

Ethical Issues in Newborn Care

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SELECT ANNIVERSARY CONTENT



Five Incredible Babies, Five Paradigm Cases That Greatly Influenced Neonatal Ethics

What Do Their Parents Say Today?

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ABSTRACT

As the National Association of Neonatal Nurses celebrates its 25th year, we look back at 5 cases that reflect the times in which these babies were born and whose stories have impacted the development of neonatal ethics. These 5 stories take us through the periods of "all must be done" to "parents can choose" and to "are we overdoing?" Neonatal nurses can receive guidance from these wise parents today.

KEY WORDS: neonatal ethics, NICU, parents

MARIANNE ROGOFF AND "SILVIE"

Silvie (Figure 1) was born on February 6, 1988, the firstborn daughter of Dan and Marianne Rogoff, young teachers and writers living in a small town on the Northern California coast. The pregnancy was happy and healthy but their full-term baby girl failed to come to life at birth. After 10 days in the NICU at the University of California, San Francisco (UCSF), Silvie's diagnosis was extreme brain damage, most likely due to oxygen deprivation during a long labor. The parents were told that their baby girl would never eat, cry, or grow, and were sent home, where she was expected to die within a day or 2. A much-loved and beautiful red-haired girl, Silvie did not die; she continued to live on in limbo, not dead, not alive—for days, weeks, and months—which raised profound medical, ethical, legal, moral, and philosophical questions.

"What is the sound of a baby who does not cry? What do you do when there are no answers to your

questions? What is the nature of Silvie's life?" These questions appear in the book Marianne Rogoff wrote in answer. *Silvie's Life*¹ was published in 1995 and is a riveting account of parents wrestling with the weight of the expectations all parents have for their newborn against the reality that life does not always turn out like we hope and plan. "Being pregnant is called expecting" is the book's first sentence.

At 7 months, Silvie was still alive, surely because of love alone. But she failed to thrive, remained unconscious, and was growing smaller and frailer despite following prescribed treatment plans. Forced to become experts on nasogastric tube feeding and to ponder the mercy of euthanasia, the Rogoffs were told in follow-up visits to UCSF physicians that they would be murderers if they withheld treatment and allowed their baby to die.

Deep soul-searching and painful observation of the baby's deteriorating condition led the Rogoffs to seek sanctioned support for her natural death from Hospice and their family doctor. The strength of the parents' desire to honor what they felt was in the baby's best interest gave them the courage to take a stance and, within the boundaries of morality and the law, provide a peaceful death at home for their baby girl.

The story of "Silvie's Life" sparked ethics researchers to develop a palliative care protocol for dire newborns and was instrumental in shaping guidelines that will allow such infants to die with dignity, supported by healthcare staff and family. The short paperback of "Silvie's Life" is used in ethics classes nationwide and has significantly influenced international neonatal ethics

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FIGURE 1.



Silvie. Reprinted with permission.

conversations in Portugal through a translated edition.¹ “Silvie’s Life” has been presented on the same program at international bioethics conferences along with *Diving Bell and the Butterfly* and *Tuesdays With Morrie*.

Marianne has these words for healthcare providers in the NICU today:

Thank you for the work you do. Thank you for respecting the complicated and personal nature of parents’ diverse responses to a newborn in crisis. Thank you for recognizing that death is not always the worst outcome, and that palliative care may sometimes be the best way to “do no harm.”

Marianne Rogoff is an author and editor who teaches Writing and Literature at the California College of the Arts. She is the mother of a grown son, Duncan, a lively, healthy college junior. She may be reached at mrogoff@cca.edu.

MARK MILLER AND SIDNEY

Sidney Miller was born to Mark and Karla Miller at approximately 22 weeks of an uneventful pregnancy, with what all agreed was a tragic miscarriage in the making. Every step, medication, and precaution were made to defer what was happening. The Millers agreed to everything to prolong the pregnancy to a time where the viability of the fetus was competent to survive. They were consulted and informed and were

in constant communication with Karla’s obstetrician, as well as with all the specialist consults he could find. Mark Miller states,

We heard detailed scenarios associated with the timelines for organ maturity during the gestational timeline for a normal pregnancy. We clearly understood that the crisis that brought us to the hospital in the middle of that night was serious, and the prognosis, agreed upon by every physician we spoke with, for success for a birth at this time in Karla’s pregnancy was non-existent and the maladies associated with survival from each and every one of the treatments would “guarantee” severe life long handicaps that would certainly rule out any quality of life for a child born too soon. We agreed with our physicians that Sidney be born, held, and allowed to die with dignity and love in her mother’s arms.

