Parental "Holding and Letting Go" in End-of-Life Decision Making in the Neonatal Intensive Care Unit

Lisa C. Freitag

ABSTRACT

By the time an infant is born, his or her life has already been woven into a family narrative that forms part of the identities of parents and family members. The parents have often begun holding an identity for the expected child, and begun processing their own new identity as a parent. Philosopher Hilde Lindemann calls this narrative process "holding in identity." When a neonate is born prematurely or with severe illness, this emerging narrative can be altered or even interrupted, leaving parents in a situation, not just of fear and uncertainty, but also questioning their own identity as parents.

This article builds on Lindemann's theories of family holding infants in identity at the beginning and end of life to explore the work that must be done by all parents of a newborn, and to consider the effect that family narrative might have on decisions at the end of life in the neonatal intensive care unit (NICU). I argue that, even early in life, conflicts over a child's best interest might be framed as misunderstandings or misconceptions about the child's and the parents' identities. This article highlights parents' difficulties adapting to their new parenthood in the NICU environment, examines the common narrative of the baby as "fighter," and explores the need for parents to "let go" as part of consenting to the withdrawal of aggressive treatment at the end of life. In order to support family in the difficult task of choosing a premature ending to their severely ill child's life narrative, we must understand the relationship between parent and infant as they struggle to get to know each other in the alien NICU environment.

INTRODUCTION

According to feminist philosopher and bioethicist Hilde Lindemann, a person's identity is formed, at least in part, from narratives constructed by family and close social contacts.[1] This narrative identity is begun before birth, and continues throughout a lifetime. Lindemann believes that maintaining and upholding a unique identity for each family member is an important function of family relationships. Parents in particular are called to guard and encourage their children's emerging, unique identity as they grow and develop their own life narrative.

At times when a person is unable to maintain her or his identity for her- or himself, such as during severe illness or dementia, families can use this ongoing narrative to uphold the identity of their loved one. In her recent book *Holding and Letting Go*, Lindemann suggests that proxy decisions at the end of life that are made by family or close friends should take into account the lifelong identity of the patient.[2] In this way, medical decisions made by family surrogates can become not just decisions about what the person might have wanted, but affirmations of who the person has been. Conflicts about withdrawal of aggressive therapy at the end of life can thus be framed as arguments about the person's iden-

---

Lisa C. Freitag, MD, MA, is a Retired Pediatrician and Independent Academic Writer in Andover, Minnesota. *frei0035@umn.edu*

tity and the most appropriate way to end the person's life narrative.

Lindemann also suggests that families continue to hold an identity for a family member after death. Family members "hold in memory" the deceased person, remembering who the person was, what the person did, and, often, how the person died. I believe that family members also take on some responsibility for the events leading up to the death, particularly if they are called upon to "let go" of their loved one by actively making an end-of-life decision. The family narrative of this time might include negative feelings that make it difficult for family members to hold onto their own narrative identity. In order to cope with the death and their responsibility for it, family members must craft a new narrative that will allow them to honor and remember the person who has died in a way that is consistent with all their identities.

For infants, the creation and upholding of identity has only just begun, but still may have an impact on parental medical decision making. Because infants have not yet had a chance to emerge as the narrators of their own story, the family's holding of the infant's identify forms an even more significant part of the infant's identity. Prior to a birth, a family will often construct a deep picture of the child's personality and life story, based on their own life situation and expectations. During the newborn period, the infant's identity remains largely in the hands of the parents, as they gather information about their newborn's personality through caring for him or her. At the same time, parents must reconstruct their own identities to become the parent of this particular child. They are simultaneously learning who their child is and examining who they themselves are becoming as a result of the new addition to the family.

When a neonate is born prematurely or with severe illness, this process is confused and interrupted. Parents are effectively thrown into a narrative that does not match what they have been preparing for. In the midst of finding themselves as new parents to a new and unique person, they must also adapt to a new and unfamiliar life situation. If the baby is critically ill or not expected to survive, they must absorb complex medical information while their own lives have been altered.

End-of-life decisions are always difficult, particularly in the NICU, where life has barely begun. It is especially difficult when parents and members of the healthcare team disagree about the best interests of the baby. There are times when the NICU team understands that it is their duty to maintain life, but parents refuse resuscitation or other procedures. It can also go the other way, when parents insist on continued efforts and neonatologists recognize that further treatment is unlikely to be of benefit. These two instances are very different, both in moral reasoning and in parental understanding and motivations, so we will consider here only the latter, when parents will not accept recommended withdrawal of aggressive treatment.

Parents and NICU staff have different levels of knowledge about the available treatments and their likelihood of success. The importance of adequate communication to narrow this gap is obvious. But despite the best of communication, parents don't always come to the same conclusion as the NICU staff do about the best interests of the baby. I argue that these differences may have very little to do with knowledge level, and might, instead, be due in part to different ways of viewing the baby's identity in the context of his or her family.

