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The role of a pediatric ethics committee in the newborn intensive care unit

MR Mercurio

Department of Pediatric, Yale Pediatric Ethics Program, Yale University School of Medicine, New Haven, CT, USA

Institutional Ethics Committees are commonly available in hospitals with newborn intensive care units, and may serve as a valuable resource for staff and parents dealing with difficult ethical decisions. Many clinicians may be unaware of when the committee might be helpful, or how it functions. After a brief historical introduction, two cases are presented as illustrations of pediatric ethics committee function. The first involves consideration of cardiac surgery for an infant with ventricular septal defect and Trisomy 13. The second involves disagreement between staff and parents regarding possible provision of cardio-pulmonary resuscitation in a terminally ill newborn. Principles and considerations often brought to bear in committee deliberations are reviewed for each case. Neonatologists, staff and families should be aware of this potentially valuable resource, and are encouraged to use it for situations of moral distress, conflict resolution or ethical uncertainty.

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Introduction

Neonatology is a field that has always been rife with ethical conflict. In the 1970s, when available technology was expanding and neonatology was being established as a separate subspecialty, major ethical concerns gained widespread attention. Duff and Campbell,[1] in a landmark paper in the New England Journal of Medicine in 1973, revealed publicly that they sometimes withheld available lifesaving technology from certain newborn patients at Yale, based on poor prognosis and parental wishes. Though this approach was not unique to Yale, their paper gained widespread attention, perhaps because, as they stated, they ‘broke a public and professional silence’ on common practices.

In that same decade, a case from Johns Hopkins that involved withholding surgical repair of duodenal atresia from a newborn because he had Trisomy 21 (and thus allowing him to die when he most likely could have been saved) caused widespread concern and debate.[2] Survey data from pediatricians and pediatric surgeons during that time suggest that this approach was not unique to Johns Hopkins, but widespread in the United States of America.[3] Perhaps the best known of such cases was ‘Baby Doe,’ born with Trisomy 21 and tracheo-esophageal fistula in 1982, in Bloomington, Indiana, USA. His parents refused surgical repair of the tracheo-esophageal fistula and thus allowed him to die in infancy, on the advice of their obstetrician, with the support of the court. That decision was based largely on predicted disability and quality of life concerns for children with Trisomy 21.[4,5]

In the wake of such cases, the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in 1983 endorsed the creation and use of hospital ethics committees, which few hospitals had in place at that time.[6] The Joint Commission on Accreditation of Healthcare Organizations has subsequently mandated that every healthcare organization in the United States have a mechanism in place to address ethical conflicts, and most US hospitals have met this requirement through the formation of an institutional ethics committee (EC).[7] The American Academy of Pediatrics and the American Medical Association have both endorsed the use of ECs for this purpose, and have provided guidelines for their use.[8,9]

Evidence of the usefulness of EC consultation has been reported by several authors. Perkins and Saathoff[10] retrospectively surveyed physicians who had requested ethics consultations, and reviewed the relevant medical records. Physicians who had requested consultations frequently responded that the consultation had identified previously unidentified ethical issues, and in 18 out of 44 cases reviewed the consultation changed patient management considerably. Schneiderman *et al.*[11,12] showed in two large randomized, controlled intervention trials that ethics consultations did not affect mortality rate, but were associated with a reduction in hospital days, ICU days and life-sustaining treatments (for example, mechanical ventilation) among patients who ultimately did not survive to discharge. Moreover, most physicians, nurses and patients or surrogates in their studies reported that the ethics consultation had been helpful in addressing treatment conflicts.

Correspondence: Dr MR Mercurio, Department of Pediatrics, Yale University School of Medicine, P.O. Box 208064, 333 Cedar St., New Haven, CT 06520, USA.
E-mail: mark.mercurio@yale.edu

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Forde *et al*.[13] reported the results of a smaller physician survey in Europe, performed after ethics consultation, again indicating that the physicians frequently found the consultation useful. Specific comments of the respondents illustrate some ways in which an ethics consult can be helpful. One respondent reported that, 'We learned that this is actually a way to do it, and one can get the case elucidated from more impartial persons, and that we do not have to sit alone with such difficult dilemmas or conflicts.' Another clinician commented that the consult had helped them to see the patient's wishes and values more clearly. One respondent reported that the discussion had given the patient's relatives a feeling of being taken seriously. Another noted that the systematic discussion had had a positive influence on how subsequent problems were dealt with in the department.[13]

While there now seems to be a consensus within neonatology on some questions faced in the 1970s and 1980s, such as treatment for newborns with Trisomy 21, ethical dilemmas have clearly remained a central component of the practice of neonatology. Ethics committees can potentially serve as a helpful resource for clinicians and families facing difficult ethical decisions in the newborn intensive care unit (NICU). What follows is a brief overview of the structure and purpose of an EC, followed by two case discussions. These are composite cases, each with elements from more than one real case. The purpose of this essay is to illustrate how an EC might evaluate a clinical ethical dilemma in the NICU, including ethical principles and considerations commonly brought to bear.

