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A Case Study in Cross-cultural Health Care and Ethics

Who Decides What Is in the Child's "Best Interest"?

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Health care in the United States is increasingly delivered in cross-cultural contexts. Empathy, mutual regard, respect, and compassionate communication are necessary to achieve the highest standard of care for each individual. Moral and ethical perspectives on life and death, health, and health care are not universal but rather have their origins within culture and societal norms. In a cross-cultural context, ''the right decision'' may be seen differently depending on an individual's cultural background, discipline, and type of education. This pediatric case study is intended to stimulate conversation on the need for culturally sensitive health care decision making and the shortcomings of a ''one-size-fits-all'' approach to bioethics in our increasingly interconnected world.

KEY WORDS

cross-cultural ethics, medical decision making, pediatrics, decision making, parental authority, cross-cultural communications

Many articles have been written in the palliative care literature about ethical dilemmas that arise when families want continued aggressive treatment when the health care team believes that further treatment is nonbeneficial, or even harmful, to the patient. However, there are fewer articles written about family requests for comfort care when the medical team recommends aggressive interventions, and these articles are most commonly based on western values.[1]

In North America, the ethical principles of autonomy, beneficence, nonmaleficence, and justice are widely accepted but are largely the product of Northern European cultural influences.[2] However, it is possible that these principals could be applied in a broader sense to incorporate other cultural views. As the patient population continues to diversify, these principles will need to be closely examined and be seen through the families' cultural and religious lenses.

The patient and family may not have the same ethnocultural understanding and acceptance as the medical team—especially in regard to autonomy.[3] In societies where the needs of the community outweigh the needs of an individual, autonomy in decision making is not the gold standard.[3] Doing what is best for the child is the ethical and right thing to do[4]; however, the definition of "best" can vary widely. The following case highlights this dilemma.

CASE STUDY

Mr and Mrs S, a professional, English-speaking couple, came to the United States from an underresourced Asian country. They arrived with their toddler daughter for a temporary stay, which they expected to last a few years. Mr S worked long hours and had many professional demands. The family enjoyed their time here, but they missed family and their community. Their feelings of isolation became even more acute when Mrs S became pregnant for the second time. Mrs S was concerned about how she would manage alone in a foreign country. At home, she would have been surrounded by a large supportive community. Despite their concerns, the couple was looking forward to the birth, and everything seemed to be going well.

Baby S was born vigorous and healthy, and was sent home after a standard 2-day stay in the hospital. A few days after arriving home, the parents received a telephone call instructing them to bring Baby S to a genetics clinic for a test to confirm the results of the newborn screening test, which had returned positive results for a rare inborn error of metabolism, which is fatal if intensive lifelong treatments are not provided. The parents were devastated. They were asked to come to the clinic

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The authors have no conflicts of interest to disclose.

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DOI: 10.1097/NJH.0000000000000529

the following day. But because Baby S was healthy, the parents were under the impression that the newborn screen was a false-positive.

That night, the infant became lethargic and was unable to feed. His parents were frightened and quickly brought him to the emergency department of a large pediatric hospital. He was found to have dangerously high ammonia levels, at this point, the diagnosis was suspected but not confirmed, as the final results were not available. The baby was deteriorating quickly. It was suspected that the newborn screen was a true-positive, but a confirmatory test needed to be sent off. The parents were informed that the rapidly rising ammonia would be fatal without emergent intubation and dialysis, and that it was too soon to tell how much neurological damage had been done by the high ammonia level. They also understood that with this diagnosis, their son would need lifelong medical treatment to keep his ammonia levels low.

The medical team informed the parents that they needed to emergently intubate and insert a hemodialysis catheter to begin dialyzing the baby. The parents were hesitant to consent to intubation and dialysis, and they were startled at the pace and quick escalation of cares. They felt worried that the medical team was recommending interventions that seemed extreme, painful, and outside their understanding.

At this point, the parents questioned whether other treatment options might be available. They wanted to avoid intubation and dialysis. They requested to take him home and allow a natural death. The medical team in the emergency department did not expect this request and strongly disagreed. They explained to the parents that this was an emergency situation and that it was unethical not to provide rapid aggressive treatment in situations like these. The providers explained to the parents that life-sustaining treatment was standard of care in the United States. The team was concerned the family would leave with the infant and so instituted a 72-hour medical hold on Baby S to initiate treatment against the parent's wishes. This also required transfer to another hospital where pediatric dialysis was available. These actions shocked the parents, whose culture and upbringing had taught them to trust health care providers. These actions permanently damaged their trust in the health care system.