This article reviews Lindemann's theories of family holding identity and identity formation in infants. Through narratives written by parents of NICU babies and statements made by parents whose infants died in the NICU, I will explore the ways that the NICU environment may alter or inhibit the identity formation of infants and parents. Parents must adapt to this environment and achieve their identities as parents despite the obstacles. We will then discuss two common narratives that might inform parental decisions at the end of life: the infant as a "fighter," and the making of memories that become an important part of "letting go."

IDENTITY FORMATION IN INFANCY

On the surface, it would seem that a newborn baby in the NICU has very little to offer in the way of a unique personal identity. Babies don't do very much that allow us to recognize their unique personalities. However, according to Lindemann, each individual's personal identity is partly formed by a narrative process she calls family "holding."[3] This holding often begins before a baby is born, as the expectation of a new member is added to existing family narratives. All infants are born not only into a time and place, but also a culture and family that will inevitably mold the person they will become. The family "holds" an identity for each member, constructed from societal expectations and, eventually, the stories told about him or her by family and close contacts. The family "maintains" this identity for each member, and it becomes the basis from which each person's individual narrative and unique identity grows. Lindemann states, "we can't be who we are without the other persons who initially hold us and maintain us in personhood."[4]

Families who are "holding well" can maintain a person's identity when it is threatened, thus maintaining their personhood for them. The most obvious example of this is in dementia in the elderly; when a family holds the person's identity for them, reminding them (and themselves) who they are through stories and photographs.[5] But this is true at other times as well. The process of maintaining an identity begins in infancy, and an identity can likewise be held for newborns, nonverbal children, and other individuals who cannot (yet) tell their own story. Eventually most children become able to tell their own story, adding to or correcting the identity formed by family. Those who cannot do so—as in severe intellectual disability—must continue in the identity crafted for them by family.[6]

In the early stages of infancy, the formation of identity takes place in the context of caregiving. As parents do routine care such as bathing, feeding, or changing, they remain open to physical cues from the infant that are clues to his or her emerging personality. They might determine oral likes and dislikes, mood or temperament, and ways of receiving comfort. Even a diaper change can become a sharing of individual attitudes. At the same time, the parents are learning their own new role as they begin to construct stories about the emerging person in their care. This process is part of parenting, and can be a source of joy as well as labor. As Noddings puts it, "When my infant wriggles with delight as I bathe or feed him, I am aware of no burden but only a special delight of my own."[7] A verbal response is not required, just responsive physical interaction.

In some cases, even this physical interaction is not required. Hilde Lindemann points out that the process of identity formation can include an individual who cannot, and may never, take part in this reciprocal responsiveness. Her example is her sister Carla, who was born with anencephaly, yet was held by her family as a valued daughter and sister. Lindemann is not alone in this. Philosopher and bioethicist Carl Elliott has suggested that we all tend to imbue even the most neurologically devastated children with personhood by treating them as persons deserving of respect, and expecting that the "child will be a part of a family like any other child, that her life will have a narrative like that of an ordinary human being."[8] He calls this "taking an attitude toward a soul." Every baby, even the most impaired, is a valued individual with a life narrative taking place within his or her family.

Families who are "holding well" can maintain a person's identity when it is threatened, thus maintaining their personhood for them.

Thus, we can assume that parents in the NICU will begin the process of discovering a unique identity for their child, even if they are unable to interact physically with a very sick baby. It is unlikely that parents will interrupt this process on being told that a poor neurological outcome is anticipated. The expected family narrative for both parents and child has been altered by the illness or disability, but parents will not hold such an infant as less of a person.[9]

Parents seem to be in agreement that each infant has a unique identity, no matter how undeveloped, when they understand that one child is not replaceable with another. In a Wisconsin study based on interviews with the parents of infants who had died in the NICU, for example, although the parents reported that focusing on their other children was "helpful" in coping with the death, all 19 of the parents who were questioned said that "having another child did not replace the child who had died."[10] I suspect that both the impact that the deceased child's existence made on the family story, and the unique identities conferred on family members by the child's life and death, contributed to this irreplaceability.

To consider an infant at the end of life in the NICU, however, we must make one more observation—that identities are reciprocal. Taking an attitude toward a soul not only creates personhood, but confers a certain identity on the person doing it. Lindemann's sister Carla, without even being aware of it, conferred on little Hilde the identity of sister, and on their mother the identity, not just of mother, but of *Carla's* mother. Thus, every child is not only presumed to have a unique identity that might emerge given time, but also gives all of the people with whom the child interacts irreplaceable identities of their own. In constructing and holding an infant's identity, family members find a new identity for themselves. I maintain that this new identity—as mother, father, sibling, grandparent—is actually more important than the infant's as yet unformed identity. Parents who must make end-of-life decisions must then defend their infant's existence and their own emerging identities in relationship to the infant.

At the end of life, "holding well" includes knowing when and how to "let go." In the final chapters of her book, Lindemann talks in detail about the ways in which an end-of-life decision might inform and be informed by a person's life narrative. She provides the example of an elderly man in an intensive care unit (ICU) following a devastating heart attack, and discusses the ways in which the medical decisions made by the patient's proxy decision maker might affirm or deny his lifelong identity. She points out that medical decisions can thus become not just decisions about what the person might have wanted, but affirmations of who the person has been.[11] Thus, conflicts about withdrawal of aggressive therapy at the end of life can be framed as arguments about the person's identity and the most appropriate way to end her or his life narrative. The events surrounding the death become part of the person's life story, and may, to some extent, redefine it.

