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Description of an Ethics Committee in a Children's Hospital

With a Case Study

Children's Hospital of Philadelphia (CHOP)

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I. Ethics Committee:

The Ethics Committee at Children's Hospital of Philadelphia includes six members of the medical staff, including the hospital vice president who serves as the chair or co-chair. Other committee members include representatives from a variety of staff from the medical, nursing, social work, chaplaincy, nutrition, pharmacy, child life, and behavioral health teams, as well as from the board of trustees and family members from the community. Responsibilities of committee members include promoting education about ethical issues, serving as consultants for families and health care providers, and reviewing policies associated with the institution's ethics board and with patient rights.

In our hospital, the members of the medical team are from diverse backgrounds of pediatric subspecialties and will serve "on call" as an ethics consultant for 2 week periods. The Ethics Committee meets monthly, and for one hour prior to the meeting, an optional case discussion and/or education session is presented.

II. Ethics Consult Intake Form:

Section 1. General patient information: Include demographic information about the patient and family, primary MD, established consult services already involved in the patient's case.

Section 2. Consultation Request Section: Describe the reason for the consult and a description of the conflict between patient/family and healthcare team.

Section 3. Medical information: Present a narrative of the patient's diagnosis, prognosis and potential treatment options.

Section 4. Patient Information: Describe the patient/family preference and any information about advance directives, and describe the patient's decision making capacity.

III. Introduction to an Ethics Committee meeting: The chair of the Ethics Committee provides a basic and professional introduction to the meeting, which is held in a private yet professional meeting place. The chair describes to attendees that an ethics consult is an impartial group of compassionate health care professionals who have come together to help sort out issues with the goal of providing excellent care delivery to the family. Other introductory remarks for the consult include an expression of gratitude that families are willing to meet to help achieve the best outcomes for the patient, assurance of confidentiality, a request that all participants (both families and health care professionals) remain judgment free, a request that all speak openly, honestly and respectfully, and a statement that specific answers will not be provided at the conclusion of the meeting. The potential for future consults, if they are needed, is made clear.

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IV. Example of a Case Review:

The patient was born at 32 weeks gestation, and had the following problems throughout the hospital stay: multiple congenital anomalies noted at birth including myelomeningocele at T11 vertebrae (repaired on the first day of life), coarctation of the aorta (repaired), craniosynostosis and cleft palate. Additionally the baby had IUGR, primordial dwarfism, retinopathy of prematurity (repaired with laser surgery), multiple feeding intolerances and an abnormal MRI suggesting profound brain dysfunction with questionable vision and hearing deficits and poor prognosis for higher developmental function.

After the baby's birth, the family elected to make the infant a comprehensive DNR. During the hospital stay, they changed the infant's status to a cardiac DNR, followed by further lessening the restrictions to a DNI (do not intubate) status. The family ultimately reversed the infant's initial DNR status to a full resuscitative code status.

The ethics consult was requested by the nursing staff after the infant had already undergone three surgeries, and the parents were considering going through with yet another surgery (repair of craniosynostosis). The baby had also had daily/weekly palliative care consults, and the family had had multiple meetings with the unit's neonatologists, nursing leadership and our NICU medical director. It was hoped that the ethics consult would be helpful both for the health care professionals, through provision of support to nurses suffering from caregiver fatigue and moral distress, and for the family, to support them through a major decision of going forward with a craniotomy and cranial reconstruction surgery for their baby.

The nursing team found it challenging to understand the parents' rationale for continuing to put the baby through painful procedures and interventions given the baby's poor prognosis for neurodevelopmental outcome, and some nurses were distressed by the ethics of continuing to provide such aggressive care given the baby's potential for future decreased quality of life. In particular, one question was raised which left an impression with the nursing team: Who would care for this child if a tragedy occurred and his parents would not be available to care for him? The thought of this baby/child/person, alone, in a long term care facility, blind, deaf, paralyzed from the waist down and feeding tube dependent, saddened many hearts.

The ethics consult was initiated with a bedside NICU nurse partnering with an ethics attending physician to complete a detailed case review for this NICU patient at 4 months of life. The nurse utilized a timeline report during the initial consult with the ethics attending. The report, organized objectively in a timeline format, incorporated highlights and major points of medical interventions for this infant. The ethics attending came to the infant's bedside every day for the first several days after the consult was requested in attempt to meet with the family for an introduction. At that time, the family started visiting in the late afternoon when most consulting services and the palliative care team have already rounded for the day.

The ethics attending then hosted a session for the front line clinicians in a private conference room to discuss issues of caregiver fatigue and moral distress surrounding the infant's care. During this meeting, the attending provided support to the caregiving staff and also provided insight for communication strategies and reviewed hospital policy for making ethical decisions. During the ethics attending's remaining two weeks on call, he followed up with bedside nurses regarding the challenges they faced as caregivers.

The ethics attending also provided support to the parents, speaking with them alone in a conference room. Their privacy was respected and no information was conveyed from the ethics' attending's meeting with the parents to the caregiving staff.

V. Resolution

After the ethics consult, the parents decided to go forward with the full craniotomy procedure to release the baby's fused suture lines with bone reconstructive surgery. Post-operatively the baby was managed on a ventilator for respiratory support, and was given opioid infusions for pain control. The parents expressed that their happiness that the procedure had been done to support the baby's potential brain growth. However, the baby's mother also expressed that the family wanted this to be the baby's last procedure for a long time, given that the baby's surgical sutures spanned a distance from ear to ear and appeared quite impressive. Post-operatively, the baby also had a PICC line placed for total parenteral nutrition; he subsequently developed a large thrombus in his heart. Lovenox therapy was started with subcutaneous injections Q 12hours. After a few weeks, the baby was extubated to CPAP and fed via nasogastric tube. With the baby in this subacute condition, the parents requested that the medical team consider transferring him to their home hospital for further evaluation, continued opioid wean, feeding tube management, cleft palate reconstruction surgery, potential gastric tube placement and continued respiratory wean from CPAP to nasal cannula. The family switched from private to state/government-supported insurance and the transfer was denied. The baby continued to wean on support and was ultimately discharged from the hospital with a custom feeding plan and minimal respiratory support.

Throughout the baby's lengthy hospitalization, the nursing team embraced and supported the parents' love for their baby and the parental duty they consistently demonstrated. The nurses also embraced the involvement of physical therapists, occupational therapists and music therapy to maximize the quality of the baby's life while in the NICU. They supported the family's request for music boxes, mobiles and even vibration boxes in the baby's crib, in the event he could benefit from any of these developmental interventions.

Despite the ethical dilemmas the nursing team encountered, their compassion and empathy for the patient and his family endured. The nurses simply had to accept the ambiguity and uncertainty of not knowing the fate and future of this and many other patients once they leave the NICU.