

Toward a Community Standard for Clinical Ethics: The South Florida Pediatric Bioethics Consortium

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INTRODUCTION

The American Academy of Pediatrics and other professional organizations develop policies to guide clinicians on ethical issues, such as forgoing life-sustaining medical treatment, and parents asking clinicians to withhold information from pediatric patients.^{1,2} In practice, individuals and institutions may differ in how such guidance is translated into institutional policy and applied to specific cases. There are more than 200 children's hospitals in the United States, and major metropolitan areas often have several hospitals serving a single community.³ Conceptual and practical ethical problems can arise when policy and practice vary within a single community. For example, families often seek care at different hospitals, and can lose trust as they encounter significant variation.⁴ Judges and child welfare agencies who determine a child's best interest may be concerned about the lack of a community standard. Clinicians face moral distress when they make difficult decisions that might be judged differently at neighboring hospitals. We describe the creation of a consortium of pediatric bioethics committees by 5 South Florida children's hospitals to develop common institutional policies, improve ethics education, and provide a forum for interinstitutional ethics consultations.

THE SOUTH FLORIDA PEDIATRIC BIOETHICS CONSORTIUM

In southeast Florida, 5 children's hospitals coexist within 100 miles (see supplement). The South Florida Pediatric Bioethics Consortium (SFPBEC) began in 2008 when 3 children's hospitals sought to update their policies regarding death by neurologic criteria (DNC) in the wake of a particularly challenging case managed differently at 2 member hospitals.⁵ It seemed logical that a child who met DNC at one institution would be regarded as having died at a neighboring hospital. However, comparison of each hospital's DNC policies and procedures revealed significant variation. The leaders of each hospital's ethics committees met to discuss key issues, shared a draft policy with relevant clinicians in neurology and critical care, included consultations with legal and risk management experts at each hospital, and ultimately secured a common policy for determining DNC at all 3 hospitals.

Subsequently, the consortium has grown to include all the children's hospitals in southeast Florida, given common referral patterns and shared patients in the region. Throughout its existence, the SFPBEC has been buoyed by the larger Florida Bioethics Network, yet it was primarily driven by individual committee chairs' pursuit of



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partnership. Through consistent in-person meetings open to all bioethics committee members, enduring interdisciplinary relationships were built, including chaplaincy, social work, nursing, and administrators. We meet 3 to 4 times per year, rotating among the hospitals, discussing cases, medical and bioethics literature, and current events relevant to pediatric bioethics. Meetings are held in hospital conference rooms with a hybrid virtual option, minimizing costs for the host institution.

At SFPBEC meetings, member hospitals can present complex clinical cases, engage in discussion of specific ethical issues, and further policy development based on review of the latest clinical guidelines. Case discussions have emanated from all areas of pediatric practice, such as withdrawal of artificial nutrition and hydration, surgical interventions for patients with rare chromosomal abnormalities, and adolescent patients declining standard chemotherapy. Cases involving parental refusal of blood and blood-product transfusions based on religious beliefs are routinely examined at interinstitutional meetings as a form of community-wide peer review.

Recently, the consortium has encouraged standardization of real-time patient and parent access to electronic medical records in adherence with the CURES Act.⁶ Families' requesting continued technological support despite a diagnosis of DNC remains a common and particularly distressing cause for consultation. The more general case of family requests for potentially inappropriate use of technological support led to the development of a common "futility" policy, endorsing the withholding of interventions lacking clear physiologic benefit.⁷ As pediatric palliative care services have grown at our institutions, other end-of-life processes and policies have been refined and revised.^{8,9} These include reassessment of whether parents must sign a "do not attempt resuscitation" (DNAR) form during inpatient stays and how to communicate and manage DNAR orders during scheduled surgical procedures.

SFPBEC CASE CONSULTATION EXAMPLES

SFPBEC member hospitals have the opportunity to leverage the benefits of this collaboration. Although individual case reflections are a cornerstone of scheduled SFPBEC meetings, exceptionally challenging cases are brought to the consortium in real time. This on-demand service facilitates rapid review of available community approaches and an in-depth discussion of ethically permissible options. Examples of cases addressed in this manner, abbreviated and redacted here, include:

1. A patient with severe neurological injury, whose parents expressed deep ambivalence regarding escalation vs withdrawal of artificial life-sustaining therapies. The treating team exhausted options for effective communication, yet failed to reach an agreement with the family. The SFPBEC was consulted to explore other mediation options and the ethical implications of pursuing a court order for escalation of mechanical support. Based on recommendations from the consortium, the clinical team resolved the case without involving the judicial system.
2. An infant with multiple chronic, complex medical conditions and an unknown prognosis, whose family requested withholding

reintubation after a trial of extubation. The treating team was unsure if this was appropriate, given the infant's unclear prognosis. They sought regional ethics opinion via the SFPBEC to determine whether withholding intubation constituted discrimination against people with disabilities. After consultation, the treating team was reassured that following the family's request was ethically appropriate and nondiscriminatory.

