

Guiding Parents Through the Death of Their Infant

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Supporting a family through the impending death of their infant challenges the health care team to create opportunities for the parents to complete the attachment process and begin to grieve. Even in the neonatal intensive-care unit, the family can be brought together with their child in activities that comfort and console, lay the foundation for positive memories, and initiate healing and closure after the death of the infant. Interventions for grieving parents are described in this article. *JOGNN*, 30, 569-573; 2001.

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In 1967, I was a new graduate nurse, beginning my career in Omaha, Nebraska. One of the memories of that time was an act of kindness involving a dying newborn and his doctor. The parents had never seen the child, who had been transferred from birth to our hospital, and our best efforts would eventually fail to save him. When the futility of further interventions was apparent, the camera and lighting used to document surgical techniques were brought up from the operating room. I watched as our pediatric surgeon nested the newborn in surgical drapes and photographed him, not as a surgical case study, but as a baby. "The parents should have at least this memory of their living child," said the surgeon. This thoughtfulness impressed upon a neophyte pediatric nurse that the tools of compassion can be found in our everyday workplace.

I've been in nursing a long time now, in neonatal intensive-care units in a variety of locations.

The death of a baby is a loss for the family and the health care team. The experience can be overwhelming when confronted by a nurse for the first time. Yesterday, I helped a colleague with her first experience of discontinuing life support.

Lisa had been part of the team as we had attempted to rescue the big, beautiful, full-term newborn. The damage from prolonged vacuum extraction and asphyxia had left the baby with persistent pulmonary hypertension of the newborn, disseminated intravascular coagulation, and intracranial hemorrhaging. Now the emphasis shifted away from aggressive, technical medical care. Faced with supporting the baby and his family through his impending death, Lisa asked, "How do I do this?" Being a skilled nurse, her question was not about the technical aspects of stopping drips, giving comfort medications, or extubation. Her question was how does one guide the family through the actual moments of the baby's death. I suggested to Lisa things that I have found to help these families.

Assessment and Planning for Family Bereavement

The unexpected death of an infant steals away the time in which a parent can proceed with the transition to closure. This is seen in the growing premature infant who suddenly develops necrotizing enterocolitis and dies in a few hours. We confront it in the emergency room when a pregnant woman with a ruptured cerebral aneurysm comes in for an emergency cesarean section and both mother and child die. These losses differ from the inevitable loss faced by families of the infants with

conditions incompatible with life, the infants without hope of recovery or deteriorating to neurologic death, all the while being supported by a phalanx of ever-evolving technology.

Nurses may ask, "Why don't they just let this poor little kid go?" Yet, we must empathize with the parents who face these decisions. Often, the obtaining of a "Do not resuscitate" status for the baby can be a prelude to the parents' acceptance of the futility of further intervention, even when they cannot yet accept the idea of stopping life support.

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Communication between the family and the health care team helps the parents comprehend the condition of their child and participate in care decisions. An opportunity to share information and validate emotions can be created by an interdisciplinary meeting. Such a gathering brings together the health care team, social worker, clergy, and all family members involved in the decision-making process. Ideally, the family is composed of both parents, along with grandparents, siblings, and close friends. The ideal family, however, is not always the family we work with, and nurses must support every family in crisis.

The smallest family I have worked with was the young mother alone with her child, abandoned by the father and rejected by her family. Our staff responded to her physical and emotional vulnerability. To quietly hold a weeping mother in one's arms gives human contact when words fail. This mother was reassured that she was seen as a good and loving parent and that she and her baby had value.

Communication can be a challenge with an ethnically diverse population. Our multinational patient base in a university town presents the need for translators. Comprehension of complex medical information is best achieved in a parent's first language. A database of supportive translators is available.

Some parents of our patients are incarcerated at the time of their baby's death. Depending upon the nature of the parent's crime and sentencing stipulations, bereavement privileges may be limited. A choice may have to be made between a deathbed visit or a funeral. When one father chose to wait for funeral leave, the nurses ensured that the physician relayed all the information over the phone to the father. The nurses did not

want the mother to have to be the conduit for complex information upon which decisions were made. With the father's limited telephone privileges, the nurses wanted to be certain that he was informed and involved at this time in his child's life.

Preparation and Ceremony

As a family makes the decision to forego further interventions for their baby, they grapple with the unknown. As one father asked, "What happens now, do we just pull the plug?" By opening the subject of what happens next, the health care team can spare the family from having to ask.

Asking opening questions can provide information and give structure to the anticipated events. For example, after the decision making, the baby's nurse may begin to guide events by asking

Would you like us to help you with any special ceremony for Brian? Can we help facilitate a baptism? We can have the hospital's chaplain attend for your family or would you like for us to help you get hold of your home pastor?

