

Session 20. Institutional Pediatric Ethics Committees

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Overview

Over the past several decades, the landscape of ethics practice in hospitals has evolved significantly in response to increasingly complex ethical questions and the changing influences of judicial and accrediting bodies. Institutional Ethics Committees (IECs), now commonplace in hospitals across the United States, help navigate these challenges by providing education, policy review/development, and consultation, though specific practices vary among institutions. As such, it is helpful to understand the form and function of IECs and how they may operate to meet the needs of the hospital.

This material will discuss the functions of IECs, the roles they play in health care institutions, and their usefulness in patient care and policy implementation. Participants are encouraged to discuss their knowledge of, experiences with, and reservations about interacting with IECs. Further, they are encouraged to learn more about the specific practices and policies of their own hospital's IEC.

Instructors Guide:

- Case Summary
- Alternative Cases
- Learning Objectives
- Suggested Reading for Instructor
- Further Reading
- Case Discussion

Case Summary

Tommy was a 3-year-old when he was hit by a car, resulting in severe traumatic brain injury (TBI). Two weeks into his stay in the pediatric intensive care unit (PICU), Tommy's parents were presented with the option of forgoing life-sustaining treatments (FLST). After a few days of reflecting and discussing the issue, they had determined that stopping the ventilator was best, but by that time there was a new ICU physician who, after review of Tommy's condition, did not think that FLST was warranted. With more intensive therapy, Tommy was able to breathe without the vent, and he was moved to the rehabilitation unit. Because of his TBI, however, he

continued to be fed through a tube. Neurologic scans indicated problems with the basal ganglia, and Tommy's parents suggested that Tommy's condition was not in his best interest, asking the palliative care physician about the possibility of stopping feeds. At the same time, the physical and occupational therapists working with Tommy, as well as nurses and social workers from the PICU who came to visit him in the rehabilitation unit, believed they saw slight but noticeable improvements in his cognitive status—possibly tracking, smiling, reacting to some stimuli. The entire unit, including these PICU staff members, is concerned about the ethics of what the parents are suggesting.

- Should a request be made for an ethics committee consult?
 - If so, at what point should it be (or have been) made?
 - If so, who should or who can call for ethics committee review?
 - What role would the ethics committee play if called?
- What can you expect from the ethics committee?
 - How will it function?
 - Do they mediate, facilitate, and/or recommend?
 - What training is involved?
- Are there good reasons to avoid calling in the ethics committee?
 - Are committee consults helpful or harmful?

Alternative Cases

1. Diagnosed with biliary atresia at 3 months, Jamie's parents reluctantly agree to a Kasai procedure to mitigate temporarily his liver problems. His parents are told that the Kasai procedure may work for as long as 5 years, but eventually, Jamie will need a liver transplant. Jamie's parents, stating both that they have seen family members do better than doctors ever thought possible and that they have faith that God is already healing Jamie, are reluctant to pursue transplant. Unfortunately, within a year Jamie's liver begins to fail, and transplant is medically indicated. The parents, however, refuse to take Jamie to a transplant center. Given the high efficacy of transplant procedures in young children, the liver specialist who has just admitted Jamie to the hospital believes that the parents' decision is unacceptable, and she calls the ethics committee hoping to convince the committee that the transplant should be pursued over the parents' objections.
 - What role should the ethics committee play?
 - Who should be involved in the ethics committee discussions?
 - Should Jamie's primary care physician be notified?
 - Should the parents be involved?
 - Should legal counsel be present?
2. Mary Jo is a chronically disabled child who has had trouble gaining weight even on full-feeds—both home and in the hospital. Her "I's and O's" are often unexplainably negative. Also, her gastrostomy tube continually has problems—including breaking. The gastroenterologist finds the myriad problems baffling, even disturbing. "Breaks almost never happen," he notes. He is concerned that Mary Jo's mom may be interfering with the tube, purposefully causing problems. He wants to put Mary Jo under video

surveillance without mom's knowledge to see if he can catch mom tampering with Mary Jo's feeds. Policy requires that the ethics committee review the case before he can proceed.

- Are you aware of institutional policies that might require ethics committee involvement? Should policies require ethics committee involvement?
- Should the ethics committee take the lead on developing policies that have ethical content?