Parents who are faced with making an end-of-life decision in the NICU must also make a decision that will define their child's life. It may be that the shortness of the life in question makes the importance of their infant's identity more, rather than less, urgent. We often speak of parents' needing to "let go" when aggressive measures are failing, but we rarely define what, exactly, it is that they are supposed to let go of. They must let go of the story they have constructed to welcome a new life into the world. I suspect that in order to properly let go, parents must first discover who they, themselves, have become as a result of the child's short existence.

Letting go is not only an action that eases the end-of-life decision. It is also the beginning of a new phase in the family's holding, in which the family holds their loved one in a new way—in memory.[12] An infant does not have a long life story to hold, but the memories of an infant's short life in the NICU are particularly intense.

The stories lived by the family, together with the act of treating the infant as though it is a full person (taking an attitude toward a soul), identify the infant as a person of value, whose short life has had an enormous impact on the stories of the family members. That impact cannot be fully encompassed in the fraught circumstances of an unexpected birth or end-of-life decision for an infant who ought to be at the beginning of life. Nonetheless, I believe that examining the way parents form an identity for their new baby, and rework their own identities in response to the birth, may be helpful in guiding parents through the most difficult decision they are likely ever to make.

We often speak of parents' needing to "let go" when aggressive measures are failing, but we rarely define what, exactly, it is that they are supposed to let go of.

IDENTIFYING AS A PARENT IN THE NICU ENVIRONMENT

In the NICU the family's narrative about what to expect at childbirth has gone wrong, often suddenly and unexpectedly. In this era of excellent prenatal care and widespread genetic screening, parents, particularly mothers, are led to believe that the outcome of their pregnancy is under their direct control. When a baby is born with serious medical issues or extreme prematurity, the family's expectations can be shattered, and the child's story is launched into a new and uncharted trajectory. The stories about what to expect can no longer be relied upon.

According to anthropologist Gail Landsman, societal pressure in the wake of improving prenatal care has created a mandate for parents to have a "perfect baby" and to become perfect parents. This expectation creates difficulties for those mothers whose babies are born with illness or disabilities, framing them as failures who "must have done something wrong." A sick baby means guilt and blame, and the parents must work doubly hard to be seen as good parents.[13] Some struggle with identifying themselves as parents at all.

Identifying as a parent is made more difficult by the NICU environment. The NICU is no place to work out the issues faced by parents who are meeting their baby for the first time. For most it is an alien place of harsh lights, urgent beeps, hushed voices, and inexplicable equipment. The expected baby's birth transmutes from an anticipated joyous event—sometimes one that wasn't due to happen for weeks or months yet—to a time of uncertainty and emotional upheaval. In this place, parents feel lost, unimportant, and perhaps not yet a parent at all. In this place a parent must go through the transition in thought and attitude that is becoming a parent.

Hendricks and Abraham, researchers in Switzerland, conducted interviews with parents who had made an end-of-life decision for their extremely premature infant.[14] Parents were asked to describe the events around their decision, recalling their experiences in the NICU one to two years after their infant's death. Some of the parents described being in a sort of mental fog of confusion and alienation. These parents were uncertain about what their contribution to the decision had been. Some reported being so dissociated from the activities in the NICU that they felt there had been no decision at all; that there never had been any choice to be made. Other parents reported being confused or in shock, and unable to make decisions. One mother stated, "I so to speak just watched as if I was not involved. . . . I was not really aware, and I could not really perceive the situation. It was as if in a dream, it could not be true, everything was fine. It took a while before I completely understood that it was my child, my child who was dying."[15]

Hendricks and Abraham state that there had been ongoing efforts in their NICU to involve parents actively in decisions. This demonstrates a level of confusion and dissociation that interferes not only with decision making, but also with coming to recognize oneself as a parent. The Swiss researchers felt that good communication between parents and staff was key, but I wonder how this can be attained if parents are in a fog of disbelief so deep that they doubt their own parenthood, if not the reality of the whole situation.

Even familiarity with the NICU environment does not immunize against this feeling of being lost and confused. When my son was born at 33 weeks, as a pediatrician who had dealt with many sicker babies, I knew that he was in no danger. I knew the function of every one of the things surrounding him, and the meaning of every monitor beep and lab result. Yet there was nothing that I could do that even resembled my idea of motherhood. Picking him up and breast-feeding him, as I was eventually urged to do, seemed preposterous. I couldn't learn how to be a mother. Instead I fell back on my role as pediatrician, examining the charts and watching the monitors until the nurses shooed me away.