After the baby was transferred that same night, he came under the care of a new team of providers in the pediatric intensive care unit at the second hospital. The parents physicians and health care institutions expressed frustration and helplessness, at times refusing to participate in conversations. The father stated that communicating was useless, as they would not be listened to anyway. All through the night and into the next morning, the parents felt helpless to care for their son and were alienated from the medical team.

A care conference was held with the parents and the various members of the medical team, including social work, spiritual health, nursing, and the critical care, genetics, and the palliative care team. The medical team explained that the suspected diagnosis had been confirmed and they could more confidently describe what lifetime treatment in the United States would be for this specific inborn error of metabolism. They explained the need for lifelong medications and dietary modification, as well as the need to live near a pediatric hospital. The parents were very worried about suffering due to high medial needs and neurologic compromise, as they had understood that there were potentially devastating neurologic consequences from exposure to high ammonia that could not be predicted until Baby S was older.

As the parents realized the severity of their son's condition and the treatment needed for his continued survival, they were sure that it was not available in their home country. The medical team contacted several physicians and health care institutions in the home country, and all confirmed the parents' fears. The specific medications and formula were not available. The parents understood the information the medical team was delivering, and integrated that information alongside their knowledge of access to health care in their country. They were filled with dread. They understood that their child would likely have already died if they had been at home. They could see no good options, only present and future suffering for their beloved son far away from their home—a fate they considered worse than death. They believed strongly that death would allow him a chance for a better life free of his body that did not work. They requested to have the same care for him that they would have at home, to allow nature to take its course and allow him to die peacefully, without tubes or medical interventions. This view was supported by their extended family and religious community.

An ethics consult was then requested. After much deliberation and hearing many professional opinions about the infant's prognosis, the ethics committee decided that given the uncertainty in the infant's prognosis and the standard of treatment in the United States, it was necessary to continue current treatment. Although there were some disagreements, the lead managing team was adamant to proceed with aggressive treatment for the infant. The parents reluctantly agreed but continued to voice their concerns about the future. After a few weeks, the infant improved, but his ability to feed orally was sporadic and expected to worsen, so a gastrostomy tube was also advised. The parents were reluctant, but again felt they did not have a choice and the procedure was done.

On discharge, the clinic attempted to engage the family providing as much flexibility and control to schedule appointment dates and times as possible, in an effort to meet the family's needs. The family remained distant and at times noncompliant, in particular the decision maker father.

The infant was discharged home with weekly home care nursing and social work visits ordered for weight, oversight of the prescribed diet, and support. At first, the family was resistant to having home visits, but soon, they saw that moving the care to the home provided them with more control. This was an important first step in regaining some of the trust in health care professionals. There were pressing needs of the family that the home care staff was able to address. The most concerning to the family was the huge medical bills that were accumulating and the frequent calls from the bill collectors. They had no idea how they would meet the payments. The home-care social worker helped the family enroll the infant on Medicaid. After completing the complex paper work, the coverage was backdated. The family avoided bankruptcy. This help was another important step in winning back some trust for health care professionals.

One of the nurses had a similar cultural background to the family and was able to connect with the mother. Connecting over shared memories of growing up, foods, and challenges in adjusting to the US society provided another opportunity to reestablish trust in a health care professional, even if not the whole health care system. The family permitted weekly nurse visits but was often noncompliant for clinic and laboratory appointments.

The family's deep desire was to return to their home country, even if just for a visit, but the fear of the medical community's potential actions kept them from pursuing this. As trust grew with the home care staff, the mother began to discuss her wishes with them. The team collaborated with the clinic team and the health insurance company to develop a plan. Finally, after complex and time-consuming negotiations, an agreement was reached for the family to return to their home country for a visit. The insurance company was willing to provide 3 months' worth of medications and specialized formula. The family longed to get back to their home and supportive community. They left successfully but did not contact the medical team again and were lost to follow-up.

This case is complex and reflects a only a small part of the complexity of ethics within a multicultural community. With rapid development in technology, cultures from across the globe are working and living together. It is increasingly important to develop best practices for building understanding and communication across difference. The international literature search did not produce as many articles as hoped for; however, there were a number that were informative.

LITERATURE SEARCH

There is relatively little in the recent literature regarding nondominant culture parent requests for palliative care over aggressive therapies for their fatally ill children. A literary search was done using CINAHL and PubMed, looking at cultural differences in choices for medical care, specifically refusing advanced medical care when the prognosis was unknown and the child would need lifelong medical intervention. However, the factors influencing these situations can be complex and multifaceted.