Mark continues,

What happened to us next and to Sidney *over our express objections* was unfortunate, misguided, and brought about by the unnecessary intervention of local corporate administration that had no stake in the outcome, nor any legal or moral business interfering in the decisions between a patient and her physician, nor with legal and competent parents to make healthcare decisions for their newborn child.

Sidney was ordered by the hospital administrator to be resuscitated and taken to the NICU for life-extending technological treatment without informing the Millers or asking their consent. The Millers then took home their physically and neurologically impaired child.

The Miller case gained worldwide recognition and garnered debate in medical and ethics journals from every country in every language. Treatment against a parent’s will was passionately debated, and the Millers were vilified by some and evoked hero status to many others. Today Sidney Miller is alive but she is multiply handicapped and severely delayed and cannot walk, talk, see past a few feet, or care for any of her own mental or physical needs. In 1998, a jury awarded the Millers compensatory funds for lifetime care, in addition to punitive damages. The jury found that 150 years of Texas law served as a foundation that the Millers’ interests were violated and that the actions of the corporate healthcare organization, Hospital Corporation of America, were indeed negligent and in fact a direct cause of all the conditions Sidney suffers from today.

Unfortunately, the Texas Supreme Court subsequently overturned this decision. One author reviewing the case claims that “A ruling in favor of the parents would have meant that parents always have the right in advance of birth to refuse treatment for premature newborns.”^{2(p39)} This left the Millers lacking in funds to care for Sidney’s many ongoing needs.

FIGURE 2.



Sidney. Reprinted with permission.

Mark Miller states today,

Our family lives with decisions made for us by others. Those are very strong words in our society and the impact is made stronger when they affect you personally and the lives of ones you are responsible for and love. We are forced to live with the devastating results of the hospital's decisions. Our most feared concerns all stem around the single question: Who will provide for our severely handicapped daughter after we are gone? (Figure 2)

DIANNE MARONEY AND MACKENZIE

Mackenzie was born 14 weeks early on April 21, 1993, weighing 1 lb, 12 oz (790 g). During her 108 days in the NICU, the severely premature infant survived lung disease, heart problems, sepsis, poor growth, eye injury, blood transfusions, and a serious aspiration of formula into her lungs. Mackenzie's struggles did not end once she came home from the hospital. As her mother puts it, "No words can begin to describe the months of heartache or the intense suffering experienced by one exceptionally strong little girl."

Dianne Maroney is, in fact, a NICU nurse and believed she could handle any medical needs Mackenzie might have. She quickly learned otherwise as the family was swept into a whirlwind of specialists, therapists, and medical supply companies. The Maroneys were overwhelmed with caring for a child

on oxygen, using machines to measure her heart rate and oxygen levels, and living with a constant need to watch her for illness. Mackenzie's esophagus and stomach were not working properly so a feeding tube was surgically placed. At 8 months, she came down with influenza and respiratory syncytial virus simultaneously and was hospitalized for 5 days.

Mackenzie required supplemental oxygen for 3½ years. Being attached to a 50-ft oxygen cord became hard for Mackenzie once she began to roll, crawl, and walk. Mackenzie developed with significant delays in her fine and gross motor skills; her speech; and her ability to absorb sounds, touch, and smells in everyday life (sensory integration problems). She saw therapists for 3 years, and over the next 5 years, Mackenzie underwent 2 more surgeries. She suffered severe oral aversion and had a terrible time eating. At the age of 6 years, Mackenzie was small for her age and her muscles tended to be weak, but the Maroneys enrolled her in a gymnastics class and it helped improve her strength and coordination.

Mackenzie is now in high school. The family members feel fortunate that their daughter has few long-term complications from her prematurity and the many early challenges she faced. Dianne reports, "Mackenzie is thin, still a picky eater, and school is challenging, but overall she is healthy, sassy, and social."

Dianne Maroney says,

I attribute much of Mackenzie's success in life to the abundance of love we gave her, our being proactive with her care, our diligence in staying on top of any issue we recognized, and being open-minded regarding her treatments. We have used a variety of alternative therapies over the years, including Homeopathy, Acupuncture, and Energy Healing Techniques. Mackenzie is the love of our lives and will forever be an inspiration for her courage through the many battles she has fought and won.