Several mothers of extremely premature infants have attested to the difficulty of accepting motherhood in the NICU. Vicki Forman, in her memoir about her 23-week premature twins, confesses that she needed several days to start to claim them as her own. Her first acknowledgment of her motherhood, seeing her helpless infants in their isolettes, was to ask herself, "Who will love them if not me?"[16] Another mother, Deanna Fei, whose daughter was born at 23 weeks, writes in her memoir, "The only way to brave this limbo is simply to bear witness. To bear witness is to know her as she is, no more and no less. To know her is to love her, because she is mine, because I am her mother. The more I love her the harder it gets."[17] Later Fei attests to the ongoing learning process of motherhood: "Each day she survives is another day she has survived. Each day I hold her is another day that I'm learning to be her mother."[18] Both of these women had difficulty accepting their premature motherhood, as well as figuring out exactly what that new identity meant to them.

Many mothers, both in memoirs and in research studies, describe the sensation of standing by helplessly as others converge on the infant to provide care. The baby seems to need doctors and nurses, not the clueless parents. Another study investigated how women experience becoming a mother in a NICU in Sweden.[19] Interviews with mothers of preterm infants who had been in several different NICUs in Sweden revealed that mothers felt a sense of separation that kept them from feeling like mothers. Some thought that they were extraneous—their baby required medically trained staff, not the sort of caregiving they had anticipated. One mother felt that she was actually in the way when she visited.[20] Another mother in the same study said, "Well, it's like having a baby but still not having . . . it's not really my baby. Because without the hospital and the incubator this baby would not live one day. So, you're having a baby in a glass cage that you can visit."[21] The baby needs so much more than the parents can provide, and nurses often must take over even basic care tasks.

Parents in both the Swiss and Swedish cohorts reported that their role as parents was made more difficult by the lack of physical contact with their baby.[22] As I mentioned earlier, much early information about a baby's personality comes through caregiving, as the baby reacts to new stimuli, foods, and experiences. The things that cause crying or give comfort become part of a developing identity. If identity formation for both parents and infant does occur in the context of physically caring for a newborn, it should not be surprising that parents in the NICU have trouble both getting to know their baby, and learning who they have become as parents.

Recognizing this, several strategies for involving parents in NICU care have been proposed. Breast-feeding is often suggested as an important maternal activity that will involve the mother and perhaps boost maternal confidence. If breast-feeding is going well, mothers did report pride in "being such good mothers." But mothers required a lot of support and reassurance to negate bad feelings if the feedings were not going so well.[23] And there are some hints that this optimistic and positive action might prove to be an additional burden if the baby dies. Mothers whose baby had died in the NICU reported that attempts to express milk had been stressful, and that lactating during the baby's death increased their suffering.[24] This is a way for mothers to connect and "do something" for their baby, but it seems inadequate if not burdensome if the infant does not ever get the milk.

In a study from the U.K., researchers observed parents' interactions with infants who were still in the NICU. Parents were actively taught to read their baby's signs of discomfort so that they could participate in comfort care. Parents were able to overcome their hesitancy to touch their infant, make acute observations about the infant's behaviors, and sometimes even contribute information valuable to the staff in providing care. This allowed parents to "develop a unique knowledge of their own infants," and "establish their own roles as caregivers."[25]

Fathers also experience difficulty with separation and are frustrated by their inability to give care. The father of a 24-week preemie writes in his memoir, "Intent on making us active, if symbolic, participant's in Josie's care, [the nurses] showed us how to change her doll-sized diapers, how to put lotion on her skin if it was dry, and how to hold her hands and feet in tight to her body to calm her if she was stressed. . . . This was as much as we could do for Josie at the time, and there were many days when she was so agitated and so stressed that we could do nothing."[26]

I suspect that any measures taken by NICU staff to increase parents' involvement can be only partly effective. Parents will have difficulty accepting their new circumstances in this alien environment where they are, essentially, helpless. Perhaps they can come to terms with this frustration as the NICU stay extends, but it certainly delays the process of feeling like one has become a parent.

Perhaps this is the reason that homecoming figures so strongly in parents' memoirs. Longing for home is a frequent theme in parents' narratives of their NICU experiences. Vicki Forman likely speaks for all parents when she writes, ". . . all you ever wanted when your child had been in the hospital for prolonged periods of time: to be home."[27] Part of this longing is undoubtedly due to the impression that the ordeal will finally be over when the baby comes home. "Graduating" from the NICU is the final step in a series of NICU achievements, and signals an end to the relentless NICU "roller coaster."[28] But home is also the place where parents are finally given charge of their own infant, and can engage in all of the activities of parenthood. They have full responsibility for caregiving, and full access to their infant. Forman states that she did not dare fall in love with her son until she got him home.[29]

There is very little we as practitioners can do to alter the NICU environment so that it is more comfortable and engaging for parents. The birth of a sick baby will remain a time of disorientation and fear. And babies will continue to need scarily dramatic and invasive care in order to survive. I believe most NICUs do well in supporting parents through the disorienting experience that must take place in this foreign and intimidating space.

But parents, particularly mothers, are searching desperately to identify themselves, not just as parents, but as good parents for their infant. There is no instruction book for becoming a parent of a baby who is very ill or dying. This is not what they were expecting when they were "expecting." They no longer know how to act or who they must become. Perhaps all we can do is be aware of the enormous shift that the altered conditions of their baby's birth has made to their life story. Rewriting this narrative is by necessity a slow process, which will likely continue well beyond the infant's NICU stay. Many parents must revise their identity as parents, and must be affirmed in that role—slowly, patiently, and persistently—while they do so.

