

Review Article

A delicate subject: The impact of cultural factors on neonatal and perinatal decision making

S. Van McCrary^{a,*}, H.C. Green^a, A. Combs^b, J.P. Mintzer^c and J.G. Quirk^d

^a*The Center for Medical Humanities, Compassionate Care, & Bioethics, Department of Preventive Medicine, Stony Brook University School of Medicine, Stony Brook, NY, USA*

^b*Stony Brook University Medical Center, Stony Brook, NY, USA*

^c*Division of Neonatal-Perinatal Medicine, Department of Pediatrics, Stony Brook University School of Medicine, Stony Brook, NY, USA*

^d*Department of Obstetrics, Gynecology & Reproductive Medicine, Stony Brook University School of Medicine, Stony Brook, NY, USA*

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Abstract. The neonatal intensive care unit (NICU) is a high-stress environment for both families and health care providers that can sometimes make appropriate medical decisions challenging. We present a review article of non-medical barriers to effective decision making in the NICU, including: miscommunication, mixed messages, denial, comparative social and cultural influences, and the possible influence of perceived legal issues and family reliance on information from the Internet. As examples of these barriers, we describe and discuss two cases that occurred simultaneously in the same NICU where decisions were influenced by social and cultural differences that were misunderstood by both medical staff and patients' families. The resulting stress and emotional discomfort created an environment with sub-optimal relationships between patients' families and health care providers. We provide background on the sources of conflict in these particular cases. We also offer suggestions for possible amelioration of similar conflicts with the twin goals of facilitating compassionate decision making in NICU settings and promoting enhanced well-being of both families and providers.

Keywords: Ethics, medical, nursing, institutional, decision making, prenatal diagnosis, consanguinity, African Americans

1. Introduction

In the neonatal intensive care unit (NICU), state-of-the-art technologies and evidence-based strategies are used to save the most vulnerable lives. However, despite impressive advances in the practice of neonatology, there will always exist a subset of babies whose medical condition thwarts attempts to promote

*Corresponding author: Dr. S. Van McCrary, The Center for Medical Humanities, Compassionate Care, & Bioethics, in the Department of Preventive Medicine, Stony Brook University School of Medicine, Stony Brook, USA. Tel.: +1 631 444 8029; Fax: +1 631 444 9744; E-mail: stephen.v.mccrary@stonybrook.edu.

survival. In cases of life-threatening genetic defects, extreme prematurity, and other morbid conditions presenting at birth, significant ethical and social challenges surround the provision of compassionate care for both the patient and family. Moreover, barriers to ethical decision-making and implementation of care plans can arise from the structure and cultural background of the family involved. In such difficult cases, health care providers' reactions to a particular family's viewpoints are likely to affect care decisions and reinforce the importance of an individualized approach to social and ethical dilemmas in the NICU.

In this review article, we present a varied array of non-medical barriers to effective decisions in the NICU. As examples, we will analyze two cases that occurred simultaneously in a tertiary care center in the metropolitan New York City area and which illustrate common themes. The first concerns a neonate with a severe genetic anomaly arising from an arranged consanguineous marriage originating from a culture in which this practice is common. The second involves a neonate with a prenatally diagnosed life-threatening skeletal anomaly in the context of a family with an inconsistent decision making process. In both cases, substantial communication barriers arose between the families and the NICU staff, resulting in delayed care decisions and potential exacerbation of the babies' suffering. By exploring these cases, we seek to elucidate the cultural influences surrounding ethically complex decisions in the NICU and highlight the communication challenges which can arise from misunderstanding familial and culturally-based viewpoints. We will also present some potential strategies to assist in ameliorating the significant stress and frustration generated by managing these challenging issues.

2. Cases

2.1. Baby A

2.1.1. Medical history

The mother of Baby A was primigravid with diet-controlled gestational diabetes who was referred prenatally to the high risk obstetrics service following the discovery of multiple fetal anomalies, including polyhydramnios; small, retracted jaw, bilateral clenched hands and feet; and significantly limited fetal movement seen on fetal ultrasound performed at 30 weeks gestation. The patient was married to her

first cousin. For that reason and identified ultrasound abnormalities, a genetics consultation was obtained. Amniocentesis was offered for genetic evaluation, but was declined by the mother.

The pregnancy was followed closely by the high risk obstetrics service with plans to await spontaneous labor anticipating vaginal delivery unless comorbid conditions arose. The mother received counseling about potential outcomes to be anticipated in a newborn with her fetus' abnormalities. This included the need for NICU admission and the likely dismal prognosis.