When Dianne is asked what she might have done differently, she states,

I would have sought help earlier for myself. The trauma I experienced around her early birth was intense and threw me into a tailspin that took years to unwind. When a mother is traumatized, the baby and family are too. It's important to find the right help and not think you can do it all alone. I would have held Mackenzie more and treated her more like a real and typical baby. My focus on her health overwhelmed our ability to bond. It's taken years to repair the lack of bonding and I think we are still working on this area.

To nurses and physicians, Dianne says,

Encourage more holding and bonding. It's extremely important in the health of the baby, mother, and family. Allow and encourage more psychological help for families, during and after the NICU. Promote alternative therapies. Educate the nurses/doctors as to the

FIGURE 3.

Mackenzie. Reprinted with permission.

options and what might help each family. I do believe that western medicine is not complete in helping anyone who has been through the intense trauma we have.

Today we see a beautiful young woman and, as neonatal nurses, we wish all of our complex infants to develop into the Mackenzie Maroneys of the world (Figure 3).

Dianne Maroney is now a clinical nurse specialist with a master's degree in psychiatric/mental health nursing. She has coauthored a book, *Your Premature Baby and Child: Helpful Answers and Advice for Parents*.³ Dianne is trained and/or certified in many forms of alternative healing. She has developed a Web site www.healthandhealingalternatives.com.

AMY KUEBELBECK AND GABRIEL

In April of 1999, Amy Kuebelbeck was 25 weeks' pregnant when she learned during a routine ultrasound that the left side of their baby's heart had not developed properly. Amy was told that the pregnancy likely would continue normally and that once the baby was born, the family would have a decision to make. They could choose to have a series of 3 high-risk open-heart surgeries, a heart transplant based upon finding an infant donor, or they could allow the baby to die receiving comfort care.

Amy's loving and intelligent book *Waiting With Gabriel: A Story of Cherishing a Baby's Brief Life*⁴ describes the devastating process of getting the news and deciding what to do. Regarding the choices, Amy writes, "Not to intervene would mean standing by helplessly while our baby died. No parent should have to face such a chilling, hopeless 'option.'" Yet, she asks, "Just because a medical course of action exists, is that reason enough to take it?"

Amy quotes Deborah L. Davis, author of *Loving and Letting Go: For Parents Who Decided to Turn Away From Aggressive Medical Intervention for Their Critically Ill Newborns*.⁵

Parents who turn away from aggressive medical intervention for their infants are sometimes scorned in this age of high technology and incredible advances. There is a lot of social pressure to "go for it" Parents who

choose 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.⁵

Amy and her husband Mark were a well-educated couple who already had 2 healthy little girls at home. The decision they made would affect the entire family, and they did not make it lightly. They researched and read everything they could find on hypoplastic left heart syndrome and talked to everyone who knew anything about the condition and the outcome of the treatments. Their priest told them, "The church teaches that one is not obligated to undertake extraordinary medical means in order to sustain life." He provided a clear distinction between active and passive euthanasia. "The church also draws a sharp ethical line between withholding extraordinary treatment, thus allowing death to come naturally, and taking direct actions intended to end a life."

As Amy and Mark tried to digest all the statistics about survival rates and risks, it became clear that their unborn boy—who they were now calling Gabriel—had a zero chance of ever having a normally functioning, reliable heart. This would be true even if they underwent—and Gabriel survived—all the surgeries available at the time. Against that zero chance of gaining a healthy life for their son, Amy writes, "His chances of unimaginable pain and a lifetime of uncertainty were 100 percent."

With the support of friends, family, community, church, nurses, doctors, and their own resolve, this family chose comfort care. They became part of a nascent "dying well" movement, emphasizing dignity, pain management, and approaches that allow for "the profound spiritual and emotional growth that can happen at the end of life—both for the person who is dying and for the ones left behind." On Gabriel's obituary, they wrote, "Baby Gabriel Kuebelbeck Neuzil, 2 1/2 hours old, and perfect except for his heart ... In his short life he knew only love."

Amy Kuebelbeck is a former reporter and editor for the Associated Press. She lives in St Paul, Minnesota, with her family. With the publication of *Waiting With Gabriel: A Story of Cherishing a Baby's Brief Life*, Amy has become a respected speaker on and organizer for the movement of perinatal ethics. Amy moderates the perinatal hospice list serve at perinatalhospice@yahoogroups.com.