THE BABY AS "FIGHTER"

Finding a new identity as a parent does not rely on specific personality traits of the baby. I found no evidence of parents who claimed specific knowledge of "what the baby wanted" or "who the baby is." But there is an identity specific to the infant that NICU babies often acquire—that of being a "fighter."

The language of illness as a personal battle is everywhere. It is high praise given to people with a serious illness—adults and children alike. It is so common that there is practically a moral mandate to be a "fighter." Woodwell says of his premature daughter, "We had a real fighter there, someone special."[30] Charlie Gard's mother, who achieved international attention and sympathy for refusing doctors' recommendations to withdraw treatment, said, "We don't know until we try. He's still fighting, and we're still fighting."[31] The moral overtones of being a "fighter" are clear. It is so special and admirable that it can be equated to a fight for justice.

It may be worth examining how babies become "fighters." I have frequently heard the term used by NICU staff as encouragement or reassurance for parents. The baby is a fighter because he or she wiggles during an exam, or resists an IV insertion, or even is able to go down a notch on ventilator settings. The praise transfers from infant to parent.

Anthropologist Linda Layne, after having her baby at 30 weeks, studied the language used with parents in the NICU. She found the metaphor of the "roller coaster ride" to be both prominent and helpful for understanding the "alternating moments of hope and despair that [she] experienced" during the "seven long weeks" that her baby was in the NICU.[32] No matter their eventual outcome, NICU babies do indeed have both progress and setbacks during their NICU stay. I believe that it is during those rebounds, at the top of the roller coaster's progress, that babies become "fighters."

Nurse researchers in Norway have been studying a quality in NICU babies that they call "vitality." They observed infants and interviewed both nurses and doctors, and conducted interviews with parents who had recently experienced making end-of-life decisions. The nurses define vitality as an elusive but observable quality that is "used synonymously with the verbal expressions 'spark of life' and 'fighting spirit.' "[33] This seems very like identifying a NICU baby as a fighter. Vitality was detectable by parents, neonatologists, and experienced NICU nurses as a certain strength, level of activity, and reactivity. Infants who demonstrated it were felt to be "able to protest and struggle in resistance, to be active and decisive," to be "demanding," "gutsy," and even "angry."[34] The researchers felt that the babies who showed vitality were more likely to survive, and proposed the use of vitality as a moral addition to the factors that should be taken into account when making end-of-life decisions.

The baby is a fighter because he or she wiggles during an exam, or resists an IV insertion, or even is able to go down a notch on ventilator settings. The praise transfers from infant to parent.

Interestingly, the researchers ascribed several moral qualities to those infants who demonstrated vitality, as though vitality was attained not by survival instincts but by strong moral fiber. Babies with vitality had "an ability to 'decide' their own fate" and babies without it seemed "as though they would rather not live." Babies with vitality were "different from all the others" and "someone special." Vitality was "a signal that they would not give up, that they were little Vikings. The infants decided themselves how things would turn out."[35] They had "the will to come out of a hopeless situation."[36]

The study did not, unfortunately, record the adoption of the term vitality by parents, although a few of the parents who were interviewed did report on the presence or absence of it in their baby. The researchers defended its use as an instinctual measure that could and should be used to aid the making of end-of-life decisions, but they did not report on its ultimate effect on such decisions in their NICU. In particular, they did not report instances when a baby's level of vitality diminished or when there were differing opinions on an infant's vitality that might have increased the difficulty of making end-of-life decisions.

I suspect that impressions of vitality or the assignment of the identity of "fighter" cannot be easily cast aside if an infant's condition declines. As the parents ride the roller coaster of the NICU experience, they are encouraged by the term. They seem to take pride in their baby's identity as a fighter, and in themselves as good parents for their part in his or her continued survival. Once a baby has been identified as a fighter, possibly merely by surviving numerous setbacks, it is perceived that he or she has declared a will to live.

Linda Layne postulated that, because our culture prefers linear narratives with a known ending, parents tend to choose between a narrative of survival or one of death. In order to cope with the day-to-day disappointments and advances, they tend to focus on and prepare for one outcome or the other.[37] However, I believe that parents alternate between these two narratives, alternately planning futures and funerals as they ride the ups and downs NICU roller coaster. When a baby overcomes multiple setbacks, thus becoming a fighter, parents are perhaps more likely to begin to insist that a positive outcome is assured.

At the end of life, an identity as a fighter can be toxic. To the parents, approached for permission to withdraw aggressive care, the idea of withdrawal looks very much like giving up. Not only is this culturally and morally impermissible, but the infant "fighter" has shown his or her preference for survival by surviving so far. He or she could not be giving up. Good parents may feel that it is their parental duty to protect their infant and stand against withdrawal of aggressive care.