3. A child with multiorgan failure and overall poor prognosis, whose family displayed significant maladaptive coping, including avoidance of the medical team and violent behaviors toward staff. Intense efforts at support and counselling of this family failed to achieve improvement in the therapeutic relationship. An SFPBEC consult was called to explore the community standards at member hospitals for legal intervention. The family, although hesitant, was reassured by the interhospital collaboration and SFPBEC discussion. With time and further trust-building efforts, they agreed to the withdrawal of technology.

BENEFITS AND POTENTIAL PITFALLS OF INTERHOSPITAL BIOETHICS COLLABORATION

Interhospital pediatric bioethics collaboration supports patients, families, individual practitioners, health care teams, and the community at large. Interinstitutional openness on shared struggles may buffer the moral distress clinicians can experience when communication breaks down at the bedside. Health care teams informally report a sense of security knowing that their policies reflect those of neighboring hospitals; this is especially important when clinicians face life-and-death decisions. Smaller community hospitals benefit from the experience of larger academic medical centers, as they follow the Joint Commission mandates that all hospitals have a process to handle ethical issues.¹⁰

In difficult clinical situations involving complex ethical issues, patients and families sometimes request a second medical opinion or transfer to a neighboring hospital. By facilitating a second opinion or transfer, medical teams can also ensure they adhere to multisociety practice guidelines for conflict mediation, particularly in cases of potentially inappropriate treatment.^{11,12} The SFPBEC provides a robust and easily deployed mechanism for obtaining expert clinical and ethical advice from nearby hospital teams. Parents typically accept the offer of an SFPBEC consultation, and the primary team shares the outcome directly with the family. In our experience, parents have valued learning the opinions of professionals from other institutions, even if they don't agree. Clinicians also learn from such consultations, and as noted above, management changes in specific cases are based on advice from other hospital ethics teams.

In some situations, an impasse between a hospital and a family leads to judicial review or a child welfare referral. The results of an SFPBEC case review can support the clinician and institution because they can credibly present their view as representing a community standard. Indeed, in one case, a judge remarked that the consensus of the SFPBEC (that placement of a tracheostomy tube was ethically appropriate) helped her decide to authorize the procedure over the family's objection. At a broader level, the SFPBEC fosters community

trust by demonstrating that a network of competing hospitals can work toward a common goal. This SFPBEC model entails potential pitfalls. The family's perspective may not be adequately highlighted because of the inherent power differential between families and hospitals. This bias is minimized through the inclusion of family and community representatives on each ethics committee, and involvement of the child's caregivers in specific consultations when appropriate.

Disagreement among committee members and hospitals is not discouraged, and sometimes, consensus is not reached. For example, one hospital requires all legal caregivers to consent to procedures, while other hospitals require only one if the second parent is unavailable. Another concern is that the SFPBEC may be seen as colluding to limit the options of families. In practice, clinical teams involved in consultations have learned from each other, providing new perspectives that have broadened options provided to families. Indeed, clinicians embroiled in the emotional aspects of conflict with families can benefit from the objective views of colleagues not engaged in the specific case. Finally, the involvement of hospital attorneys and risk managers ensures that our cross-institutional collaboration operates strictly within recognized legal and professional standards.

CONCLUSION

Variation in ethics policies and practices among closely situated children's hospitals can lead to confusion and loss of faith in clinicians and institutions. Our consortium is an effort led by health professionals who value the utility of applied ethics in hospital care. We believe this form of interhospital collaboration has significant benefits for institutions, clinicians, patients, and communities. The SFPBEC offers a model for mitigating mistrust of medicine, which has grown increasingly prevalent in modern society.

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ABBREVIATIONS

DNC: death by neurologic criteria

DNAR: do not attempt resuscitation

SFPBEC: South Florida Pediatric Bioethics Consortium

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