Institutional Ethics Committees

The EC should ideally be a group of individuals from various disciplines including medicine, nursing, law, clergy, social work, behavioral sciences, ethics/philosophy and members of the community not otherwise affiliated with the hospital. While it is not feasible that every member will be expert in the area of bioethics, the members of the committee should have specific training in ethics consultation such that the EC can provide not only different perspectives, but also a level of expertise in ethics beyond that of most clinicians. This is essential for their function in case reviews, and also for their credibility as a valuable resource to the clinical team. The committee should be available on short notice to provide consultation and guidance to clinicians, patients, family members and/or others as needed.

Ethics committees generally do not carry any direct decision-making authority, but serve solely in an advisory role. At the outset of each consultation that role should be made clear to staff and parents; they are under no obligation to follow the recommendations of the committee. However, it should be acknowledged that the opinion of the committee often carries with it some degree of influence or 'moral authority,' which is reasonable, provided they have prepared for and carried out their role appropriately. The EC should not serve as legal counsel. The two questions, 'Is it legal?' and 'Is it ethically permissible?' can both loom large in the practice of neonatology, but they are separate questions, and should not be conflated. Clinicians or parents with a legal question should be appropriately referred to legal counsel.

Ethics committees commonly serve three major functions within the hospital: case consultation, education and policy development. This essay focuses on the EC's role in case consultation. There are various ways that the EC could be structured, and might approach a case consultation, which are described elsewhere.[14,15] Possible mechanisms for ethics case consultation include using an individual consultant, a small consulting team, or the entire EC. For most hospitals, one EC serves both the adult and pediatric patients, and with the appropriate committee training and membership (which would hopefully include experienced pediatric clinicians), this may adequately serve the needs of the pediatric population. However, Lyren and Ford have rightly pointed out that, just as there are substantial differences in adult and pediatric medicine, differences can also be seen in the ethical questions faced by those caring for these two populations, and in the ways those questions might need to be approached.[16] Thus many larger pediatric centers have a separate pediatric ethics committee (PEC).

In our institution there is a separate PEC, and a subset (generally five to eight members) is usually called upon to hear and discuss each case. This group meets with the individual(s) who have requested the consultation, and encourages the participation of all involved (for example, physicians, nurses, and parents). The function and deliberations of a PEC are illustrated by the following two cases from an academic medical center. All points made herein regarding a PEC should be seen as applicable to any EC that covers a pediatric population.

Case no. 1: Trisomy 13 and ventricular septal defect

A 2300-gram male infant ('Daniel') was born at 38 weeks gestation to a 36-year-old woman with two other living children. Prenatal studies revealed Trisomy 13 and a large ventricular septal defect (VSD). Parents were counseled at length regarding the very poor prognosis, including likelihood of death in infancy. They were offered termination of the pregnancy but declined. He did well at delivery, but was noted to be hypotonic, in addition to physical appearance consistent with the diagnosis of Trisomy 13, and was sent to the NICU for observation and care.

For the first several days of hospitalization Daniel was noted to be stable in room air, with no other major anomalies, but required feeding via a naso-gastric tube due to a poor suck reflex. Cardiac ultrasound confirmed a large VSD. He remained in the NICU, and oral feeding slowly improved over the next 4 weeks. By 4 weeks of age he was feeding nearly entirely by mouth, but then began to show early signs of pulmonary edema/congestive heart failure, presumed due to the VSD. It was explained to the parents that progression of his pulmonary edema and respiratory distress would most likely gradually lead to respiratory failure and death, and this was often how patients with Trisomy 13 died. The parents, who had studied this issue on the internet, asked to speak with a pediatric cardio-thoracic surgeon, and after that meeting requested that Daniel's VSD be surgically repaired. The surgeon expressed a willingness to do it, but given Daniel's underlying condition, and the fact that a child with Trisomy 13 had never undergone cardiac surgery in this institution before, the physicians involved were unsure whether it was appropriate, and requested a consultation with the PEC.