The spiritual needs of the families range across cultural and denominational affiliation: baptism, christening, naming, blessing, dedication, anointing, or other prayer gatherings. Even parents who may not participate in religious traditions will sometimes choose to embrace communal support in their time of grieving. A nurse could ask, "Is everyone here with you now, or would you like to have other family and friends to be with you and Kayla?" Having offered services, the nurse should not insist or pursue this avenue if it is declined. Whether there is to be a ceremony or not, this discussion can lead to a participatory preparation of the baby.

Do you think you could help me with Amy's bath, and then shall we dress her and make her comfortable? Would you like to do that with me, and then I'll help you hold her. Everyone you would like to can take a turn, if that sounds okay to you. You can all have time to hold her before we take out the breathing tube. Is this something you would like to do?

By asking the parents "Would you like to do this? Is this something you would like? Is this okay with you?" as care progresses step-by-step, the nurse can help the parents direct what is comforting and meaningful to them.

I have found the bathing and dressing to be important for the parents. The baby does not need a bath, but the parents need to be parents and have restored these last few chances to do what they had planned to build a lifetime doing. Sometimes I have to start the touching

and bathing. Some parents are scared of the baby or even repulsed. Maybe they can only wash the face or shampoo the hair. With the warm baby shampoo, the experience can become comforting and sweet smelling. The intention is that the parents come away with an olfactory memory of the sweet baby smell of their child. I may guide the mother's hand to stroke the baby's head, making it easier to coax her to brush the hair into the style she would have done in a better time. The parents may have brought clothes for the baby, the anticipated going home outfit, or they may have a family baptismal gown. If this is not the case, the neonatal intensive-care unit has a collection of gowns, caps, and blankets made by volunteers. A variety of ensembles is offered to the mother so that the baby is dressed in the clothing of her choice. All are white trimmed in pink or blue, with velcro seams and closures to fit the most edematous or cannulated baby.

The time spent bathing and dressing is with full respiratory support. As many invasive sites as possible are discontinued as we go. Gastric suction catheters, urinary catheters, and as many IV lines as possible are removed. If pressor support is necessary, those drips are maintained until the family has had the chance to complete their care and holding of the baby, then discontinued before extubation. One intravenous line is left in for analgesic administration.

Easing Fear

This is the time to prepare the parents for extubation. I often phrase things in examples of choices others have faced.

Sometimes parents want us to take away the vent and the breathing tube while they are holding their baby, but others would rather just hold their baby until they are ready, then we will put him back in bed. These parents feel more comfortable if they can go to the nesting room, and we will take out the breathing tube and bring the baby to be with them to hold again. You can decide if either of these sounds like what you would like to do.

Many parents are terrified of the idea of watching the baby die. I talk to the parents and their support people about how the baby will look and what to expect. I explain that after we take away the support ventilator and remove the breathing tube their baby, like many others, probably will continue to have some respiratory activity. I explain that these efforts will not sustain the baby, but he or she will not be in pain. I reassure them that we generously give medications as needed to keep the baby free of pain or anxiety. I use the analogy of the flickering out of a candle or the burning out of an ember for the baby's release of life.

He may seem to have faded away, yet still flicker with a breath now and then, until he is finally ready to let go.

I avoid using negative words that may make the experience harder for parents. I find that preparing parents not to be frightened by the sound of "a sigh, a hiccup, a yawn, or a murmur" is better than using terms like "agonal gasping," "struggling to breathe," or "choking." The use of morphine is explained, and I reassure the family that the baby is not in pain. At the same time, I do not set any timetable for how quickly or how long until death occurs.

Some little ones give up their hold on life very shortly after we take out the breathing tube. Others let go much more slowly, but we will be with you as much as you need us, to help you get through this.

The time spent by the parents during the bathing and dressing ritual can be enhanced by playing music for the baby, speaking to the baby, using the baby's name, telling the baby that he or she is dearly loved, and praising the baby's courage and strength. If no music is

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brought by the family, I try to use a selection that avoids the traditional nursery pieces that may bring back the time of the death of this baby when heard in the future. The sounds of nature and some classical recordings can be soothing without being funereal. Music can help screen out some of the other activities that must continue in an intensive-care unit.

If a baptism or other ceremony is planned, the family and clergy can gather as the parents complete dressing their child. With the assembly gathered, the rites and ceremonies can be performed at the bedside, as the baby is held prior to extubation. Privacy and respect for the occasion necessitates closing the area to other visitors, minimizing procedures in the area, and if possible, moving crying infants to another location. We ask the family if they want the events photographed. Family members may have brought their own camera or video equipment. If not, we offer to use our unit's 35-mm camera to record the family gathering and ceremony. This is a time when we lift limitations on the number of visitors at the bedside. If there is a difficulty with any

particular relative, we assume the blame and impose whatever limitations best suit the parents.