While in spontaneous labor at 38 weeks gestation an abnormal fetal heart rate pattern developed necessitating cesarean delivery. At birth, the neonate showed no breathing movements; positive-pressure ventilation was initiated with the eventual onset of spontaneous respiratory effort. There were no spontaneous movements apart from those associated with breathing, and bilateral upper and lower extremity contractures were seen with tightly clenched hands and bilateral club feet. The trunk and extremities had excessive hair; the palms and soles were smooth, consistent with long standing lack of fetal movement. Global hypotonia and absent reflexes, including gag, were noted on initial exam, as was a skeletal deformity of the left humerus.

In the NICU, Baby A demonstrated additional significant respiratory, neurologic, renal, gastrointestinal, and musculoskeletal problems. During the first day of life, the baby demonstrated inadequate respiratory drive and required intubation and mechanical ventilation. Considering the baby's overall clinical status, a tracheostomy was performed at one week of life given the poor likelihood that spontaneous adequate respiratory effort would return.

On neurologic evaluation, significant hypotonia and absent reflexes were noted. Multiple video electroencephalograms demonstrated excessive sharp waves consistent with encephalopathy. Head/brain imaging demonstrated small bilateral subdural hematomas, though the overall structure of the brain appeared normal. Nerve conduction studies were performed which demonstrated no muscular response, consistent with a severe sensory neuropathy. Ophthalmology evaluation revealed miotic pupils with an inconsistent light reflex. Despite these numerous abnormalities, a cardiology evaluation revealed normal cardiac structure and function. Orthopedic evaluation was obtained for the left humerus abnormality and bilateral club feet.

In the second week of life, the baby developed significant edema most likely due to renal protein loss. Finally, genetics evaluation revealed a normal male karyotype (46, XY) and negative findings on an initial series of testing. Further microarray evaluation remained in progress. Over the second and third weeks of life, the baby demonstrated worsening fluid and electrolyte disturbances, significant edema, and oliguria. Numerous multidisciplinary family meetings were conducted. Included was a discussion of the life-threatening nature of multisystem organ failure in the face of numerous anomalies. In the fourth week of life, the baby developed worsening respiratory function despite increasing support, culminating in cardiovascular instability. With worsening episodes of bradycardia, the futility of resuscitative measures was explained to the mother, who then held and caressed her baby in his final moments. The baby died in her arms on the twenty-sixth day of life, she subsequently consented to autopsy.

2.1.2. Family structure

Baby A's parents were from South Asia and were first cousins in an arranged marriage. Mrs. A. was 24 years old, and this was her first pregnancy. During her twenty-eighth week of pregnancy she came to the United States to join her mother and siblings. Throughout gestation and following childbirth, the father of the baby continued to live abroad. Other family members were typically present in the NICU throughout the baby's care. Because Mrs. A's father was also absent, her brother was the recognized patriarch in this family. Mrs. A spoke limited English, and her sister often served as interpreter. The family described themselves as Muslim, but did not appear particularly observant.

Here, it is important to emphasize the risks of a consanguineous pregnancy. Although consanguineous marriages are unusual and infrequently practiced in the United States, they can account for 20% to over 50% [1] of unions in certain Arabic, South Asian and African societies. A majority of these unions are first cousin marriages [1–6]. Consanguineous parents share a higher number of identical genes compared to unrelated parents, and this creates a higher probability of homozygosity at certain loci in their offspring [1, 6–8]. This higher level of homozygosity increases the risk of autosomal recessive disorders [1, 2, 5–8]. A carrier of a rare recessive mutation is unlikely to reproduce with another carrier unless they are either related or from a small endogamous community [1, 7]. In addition,

when compared to the offspring of unrelated parents, first cousin progeny are at a higher than average risk for multifactorial disorders, congenital malformations, visual and/or hearing impairments, intellectual disabilities, metabolic disorders and adult onset disorders [1, 5, 6, 8, 9]. To a lesser degree, this is also true when compared to the offspring of parents who are second cousins [2, 5, 6]. First cousin progeny also have a 3.7% higher risk of infant mortality than the progeny of unrelated couples [1].

2.2. Baby B

2.2.1. Medical history

The mother of Baby B was referred prenatally to the high risk obstetrics service at sixteen weeks gestation following a sonographic diagnosis of campomelic dysplasia (CMD) of an individual fetus in a twin gestation. Ms. B was in her second pregnancy with poorly-controlled insulin-dependent gestational diabetes. Her prenatal care was notable for multiple missed appointments and non-adherence to changes in her insulin regimen. During her third trimester, she required hospital admission for an episode of diabetic ketoacidosis.

The mother was counseled by both the obstetrics and maternal-fetal medicine services regarding the severity and poor outcomes associated with CMD. On follow-up fetal sonograms, additional features including cardiac enlargement, cystic hygroma, and progressive polyhydramnios were noted. A cardiology consultation was obtained, and fetal echocardiography demonstrated severe biventricular hypertrophic cardiomyopathy. A genetics consultation was obtained during which the life-threatening nature of the fetus's condition was discussed. Amniocentesis was offered for chromosomal analysis, but the family did not return for scheduled follow-up appointments. The neonate's physicians discussed this constellation of findings with the parents, including the possibility of miscarriage or stillbirth. The other fetus in this twin gestation underwent similar follow-up exams with no abnormal findings discovered.