At such times, NICU staff often resorts to the language of suffering. But once a baby becomes a fighter, suffering becomes inconsequential. Several of the words used to describe vitality can also be used to describe discomfort; protesting and struggling perhaps in response to painful procedures. Parents have probably been reassured that none of the intrusive things that have been done so far are hurting their baby and that any pain was treated with narcotics. So, for a fighter baby, either suffering has been negated by comfort measures, or any suffering is a sign of life, a ticket that has already been at least partially paid. The baby has consented to it by the fact of survival, demonstrating a will to live.

When we ask parents for permission to withdraw aggressive care, we are telling them that it is time to give up, and perhaps implying that their baby is not a fighter after all. Perhaps it signifies that all of the suffering the baby (and they) have been through was a wasted effort. If so, we need to provide a more appropriate identity that does not negate the struggle so far. Perhaps the metaphor of a battle valiantly lost would suffice, although I rather dislike war metaphors in medicine. Perhaps a tragic destiny too strong to be overcome would be more poetic. Or perhaps we should just own up to the fact that medicine cannot make good on all of its perceived promises. Death is no one's fault, dying is not a tragic flaw, and our mistake is in overstepping our bounds once again, like Icarus flying too close to the sun.

HOLDING IN MEMORY

I mentioned above that Hilde Lindemann's theories of family holding suggest that, after the death of any family member at any age, the survivors must learn to hold their loved one in memory. This holding encompasses grieving for the death and remembering the ways in which the dead person held you, while alive. The person's life story can be told and retold at funerals, ceremonies, and by other memorials.[38]

The families of neonates who have died also have their infant's life story, however brief, to remember and to tell. In the Wisconsin study of parents' experiences with end-of-life care in the NICU, the participating parents all brought mementos of their deceased baby to show the researchers. These families saved and cherished artifacts from the infant's NICU stay: photographs, footprints, and clothing. Many still celebrated the infant's birthday, or acknowledged their child's absence at holidays to keep the infant's memory alive. Several wished to make donations or participated in volunteer activities as a legacy to their child.[39]

A study of parents' narratives following the death of a baby with trisomy 13 or 18 done in Saint Louis, Missouri, found that telling the child's story was very important to parents. Many reported that telling this story was the reason they'd agreed to participate in the study, that they found the telling helped to support themselves, and, they hoped, would have an impact on others.[40] Their infants had spent an average of 74 days in the NICU, and some had gone home before dying. The infants had an identifiable genetic trisomy known to have dire consequences on survival. However, I doubt that this significantly alters the importance to parents of the infant's life story.

The researchers reported that parents "saw their child as having a name, a personality, meaning and purpose. They understood them as being woven into a framework of relationships that included their family, their friends and their God."[41] This echoes Lindemann's theories about family holding, and the way in which we actively bestow personhood through taking "an attitude toward a soul." These are babies who would not have been resuscitated a decade ago. Perhaps resuscitation both creates and confirms their identities as persons or "souls." The NICU made it possible for them to have a life story, but their families are responsible for living the story and holding it in memory or otherwise.

The way in which a person dies, in my experience, is a large part of the story that is eventually told about them. The family must deal with, not just the loss of their loved one, but the memory of the part they may have played in the death and the events leading up to it. Survivors often accept guilt that is not rationally theirs, and continue processing the experience for years after a death, making statements like, "If only I had called the ambulance sooner," or "Maybe we should have transferred to a different hospital." I have concluded that all of the survivors (including medical staff) need to arrive at a story they can live with. That story is likely to be less painful if they do not feel personally responsible for causing or contributing to the death.

Anthropologist and nurse Jacquelyn Slomka has reported that end-of-life discussions between physicians and families often become a form of negotiation during which "moral responsibility" for the death is shared. Everyone desires to avoid responsibility for causing the death. In her study of adult patients in the ICU, she observed that physicians attempted to shift responsibility to the family or to the patient, who would be encouraged to decide to withdraw aggressive treatment. Or all parties might wait for an unresponsive patient to "declare himself." Both the family and the staff needed eventually to accept some of the moral responsibility for the failure of medicine to prevent the death.[42]

It is perhaps not surprising that some parents, faced with tragedy at a time that should have been the beginning of a life, will refuse to share that responsibility. Perhaps their confusion and denial will allow them to avoid the decision, or their part in it, altogether. However, in my experience, some perceive a request for permission to withdraw aggressive treatment as an effort to make them help "kill their baby." If the baby has previously declared him- or herself to be a fighter, the parents might take an even more active stance, insisting that the baby deserves to stay alive no matter what support might be required to maintain that life.

The NICU made it possible for them to have a life story, but their families are responsible for living the story and holding it in memory or otherwise.

When parents are studied regarding their perspectives on end-of-life care, they agree that parents should participate in end-of-life decisions, although the actual extent of their participation varies.[43] In addition, several parents in the Swiss study who had fully accepted their part in making a decision to withdraw aggressive therapy pointed out that making that decision required a high level of parental responsibility.[44] It is likely that some parents are not ready to accept this responsibility. Some are in shock or denial, and perhaps do not recognize the decision they are helping to make. Others, however, seem to refuse to participate.

