

COMMENTARY

When worlds intersect: practical and ethical challenges when caring for international patients in the NICU

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Pediatric health care has become increasingly globalized, even in the neonatal intensive care unit (NICU).¹ Health-care teams from industrialized countries frequently provide pediatric care in poorer resource settings. Conversely, families sometimes travel across the globe to pursue specialized medical care for their infant or child that is otherwise unavailable in their country of origin, including neonatal intensive care.^{1–4} Worldwide, over the past 2 decades there has been a rapid increase in ‘medical tourism’ or ‘international medical travel’ (IMT). Improved access to health-care information online and lowered transportation costs have contributed to an increase in IMT.⁵ Recognizing entrepreneurial opportunity, health-care institutions have also started to actively recruit patients outside their domestic markets.⁶

Opportunities for high quality pediatric care through IMT can be extremely beneficial for some patients and families. They may receive a diagnosis formerly not known to them or a treatment becomes available which substantially improves the quality of life or is even curative. For other patients and families, however, such opportunities may lead to sub-optimal outcomes, posing unique practical and ethical challenges. Differences in culture, language and values can all contribute to potential miscommunication and misalignment of expectations, possibly leading to disappointment, frustration or even moral distress for all parties involved. Such cross-cultural challenges are not unique to international patients, but can be compounded by additional factors, including unfamiliarity with the US health-care system, misaligned expectations and great distances away from home without necessary support systems.

This article addresses some common issues that can arise when caring for international patients and their families in NICUs in the United States. For this discussion, an international patient can be defined as a person who travels with the ‘express purpose of obtaining health-care services abroad,⁷ who either pays out-of-pocket for the services received or is covered through a foreign payer/sponsor.²

The discussion builds on a series of three interprofessional, educational Rounds held at the NICU at Boston Children’s Hospital and facilitated by the Program to Enhance Relational and Communication Skills (PERCS) NICU Rounds.^{8–10} PERCS NICU Rounds are educational and supportive in nature and held monthly. Topics, suggested from unit-based champions and participating staff in the NICU, usually represent challenges occurring in the interpersonal and ethical dimensions of care. The goals of these PERCS NICU Rounds were to

- (1) identify the practical and ethical challenges that can commonly occur in the care of international patients in the NICU;
- (2) initiate reflection and discussion through interprofessional exchange; and
- (3) share and generate strategies for improvement of care.

To achieve these goals, members of the hospital’s International Office, Interpreter Services, Chaplaincy and the Ethics Advisory Committee were invited to share their perspectives, provide education, stimulate discussion and engage in generating strategies for care improvement. What follows is the product of such discussion, which will hopefully be useful to other institutions providing neonatal intensive care for international patients. Given the paucity of data on the care of international patients in neonatology, we also hope that this commentary will highlight a need for and raise interest in conducting empirical research in this domain.

Communication

A characteristic feature of IMT is the role of a third party or *facilitator* who aids patients and/or families in arranging the medical care abroad and making outreach with health-care providers.¹¹ The facilitator has a key role in the information exchange between the patient’s family and the accepting hospital before admission. International patients being cared for in the NICU in the US often have complex diagnoses or have yet to be diagnosed.

Before arriving at the hospital, international patients and their families have likely already endured a long journey, often having included contact with their local physicians and embassy to obtain records and visas, secured funding and organized logistics and travel. However, accompanying medical records upon admission may be sparse or even inaccurate, often with even fewer details regarding the psychosocial situation. Effective communication is thus essential, beginning with the initial inquiry from the facilitator, that is the embassy, and/or international medical team to the US hospital to determine whether the patient is even an appropriate candidate for international transfer or not.

This preliminary conversation should involve physicians, nurses, representatives from the International Office, embassy and medical interpreters if needed. Topics should include discussion of potential benefits and risks of such a long-distance transfer, as well as family goals and expectations for their child, and criteria for retro-transfer back to the country of origin. The discussion should also cover anticipated health-care needs once home in addition to ensure adequate follow-up care. If a patient is accepted for

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transfer, then ongoing conversations with the international medical team, embassy and family throughout the hospital stay are crucial.