Spirituality and religion are major factors in decision making for many families, and their experience and views are based on their background and upbringing, which may be very different from those of the medical providers.[5] This is particularly true when there are ethical or end-of-life decisions to be made.[6] Death for some is the end, and for others, a new beginning. In eastern religions—for example, Hinduism—the death of the body is like changing clothes; reincarnation happens after death, and the ultimate goal is to obtain Moksha or release from the cycle of death and rebirth. For some, there is concern about making heroic attempts to interfere with the timing of death. Prolonging the life of someone who is suffering is seen as putting the person in the prison of his/her disabled body.[7] Some families' religious beliefs conflict with prescribed medical treatments, with the belief that the intervention would cause more harm than good.[8] Examples are Jehovah Witnesses' refusal of blood transfusions[9] and the Christian Science belief in prayer rather than medical interventions.[10] Other communities such as the Amish may choose complementary methods rather than the allopathic tradition more commonly used in the United States.[11]

Culture is often closely tied to religion. The United Nations Education, Scientific and Cultural Organization describes it as a set of features of a society that encompasses all aspects of life, including spirituality.[12] Culture is more than one aspect of life, rather it is how a person's life is lived.[13] It affects the view of health; for example, in some cultures, it is about a balance between individual, society, and the universe rather than patient autonomy.[13] Cultural values and beliefs significantly affect parenting and decision making, especially in times of a critical illness.[5,14] Hospitals and medical professionals care for families from many different cultures and backgrounds that may challenge western beliefs and traditional view of ethics.[15] When such challenges occur, bidirectional communication is essential. This includes active listening on the part of the health care professional to better ensure understanding of the families' background and how it may affect their decision-making process.[5] A lack of understanding of this may contribute to disparities in care.[5]

Society and community often play a large role in decision making, where the emphasis is on the good of the society, not just the individual; for example, in the United States, this is seen in the Amish community.[11] In this group, the focus on the good of the community ensures that all members are cared for. Although there are many different views within this group, many do not ascribe to social security or government aid, including medical insurance,[16] and have developed their own community medical funding. Their "Hospital Aid" provides assistance to families who have major medical expenses but pool resources to administer their own health care.[11] In the latter, the well-being of the community as a whole is highly valued, and cost containment and interdependency of the community play a large role in health care choices.[11]

Public health focuses on the good of the community, but how that is administered varies according to the society and politics at the time.

Individuals connect by both verbal and nonverbal methods. There are many different accepted norms and languages across the world and are seen in the patients and families in our health care institutions. A lack of understanding of the differences and what they mean can be a critical barrier to good care.[17] Awareness of cultural influences is essential, yet it is important not stereotype by appearance or language.[18] Cultural humility and openness can help avoid this pitfall for health care professionals.

Even with all these differences, generally, both parents and health care providers seek the best interest of the child. However, when the definition of what is in the child's "best interest" differs, problems often occur. When considering what is in the child's best interest, one must look at the holistic picture of what is the best interest.[19] When the family's world view differs from the that of the medical team, there are often no straightforward solutions to the dilemma. It is essential for the health care team to have a thorough understanding of the parents' religious and cultural views that may challenge the accepted norm.[19]

In this case report, the parents' view of what was best for the child was based on religious beliefs, community support, and cultural norms that they would return to, and not on Western medical ethics. Yet the child was born in the United States, where there are different medical practices, standards of care, and ethical guidelines.

ETHICAL CONSIDERATIONS

When encountering any complex pediatric case, sound ethical analysis must be used, including analysis of the principles of beneficence, nonmaleficence, decision-making authority, and justice. In this case, both providers and parents believed they were advocating for the child's best interest, although they used different metrics of beneficence. The 2 parties disagreed intensely about the level of harm inherent in treatment. The medical team perceived the treatments to be low risk and not overly burdensome. The family saw extreme suffering as their son was forced to endure a highly medicalized life and frequent and unpleasant interventions and assessments and to accept a limited ability to participate in aspects of family life and culture. The question of justice is primary to this case as it concerns fair resolution between competing points of view.