Following the ceremony, the baby is bundled, and with the continued support of the ventilator, is held, first by the mother and father, then by whomever else they wish. The respiratory therapist secures the airway and vent tubing to allow the baby to be cuddled and rocked by the family. This is another opportunity for the instant snapshots as well as 35-mm photos. With the parents holding their baby, there may be a final group prayer. A plentiful supply of tissues is provided for everyone in attendance.

Withdrawing Life Support

The family usually tells us when the time has come to "let go." Sometimes it may be approached as a quest for release or "getting it over with," especially if the parents feel the baby has suffered enough. After the subject of being present for the extubation is broached, a direct question is in order.

It's time now, isn't it? Do you want us to take the tube out now, or would you like to go to the nesting room and we will bring Matthew to you after he has had the breathing tube removed?

Each family has its own needs in completing the attachment process and beginning to grieve.

It helps the family to have our social workers accompany them to the nesting room, which has been prepared with tissues, drinking water, a private phone, and prepaid long distance calling cards, if needed. The social workers give the families comfort, in these practical ways, during these sad times.

If the parents wish to continue to hold their baby for extubation, our respiratory therapist applies adhesive remover to clean the face of all traces of tape. I may say to the parents that we are taking away the mask that has hidden the baby's beautiful face, and we will now see the baby with nothing in the way. The endotracheal tube is withdrawn, and the family is permitted to hold the baby at the bedside for as long as they like, then helped to take their child to the nesting room. If the parents elected to forego being present for the extubation, the same sequence is followed, and the baby is carried to them.

This is the time when preparation for what to expect helps alleviate some of the family's fears. I reinforce that the sounds they may hear are the soft sounds of the baby letting go of his or her hold on life. I give medication any time the parents express concern about discomfort. The lighting is kept soft, and I may comment that the baby's color changes are just part of the gradual slipping away. The promise to be there for the family is restated, but the offer also is made to give whatever privacy they may desire. If they want to be alone, they have the number to call into the unit, or we offer to check back in on them every few minutes.

Letting Go

Each family has its own needs in completing the attachment process with their child and beginning to grieve. A family who had always visualized the "family bed" was provided their chance to experience it. The nesting room has a sofa bed, which the mother's sisters made up for the mother and father to rest in with their baby until he died. The mother, who had decided that breastfeeding was an essential part of her relationship with her infant, was assisted in holding the baby at her breast and moistening the dead child's lips with her milk. Sometimes, an act of grief can be unsettling, as when a father threw himself over his baby's body, wailing his distress. While remaining sensitive to the differences in expressions of emotion, the health care team can have a back-up plan for support if psychiatric or security intervention is necessary. Expressions of suicidal thoughts should be taken seriously from either parent, and the appropriate referrals made to staff trained in assessment and treatment.

When the time comes for the physician to pronounce the death of the child, and the last visit has been exhausted, a remembrance box is presented to the family. Filled with the memorabilia of the last hours (locks of hair, footprints, the soap used for the bath, the gown worn for the baptism, all instant photos taken), the remembrance box is supplemented by a bereavement folder supplying information on such needs as bringing lactation to an end and finding a perinatal loss support group in the family's home area. The needs of siblings should not be forgotten. Age-appropriate material is available to help the children in the family deal with the loss of the new baby and the grieving they see their parents express. For many young couples, the experience of making funeral arrangements is something they had never envisioned at this time in their lives. Referrals to mortuary services in their home areas that provide sensitive support in perinatal loss are appreciated by the parents and extended family. The neonatal intensive-care unit's bereavement support program processes all

photos taken by our unit's camera and provides these to the family, as well as a portrait-quality enlargement at no expense to the family. The photographs are sent to the families and are part of the program's follow-up contact and assessment.

Conclusion

In his book *The Undertaking, Life Studies from the Dismal Trade*, poet and Michigan funeral director Thomas Lynch (1997, p. 51) writes

But burying infants, we bury the future, unwieldy and unknown, full of promise and possibilities, outcomes punctuated by our rosy hopes. The grief has no borders, no limits, no known ends, and the little infant graves that edge the corners and fencerows of every cemetery are never quite big enough to contain

that grief. Some sadnesses are permanent. Dead babies do not give us memories. They give us dreams.

With care and compassion, perhaps we can help bring peace to those dreams.

REFERENCE

Lynch, T. (1997). *The undertaking, Life studies from the dismal trade*. New York: W. W. Norton.

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