One Facility’s Experience in Reframing Nonfeeding into a Comprehensive Palliative Care Model

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ABSTRACT

In Western culture, feeding is viewed as symbolic of life, and nonfeeding at the end of life is often considered unacceptable. This sentiment is magnified for infants. Reframing nonfeeding into comprehensive care can be achieved by anticipatory guidance, which can make the experience of infant death meaningful for parents. Since 2004, the George Mark Children’s House, an inpatient pediatric palliative care center, has offered this model of care and supported families with challenging clinical experiences. A case study is provided.

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Implementing nonfeeding as part of acceptable palliative care for infants remains elusive.

Artificial nutrition and intravenous fluids can be initiated, they can also be discontinued. Many professional organizations have supported families and health care providers in withholding artificial nutrition in association with end of life comfort. The American Academy of Pediatrics (AAP; 2007; Diekema, Botkin, & Committee on Bioethics, 2009), the American Academy of Hospice and Palliative Medicine (2006), the Hospice and Palliative Nursing Association (2003), the American Nurses Association (2011), Academy of Nutrition and Dietetics (2008), and the National Hospice and Palliative Care Organization (2010) have released supportive guidelines and position statements for healthcare professionals on this topic. These recent guidelines are helpful, as limitation of feeding has not always been supported. Rogoff (1995) related the experience of explaining her family’s decision to limit tube feeding for her non-responsive four month old daughter with an asphyxiated brain to physicians:

The tall doctor said, “If you don’t feed her, she’s going to die.”

“We all know she is going to die.”

“Legally, you still have to feed her.”

“I am feeding her. She can’t eat.”

“That’s why we gave you those feeding catheters.”

Should I try to tell him what it has taken for us to come to this conclusion, to allow her to die? I decided to try. “If we feed her with the tube again, and if, by some miracle, we manage to stave off death again, what will we accomplish? Look at her, doctor. SHE CAN’T DO ANYTHING, SHE CAN’T GROW, SHE CAN’T CRY, SHE CAN’T EVEN EAT.”

“We’re not here to talk philosophy,” the short doctor said, “We’re talking about murder” (p. 82).

As illustrated in this example, even though professional associations support limiting life-sustaining artificial nutrition and hydration, implementing this practice as part of an acceptable palliative care plan for infants facing life limiting trajectories remains emotionally complex. We are told that this action is ethically permissible and morally acceptable, but for families and providers, distress can occur.

Many researchers, such as Catlin (2011), Diekema and colleagues (2009), Feltman, Du and Leuthner (2011), Geppert, Andrews, and Druyan (2010), Porta and Frader (2007), and Tsai (2011) described the moral distress that all manner of end-of-life care can cause. Moral distress in health care for an infant most often results when parents or professionals want to continue life-sustaining treatment beyond what seems to be in the infant’s best interest. Medical professionals are reticent to go against a parent’s request to continue burdensome treatments at all costs. Paternalistic decision making has lessened, and parents are given autonomy to make health care decisions for their infants, even when providers know that ongoing intensive care would prolong suffering (Tsai).

In our experience with dying children, parents typically hold on to hope: hope for a cure, hope for a miracle from God, hope for recovery, hope to take the infant home. When surrounded by the most advanced technology our United States can offer, it is almost impossible for parents to not consider providing this technology for their infants. Doing everything is rewarded outwardly by friends and family as opposed to the perceived opposite, giving up. As Davis (2002) noted, “As a result of this public admiration, parents who chose non-intervention can feel put on the defensive, even though by some standards, theirs was the more heroic decision. Indeed, it is much harder to let go than to hold on” (p. 15). Parents may be seen as selfish for not wanting to provide ongoing care to a child with severe physical problems and for considering equally the effects on a marriage, siblings, finances, and the community.

In the face of an extremely poor prognosis, it is almost impossible for parents to agree to withhold artificial fluids or nutrition, even though physiologically this has been found to be a more comfortable way to end life (Winter, 2000). It is often assumed professionally and socially that feeding provides ongoing comfort at the end of life and that withdrawing feeding increases suffering during the dying process. Parents frequently state in family meetings that they are being asked to “starve or kill” their infants or are accused of this by friends or extended family members. Parents and health team members have expressed sincere concerns
for the possible legal ramifications associated with this choice.

As medical teams meet with parents to discuss goals of care and to make recommendations for withdrawing or withholding of artificial nutrition, parents need to know they are not alone in making this decision; the decision and burden are shared by the team (Carter & Leuthner, 2003; Wright et al., 2009). Teams should reach internal agreement regarding the plan of care to present a united front to parents and to be prepared to designate members who are comfortable with the care of an infant with feeding withheld. Parents need to be reassured that their infants will still receive intensive care of a different variety that will continue with a palliative care focus to manage pain and symptoms and optimize quality of life (Murphy & Price, 1995).