(Re-)Aligning expectations

Alignment, or re-alignment, of expectations between the family and the US-based NICU health-care team can be challenging. Families often seek medical care in the United States because of unavailable treatments in their country of origin, and they can have unrealistically high expectations for cure fueled, in part, by institutional marketing campaigns on readily accessible websites. After having invested significant emotional and financial resources into the trip, most families arrive with high hopes and, far too often, unrealistic expectations regarding outcome. Parents are also confronted with an unfamiliar health-care system and unanticipated treatment options.¹² For example, parents hoping for a cure may be counseled instead about insertion of a tracheal tube for a home ventilator. Ideally, it is important to determine parental goals, hopes and visions for their child, before arrival. If not, health-care providers can find themselves in the unfortunate position of having inherited patients for whom little can be offered, and families who are upset, disappointed, frustrated and angry. Realistic goals should be clearly communicated with the family, and revisited often, as these may change and evolve over time. While mutual agreement between the family and the clinical team is often achievable via thoughtful discussions, this may not always be possible.

Cultural humility and sensitivity

Differences in language, culture and values between clinicians and international patients/families may be even more pronounced than patients/families from diverse backgrounds residing in the United States. In addition, standards of care, available treatment options and resources can vary significantly between a patient's country of origin and the United States. Therefore cultural sensitivity, conceptualized as 'respect for others,' is essential and represents one of the eight components of professionalism endorsed by the American Academy of Pediatrics.¹³ Specifically, cultural sensitivity requires 'treating all persons with respect and regard for individual worth and dignity, including sensitivity to gender, race and cultural differences [...].'¹³ This can be accomplished through an 'ethnographic' approach, which actively explores 'what matters most to the patient' instead of assuming a core set of beliefs and habits on the basis of a certain ethnicity.¹⁴ Cultural humility reflects a willingness to be curious, open and to learn about another's perspective without judgment or preconception. Other important questions to consider include, for instance, what language do the parents prefer? What are the family dynamics? Who is responsible for making decisions on the child's behalf? How does the family prefer to communicate and interact with the medical team? What roles do the family members in the home country play? Such information is critical, as views may differ significantly from those commonly held in the United States. If language issues exist or arise, establishing a close collaboration with qualified medical interpreters is vital, for these members of the health-care team can provide not only language interpretation, but also serve as invaluable cultural interpreters and brokers.¹⁵

Ethical conflicts, cultural accommodation and moral distress

Differences in cultural and ethical values may sometimes lead to ethical dilemmas and entrenched conflicts regarding goals of care. For instance, a treatment that one person or family feels is medically futile and not in the child's best interest may be viewed as life saving by another, regardless of quality of life. As one mother succinctly put it, 'This may not be your reality, but it is

mine.' Her words reflect those of Wade Davis, a Canadian anthropologist and ethno-botanist, who eloquently said, 'The world into which you were born is just one model of reality. Other cultures are not failed attempts at being you: they are unique manifestations of the human spirit.'¹⁶

However, how much should health-care providers suspend, adapt or change their own ethical beliefs to accommodate those with differing ethical frameworks? When does cultural sensitivity become *cultural accommodation*? For example, do you leave a dying infant alone in her crib per parental request because touching the body would be considered unclean? Do you conserve pain control for a dying infant at the insistence of his parents so that karmic debt can be paid, ensuring good karma with reincarnation? Do you proceed with aggressive life-sustaining measures for an infant who will surely die or suffer from severe neurologic impairment because her parents believe that any life is better than none at all, despite significant suffering? Do you refrain from putting in a tracheostomy or gastrostomy tube in an infant whom you feel would surely benefit because the parents are concerned about the very real fear that they will be shunned by their community once back home? Do the burdens of international transfer (physically for the patient, emotionally for the family) outweigh the possible benefit of medical treatment in a US NICU?

Some staff may also wonder why the patient was accepted for transfer at all, particularly if the parents are opposed, sometimes vehemently, to certain suggested treatments or interventions. There are many institutional incentives for accepting such international patients, including beneficence, global recognition, as well as potential significant financial incentives, as many of these heavy-resource hospitalizations are paid for in full, often by cash, by the family or embassy. Who will support the patient and family emotionally and financially once they return home, or if they decide to remain in the United States? These questions, in addition to others, were raised, thoughtfully discussed and reflected upon in the context of PERCS Rounds.

Such ethical conflicts can create moral distress for the health-care team, the 'result of a perceived violation of one's core values and duties concurrent with a feeling of being constrained from taking ethically appropriate action.'¹⁷ Although some conflicts may be prevented or mitigated through anticipatory guidance, thoughtful communication and customized culturally sensitive care, the conditions are rife for ethical challenges and the stakes are high. Inevitably, some conflicts may still arise without being resolved. Acknowledging such challenges and resulting distress within the care team may offer some relief. Ongoing education, opportunities for discussion and ethics consultation may provide additional support and guidance.