Pediatric ethics committee meeting and ethical considerations

The PEC met with the parents, cardiologist, surgeon, neonatologist, NICU nurse and geneticist. The case was presented, and the question posed to the committee was: Should Daniel undergo VSD repair in accordance with his parents' wishes? All were in agreement that the timing of the surgery, if it was to be done at all, would be left to the medical and surgical teams depending on his clinical course. But should it be done at all? The following points were discussed and considered in the recommendation.

The standard of care at this institution was to provide children with Trisomy 13 with comfort measures only and allow them to die without surgery or any intensive measures such as mechanical ventilation. For many questions in medicine, the standard of care is often used to determine the best course of action, but a good physician will always want to know upon what that standard is based. It might be based on several large controlled trials, on sound physiological reasoning in the absence of trials, on anecdotal experience, or simply on habit. Good medical practice requires knowing the strength of the evidence and arguments that support any standard, and basing one's degree of flexibility with regard to the standard on the strength of its foundation. A similar point could be made with regard to ethical questions in medicine: our obligation to adhere to a standard of care should be greatly informed by the strength of the data and the ethical reasoning that support that standard.[17]

The first thing to be clarified should be the data. ECs are generally dependent on the clinicians who bring a case before them to provide unbiased current data. Unless the EC happens to have a member with particular expertise in the subject in question, or they choose to do exhaustive research before the consultation (which is generally impractical), their deliberations, and ultimately their recommendation, can only be as good as the data provided. Though not generally the case, it has occurred that clinicians have presented incorrect or outdated outcome information. In this case, all of the physicians agreed that the vast majority of infants with Trisomy 13 die within the first year, often from untreated cardiac disease, sometimes from other causes. Furthermore, though some have survived for many years, all survivors are left with a profound level of disability.

With regard to the probability of early death, however, there is an important problem with the data: the risk of self-fulfilling prophecy.[18] Most die a very early death, but that may be at least in part because efforts are generally not made to save them. Of course, this perpetuates the high early mortality, which is then used to justify non-treatment. What would happen to such children, the committee asked, if more efforts such as VSD repair were made to save them? The cardiologist reported that cardiac surgery has been carried out on some children with Trisomy 13, and data suggest that life expectancy can sometimes be extended, which seemed to make sense.[19,20] However, as consistently aggressive care is relatively new and not widespread, it remains unclear what the life expectancy under such circumstances would be. Mortality data were thus understood to be generally grim but uncertain, and the discussion turned to predicted morbidity.

Exactly how severe is the disability among survivors? The parents reported information obtained from the internet, primarily parent support group sites, suggesting that some of these children seem to be aware of their surroundings, and capable of feeling pleasure and happiness. They are also said to be able to interact with others, including some rudimentary speech. Clearly great caution is advised when obtaining medical information from the internet, and the EC is well advised to seek information from an experienced and unbiased individual; they turned in this case to the geneticist for confirmation of these facts. She reported that though she had heard parents say their child with Trisomy 13 could speak, she herself had never heard it. When asked if such children are aware and able to interact with their environment, she said that some parents would say yes, but she herself was not sure.

The ethical reasoning applied in this case was based primarily on two fundamental principles: *parental authority* and *patient's best interest*. In our society parents are generally accorded the right to decide what is done to their children, including medical matters. The long history of this right cannot be adequately covered in this essay, but suffice it to say that it is widely accepted, and is not refuted here. With regard to major medical decisions, the American Academy of Pediatrics Committee on Bioethics Guidelines on Forgoing Life-sustaining Medical Treatment has rightly stated that in difficult ethical matters the values and judgments of the parents should generally be honored. However, in that same document they acknowledge that medical professionals should seek to override parental wishes when their request is clearly opposed to the child's best interest.[21] Thus, parental authority is seen as strong, but not absolute, and may be limited by an understanding of the child's best interest, which is assessed by comparing the anticipated benefits and burdens of the proposed treatment.

This is not to say that for a parental decision to be supported it must always be clearly consistent with the child's best interest, but rather that there is some lower threshold (that is, clearly opposed to the child's best interest) below which the physician should no longer support the decision. Indeed, many ethicists have argued that the harm principle, rather than the best interest standard, best describes obligations to the pediatric patient. As explained by Diekema: 'The real question is not so much about identifying which medical alternative represents the best interest of the child, but rather about identifying a harm threshold below which parental decisions will not be tolerated.'[22] In Diekema's article, however, application of the harm principle is recommended to determine when clinicians or the state should override parental choice for cases in which parents refuse recommended medical treatment, which was not the issue here. Whether it is also applicable to parental requests or demands for treatment about which the clinical team is opposed or unsure, is possible but less clear. That question was not addressed in this consultation, and is not addressed in this essay.