Reframing nonfeeding into comprehensive care includes reviewing with parents the benefits of this type of end-of-life care. Documented physical and psychological benefits are available regarding withdrawing or withholding feeds compared to complications, such as release of endorphins and pain relief that can occur if medical intervention is continued. When nutrition and fluids continue to be administered parenterally at the end of life, a 15% complication rate can result with the possibility of infection, thrombosis and bleeding, electrolyte imbalance, and loss of the intravenous catheter site. When nutrition and fluids are administered enterally at the end of life, the rate of complications increases to 76% (Diekema et al., 2009; Geppert et al., 2010; Keeler, 2010; Winter, 2000). These complications can include one or all of the following: (a) increased secretions with associated increased respiratory distress including coughing, gagging, and choking episodes as with a natural decline the body loses its ability to swallow; (b) risk of pulmonary edema and/or generalized edema to the body with the latter increasing the risk of skin breakdown and compromised wound healing; (c) nausea and vomiting as the digestive system is on a natural decline but is expected to continue to process food and fluids at the end of life coupled then with an increased risk of aspiration pneumonia and resultant increased respiratory distress; (d) nutritional excesses and deficiencies; (e) discomfort with replacement of a feeding tube if naso or orogastric.

Undoubtedly, parents will be concerned that their infants will feel hungry and deprived. However, research and feedback from adults who have ceased eating indicate that the sensations of hunger and thirst lessen after the first 1 to 2 days in response to the increased production of ketones as muscle mass is broken down and the body naturally releases endogenous endorphins. These circulating endorphins have an analgesic effect leading to decreased perception of pain, and often a feeling of euphoria has been reported (Carter & Leuthner, 2003; Diekema et al., 2009; Geppert et al., 2010; Keeler, 2010). Despite the fact that infants are unable to self-report their experiences with nonfeeding, parents who have witnessed this type of end of life with their infants describe a peaceful death without any observable suffering or struggling. Death is perceived as comfortable and often occurring during sleep. Dignity in death is achieved and bereavement is improved as a result of a quiet end.

The most difficult challenge parents face with nonfeeding is the length of time and unpredictability of the exact point of end of life. In contrast, when mechanical ventilation is discontinued, death most often occurs rapidly. When nonfeeding is implemented as end-of-life palliative care, the time to the point of arrested heart rate can take days to weeks. Infants are especially tenacious when it comes to surviving without food or fluids except for medicines (Carter & Leuthner, 2003; Johnson, 2010), and the length of time can range from 2 to 37 days. Anticipatory guidance for parents is essential, as they will observe weight loss and unpredictable and sometimes long periods of apnea.

Parents require ongoing emotional support as they can begin to doubt and question the moral and medical decisions made. Parents can comfort their infants with skin-to-skin care, holding, rocking, and massage. They can bathe and dress their infants in cherished clothes. If the infant begins to look emaciated and this change causes the parents distress, the staff can assist and bathe the infant, hold the infant, and change the clothing and diapers. In addition, as the infant starts to actively approach the last hours of life, parents need to be informed that apneic episodes of up to 10 minutes can occur after which breathing can resume. Parents and staff have been caught off guard thinking that death had occurred, but the absence of heart rate is the final confirmation of end of life.
Most end-of-life care for infants occurs in the NICU, and this environment can have its own challenges. The NICU staff by and large are trained and dedicated to improving an infant’s medical condition to extend life so that discharge to home can occur. When parents and the health care team agree to limit medically ineffective care and allow the dying process to occur, moral distress can result. Therefore, staff should also be supported during this difficult process. If a staff member is not comfortable with the plan of care for end of life, the staff member may ask not to be one of this infant’s caregivers, and this request should be granted (Catlin et al., 2008) Parents should see a united team and should not have to cope with what can be interpreted as ambiguous support. It is important to have a dedicated team that is comfortable and in agreement with the proposed care plan (Catlin & Carter, 2002).

The physical environment of the NICU can often feel daunting and overwhelming to a family, especially when faced with what may feel like a more undignified and sad end to their infant’s life. Some units have private rooms whereas other units have limited resources for family privacy, but with increased attention on pediatric palliative care, more focus is given to creating optimum infant or child palliative care environments. Anticipatory guidance for parents allows time to plan for a gradual move to more purely palliative and supportive care modalities. For example, in a recent article addressing parents’ wishes for their dying infants, four simple requests emerged: (a) no restriction for the number of visitors, (b) providing a bed that the mother can lie in beside her child, (c) arranging for the parents to take their infants outside to experience the sensation of the sun and the breeze, and (d) opportunities for special family photos (Carter, Brown, Brown, & Meyer, 2012). These simple yet meaningful wishes can be honored.