The mother presented to labor and delivery at 35 weeks gestation with spontaneous rupture of membranes. Cesarean delivery was performed due to the multiple congenital anomalies of Baby B and mild, persistent tachycardia of the unaffected twin A. Baby B required endotracheal intubation shortly following delivery; twin A demonstrated spontaneous breathing and required no interventions. Because baby B was

born alive, it appeared the parents believed that a miracle had occurred. Both babies were transferred to the NICU for further management.

In the NICU, Baby B was noted to have short limbs consistent with the prenatal diagnosis of campomelic dysplasia. Additional congenital anomalies, including an enlarged head; cleft palate; a small, retracted jaw; short neck; bilateral club feet; multiple fused fingers; and ambiguous genitalia were present. Phenotypically, Baby B was designated female, and subsequent evaluation revealed a male genotype; this typically occurs in about 75% of similar cases [10]. Baby B's early NICU course was notable for a critical airway and severe hypoglycemia. Additionally, during the first postnatal weeks, she experienced frequent episodes of cardiac arrest, up to ten times daily, resulting in multiple episodes of cardiopulmonary resuscitation including chest compressions and epinephrine administration.

Throughout her NICU course, Baby B required continuous one-to-one bedside nursing care, frequent interventions and procedures, ventilator adjustments, central venous access, multiple blood draws, fluid adjustments, and numerous medications including a fentanyl drip for sedation. She underwent several antibiotic courses for clinical sepsis. Considering her craniofacial anomalies, nasotracheal intubation was eventually performed to decrease the likelihood of spontaneous extubation. Numerous clinical services consulted on her care, including cardiology, surgery, otolaryngology, genetics, endocrinology, gastroenterology, and orthopedic surgery. During her second month of life, Baby B slowly became more labile, requiring advancing ventilator settings and more frequent interventions at the bedside. During this period, Baby B developed an "air-hungry" arched posture with frequent wincing and other clinical evidence of pain, including intermittent elevations in her heart rate and blood pressure, for which she was placed on an opiate drip. In the eighth week of life, Baby B died during an episode of bradycardia and desaturation, which was unresponsive to aggressive resuscitative efforts. The bedside staff held her until her parents arrived. In contrast, her twin brother's NICU course was uneventful, resulting in discharge home during the first week of life.

2.2.2. *Family structure*

The parents of Baby B had a complicated relationship. Although not married, they had been partners for approximately ten years, yet currently lived forty miles

apart. They both had young children from other relationships. The NICU staff was troubled by the nature of their relationship; for example one day the father contacted the NICU and asked for the mother's address. While providing such information to an unmarried partner would typically be against hospital policy, this question could plausibly be one reflection of the tenuous nature of the relationship. Each time that they visited the NICU their relationship status seemed to change: at times they would not talk with each other, and at other times they could appear affectionate and loving. Because they were not married, the father had no legal authority over the baby's treatment, yet the mother would always defer to his judgment. Both parents were in their mid twenties, were African American and were of low socioeconomic status. The mother did not have a car, or easy access to childcare, so she often found it difficult to travel to the hospital.

The parents were kept informed of the baby's generalized deterioration in clinical status over the first several weeks of life. Multiple family meetings were arranged with ancillary and consultation services present, during which the family was informed that the baby was likely to die in the short term and that further interventions would not necessarily improve the chances for a favorable long-term outcome. However, such meetings were not as frequent as they should have been because the parents were either hours late for the meetings or did not attend them at all. In fact, they rarely visited the NICU. This was a concern among the staff, as the parents were not able to visibly experience the grim nature of Baby B's condition.

As Baby B matured, her arched posture and increased respiratory effort displayed chronic discomfort. She distorted her position to allow for the maximum amount of air exchange with each difficult breath. Even in this abnormal position she gazed upon her caretakers in what was interpreted as a soulful fashion. To the NICU staff she seemed to want to express that she was in pain and was unsure of what was happening. This created tremendous discomfort among members of the bedside caretaking staff, ethics consultants, and attending physicians. This discomfort was heightened by the fact that the parents were not present to observe the apparent pain that she was experiencing. The parents repeatedly demanded via telephone that aggressive life-sustaining medical treatment (LSMT) should continue, treatments which again they were not present to witness. As Gayle Whittier has written, "When verbal denial of suffering

exists throughout the NICU scene, it necessarily skews communication and generates distrust among medical personnel and between them and the parents" [11]. The atmosphere around Baby B and her family became increasingly tense and distrustful. The staff suggested three alternative explanations for the parents' continued demands: first, the parents did not comprehend the extreme burdens on the baby and the very low likelihood of survival; second, the parents were in denial and unwilling to confront reality; or third, the parents were not deciding based on the best interests of their child, but of themselves. This continued incongruence between staff perceptions and family demands created extreme moral distress among the bedside caregivers, and contributed to the conflict with the family.