I believe that many parents who refuse to allow withdrawal of aggressive therapy fully understand what they have been told about their child's dire illness, the story as told by the physicians and the medical records. Even when parents do not understand or are in a fog of disbelief, it is unlikely that it will be effective to simply repeat the medical staff's story. Instead, parents need to be given a different story, a different way of being a parent, rather than fiercely guarding life. This story is not told by the infant's medical course, but must be found in the parents' stories of becoming parents in a hostile environment and accepting the child as their own.

They must remember that they were good parents, standing by their child in crisis, and giving him or her every chance. They must remember that their child—whose identity and life narrative will always be held only by themselves—was resuscitated, lived in the NICU, and ultimately could not stay with them.

Vicky Forman asked for, and was reluctantly granted, withdrawal of life support for her daughter Ellie, who was born at 23 weeks and lived for three days on maximal life support before having a grade IV intraventricular hemorrhage. In her memoir written 10 years after Ellie's death, Forman wrote, "I will never have the answers to the questions surrounding Ellie and her short life. What if we hadn't insisted—would she have survived? What if I had been more ready to raise a profoundly disabled child—would that have made us better people? What if another set of parents had been in the same situation—would they have made the same decision?"[45] Her memoir attempted to find an answer to these questions, but did not entirely succeed. She lived those 10 years with sole responsibility for her daughter's death.

A more desirable outcome was expressed by one of the parents who participated in the study in Switzerland. Recalling the decision she shared with her physicians at the end of her baby's life in the NICU, the mother said, "I did not experience this moment as a freedom but rather as a responsibility of course because the baby could not decide for herself. We are her parents and we should make this decision. . . . Now in retrospect, I regard that as a great act of love. But in those hours, I thought I would die. But you do not die and you go on and you have to decide."[46] This is a statement full of sorrow, but also of strength. It acknowledges the difficulty and responsibility of her decision to allow the neonatologists to withdraw therapy. She can carry forward this singular act of love as she holds in memory the infant who is still, and always will be, hers.

We must find a way to promote the sort of strength that makes allowing death into an act of profound parental love, although I suspect that, since each parent's narrative is different, there is no consistent way to do this.

We must find a way to promote the sort of strength that makes allowing death into an act of profound parental love, although I suspect that, since each parent's narrative is different, there is no consistent was to do this. Perhaps we, too, must learn to accept the inevitability of death. Perhaps we must assume more responsibility for death ourselves by admitting the limitations of medicine more often. Or perhaps we can allow death to occur without assigning fault or failure to anyone. At best, we can hope to stand by the parents' side while they begin rewriting the narrative of their baby's life. We can acknowledge that, whatever happens to their baby, they remain forever the mother or father of that particular life. Even if the baby dies, the parents will be coming to terms with their NICU story, and holding their infant in memory for the rest of their lives.

CONCLUSION

Infants have a unique identity that begins to be formed by their families before birth. This identity is relational, and the infant's identity grows along with his or her parents' identities as the parents of that particular child. In the NICU, some of the identity work that must be done by the parents is interrupted by the suddenness of the birth, the presence of illness, and/or the assumption of specialized care by the NICU staff. When a baby is unlikely to survive and withdrawal of aggressive care is recommended, the fragility of the parents' identities may add to the difficulties with parental decision making.

Each infant's identity is unique, and every story must be different, but there are common themes. The NICU environment is almost universally foreign and overwhelming. This, as well as the unexpectedness of a sudden birth, contributes to a sense of disorientation and unreality. Parents are thrown into this new narrative and don't know how to act. Some have difficulty assigning themselves the identity of parents, and will need to be shown the way to becoming good parents despite the infant's setbacks.

It is perhaps unfortunate that parents and neonatal staff alike have adapted the language of battle and assign to infants the title of "fighter." This is both a descriptive and moral term. It is given to babies who survive multiple setbacks, and identifies them as having an admirable desire to live. However, we must be aware that it may become a difficult label to overcome if medical treatment is not sufficient. There are times when the fighter narrative must be set aside and a new story created. This narrative is only partly found in medical facts, so the identity work cannot be done by bluntly repeating a dismal prognosis. It must be done by gently reconstructing the parents' ideas of what it means to be parents.

Parents can perhaps be guided toward a story that works for them, acknowledging the infant's difficult life while still preserving its meaning. In the midst of confusion and grief, parents need to find a story where the best and most loving thing they can do for their baby is accept death. They need to be shown how to hold their child and themselves in their identities, and also to let go, so that they can continue to hold their child in memory. Those identities must not burden them with guilt or label them as bad parents. They need help to craft memories that celebrate the child's existence, yet permit that existence to end.

They need to create a story they can live with.

NOTES

1. H. Lindemann, *Holding and Letting Go: The Social Practice of Personal Identities* (New York, N.Y.: Oxford University Press, 2014).

2. Ibid.

3. Ibid.

4. Ibid.

5. H. Lindemann, "Holding one another (well, wrongly, clumsily) in a time of dementia," *Metaphilosophy* 40, no. 3-4 (2009): 416-24.