In this case, the PEC felt that the surgery should not be withheld simply because that had been the standard of care, and should not be provided simply because the parents had requested it. In the final analysis, the recommendation regarding whether the procedure should be done would hinge on an assessment of the child's best interest, by weighing the potential benefits and burdens (harm) of the requested treatment.

The potential benefit of surgery would be the chance of longer life. Whatever pleasures Daniel might experience in the future could be seen as a benefit of the surgery. That might be as simple as the pleasure of human touch, laughter or a full stomach. The degree to which he might experience such pleasures was not clear to the committee members even after hearing from all involved. In addition, the surgeon noted that, in his opinion, congestive heart failure was a very difficult way to die, and the surgery might reduce the total amount of suffering Daniel would experience. The cardiologist agreed, stating that VSD repair could even be described as optimizing 'comfort care.' The parents also felt that his life would be a benefit to them and to their two older children, giving them an opportunity to give love and learn to care for someone less fortunate. The committee took note of this, but understood the need to be cautious about considering the benefits to others in the family. On that question there is a difference of opinion among ethicists: some feel the best interest standard requires weighing the benefits and burdens to the patient only, others believe that the interests of others affected by the decision, particularly the family, should also be taken into account.

The potential burdens of the surgery included pain, risk of complications and the ongoing burdens of severe disability for the time his life may be extended by the procedure. The potential burdens on the siblings and on society were also raised, but again the committee considered these with caution for the reason cited above. The physicians felt the pain could be kept to a minimum with proper anesthesia/analgesia, and the risk of surgical complications, including death, was very low. The primary burden to the child, then, seemed to be the burden of the ongoing disability from potentially prolonging his life.

Next the social setting and family situation was discussed. The parents were married and highly educated. There were two other healthy children, ages 5 and 8 years. The mother was at home with the children, the father was self-employed, and they were financially very well off. They would easily be able to pay for help with Daniel and the other children as needed. When asked if they felt having Daniel at home might be a burden to the other children, they acknowledged there could be some difficulties, but also felt there could be some advantages to them in learning to love and care for someone like Daniel. The parents talked at length about how they felt this could be a good thing for their family, but in any case they felt the surgery and prolonging his life as much as possible was good for Daniel. They seemed to understand the idea of patient's best interest, heard the concerns of the physicians, in particular the geneticist, about the severity of the disability, and nevertheless felt it was in his best interest to have the surgery. They reported having done extensive research on Trisomy 13 and the availability of cardiac surgery, and informed the committee that if they could not get the surgery done at this center they would find another that would do it, but preferred to have it done here, and by this surgeon.

The Chair of the PEC then asked everyone else present if they wished to express an opinion as to whether the surgery should be provided, based at least on the arguments and considerations put forth at the meeting. The surgeon felt it should; others were unsure or declined to give an opinion. No one voiced opposition to the surgery. It is possible that some were opposed to the surgery but felt uncomfortable saying so in the presence of others, including the parents. One important purpose of the meeting is to give everyone involved the opportunity to hear the opinions and reasoning of the others, and it is important that an environment be established that is open to honest discourse. For this reason parents should be encouraged to invite others of their choosing (for example, grandparents, friends, clergy) as support, and all should be encouraged to speak freely. Also, the Chair of the committee may for certain cases choose to offer some individuals the opportunity to share their opinion in private. In this case, no one involved voiced opposition to the surgery, at the meeting or afterward.

Further discussion

Immediately after this meeting the members of the PEC met alone and reviewed the case. This second, separate session offers EC members an opportunity before making a recommendation to share further impressions, concerns and opinions with one another that they may not have wished to share in the larger meeting.

The question of improper use of resources was raised, in terms of the surgery and hospitalization, and the ongoing services that would be required should Daniel survive long-term. This is a reasonable consideration, often raised under the heading of distributive justice, the fair allocation of scarce resources. Surely this money could be used to help far more children, who could appreciate a far greater benefit. Would the procedure have been a consideration if the parents had fewer financial resources? Should parental wealth be a consideration in such decisions? The point here, the committee determined, was that very often patients in this hospital are provided with resources that could perhaps have been allocated to help far more children, but they generally receive those resources based on an assessment of the needs and interest of the patient in question. It did not seem fair to single out this child for a different approach. Should a different, broad-based approach be chosen by the medical profession or society for all such patients, it might lead to a different conclusion, but unless and until that occurs the PEC felt that it would not be fair to apply the patient's best interest standard inconsistently.