3. Miscommunication, culture, and staff concerns

3.1. Barriers to effective decision making

Although the technical quality of medical treatment was not compromised in either case, numerous factors acted as barriers to optimal care of in terms of good relationships between staff and family. These variables combined and interacted to produce situations where some goals of treatment were thwarted. We will discuss these barriers individually. First, however, brief comments on both the concepts of "futility" and "culture" are needed to supplement the discussion of staff and family attitudes in the cases of Babies A and B. At numerous times during discussions, the word "futility" was employed to justify staff opinions that treatment should be withdrawn, and both of these particular cases certainly reached the state of physiologic futility. Both of these medical conditions are lethal within months in a large majority of patients, yet rare outliers may survive for years with extensive treatment. Staff may have not fully considered that these families had placed their hopes on their child being such an outlier; in such cases, a label of "futility" may be interpreted by family members as a lack of caring. Hence, we do not find futility to be a useful concept for resolving such disputes, due to the well-known tendency of some health care providers to conflate value-laden decisions with scientific fact when considering complex, frustrating end-of-life cases [12]. Accordingly, we refer instead to assessments of the proportionality of burdens and benefits. For a definition of "culture," we refer to Joseph

Betancourt who notes: "Culture is a pattern of learned beliefs, values, and behavior that are shared within a group; it includes language, styles of communication, practices, customs, and views on relationships" [13].

3.1.1. Miscommunication and mixed messages

Communication problems abounded in these cases. Baby A's family was unable to understand that consanguinity was the probable cause of their baby's condition. The staff repeatedly explained the genetic risk factors of a consanguineous pregnancy, yet they were met with the utmost confusion. The mother's younger sister, who was receiving an American high-school education, would ask, "Are you *sure* this is because they are cousins?" Similar questions would be repeated numerous times daily to a variety of bedside staff. The family was explicit: "We never see this condition in [our home country]." This misunderstanding and conflict, which repeatedly arose between staff and family regarding interpretation of statistical and genetic data, illustrates the communication difficulty of conveying statistical information to family members without misleading them. For example, Baby A's family also frequently expressed their belief that a 25% chance of the syndrome recurring in further pregnancies meant that the next three babies would be fine [1, 7]. Scholars have found that misunderstandings of probabilities among the general public are quite common [1]. Further complicating matters were difficulties in obtaining telephone interpreters that sometimes necessitated the use of family members. Relying on family members as interpreters usually is not best practice because of the risk that a person close to the patient will allow his or her personal views to affect the content of the message and thus possibly compromise quality of care; yet, some scholars have suggested that, in limited contexts, use of family-member interpreters may have some benefits [14]. Mixed messages about prognosis were sometimes conveyed inadvertently when attending physicians changed. In such cases, describing the prognosis with clarity and consistency is vital.

During Baby A's time in the NICU, the patriarchal structure of this family and of their culture was evident. The family expressed a strong preference for male physicians and sought to have female physicians transferred to other patients. It was clearly apparent that the mother's brother was the head of the family in the US. On occasion, he would enter the baby's room, make a loud command, and the rest of the family would immediately leave, including his own mother. Whether

a marriage is consanguineous or not, in traditional societies a family line continues through the birth of a healthy male son [7, 15]. Mrs. A's brother demanded that the staff "fix the baby," with the explanation that he needed to be saved "because he is the first born male." As noted by Isran and Isran, in a patriarchal culture "... women only have access to the only type of labour power they can control, and to old-age security, through their married sons. Since sons are a woman's most critical resource, ensuring their life-long loyalty is an enduring pre-occupation" [15]. If Mrs. A. returns to her home country, it is uncertain whether her husband's family will accept her. Using the example of Pakistan, scholars have noted that the acceptance of a married woman into her new family is accomplished through her children and that her stature as a family member remains unrecognized until she has a child [15]. These reasons may highlight why this mother needed her baby "fixed" so badly. Yet, this command was interpreted by some staff members as imperious and controlling. Thus, without staff understanding of the cultural norms, miscommunication and tension was perpetuated.

In the case of Baby B, a primary factor in miscommunication was the frequent absence from the NICU of one or both parents. Because the couple lived apart and did not appear to have frequent and clear communication between them, communication with staff was erratic and inconsistent. Recall that the father once telephoned the NICU to obtain personal information about the mother's living arrangements. An especially pertinent example was that during a hospital visit, the mother agreed to a Do Not Resuscitate (DNR) order after a long discussion with the attending physician but within 24 hours rescinded it by telephone, presumably after speaking with the father. Certainly, it is not atypical to rescind such an order in the face of changed medical circumstances, but miscommunication appeared to be at the heart of this and numerous other instances. The fact that parents of Baby B were chronically late, or did not appear, for arranged family meetings also built resentment among the staff. Even minor changes in Baby B's condition, for example seeming to be more comfortable when positioned on the stomach instead of the back, caused an angry outburst in the father because he had not been present to learn of such changed preferences. This further alienated some staff members.