NICOLE CONN AND NICHOLAS

When Nicholas was born at 25 1/2 weeks' gestation, doctors told Nicole Conn that they would place him on her chest so that she could hold him as he passed on. Horrified by this prospect, Nicole pleaded with the resuscitation team to "pull every magic trick out of your bag. As long as my son is not in pain or will not suffer from poor quality of life, I want you to do everything you can."

Nicholas weighed 475 g (1 lb) at the time of his birth. More than 4 million infants are born annually; Nicholas is 1 out of 1200 born less than 500 g. Of these, 15% survive. Nicholas is Cedar Sinai Hospital's smallest male patient to survive since 1998.

Thrust into the surreal and challenging world of the NICU, Nicholas spent his first 5½ months undergoing blood transfusions, high-risk procedures, and emergency surgeries. The baby endured countless kidney failures, pulmonary hypertension that leads to congestive heart failure, necrotizing enterocolitis, and resuscitations. Nicole states that "While many dedicated doctors, surgeons, and respiratory therapists all pulled for their tiny special patient, it was the nurses, the primary caregivers, who became Nicole's—Nicholas's—best friends."

With the advent of the surfactant and technological advances in the field of neonatology, Nicole says, "The world of the NICU has become an incredible and bizarre setting where medicine meets magic and miracles." Nicole attempted to make the right decisions for her son at every turn, feeling ripped in half as she saw her 2-year-old daughter Gabrielle only every few nights, unable to leave Nicholas, knowing each time she left that it might be the last time she saw him.

Nicole has produced a documentary film, *little man*, which tells the story of Nicholas's day-to-day fight for survival, and "how a micro-preemie brought a family to its knees." Amazing footage of his journey through his hospital stay, his homecoming, and his first-year birthday is combined with exploration of the philosophical and moral question: "At what price life?"

Nicholas is now 7 years old. He suffers from dysautonomia of prematurity, a condition where he basically goes into a coma when he sleeps and must have oxygen and all the monitors on him. He remains bradycardic and experiences many apnea episodes on any given night. He cannot control his body temperature or bowel function. He has visual and motor problems. He is fed with a feeding tube.

Nicole's film was very troubling to neonatal nurses and physicians. For many, her fight to save Nicholas seemed to cause him extreme pain and suffering. Parental choice to keep infants alive who others see as nonviable contributed to neonatal sociologist Kristina Orfali's opinions that "parental autonomy has run amok." Nicole's film influenced nurse researchers to develop a conscientious objection policy for neonatal nurses when the treatment orders appear to create suffering that constitutes burden greater than benefit.

And yet, when asked, Nicole states,

Today Nicholas is doing amazingly well. He's only got a 250-word vocabulary but his communication has become purposeful. Fighting to have him integrated at school in his IEP led to him being voted "Most Improved" student. He's extremely fond of the water and spends many hours in the pool with a floatation device.

FIGURE 4.



Nicholas. Reprinted with permission.

Together with Deb Discenza of *Preemie* magazine, Nicole has also written the book, *The Preemie Parent Survival Guide to the NICU*. Their Web site PreemieWorld.com will offer the best preemie products, including the *little man* DVD and soundtrack.

Today, Nicole and Nicholas live in a blended family with her partner Marina and her 4 children. Nicole says, "It's one big happy (and chaotic) household. Nicholas is so well loved and cared-for in this family and I cannot tell you what a difference he makes to all our lives" (Figure 4).

SUMMARY

For the Rogoffs and the Millers, in the late 1980s, the impact of the Baby Doe rules was evident. Infants were to be treated and were not allowed to die, regardless of the long-term morbidity ahead or the effect upon the lives of their families. For the Maroneys, in the 1990s, it was a roller coaster ride, a time of experimentation and new technologies. For Amy Kuebelbeck and Nicole Cohn, the transition to honoring parental choice was seen and they themselves determined what would occur with their children.

Each of these parents has gone on to contribute widely to the field of neonatal ethics. Marianne Rogoff's book influenced worldwide calls for neonatal palliative care. Mark Miller became a speaker and public advocate for parents who want to say no. Diane Maroney became a family network advocate for parents of preemies everywhere. Amy Kuebelbeck is credited with bringing perinatal hospice to fruition. Nicole Cohn produced and directed the multiple award-winning movie, *little man*. The generosity of these parents in telling their stories can be appreciated by neonatal nurses and physicians everywhere. While we may individually

question their choices, collectively we celebrate their bravery and respect their love for their children and the way they each chose to express that love.

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