In response to the needs of this special population, an alternate site of care has emerged in the United States. Families with infants and children requiring ongoing palliative care for the duration of their lives, however long or short, can now go to inpatient pediatric palliative care centers in select areas of the United States. These centers are based on models from the United Kingdom and Canada, and these homelike facilities provide the ideal space for loving and dignified pediatric palliative care to occur. Here teams are specifically trained and have chosen to work with a pediatric population expected to have a shortened life. An interdisciplinary team focus allows for holistic support of the child and family. Close collaboration with the preexisting medical team at the hospital or with the local community doctor encourages the continuum of care and eliminates parental fear of abandonment when leaving behind their familiar hospital team or doctor. Staff at palliative care centers are more comfortable and practiced with the limitation of medical interventions in end-of-life care and are thus willing to engage in ongoing dialogue with parents who may continue to struggle with the decisions made.

Through philanthropy, the George Mark Children’s House (GMCH) in San Leandro, California, was created to provide this type of holistic care. This center is staffed around the clock by experienced pediatric nurses and provides palliative care for children from birth through young adulthood (early to midtwenties). Although a full spectrum of medical services are provided (respite, transitional care from hospital to home, and end-of-life care), this discussion will focus on neonatal end-of-life care, specifically with infants for whom artificial nutrition and hydration are being withheld. Multiple aspects of end-of-life care suggest that this alternate setting can provide a more appropriate environment than a busy NICU. The following is a case study that illustrates the unique differences a palliative care center can make in the sensitive care required when an infant is allowed a natural death without insertion of artificial feeding lines or tubes.

**Case**

Baby Amy (pseudonym) was born at 37 1/2-weeks gestation to a married couple. At 32-weeks gestation, the pregnancy was complicated by intrauterine growth restriction, oligohydramnios, and poor fetal monitoring testing results with spontaneous decelerations. Subsequently, Amy was born by a vaginal birth with Apgars of 2 at 1 minute and 8 at 5 minutes. Amy was apneic, treated with nasal continuous positive airway pressure (NCPAP), and eventually intubated. She was then treated for suspected sepsis, but the blood culture was negative. A loading dose of phenobarbital was administered for apnea suspected to be related to seizure activity although this finding was not confirmed by electroencephalogram (EEG), and the phenobarbital was discontinued. The profound apneic episodes were associated with oxygen desaturations but not with bradycardic episodes. Amy’s physical exam was remarkable for a small head and a prominent flat hemangioma over the center forehead, eyelids, nose, and maxilla. At 2 days of life, magnetic resolution imaging of her head revealed diffuse...
polymicrogyria with involvement of the bilateral frontal, temporal and parietal lobes, affecting 60% to 70% of the brain.

The parents were informed of the diagnostic findings and told of the associated very poor prognosis. After multiple consultations with various specialists local and nationally, they decided to limit medical interventions to minimize Amy’s suffering. The parents were very eloquent in describing to the hospital medical team their personal and emotional conflict in choosing to allow a natural death for Amy. They described not wanting to watch her suffer over the months ahead, with the anticipated downward spiral and painful death with predicted complications from intractable seizures and the need for intensive care. The quality of Amy’s life as well as that of her parents and the effect this would have on their immediate family and extended community was discussed. Together the team agreed to remove all invasive lines and machines and concentrate on the quality of Amy’s remaining life.

Following extubation Amy was weaned to room air and did not require any further respiratory support. The nasogastric tube was removed, and Amy was allowed to feed as needed from a bottle with the assistance of an experienced NICU nurse. The medical team and parents discussed the difficult choice of withholding nutrition from an infant who was presently able to suck enough to receive some fluids by mouth. It appeared likely that she would not spontaneously nipple feed enough volume to support growth or development. The situation was discussed at the hospital’s ethics committee, and it was decided that it was morally and ethically permissible for nutrition and hydration to be withheld. This intervention was considered a means of palliation (Winter, 2000) causing less physiological stress and more endorphin release.

The parents, who previously had participated in vigorous attempts to provide optimal nutrition for their daughter, now supported cessation of oral and parenteral nutritional support. This decision was very difficult for them, and it was recommended that they investigate receiving care at the GMCH. They accepted and expressed that their goals were to minimize Amy’s suffering while maximizing the quality of her short life and their limited time with her. They expressed concern about remaining in the NICU where all staff were not necessarily comfortable with this choice and were reassured that the staff choose to work at GMCH because of their commitment to providing palliative and end of life care for other infants in similar situations.