In the case of both babies, denial among family of the severity of existing medical problems also con-

tributed much to the miscommunication and tension. Although it is normal for many families to require days or weeks to assimilate such unwelcome news, denial clearly worsened the other existing issues. We must also consider the emotional turmoil that Baby B's mother must have been experiencing. Her baby was dying in the NICU, and at the same time she was caring for the baby's twin brother at home. Such "contradictory psychological processes" must have started to exhaust her [16]. Lewis and Bryan have noted that, "Parents of a surviving twin are often made to feel guilty about their grief" [16]. Perhaps some friends and family members interpret the grief as a sign of not feeling fortunate that one twin is still alive. But grieving is a natural process that mothers in this situation should be allowed to undergo, yet a difficult process to undertake without neglecting their healthy baby. This healthy baby will always be a reminder of what might have been, and each joyful milestone that the surviving twin achieves will be contrasted with Baby B's experience. Such a delicate balance of emotions must be taken into consideration when trying to understand everything that this mother was experiencing.

3.1.2. Comparative cultural influences

Throughout both antenatal and NICU periods, the medical staff wanted to offer these babies and their families optimal and compassionate care. This proved difficult in both cases. The families wanted their babies treated aggressively when there was an informal consensus among the staff that such treatment was not appropriate considering the extreme burdens of treatment combined with dire prognoses. In both cases, many staff members did not fully appreciate the degree to which cultural differences were having an impact on interactions with the families, and were ill-equipped to respond to the tension that resulted. Regarding Baby A, some of the staff was obviously troubled by the consanguinity issue in this family. Although subtle and voiced softly, these concerns were persistent throughout the course of treatment and clearly contributed to an atmosphere of tension with the family. This was exacerbated by the apparent refusal of the family to understand that their actions may have contributed to the baby's condition. Recall the family's skepticism and often-repeated request for clarification that Baby A's condition was due to the consanguineous relationship. Also, consider the disbelief manifested by staff about their claim never to have seen such a baby before. The tension that repeatedly arose between staff and family regarding

interpretation of statistical and genetic data about Baby A's medical condition may be another indirect symptom of this cultural dissonance. It appears likely that the family's claims were true—they had not, in fact, seen a baby in such a condition; nonetheless, it was not apparent to them that dramatic differences in availability and quality of intensive care services between their home country and the US may have produced this situation. Mrs. A. was genuinely devastated and would cry and wail over her baby's condition. The staff members felt very sorry for her loss, but were not entirely empathetic. Few, if any, staff members understood the differences between what is considered standard in the US and the prevailing cultural norm in many South Asian families.

It appears likely that a large proportion of the US population shares such misunderstandings. Westerners often view consanguineous unions with what Alan Bittles, a leading scholar in the field, has termed "embarrassed astonishment" [1]. Hence, American attitudes about consanguinity are reflected in, and perhaps reinforced by, popular culture. Consider the character Cletus the Slack-Jawed Yokel, aka Cletus Spuckler, in the long-running television show *The Simpsons*. Cletus corresponds neatly with the stereotypical hillbilly, being clothed in rags, virtually toothless, married to his sister, and possessed of an enormous brood of dim-witted children. While the character is obviously an overblown parody, it nonetheless contains at least a grain of truth for many Americans. Yet, consanguinity should not be a completely foreign idea to westerners because it was historically practiced in European monarchies, for example Queen Victoria married her first cousin. Bittles has noted that in the view of many westerners, "Consanguineous marriage seems to be acceptable if families are well-to-do and generally regarded as pillars of society..." [1]. Yet, in at least 23 other non-Western countries around the world, marrying a relative is completely normal, and is not restricted to wealthy, powerful families. Countries where consanguinity is prevalent include: Afghanistan, Algeria, Bahrain, Egypt, Iran, Iraq, Jordan, Kuwait, Lebanon, Libya, Mauritania, Morocco, Oman, Pakistan, Qatar, Saudi Arabia, Sierra Leone, Sudan, Syria, Tunisia, Turkey, United Arab Emirates, and Yemen [1, 4, 5, 7–9]. Twenty percent of the world's population lives in communities where consanguineous marriages are preferred [7, 8] and this accounts for at least 1.1 billion people. [1] Also, studies done within immigrant com-

munities in the United Kingdom and Norway found a very high prevalence of consanguineous marriages [6, 9]. It even appears that there is a higher consanguinity rate in the Pakistani community within the UK (69%) than in Pakistan itself (61.6%) [6]. Although there are differences both between and within cultures, there are generalizable positive social and economic impacts of a consanguineous marriage [1, 8]. According to Bittles, such perceived benefits include:

- "Simplified premarital negotiations;
- Assurance of marrying within the family and strengthening of family ties;
- Assurance of knowing one's spouse before marriage;
- Avoidance of unexpected, and unwelcome, health issues;
- Reduced chances of marital maltreatment or desertion;
- Social protection due to greater compatibility of the bride with her husband's family, especially her mother-in-law;
- Reduced dowry or bride wealth payments, with the maintenance of family goods;
- Maintenance of the integrity of family landholdings." [1]

In fact, if a woman marries outside of her family then it often indicates that either the family is not desirable enough to remain a part of, or that she has a moral or physical defect that family members found to be unacceptable [3, 9]. Ironically, as seen in the fourth point above, many who practice this tradition believe that it is better to marry within the family, as there is less chance of a spouse hiding a health problem, or the health problem can be kept within the family [1, 3, 4, 7]. This highlights a potential reason why the family was so confused about the health risks of an intra-family marriage. If it is ingrained in their culture that this is the social standard to do something, it would seem almost blasphemous to say that it was the cause of an unhealthy child. Finally, a marriage within the family can strengthen the position of the wife, so she may not be so subordinated by her in-laws if a male heir is not quickly born [7].

Most of the NICU staff who cared for Baby A believed that a consanguineous marriage was a religious requirement. However, in most countries it is the social and cultural reasons listed above that are the driving force for these marriages, rather than religious considerations [1, 3, 9]. Research suggests that, even

within an individual religion, there is non-uniformity in whether such marriages are forbidden or encouraged, and that traditions have changed over time [1, 3]. For example, the Aryan Hindus of Northern India forbid such marriages, whereas the Dravidian Hindus of Southern India strongly encourage them. In South Asia, Islam, Buddhism and Zoroastrian/Parsi traditions allow first cousin marriages, whereas the Sikh religion usually forbids it [1, 3, 9]. However, even though a religion permits consanguinity, this does not mean that it is the reason behind a culture's decision to practice it. For example, a researcher who interviewed Muslim women in Pakistan found that a majority of them did not agree with him when he suggested that there was a religious tradition governing consanguineous marriages [3].

Although many Westerners disagree with consanguinity and believe it to be irresponsible parenting, especially in a time where "we know better," this view does not give medical staff a right to negatively judge Mrs. A., nor to allow it to influence care. We do not know how much power she has over her family structure, nor do we fully understand her position in her society as a childless woman. We can postulate that she had little role in any decision making process over her arranged marriage. Even if we do feel sympathetic towards her, it is also frustrating for the staff to be continually asked to produce a technology or treatment that does not exist. This becomes particularly trying when the family did not use the knowledge that science had already provided about the risks of consanguinity, which could have possibly prevented the situation in the first place. Even Baby A's nurse, who developed a close and understanding relationship with the family, still found their procreation beliefs archaic. He noted, "The Catholic faith has known for 400 years that marrying your first cousin is not healthy. You learn about 'third degree kindred' in the first grade, before your first communion." This anecdote illustrates that it is important for health care providers to understand where their beliefs originate, why they think a certain way, what they consider "normal," and why this may not be the case for someone else. Baby A's nurse was able to do this, as he talked to the family and learned about their culture. Of course, education for all staff on these cultural practices is imperative, and will be discussed later in this article.

The fact that the family of Baby B was African American was also significant, especially in the context of end-of-life decision-making. Numerous studies

have reported that, when compared to European Americans, African American patients are less likely to approve do-not-resuscitate orders, less likely to refuse LSMT, and more likely to reject physician-assisted death [17–20]. They also are more likely to accept a life with a severe disability [17]. One pilot study found similar results in the NICU, with 62% of African American parents agreeing to withdraw LSMT contrasted with 80% of European American families [20]. Further, in another study, Singh, Lantos and Meadow noted that LSMT was rarely withdrawn or withheld in their hospital and wrote: "We think that these frequencies reflect the wishes of our relatively homogenous patient population: single, black, matriarchal, religious, poor, and distrustful. Most of our parents do not want to stop intensive care if there is a chance of survival, and most are willing to continue medical intervention even in the face of a high probabilistic prediction of morbidity" [21].