Most often PEC consults involve a conflict or disagreement between two parties, commonly parents and staff. In this case, it was noted, the parents wanted the procedure, the surgeon was willing to provide it, and no one had voiced opposition. Thus, it might seem that there was no real need for the PEC, but that is not the case. Put simply, the fact that a physician and parents agree on a course of action does not insure that the course is ethically advisable, or even permissible. The role of the committee is to work through their reasoning with them, in light of important ethical considerations and relevant past cases. And, ultimately, if the committee concludes that the parents and staff have together reached an inappropriate decision, that conclusion needs to be shared and explained.

Recall that in the Baby Doe case in 1982, a physician and parents agreed that it was best to withhold lifesaving surgery from a child with Trisomy 21 due to the predicted disability, and the child was allowed to die. Though this was consistent with the standard of care at that time, in retrospect was felt to be a poor decision. The degree of disability had been exaggerated, and it was almost certainly in that child's best interest to be kept alive. It was largely in response to that case that ECs were recommended to provide guidance with such decisions, and have now become nearly ubiquitous in US hospitals. For Daniel, it was considered that the opposite mistake could be made. That is, the parents and physician might agree to keep a child alive even though it would be opposed to his best interest to do so. Parent/physician agreement did not guarantee an ethically acceptable answer, and further discussion and analysis was appropriate.

Surrogate decision-makers, in this case the parents, are expected to decide based on their assessment of the patient's best interest, and there seemed to be no compelling evidence that these parents were doing otherwise. In addition, the medical team is expected to support the parental decision whenever feasible, unless it is clearly opposed to the child's interests. To the PEC, both the potential benefits and potential burdens/harms seemed difficult to discern. How much benefit or burden would he appreciate from being kept alive longer? Would he be aware of his surroundings? Would he be suffering? Had the committee felt that the burdens clearly outweighed the benefits, they would have recommended against the surgery. Though many felt that burdens may well outweigh the benefits, none believed it was clearly so. Given that lack of clarity, it was ultimately agreed to defer to the parents' assessment of the child's interests.

For this case, despite the well-established standard to the contrary, the PEC felt it was ethically permissible to provide the surgery for Daniel. Moreover, given that reasonably informed parents clearly wanted it, and the surgeon clearly wanted to do it, and the PEC had been asked to make a recommendation, the committee recommended that it be done.

Follow-up

The surgery was performed without incident, and Daniel is now 4 years old, living at home with his family. The question of whether cardiac surgery or other intensive care measures should be offered to parents of patients with Trisomy 13 remains controversial within this institution and beyond.

Case no. 2: Resuscitation in the setting of terminal malignancy

A 1680-gram female ('Katherine') was born at 32 weeks gestation, after a pregnancy notable only for preterm labor. Parents were married, with three other children at home. Katherine had Respiratory Distress Syndrome requiring mechanical ventilation until day 4, and was then maintained on nasal continuous positive airway pressure for an additional 4 days. Thereafter her course was notable for apnea consistent with gestational age, and gradually increasing enteral feeds. On the twenty-fifth day of life she was noted to have a distended abdomen, and significant deterioration in her clinical status required reintubation. Evaluation, ultimately including laparotomy, revealed significant intra-abdominal bleeding, and malignancy involving her small bowel, liver, diaphragm, and abdominal wall. Resection was not possible. The abdomen was closed, and the patient remained on a ventilator and critically ill after surgery.

The pediatric oncologist on service was consulted, and determined that the prognosis was very poor. Median survival for infants diagnosed with this particularly aggressive malignancy was 2 months, and there were no long-term survivors known. The case was reviewed with the three other members of the Pediatric Heme-Onc section, and chemotherapy was not recommended due to lack of efficacy, and the fear that it could precipitate further intra-abdominal bleeding. The oncologist contacted an authority on this particular disease at another medical center, who reviewed the record and the diagnostic studies, and examined the biopsy specimens. She confirmed the diagnosis, and also believed the prognosis was dismal. She told Katherine's oncologist that the patient would likely die within the next several weeks, and did not recommend chemotherapy.

