risks, responding to discomforts, and ensuring a basic plan for follow-up. Five aspects of physician communication that are important for quality of care are: relationship building, demonstration of effort and competence, information exchange, availability, and appropriate level of child and parent involvement.<sup>1</sup> Aspects of communication to be avoided include: having a disrespectful or arrogant attitude, not establishing a relationship with the family, breaking bad news in an insensitive manner, withholding information, and changing a treatment course without preparing the patient and family.<sup>1</sup> Our goal was to provide a common perception of the infant's problems, full disclosure of the medical condition, and time for emotional ventilation by the family unit.

We offered information on the infant's condition in small increments, taking care to use terms that the teen parents could understand and avoid medical jargon. We discussed each diagnosis the child faced and the likely repercussions that would follow. Between each piece of information, we allowed time for processing, grieving, and questioning. All of this was done in a compassionate manner, as respect and empathy are the crux of breaking bad news. For example, the infant was referred to by his name, to reassure the parents that we viewed him as a child and person, not just a set of diagnoses. A summary and assessment of their comprehension was performed and though there were powerful emotions of grief and despair, the parents understood the poor prognosis of the child. Time was given for them to be alone and ruminate on the life-altering news they received. Information on family support programs, therapy services, and intervention services was provided. We scheduled a time to follow-up to answer questions and negotiate a strategy for care. This

is an excellent time to address lingering negative feelings in parents, such as the perception of failure, unresolved feelings about death and dying, concerns about family's response to the news, and the emotional response to the circumstances.<sup>2</sup> Unfortunately, in a situation of inevitable death such as this, breaking bad news precedes the discussion of palliative care.

The strategy for introducing palliative care to the parents of a prospective patient is delicate and must be approached with sensitivity and empathy. The family should be ensured that they will not be abandoned during this process, and it should be voiced that the healthcare team will continue to provide compassionate and optimal medical care.<sup>3</sup> This includes continuing nursing care and comfort medications, as well as extensive holistic care including physical, psychosocial, and spiritual care to prevent and relieve the infant's and parent's pain and suffering.<sup>4</sup> The health-care providers must understand that the family unit is experiencing extreme stress in a time that was planned to joyfully welcome a new infant. The intervention should be performed by trained staff members in pursuit to achieve the goals of support for the infant's time on Earth with dignity, warmth, compassion, and to support the family's experience with empathy and respect, punctuated with cultural and religious sensitivity. Some important and influential aspects of palliative care include providing a contact number to the parents, asking for a support person and/or spiritual or cultural leader to be present, always using simple lay-person and non-judgmental language, avoiding offensive language and terms such as "withdrawal of treatment" and ensuring that the infant will be provided compassionate and individualized care.<sup>5</sup> The parents of the patient agreed to palliative care and to allow natural death. On day of life 6, the child passed away in the arms of his mother and father.

A newborn qualifies for palliative care if born at the threshold of viability (defined as gestational age less than or equal to 23 weeks), weighs 500 grams or less without growth restriction, or is not responsive to therapy.<sup>4</sup> Other infant groups included are those with genetic problems incompatible with life, kidney problems such as Potter syndrome and renal agenesis, central nervous system disorders and anatomical incompatibilities such as anencephaly, massive intraventricular hemorrhage, cardiac abnormalities such as acardia and inoperable cardiac defects, and structural defects such as giant anterior abdominal wall defects that cannot be surgically managed, congenital diaphragmatic hernia and hypoplastic lung unresponsive to therapy, and lastly newborns not responsive to intensive care interventions with multiple organ failure.<sup>4</sup>

The strategies implemented in palliative care for the newborn can initially be combined with cure-oriented, disease-modifying therapies.<sup>4</sup> Once these therapies are no

longer progressing the infant towards treatment and cure and the infant's status has plateaued, the skills used to care for the patient shifts towards those specific for palliative care. The physician leader of the team should be familiar with family-centered care with nursing, social services, and clergy supporting this philosophy. The parents must agree to cease invasive care—obtaining vital signs as needed and silencing medical equipment, but continuing to allow tube feeding if the parents desire.<sup>6</sup> Management should be congruent and respectful to family preference, culture, and faith and can expand to those of siblings, grandparents, or extended family, depending on the patient's support network. All medications should be removed except those administered for comfort care. Blow-by oxygen and suction may be continued as well as continued observation and gentle assessment by the nursing staff. The physician leader should document progress notes describing level of care and status of the infant. It is essential to note the palliative care orders on the chart so that there is no confusion within the various healthcare providers accommodating this patient about how the infant should be managed.