Upon arrival at the GMCH, Amy and her parents moved into a one-bedroom apartment suite a short distance from the nurses’ station. They shared with staff their decision to provide Amy with the opportunity to nurse at her mother’s breast for comfort only and not offer any supplemental bottle feedings. Physician orders were written for doses of Lorazepam and morphine sulfate as needed should the infant show any discomfort. The first doses were administered on the third day after admission. She generally nursed for no more than 5 minutes a few times each day but was frequently comforted by being put to breast. She gradually became more lethargic with less desire to use the breast for comfort. Amy’s parents remained with her around the clock except for occasional periods of a few hours when they left her with the nurses who cared for her in a bassinet at the nurses’ station. She died in the bed with her parents on the 10th day after coming to GMCH.

Discussion

The advantages of an inpatient pediatric palliative care center for end-of-life care for Amy and her family were numerous. Probably the most fundamental was the paradigm shift of being able to let parents be just that, parents. Amy’s parents had been unwilling to take her home with hospice fearing that they would be unable to respond to her needs promptly in the wake of her changing medical condition. At GMCH they were able to be her parents with the assurance that expert advice and interventions were available at all hours. The role of the nurse was not to “take care” of Amy as that was her parents’ role but rather to provide anticipatory guidance and expert pain and symptom management. Her parents were able to have complete privacy and to normalize their parenting experience as much as possible. They co-slept with Amy in a king-sized bed and spent many hours outdoors on long walks. Because of the policy of patient passes, they were able to take Amy for a few hours to hike in a local redwood forest, another way in which their parenting experience was normalized.

Implementing the tenants of palliative care and demonstrating creativity in honoring a family’s wishes can lead to a meaningful death in association with non-feeding.
A unique opportunity afforded families at the GMCH is the access to palliative aquatics. The indoor warm pool located steps from the apartment suites is used to provide hydrotherapy for children and their parents. The team's observation has been that sessions in the water under the guidance of a skilled hydrotherapy nurse are powerful, therapeutic, and memorable experiences for families and infants. A staff nurse trained in palliative aquatics noted the following:

Amy is actively dying. There had been some discussion about whether it was advisable to take her in the water. She was apneic and at one point had stopped breathing for 4 minutes. We carefully discussed the details of how we would transition from land to water to land again without chilling Amy. We moved Amy carefully from suite to pool. She is on 1L of O2. We carefully placed the O2 tank near the edge of the pool. Amy's mother placed her on the mat. I lifted Amy from the mat and placed her in her father's arms. Her father (in the pool) stabilized her body in the water. We did very little movement of Amy. I did move the water under her making very gentle waves to move the water around her. Gradually Amy's arms relaxed and floated to her abdomen. She stretched out both legs. Her breathing relaxed and became deeper and more regular. Her expression was utterly peaceful. Her parents were enormously relieved that Amy responded so well to being in the water. After about a half-hour we removed Amy from the water. I called the nurses' station and warm blankets were promptly brought to the spa. We quickly rinsed Amy and wrapped her in these warm blankets and returned her to her room. The parents were very happy to have had this experience, and their anxiety was relieved somewhat.

In addition to the palliative aquatics experience, Amy's parents were able to benefit from access to the counseling services of the onsite clinical psychologist who is experienced in working with families whose children are receiving palliative care or have died after receiving care in the facility. The psychologist was able to assist them in explaining to family members the validity of and rationale for their difficult decision to limit medical interventions for their daughter.

Another unique feature of the facility and its setting is the nondenominational sanctuary located on the grounds. Amy's family, like many others, chose to use it as the location for their daughter's memorial service. Prior to that, for 2 days after her death, they were able to spend time with her body, which was kept cool in the wake room and to receive family and friends who came to pay their respects. It has been observed that many families spend up to 3 days following their children’s' death with the body in the sheltered environment in the company of supportive staff they have grown to trust. Many parents have stated that this time offers them a brief respite prior to returning to everyday life during which they don't need to explain their emotions or the death. They can just be themselves, because people here "understand what has happened and have been there with us during our very difficult time.”

Baergin (2006) discussed the need to reframe hope. Hope for quantity of time together becomes hope for quality of time together. Reframing is a hallmark of pediatric palliative care in addition to providing ongoing emotional support, shared decision making, and anticipatory guidance in what to expect and how to manage an infant or child facing a shortened life. The goal is to ensure quality, meaning, and dignity from birth to death by offering choices, communicating empathetically and honestly, and honoring wishes. Providing a loving and professionally supported environment when an infant is not fed artificially is essential whether the setting is a NICU, home, or palliative care center. Management of any untoward symptom is critical as is an understanding that no one is starving the infant, rather the infant is simply shutting down naturally. Those of us who offer end of life care feel honored to be a part of these sacred moments.

REFERENCES