The parents understood the prognosis, and agreed with the plan not to provide chemotherapy, They did, however, ask that everything be done to keep Katherine alive as long as possible, including mechanical ventilation, intravenous nutrition, and transfusions as needed, and the clinical team agreed. They offered the parents Do Not Resuscitate (DNR) status, but the parents insisted that cardio-pulmonary resuscitation (CPR) be carried out when her heart slowed or stopped. Over the next 3 weeks Katherine continued to deteriorate, requiring very high ventilator settings, frequent transfusions, pressor support, and high doses of pain medication. She was markedly and increasingly edematous, and her abdominal incision had reopened. She appeared to be in a chronic state of disseminated intravascular coagulation. It became increasingly difficult to maintain her oxygenation and blood pressure in acceptable ranges, and they fell below acceptable ranges increasingly more often. The staff was convinced that, despite pain meds, she was often in pain. Parents had been offered withdrawal of mechanical ventilation and had declined. The neonatologist, on more than one occasion, recommended DNR status, but the parents refused, so full resuscitation was planned. A new neonatologist rotated on service and, after assessing the situation, requested a PEC consultation.

Pediatric ethics committee meeting and ethical considerations

Several members of the PEC met with the parents, the maternal grandmother (attending at the parents' invitation), the neonatologist on service, the neonatology fellow, the oncologist, one nurse practitioner, and two nurses. The meeting was run by the Chair of the PEC, who had everyone introduce themselves, and reviewed the purpose of the committee and the meeting. After the facts of the case as were presented by the medical team, the question presented to the PEC by the neonatologist was: 'Are we obligated to do chest compressions and provide other resuscitative measures when Katherine's heart slows or stops?'

All members of the clinical team expressed a firm belief that CPR would not be effective. That is, 'it would not bring her back,' except possibly for minutes or at the most hours, which would, in their judgment, only add to her suffering. It seemed, they all felt, like the wrong thing to do. The neonatologist stated that she strongly preferred not even to continue with mechanical ventilation, but was willing to do so to comply with the parents' wishes. The nurses were particularly focused on the baby's apparent suffering; she grimaced and often increased her heart rate when they had to touch her even to provide basic care. In addition to the specific question regarding CPR, it was clear that many members of the clinical team, in particular the nurses, were experiencing 'moral distress.' Moral distress is here meant to refer to the feeling that they are participating in something immoral, and feel powerless to change the situation. Giving the nurses a forum to discuss that concern, openly and frankly, was an important part of the meeting, aside from the primary goal of providing advice on the specific question of DNR status.

The parents stated that they did not wish to give up hope if there was any chance her life could be extended. They believed, in their words, that there could still be 'a miracle,' such that she would survive and do well. The child's grandmother expressed support for that belief. The parents described themselves as Christians. They attend church regularly, but had declined to bring a member of their clergy to the meeting when it had been suggested. They expressed gratitude for what had been done by the doctors and nurses, but insisted that all efforts must be provided. A member of the PEC, himself a clergyman, offered the belief that making the child DNR did not close the door to a miracle. The parents understood the point but did not change their position.

The Chair of the committee reviewed the concept of patient's best interest, and suggested they try to discuss the possible benefits and burdens to Katherine of performing CPR. No clinician present felt there was any apparent benefit. She would, they felt, not survive it, though it was remotely possibly she could be 'brought back' for a few minutes, only to die after that. It was then asked, what was the harm to her of trying, as the parents had requested? The neonatologist suggested that, though it was not clear, she might possibly experience pain during the procedure, especially if perfusion of the brain were briefly restored, and that it was possible for a rib to be fractured, which she might feel. The oncologist opined that performing CPR would be an affront to Katherine's dignity. Lastly, the neonatology fellow noted that, if by some small chance CPR did extend her life by minutes (that is, vital signs restored briefly), those could be very painful minutes. A member of the PEC asked if the risks of pain could be reduced or eliminated through the use of analgesia. A nurse responded, and all clinicians agreed, that despite such efforts pain remained a possibility.

Because the parents had agreed with the plan not to provide chemotherapy, a member of the PEC tried to draw an analogy between chemotherapy and CPR. Chemotherapy was withheld because it offered no benefit to her, and might possibly hurt her. Could they consider the possibility, using the same reasoning, that CPR should be withheld? The parents did not accept the analogy, stating that it remained possible that CPR might make her live longer.

After discussion for approximately an hour, the parents continued to insist that CPR be provided, and the clinical team felt strongly that to do so was inappropriate. After everyone had a chance to ask their questions and give their point of view, the meeting was adjourned, and the Chair promised to contact the parents, neonatologist, and nurse with the committee recommendation that evening.