While these strategies are generally initiated in the NICU, the location of palliative care does not always need to continue where it had begun.<sup>7</sup> The infant can be managed in a private NICU room away from the main intensive care unit or even in the home of the family, outside of the walls of the hospital. If the family decides to continue care outside of the hospital, the hospice care plans including Allow Natural Death orders should be provided to the primary physician, home health, and hospice agency. The hospice care nurses have the authority to pronounce the baby's death. The location of care is not as important as the team approach and mindset of the healthcare team, focused on the philosophy of patient-centered care.

The management of the infant with palliative care ends with the infant's death. The most important component of this highly emotional and influential time in the family of the infant is to ensure that the parents are aware of and are a part of the next steps in the infant's care. If the infant has been on a ventilator or pain management, the removal of the ventilator and withdrawal of pain medications should be performed in a private room at a time at which the parents agree and with or without their presence at the bedside.<sup>6</sup> All vasopressors and antibiotics should be stopped and all alarms of the machinery should be silenced. The family members should be provided an opportunity to hold, bathe, and dress their baby. All parents should be encouraged to see their child's body post-mortem, as 61% of parents who refused to see their child's body regret doing so later on.<sup>7</sup> Spiritual support and prayers should be offered and encouraged as desired by the family and mementos in a memory box (Figure 1) should be offered. Some components of the memory box may include locks of hair, hand and footprints molds,

record of the baby's weight, length, and head circumference, identification bracelets, and photography or videography that was recorded. An important conversation that is to be had next is the discussion about organ donation. One study demonstrated that 59% of parents who did not get approached about organ donation wish they had been.<sup>7</sup> This should be discussed by the primary physician who has been working with the family. The environment should be nurturing, quiet, and dimly-lit.

After this process has been completed and the family is ready to leave the hospital, the physician leader and ideally the palliative care team should walk with the parents as they depart the unit. Parents should not be allowed to walk out with empty arms - they should be given a memory box to hold and accompanied as they leave the hospital. A follow-up call by the caregiver and a bereavement card should be sent to the family a week after the time of death. A follow-up meeting should be scheduled 4 to 6 weeks after departure from the hospital to discuss the clinical situation, autopsy results, lab reports, and general support of the grieving process.

Although fetal morbidity and mortality remains relatively common, very little formal training is offered to physicians on the practice of breaking bad news. One model for delivering bad news commonly taught is SPIKES (Table 1). However, many practicing physicians, residents, and other trainees lack skills and confidence in delivering bad news, leading to patient and family anguish.<sup>8</sup> The literature consistently demonstrates that current training of students and residents remains insufficient in preparing healthcare professionals to break bad news to the pediatric population. Of practicing physicians, 12% report never getting formal training in terms of pediatric patients and 11% report never getting any training in terms of adolescent patients.<sup>9</sup> Moreover, faculty observation of student interaction with families and feedback from attendings is also lower for pediatric patients than adult patients.<sup>9</sup> However, multiple site programs have shown that even just a one hour module on how to break bad news can offer increased sensitivity to family needs, emotional responses, self-efficacy is delivering bad news.<sup>10</sup> Formal educational programs with training modules demonstrate that the art of breaking bad news is both teachable and retainable and, as such, increased application of such training modules would be efficacious in improving healthcare quality and patient care.<sup>11</sup> Additionally, training modules may provide healthcare providers with strategies to bolster resilience and support self-care as they intimately involve themselves in the bereavement process. With effort and training on behalf of the healthcare provider, the process of breaking bad news can become a better experience for all parties involved.

Figure 1. Memory Box



Table 1. A mnemonic that has been used to educate clinicians about breaking bad news is SPIKES.<sup>12</sup> This strives to minimize parental confusion and provide authentic empathy to help alleviate some of the family’s grief.

<b>S - Setting</b>	Considerations for an optimal setting to deliver bad news include timing, privacy of location, presence of pertinent members, and freedom from distractions
<b>P - Perception</b>	Using open ended questions to elicit the patient’s or family’s perception of the situation and medical diagnosis. This should be obtained by the healthcare provider and evaluated for accuracy.
<b>I - Invitation</b>	Getting permission from the patient or family to share their feelings and apprehensions, determine what information they want to know and options to postpone the delivery of bad news
<b>K - Knowledge</b>	Providing medical knowledge in a manner sensitive to educational level, culture, ethnicity, religion, and values. Ascertain understanding.
<b>E - Empathy</b>	Responding with empathy, active listening, and providing necessary time, space, and resources for emotional responses.
<b>S - Summary and Strategies</b>	Summarize decisions, allow time for questions, schedule follow up, provide resources such as support groups, and provide a concrete plan for the future

Our story represents just one of the many heartbreaking stories from the NICU. “Bad news” is never desired, but proper training, awareness, and preparation can make the experience less traumatic for the patient, family unit, and healthcare team. Bad outcomes in pediatrics are inevitable at one time or another and it is important to not only manage the patient, but also provide the most empathetic care to alleviate the pain and suffering associated with neonatal mortality.

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