6. L. Freitag and J. Liaschenko, "Holding Ashley (X): Bestowing Identity through Caregiving in Profound Intellectual Disability," *The Journal of Clinical Ethics* 28, no. 3 (Fall 2017): 189-96.

7. N. Noddings, *Caring: A Feminine Approach to Ethics and Moral Education* (Berkeley, Calif.: University of California Press, 1984), 52

8. C. Elliott, "Attitudes, souls and persons: Children with severe neurological impairment," *Mental Retardation and Developmental Disabilities Research Reviews* 9 (2003): 16-20, 18.

9. L. Freitag, *Extreme Caregiving: The Moral Work of Raising Children with Special Needs* (New York, N.Y.: Oxford University Press, 2018).

10. C.L. Brosig, R.I Pierucci, M.J. Kupst, and S.R. Leuthner, "Infant end-of-life care: The parents' perspective," *Journal of Perinatology* 27, no. 8 (2017): 510-6, 514.

11. Lindemann, *Holding and Letting Go*, see note 1 above, pp. 160-201.

12. Ibid.

13. G.H. Landsman, "Reconstructing motherhood in the age of 'perfect' babies: Mothers of infants and toddlers with disabilities," *Signs: Journal of Women in Culture and Society* 24, no. 1 (1998): 69-99.

14. M.J. Hendriks and A. Abraham, "End-of-Life Decision Making for Parents of Extremely Preterm Infants," *Journal of Obstetric, Gynecologic and Neonatal Nursing* 46, no. 5 (2017): 727-36.

15. Ibid., 732.

16. V. Forman, *This Lovely Life: A Memoir of Premature Motherhood* (New York, N.Y.: Houghton Mifflin Harcourt, 2009).

17. D. Fei, *Girl in Glass* (New York, N.Y.: Bloomsbury, 2015), 71.

18. Ibid., 181.

19. R. Flacking, U. Ewald, K.H. Nyqvist, and B. Starrin, "Trustful bonds: A key to 'becoming a mother' and to reciprocal breastfeeding: Stories of mothers of very preterm infants at a neonatal unit," *Social Science & Medicine* 62, no. 1 (2006): 70-80.

20. Ibid., 74.

21. Ibid.

22. A. Abraham and M.J. Hendriks, " 'You can only give warmth to your baby when it's too late': Parents bonding with their extremely preterm and dying child," *Qualitative Health Research* 27, no. 14 (2017): 2100-15; Flacking, Ewald, Nyqvist, and Starrin, "Trustful bonds," see note 18 above.

23. Flacking, Ewald, Nyqvist, and Starrin, "Trustful bonds," see note 19 above, p. 76.

24. Abraham and Hendriks, " 'You can only give warmth to your baby when it's too late,' " see note 22 above.

25. C. Skene, L. Franck, P. Curtis, and K. Gerrish, "Parental involvement in neonatal comfort care," *Journal of Obstetric, Gynecologic, and Neonatal Nursing* 41, no. 6 (2012): 786-97, 795.

26. W.H. Woodwell, *Coming to Term: A Father's Story of Birth, Loss, and Survival* (Jackson, Miss.: University Press of Mississippi, 2001), 135.

27. Forman, *This Lovely Life, see* note 16 above, p. 139.

28. L.L. Layne, " 'How's the baby doing?' Struggling with narratives of progress in a neonatal intensive care unit," *Medical Anthropology Quarterly* (December 1996): 624-56.

29. Forman, *This Lovely Life, see* note 16 above, p. 146.

30. Woodwell, *Coming to Term,* see note 26 above, p. 288.

31. A. Park, "When Parents and Doctors Disagree on What Futile Means," *Time,* 13 July 2017, *https://time.com/4856228/charlie-gard-parents-doctors-trump-pope/.*

32. Layne, " 'How's the baby doing?' " see note 28 above, p. 632.

33. B.S. Brinchmann and P. Nortvedt, "Ethical decision making in neonatal units: The normative significance of vitality," *Medicine, Health Care, and Philosophy* 4 (2001); 193-200, 194.

34. Ibid., 195.

35. Ibid.

36. Ibid., 196.

37. Layne, " 'How's the baby doing?' " see note 28 above.

38. Lindemann, *Holding and Letting Go,* see note 1 above, pp. 193-201.

39. Brosig, Pierucci, Kupst, and Leuthner, "Infant end-of-life care, see note 10 above.

40. J.D. Arthur and D. Gupta, " 'You Can Carry the Torch Now:"' A Qualitative Analysis of Parents' Experiences Caring for a Child with Trisomy 13 or 18," *HEC Forum* (May 2017): 1-18.

41. Ibid., 234.

42. J. Slomka, "The negotiation of death: Clinical decision making at the end of life," *Social Science & Medicine* 35, no. 3 (1992): 251-9.

43. Hendriks and Abraham, "End-of-Life Decision Making for Parents," see note 15 above.

44. Ibid.

45. Forman, *This Lovely Life,* see note 16 above, p. 31.

46. Hendriks and Abraham, "End-of-Life Decision Making for Parents," see note 14 above.