One major reason for these trends is the historically-based lack of trust that the African American community in the US has toward the medical profession and biomedical research. This mistrust has deep roots, beginning hundreds of years ago. During the time of slavery, including the first half of the 19th century, medical professionals were involved in justifying racism by using medical reasoning for perceived black inferiority, and were documented as conducting medical experiments on slaves [22, 23]. Experiments on African Americans also continued well into the twentieth century. The largest and most famous example of such research is the Tuskegee Syphilis Study, which has been "frequently described as the singular reason behind African American distrust of the institutions of medicine and public health" [24]. Also, the appropriation of cells for profit in the 1950s, without disclosure or consent, of the cancer patient Henrietta Lacks, highlighted in a recent widely-read book, adds further fuel to this fire [25]. Research also suggests that health disparities between races continue today, and African Americans fare the worst. To note just a few findings, when compared with other patients, African American patients overall received fewer cardiac procedures, renal dialysis, and organ transplants, as well as a lower quality of care and less access to preventive care, such as mammograms [17, 24, 26]. Thus, African Americans have legitimate reasons for their lingering distrust of the health care system, despite the contemporary efforts to ameliorate the impact of history on the care of current patients. This is not to suggest that such

distrust is universal throughout the African American community, but that it continues to persist in some families. All medical staff should be aware that this history may affect their interactions with African Americans and respond with sensitivity. In Baby B's case, these issues did not affect the care provided, but appeared to impair some staff members' comprehension of the complex reasons why the family was especially resistant to withdrawing treatment. Further, the perception that Baby B was suffering severely, and unnecessarily, due to misplaced parental preferences strongly affected the staff's view of these parents.

A reinforcing cycle of disapproval had formed in both cases. Each family made, or had previously made, decisions that the NICU staff did not agree with, so they implicitly resented the family. This may have led the staff to be less sympathetic toward the family. The family was probably alert to this, and in turn resented the staff for not understanding their point of view, even if it was permeated with denial. This would have contributed to a breakdown of any effective communication that may have once been possible, and increased mutual frustration.

3.1.3. Legal liability concerns

Another stress-inducing factor for NICU staff is concern about possible legal liability for abating treatment against expressed parental preferences. In most states, when family members demand that life-sustaining treatment continue even though such ongoing treatment would not correspond to the standard of care or promote patients' best interests, laws may not necessarily require physicians to adhere strictly to family demands (with the possible exception of Texas [27]). In contrast, a 2010 New York statute, the Family Health Care Decisions Act, specifically mandates that health care providers continue such treatment, pending either transfer of the patient to a willing provider or judicial review of the case [28]. In the cases of Babies A and B, transfer was extremely impractical due to a lack of willing providers, and judicial review would entail protracted court proceedings due to the lack of a formal expedited legal review process for critical health care cases. Hence, the practical impact of the New York law essentially constitutes a legal mandate for indefinite treatment on parental demand. In these particular cases, no physicians or nurses voiced concerns about such legal implications, but it is possible such fears were a contributing factor to the stressful environment.

3.1.4. Family reliance on the internet

A final barrier to high-quality decision making in cases like these is uncritical reliance by family members on information obtained from the World Wide Web. This may have played a role in both cases that we have discussed. Online support groups for severe disorders like trisomy 13, trisomy 18, and camptomelic dysplasia have proliferated in recent years. Such groups play a helpful role by offering emotional support and promoting solidarity among families with affected children. However, these groups may also produce unrealistic expectations in family members, raise false hopes for full recovery, and offer confusing or inaccurate medical information. This frustrates healthcare providers, because they then have to negate the information that these websites provide. This can make the family feel like the staff is being overly negative about their baby's prognosis, as opposed to cautiously realistic. On the other side, previous usage by physicians and nurses of unequivocal phrases such as "uniformly lethal" and "incompatible with life" have also complicated decision making. Because virtually all these conditions present at least some slight range of severity and life-expectancy, including outlier patients who defy the odds, casual mentions of such phrases by providers describing absolutely certain outcomes have the power to exacerbate miscommunication between families and providers. Such communication failures may destroy trust and complicate attempts by providers to convey to parents the severity of the child's disorder and the extent of suffering imposed by continued treatment.

4. Toward the future: Overcoming barriers and accepting challenges

These cases illustrate how low awareness among health care providers of salient cultural and social factors may reduce the effectiveness of communication with families in the NICU, exacerbate family denial, erode trust, and have a generally corrosive effect on interactions between staff and families. We offer some suggestions for potential amelioration of this phenomenon.

First, we suggest adoption of ongoing educational efforts about cultural issues for NICU staff at all levels, including curriculum development by knowledgeable faculty. Even the most experienced health care provider may have gaps in knowledge about the complexities

of topics such as consanguinity, improvement of communications skills, and incorporating such knowledge into regular practice. This may be an obstacle amid an already-crowded educational schedule for intensive care providers, in which increasingly more time is being devoted to evidence-based practice. However, training on cultural and social-science aspects of care delivery has potential to yield an improved experience for patients, family, and staff. Also, training staff members how to better educate family members about the implications of relevant genetic factors would also be useful, but may be challenging to implement.