Learning Objectives

1. Understand reasons that IECs exist, and the functions they can play in the institution.
2. Understand the different ways that IECs provide case review/consults.
3. Recognize the benefits of IEC involvement when challenging ethical issues arise.

Suggested Reading for Instructor

American Academy of Pediatrics, Committee on Bioethics. Institutional ethics committees. *Pediatrics*. 2001;107(1):205-209

DuVal G, Clarridge B, Gensler G, Danis M. A national survey of U.S. internists' experiences with ethical dilemmas and ethics consultation. *J Gen Intern Med*. 2004;19(3):251-258

Hester DM, Schonfeld TL, eds. *Guidance for Healthcare Ethics Committees*. Cambridge, United Kingdom: Cambridge University Press; 2012

Kessleheim JC, et al. Ethics consultation in children's hospitals: results from a survey of pediatric clinical ethicists. *Pediatrics*. 2010;125(4):742-746

Lyren A, Ford PJ. Special considerations for clinical ethics consultations in pediatrics: pediatric care provider as advocate. *Clin Pediatr (Phila)*. 2007;46(9):771-776

Mercurio MR. The role of a pediatric ethics committee in the newborn intensive care unit. *J Perinatol*. 2011;31(1):1-9

Morrison W, Womer J, Nathanson P, et al. Pediatricians' experience with clinical ethics consultation: a national survey. *J Pediatr*. 2015;167(4):919-924.e1

Schneiderman LJ, Gilmer T, Teetzel HD, et al. Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: a randomized controlled trial. *JAMA*. 2003;290(9):1166-1172

Case Discussion

What do you know about the prognostics of TBIs and the interests/values of the parents/family, and in light of that knowledge, is the option of FLST one that should be offered at this time?

It is often said that careful ethical reasoning relies on a strong understanding of the situation at hand—that is, good ethics begin with good facts. The emphasis here, then, should be on beginning with good clinical knowledge in relationship to the determining what options are materially relevant to consider.

Of course, ethical reasoning cannot be predicated on medical facts alone. A robust understanding of personal, social, and institutional factors are fundamental as well. In fact, the personal and social are not simply fundamental to ethics, but to medicine itself. No medical “fact” can be understood in a vacuum; they are interpreted in light of one’s personal, professional, and cultural influences.

After a few days of reflecting and discussing the issue, Tommy’s parents had determined that stopping the ventilator was best, but by that time there was a new PICU physician who, after review of Tommy’s condition, did not think that FLST was warranted.

The option for FLST was, in fact, given to the parents and then later taken off the table. If you disagree with either action, should that trigger a call to the ethics committee? If you agree with either, is this still worth calling the ethics committee about? Are there any concerns about taking the step to call for ethics committee involvement?

Many ethically charged situations do not result in a call for an ethical consultation. Explore here why ethics consults might or might not be triggered. Discuss barriers to or concern about contacting the ethics committee. In what ways do personal opinions or institutional pressures influence the decision to call or not call for a consult.

With more intensive therapy, Tommy was able to breathe without the vent, and he was moved to the rehabilitation unit. Because of his TBI, however, he continued to be fed through a tube. Neurologic scans indicated problems with the basal ganglia, and Tommy’s parents suggested that Tommy’s condition was not in his best interest and asked the palliative care physician about the possibility of stopping feeds. At the same time, the physical and occupational therapists working with Tommy, as well as nurses and social workers from the PICU who came to visit him in the rehabilitation unit, believed they saw slight but noticeable improvements in his cognitive status—possibly tracking, smiling, reacting to some stimuli. These health care workers call for an ethics committee consult.

Were they right to call for a consult?

Most hospitals' policies allow anyone related to the case to call for an ethics consultations. Should an ethics committee consult have been called? Were these particular health care providers overstepping their authority in doing so?

It is important to discuss briefly what reactions the group has regarding how the scenario played out. Moving too quickly to a discussion of the role and functions of the ethics committee may leave the group distracted by their own lingering opinions about the case.

Discussion about Ethics Committees

What is an ethics committee?