This case highlights a growing challenge in an increasingly global world: Whose ethics and whose cultural norms will guide us? Ethical perspective is context specific and cannot be separated from cultural norms and values.[20] Culture also informs our understanding of parental duties and what it means to be a good parent.[21] And while western societies typically place higher value on individual rights, many cultures view the family as the essential unit when considering health care options.[22] In addition, many current bioethical dilemmas involve new forms of treatments not previously available or that are available inconsistently. These situations are simply too new to have a universal moral viewpoint—one that would be true across all cultural contexts.[23]

The story of these parents invites the inquiry, who has the right to determine the course of action and what criteria should guide that decision making? In the United States, it is widely accepted that parents have the right to make decisions for their children. There is widespread agreement that parents generally love their children, make lifelong commitments them, and will be the ones to care for the children throughout their lives.[24] Along with the child, these parents' lives will be most impacted by health care decisions made for him/her.[25] To override parental authority, a child must be in danger of suffering serious harm.[26] But whose definition of harm is correct?[27]

In keeping with the 1944 Supreme Court decision, Prince v. Massachusetts, the American Academy of Pediatrics advises that physicians must intervene when parental refusal puts the child in imminent physical harm.[28] In our case, the initial medical hold accomplished this goal. However, the dilemma becomes more complicated once the most urgent action has been taken. Current ethical consensus advises that health care decisions for a child should be made through shared decision making between parents and providers,[29] but there are often barriers to achieving this goal.[30,31] When the decision-making process can be extended, it is important to better understand the family constellation that surrounds the child and the unique set of core values that the family holds.

Although all parties agreed on wanting the best for this baby, it is rarely possible to achieve the aspirational "best" and it is impossible to define "best" across cultures.[32] Are decisions limited to a child's best medical interests and maintaining life—or do they also include emotional, spiritual, and cultural interests? Even if, in the end, the recommended course of care cannot be altered, are there ways to honor parents' concerns about their child's emotional and spiritual well-being with the respect and sacred attention that these concerns deserve?

In this case, the parents assigned greater value to emotional and spiritual harm, along with issues of identity and culture. They did not want their baby to live an "abnormal, highly medicalized life," with frequent hospital admissions. Health care providers working in pediatric critical care have necessarily accepted highly medicalized lives for some children, but this does not make it universally acceptable. These parents also recognized that this condition would alter their baby's ability to participate in the fullness of life within their family's culture, including his capacity to become a parent himself someday. Within their religious framework, they believed their most compassionate act as parents would be to allow their baby to die peacefully and move on to his next place in God's plan, rather than suffer.

Perhaps most importantly, the parents were quite well informed and knew that treatment would be unavailable when they returned home. Neither ongoing nutritional management via specialty formulas nor necessary pharmaceuticals would be available to them. This family eventually returned home and their son was lost to follow-up. By mandating medical interventions, was this baby's life extended, or was his dying process prolonged?

LESSONS LEARNED

As with any difficult case, there are lessons learned from this difficult situation. Here are some of them:

1. *The need for cultural humility*: Cultural humility is the ability to open to others' important points of view within their cultural background. At times, health care teams may have care conferences to try to convince the family of the right path to take, rather than deeply listening to what they have to say. When health care professionals view themselves as experts, they may see parental concerns as irrational or uninformed. Clinicians may try to bring rational responses to a parent's emotional concerns. They may try to address a family's concerns about suffering with reassurance that, "oh, that isn't really suffering." Perhaps, a more open dialogue of asking "what does suffering mean to you?" may be more helpful. Listening deeply to the family's –definition of suffering, spiritual-emotional wellness, and quality of life opens the possibility to a greater understanding.
2. *The importance of "being with"*: Even if we disagree with the parents' decision, we can still provide support and care without judgment. This may mean building a relationship around safe nonmedical things that are in common with the parents—perhaps a favorite movie or favorite food. This provides some social connections, which can act as a bridge to help build rapport and, eventually, trust. Allowing the parents to have as much control as possible and accepting where they are at the moment allowed a fragile trust to grow.
3. *Appropriate needs assessment*: Home care was ordered for weights and feeding checks. What the parents really needed was help managing the overwhelming issues of medical bills, bill collectors, transportation, and the mother's isolation. The palliative care team met with them in the home, identified their most important concerns, and worked with them to address them. When the parents saw how the team could help them, they started to build a fragile trust.
4. *Communication*: In palliative care, communication is our most important tool. This includes the delivery of information, engaged listening, and the ability to identify and understand another's perspective. Careful, open communication may take more time, but it can also save time and prevent adverse consequences. Listening to this family's concerns was essential. Whereas rapid action was necessary upon initial presentation to the emergency department, the parents may have felt less threatened if they had known that the care goals could be explored again once the child was stable. That reassurance may have served the family, the child and even the health care team better.

CONCLUSION

This case study leaves many unanswered questions as to what is the best decision choice in difficult situations. But it also encourages us to look more deeply at our own beliefs and practices. Nurses often act as the intermediary between the health care team and the family. As we become more culturally diverse and enriched, this role becomes even more essential in our every changing health care system. Nurses can intervene to act as advocates and health care interpreters for the family. This important nursing role will continue to be present as technology progresses and frequency of cross-cultural care increases.

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