This article has highlighted two distinct cultural and social phenomena which created significant communication barriers between medical staff, patients, and their families. They include perceptions of consanguinity in many different cultures, as well as African Americans' historic experiences with the US health-care system. Of course, many other cultural differences exist that can contribute in different ways to such confusion and tension. We suggest the following as an example of a model cultural and social awareness curriculum to assist providers. The content of such a curriculum would emphasize that low awareness of cultural and social differences in clinical medicine can have tangible effects on the well-being of patients, families, and staff. The curriculum would emphasize that different patients have different "explanatory models" for understanding theirs, or their family member's, illness and condition, based on cultural and educational differences [13]. Further, the curriculum would recognize that there are varying levels of cultural competence among staff at all levels of medical expertise. So, a basic set of readings, lectures, and discussions addressing some of the more common cultural issues encountered in the geographic region of the practice, could raise the level of awareness. Betancourt has suggested, and we agree, that "interactive case-based sessions that highlight clinical applications" are an excellent way of promoting cultural competence [13]. Ideally, such a curriculum would eventually be sufficiently broad-based to encompass most of the probable cultural issues that would be encountered. Further, the curriculum could include staff education regarding how the general public understands, and misunderstands, medical genetics and probability, and their implications in perinatal and neonatal contexts. Teaching techniques for making such material more understandable to patients and families would be an essential part of this effort. The curriculum could

include staff education about the impact on the general public of information obtained from browsing web sites. An essential part of this component would be developing among staff members proper techniques for assisting families and patients to interpret the content of internet-based health materials. Of course, these cultural and social differences are not limited to the NICU, and all health care providers should be aware of them. Such a curriculum could be tailored to the particular needs of individual medical specialties.

Second, we recommend increased emotional and psychological support strategies and techniques to promote staff well-being. The unit where these cases occurred has only limited organized staff support in this regard. It is crucial to acknowledge the toll that complex medical and social circumstances exact on health care providers. In response we strongly recommend facilitated, structured debriefing sessions where any affected staff member can safely process his or her feelings and emotions. Other examples of such support could include Balint-type groups, regularly scheduled care-team meetings without presence of family, more-frequent family meetings to encourage family participation, hospital employee-assistance programs, and where available, reminders that obtaining support from ethics consultants is encouraged.

Drawing from discussions of futility in the cases of Babies A and B, staff could be made aware that demands for futile treatment are inevitable in some cases, due to misunderstanding, poor communication skills, family denial, mistrust, or inadequate time to assimilate the realistic medical options (or lack thereof) [29]. Sensitive handling of such situations requires attention to the two interrelated goals of promoting patients' well-being and, where possible, avoiding negative long-term effects on surviving family members [29]. Even though futility as a concept is not helpful for achieving these dual goals, consideration of staff emotional perceptions of being forced to provide treatments they believe to be useless or harmful, remains a necessary component of such cases in terms of optimizing staff well-being. As such, attention to staff concerns through ongoing support sessions appears both humane and essential. These concerns would be reinforced by regularly-scheduled support activities, and supplemental meetings as needed in urgent cases. We think that attention to increased staff education and emotional support has potential to reduce both the incidence and negative effects of such occurrences over time.

Third, we suggest consideration of structural changes in NICU operations for specific cases identified as more likely than usual to result in conflict or tension. Identification could be made on the basis of a variety of factors including severity of disease, extremely poor prognosis, and observed family dynamics. When such cases are identified, a “care coordination team” could be designated to deliver ongoing, consistent care for a single patient, or a very small number of similar patients. In addition to providing excellent treatment, specific goals of such a team could include building trust with the family, fostering good communication, offering and obtaining referrals for external assistance for urgent family needs, delivering and reinforcing bad news in a consistent and compassionate manner, and establishing with the family medically and ethically appropriate goals of treatment and care. Such an approach would face many institutional and practical barriers in a typical tertiary-care NICU, including: determining how designation of team members would occur, e.g., volunteer basis or otherwise; changes in professional responsibilities, on-call and service schedules, and financial compensation for health care providers of all levels (for both team members and those not part of the team); determining how to minimize impact on non-team members by maintaining a fair distribution of patients; institutional resistance to change; complex problems with third-party reimbursement; effects of cost-containment efforts; as well as unforeseeable challenges in many areas of health care delivery. We recognize this suggestion may be considered quixotic; however if the foundation could be laid by a bold institution, such an approach might provide a higher level of care for all patients, with the added benefit of improved family outcomes and happier staff.

Fortunately, the cases of Babies A and B are the exception rather than the rule in most NICU settings. However when they arise, such cases have the potential to radically disrupt functioning of the entire unit, with direct and indirect adverse consequences to patients, families, and staff. In our view, concerted institutional attempts to improve education and staff support to avoid or lessen the impact of cultural factors are an ethical imperative.

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Masking of the cases

Numerous non-essential medical and personal details were altered for both family and staff. We did not obtain written informed consent. We believe masking enabled us to retain the complex nuances of the cases without sacrificing privacy of the families.

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