Medical interpreters as educators

Traditionally, medical interpreters have provided literal translations to facilitate conversations related to medical care between the health-care team and non-English or limited English proficient patients and/or their families.¹⁵ Medical interpreters can also serve as cultural brokers, offering knowledge and insight regarding particular cultures to fellow providers to help the team better prepare and reduce potential misunderstanding.¹⁸ For instance, knowledge of subtle cultural differences regarding appropriate dress, communication habits, such as eye contact, interaction between sexes or physical touch during conversation, can help promote ever-important trust between families and the health-care team.

Improving coordination of care

Communication and coordination with the hospital's Interpreter Services, Social Services, Chaplaincy, Office of Ethics and International Office, if applicable, can help improve the complex

process of accepting and caring for international patients in the NICU. Our institution now attempts to facilitate such discussions before transfer, including physician-to-physician conversation of shared medical goals, expectations and criteria for retro-transfer back to the country of origin. An interprofessional team, consisting of an accepting attending, nurse, social worker, interpreter, and representative from the International Office, may aid in improving the patient/family experience and coordination of care from beginning to end. Feedback from the family as well as the health-care team may be useful to continually evaluate and improve collaboration between services.

Social responsibility

Ethical conflicts relative to social responsibility may also arise when caring for international patients and their families. Physicians and other health professionals have long-standing traditions of helping individual patients, regardless of their cultural background, beliefs or ability to pay. This is reflected in the previously mentioned principles of cultural sensitivity and professionalism published by the American Academy of Pediatrics.¹³ At the same time, the concept of social responsibility implies that clinicians have a responsibility for the health status of their society,⁴ especially with regard to poor and disadvantaged communities.¹⁹ Thus, the use of resources should ideally be balanced between the needs of the individual and the society. In the care of international patients and their families, these principles can get into conflict. Clinicians may experience difficulties in optimally caring for 'local' patients and communities while simultaneously caring for international patients without additional resources. This conflict of resource allocation may be highlighted when care for international patient is perceived as an entrepreneurial opportunity for the health-care organization instead of a humanitarian duty. One way to possibly ease the tension is to encourage open exchange between clinicians and representatives of the International Office or business development. An enhanced mutual understanding between clinicians and administrative leadership regarding the mechanisms of IMT holds promise. As demonstrated in the series of PERCS Rounds described herein, acknowledgment, discussion and resources to address the increased moral, physical and emotional burdens of caring for international patients and their families can serve as the basis for effective teamwork and collaboration within the institution.

Summary

Caring for international patients and their families in the NICU can pose unique practical, relational and ethical challenges to health-care providers. The strategies described here may help better address these challenges and largely aim at improving clinician-parent-institutional relationship by (1) enhancing communication, (2) realigning expectations, (3) increasing cultural sensitivity, (4) identifying ethical conflict and acknowledging moral distress and (5) improving the coordination of care through existing hospital resources which often seem underutilized, as well as relevant embassies. Creating interprofessional opportunities for education, reflection, support and discussion of such challenging issues, in a format as PERCS-NICU Rounds, may be a promising approach.

Given that IMT is a relatively new and complex phenomenon, which is only likely to increase in the future, engaging clinicians in conversation with health-care managers, global health specialists and ethicists seems important to help develop frameworks to reconcile the demands of good clinical practice (both locally and globally), social responsibility and economic growth. The need for development of protocols on a systems level should also be considered to further improve the quality of care for international patients.²⁰ Policies and approaches could include a

more refined patient selection criteria and coordinated process for hospital admission to ensure optimal care for international patients and their families. Finally, there is need for more empirical research in this domain. While most studies focus on the experience of international patients travelling to countries to receive care at lower costs, the practical and ethical challenges of international patients and their families seeking specialized health care in the United States, specifically in pediatrics and neonatology, have been largely unaddressed.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

ACKNOWLEDGEMENTS

We would like to thank members of the International Office, Interpreter Services, Social Work Department, Chaplaincy and the Ethics Advisory Committee at Boston Children's Hospital for their invaluable input during PERCS Rounds, as well as Robert Truog, MD and Deborah White, RN for thoughtful review.

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