Further discussion

The PEC met privately immediately afterward. The conversation focused first on the possible effectiveness of CPR. There should be a healthy skepticism when the clinical team presents great confidence in a dismal prognosis, and refuses to provide a treatment on that basis, but this case seemed to warrant it. The clinicians were convinced that CPR would not be effective. One possible consideration in such cases is an ethical justification of physician refusal based on futility. It is widely held within the medical profession that if a requested treatment is truly futile, it is ethically permissible to withhold it. 'Futile' is defined in common language as being unable to accomplish the desired goal, or as 'having no useful result.'[23] If CPR cannot save or significantly prolong this child's life (the presumed desired result), it could then be argued that the clinical team is not obligated to provide it. A similar argument might have been used to justify withholding chemotherapy or partial surgical resection, had either of those been the point of disagreement.

In recent years many medical ethicists have advocated moving away from claims of futility as a justification for refusing patient or family requests, however, for a variety of valid reasons.[24] For example, despite the understanding of futility in common language, it remains unclear how much data are required (for example, how many previous attempts in similar cases) to justifiably call a proposed treatment futile. In addition, there may be an unfortunate tendency among some physicians to inappropriately invoke the concept of futility, to avoid difficult conversations or conflict with patients/families. Nevertheless, in some extreme situations, if a treatment truly offers no possibility of achieving the goal, futility could stand as a valid justification for physician refusal. Providing Katherine with CPR could be such a case. However, before a determination of futility can be made, the goal must be clear, which points out another potential problem with invoking futility to justify physician refusal: lack of communication and/or agreement between physician and family concerning the goal of the treatment in question, or what would be considered a 'useful result.' The family might perceive prolonging Katherine's heartbeat, even for as short as just a few minutes or hours, to be worthwhile, whereas the physicians and nurses might not. The clinical team could find no benefit to Katherine in attempting CPR. It was understood that the parents saw it differently, particularly the benefit of holding out for a miracle as long as possible.

The discussion of this case did not focus directly on the question of futility *per se*, but rather on consideration of both potential benefits and burdens of attempting CPR, consistent with the patient's best interest standard. The PEC felt that the small possibility of prolonging Katherine's life very briefly in her current state (or worse) did not represent a significant benefit to her. Regarding potential burdens, much of the conversation centered on the child's pain, and the absolute imperative to treat it adequately, not just at the time of CPR, but throughout her course. The nurses' observations of 'grimacing' and other signs of pain despite attempted pain control were a great concern. By treating the pain aggressively, it was understood that there was a chance death might be hastened, for example by worsening hypotension. However, it was noted that the risk of hastening death could be reduced by appropriate use of the correct analgesics. Moreover, each member felt that adequate pain relief was ethically acceptable even if it did hasten her death.

This is consistent with the philosophical *Doctrine of Double Effect*, which states that an act (here aggressive pain treatment) may be permissible if the primary goal is permissible, and the undesirable secondary effect is foreseen but not intended.[25] The primary goal in this case would be relief of pain, and the foreseen but unintended consequence would be hypotension and/or other side-effects of the treatment, possibly even hastened death. Of course, if one were to give one hundred times the normal dose of morphine to an unintubated patient, a primary goal of pain relief seems dubious at best. However, in patients such as Katherine, who have been on substantial doses of analgesia for an extended period of time, it is believable and in fact likely that a very high dosage will be needed to control pain adequately. The members of the committee felt strongly and unanimously that the pain should be adequately treated despite any theoretical or real risk of hastening death.

Would it be unfair to the parents, perhaps a violation of their right to parental authority, to withhold CPR despite their request? Given the very grim prognosis, and the child's apparently miserable situation, all felt that any concerns about parental rights were trumped by concern for the child's burden. It was considered whether providing the CPR might give them some comfort that 'everything possible' was done. By that reasoning, however, one could justify chemotherapy, or another laparotomy. Those interventions were not under consideration, and were never offered to the parents, because no clinician felt they offered any benefit to the child. And no one, including the parents, seemed troubled by that limitation of their options. The same rationale was felt by most committee members to hold for CPR: it need not be given, or even offered, because it offers no benefit to the child. Some suggested that perhaps CPR should be viewed differently than other procedures or treatments, but a sound ethical argument for doing so was not apparent to the committee. Moreover, withholding CPR because it offers no benefit is a practice familiar to nearly every neonatologist; for example, few, if any, offer resuscitation to parents of a child born at 20 weeks gestation. Also, even if performing chest compressions on Katherine provided the parents with comfort, many on the committee felt that should be only a secondary consideration, and the potential burden to Katherine should be given greater weight.

Perhaps the real problem in this case was the fact that CPR had already been offered to the parents. The previous attending neonatologist, in an effort to make official what seemed like an obvious choice, had offered the parents DNR status. Offering parents DNR is, by definition, offering them a choice, which then seems equivalent to also offering them CPR. If CPR offered no potential benefit to the patient when it was initially offered, then it seemed it should never have been offered. This same situation had been observed by the PEC on more than one occasion: the attending offers DNR in an apparently terminal case, the family refuses, and the attending thus seems bound to provide a procedure that neither he nor anyone else on the clinical team thinks is medically appropriate. The reason DNR is offered in this way is not immediately clear. Perhaps the attending thinks he is legally obligated (probably not the case, but legal consultation is advised), or perhaps he does not wish to make that decision alone. Of course, he need not make it alone, any more than the surgeon alone must decide about offering a repeat laparotomy, or the oncologist must decide about offering chemotherapy. For those physicians, the common course would be to confer with colleagues about efficacy, and the wisdom of offering the treatment. Why should neonatologists and other intensivists, it was asked, approach CPR differently?

While offering the parents the choice might seem an appropriate deference to their authority, one could argue that, in cases where it cannot benefit the patient, offering the parents a choice places an unnecessary burden on them. In addition, to offer them CPR in such a setting may be misleading, perhaps sending the unintended message that it could potentially work. Why else, parents might say to themselves, would they do it? The PEC next considered the option of a 'slow code,' wherein the clinicians try briefly and very half-heartedly to resuscitate, essentially feigning an effort to revive the patient, and informing the family that resuscitation was attempted. This was also rejected by the committee as misleading, or worse, fundamentally dishonest.

The committee determined that the point should be made to the attending, and perhaps all of the attendings: the best course may well have been to consider whether CPR was an ethically permissible option before offering it to the parents, by discussion within the neonatology section and/or with the PEC. This advice might prove helpful for future cases, but would not help here. These parents had already been offered CPR. Could the offer now be withdrawn? Despite the earlier offer, the PEC did not feel that the clinical team was obligated to do something that offered no benefit to the patient. The neonatologist and the clinical team, including the original neonatology attending, all felt strongly that CPR offered no benefit to Katherine, and could potentially cause her harm.

The recommendation of the committee was that, based on the information provided, the clinical team was not obligated to provide CPR if they felt it offered no benefit to Katherine, and/or that the potential benefits to her were clearly outweighed by the potential burdens. If the parents continued to insist on the procedure even after being told of this assessment, and the clinical team chose not to provide it, the clinical team could ethically withhold the procedure after completing the requirements of the hospital's Conscientious Practice Policy (CPP). This recommendation, along with a strong recommendation to be vigilant regarding pain control, was shared with all parties that same evening.

The CPP was written by a combined group of the adult EC and PEC, based on a similar policy at another institution, which has been adopted by several hospitals in this state.[26] It was developed in response to a recommendation by the American Medical Association that every hospital have a policy for addressing such disputes.[27] It outlines a procedure to be followed when patients or family members insist on a specific treatment or procedure that the physician feels is inappropriate, for ethical or other reasons. The major steps include offering transfer to another physician or hospital when feasible, obtaining a second opinion (preferably with the relevant department chair or section chief), and consultation with the PEC. If conflict persists, a final decision is made by the Hospital Chief of Staff and/or a special committee selected by him. That decision will likely be influenced by the recommendation of the PEC, though the special committee and Chief of Staff are not bound by it. This, again, points out that while the PEC has no direct decision-making authority, their opinions and recommendations can sometimes have significant influence in the clinical setting. If parents disagree with the final decision of the Chief of Staff, they retain the right to seek redress with the Court. The CPP is a hospital policy and does not necessarily provide legal protection to physicians who refuse to comply with a family's request for a specific treatment, as found, for example, in the process outlined in the Texas Advance Directive Act.

Follow-up

The neonatology attending chose to invoke the CPP, and after the necessary steps were carried out, a DNR order was written and signed by the Chief of Staff 2 days after the consult. The hospital legal office had previously been made aware of the case and of the decision. The Chief of Staff met with the parents and explained what he was doing and why. Though they never consented to the DNR status, the parents did not elect to challenge it legally.

Katherine died 7 days after the PEC consult. CPR was not attempted.

Conclusion

Ethics committees can be a useful resource for clinicians and/or parents when facing difficult ethical decisions, or attempting to resolve disputes. The purpose of these committees is to help those making such decisions to understand the ethical issues that may be involved, to facilitate discussion, and often to make specific recommendations. Physicians and parents in ethically uncertain situations, or making potentially controversial decisions, stand to benefit from an EC's insight, whether that insight provides support for their decision, or a better understanding of why they may be choosing the wrong path.

Conflict of interest

The author declares no conflict of interest.

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