Most institutional ethics committees are developed as mechanisms to handle ethically challenging issues in a hospital or other health care institution. The committee is tasked with addressing clinically relevant ethical issues (research ethics is typically handled by an institutional review board), be they bedside situations or policy concerns. The membership of an ethics committee is often composed of institutional staff members—physicians, nurses, social workers, even chaplains, administrators, and sometimes legal counsel (these last 3 groups are not always included because of conflict of interest concerns). Many use community/unaffiliated people as well to serve as a check on institutional bias and provide greater insight. When available, someone educated in philosophical and/or religious ethics is often included as well.

What functions does an ethics committee serve; what place in your organization does it hold?

Aside from serving the institutional function of satisfying The Joint Commission's (accreditation) requirements calling for a mechanism to handle ethical concerns in the institution, ethics committees traditionally serve 3 functions within the institution:

- Review and/or develop institutional policies
- Educate staff in the institution
- Provide consults/case reviews

Not all committees perform all 3 functions, as some institutions have a separate ethics consultation service, and some ethics committees may do little to no policy review and other “organizational” ethics activities—these may be performed by other committees or by a compliance/ethics officer in the institution.

Also, it can prove useful to know whether your institution's ethics committee is a medical staff committee, a committee that reports directly to the institution's board of directors or resides in some other part of the organizational structure. Its place in the organization can affect the IEC's functional scope, practices, and authority.

What does an ethics committee consult look like?

Consults may occur in 3 general ways:

1. Singular consultant –an individual (hopefully well trained) is tasked (either by the institution or the committee) with consulting. That person would take the call and

respond as needed. This process allows for maximum expediency and flexibility but provides a smaller range of perspective and knowledge.

2. Small team consult – some institutions use a small team (typically 3-5 people from the larger ethics committee) to consult. This process provides a bit less flexibility and expediency than the single consultant model but in turn provides a greater variety of perspectives and a larger knowledge base.
3. Full committee consult –at least a quorum of the entire committee meets to discuss an ongoing case. Needless to say, this is the least expedient and flexible approach, but it maximizes the number of perspectives (see the description of the committee makeup above) and broadens the knowledge base.

Like many aspects of ethics committee work, the details of how the committee functions in a consult are specific to each institution. In fact, some institutions may use a combination of the consulting models listed above depending on the type and source of the consult request.

What does an ethics committee consult try to accomplish?

There are different “philosophies” that ethics committees live by in relation to consults. In general, they may try to:

- Facilitate discussion among different and differing parties
- Elucidate and clarify values-based concerns within a situation
- Mediate disputes to dissolve or resolve conflicts
- Analyze ethical concerns in a situation and provide a recommendation

The actions required to fulfill these objectives are not necessarily unique to each objective, but the primary outcomes of a consultation will be driven by one or more of these objectives. Thus, it is important to know what your ethics committee’s consult (or your ethics consult service) attempts to accomplish and with what methods. Further, especially in hospitals that treat both adults and children, you may want to make sure that the committee representatives have an understanding of the unique aspects of *pediatric* care and decision making.

Although in almost all cases, ethics committees have no decision making *authority*, a consultation often results in a recommendation regarding the committee’s view of the ethically best decisions or approaches available. In such cases, patients/families and physicians are typically not bound to those recommendations, but they should be aware that committee recommendations do carry some amount of “moral authority.” Also, some institutional policies may give a determinative role in decision making to ethics committees for specific situations. For example, a policy on the use of covert patient monitoring (ie, hidden video surveillance) in cases of suspect patient condition falsification (ie, Munchausen syndrome by proxy) may require that before monitoring can be implemented the ethics committee review and approve its use for the case at hand.

Who may call for a consult?

The answer to this question depends entirely on the ethics consult policy of your institution. However, most institutions allow for consults to be called by a wide variety of people—not simply attending physicians or unit directors, but most anyone in the institution who have some

involvement with the situation, including patients and family members (in fact, this breadth is recommended by the AAP Committee on Bioethics). Again, there may be some limits specific to your institution.

Do ethics committees really help? If so, how?

Limited research indicates that ethics committee consults can provide help for institutions, practitioners, and patients/families. For institutions, consults have been shown to help reduce costs, shorten length of stay, and champion positive professional and organizational values. Practitioners who have triggered ethics consultations indicate satisfaction with help in clarifying unrecognized values at stake, opening lines of communication, and reducing tensions with others. Families report that consults offer support, provide a forum in which to be heard, and help them better understand the complexities of the medical and ethical situations.

What more might an ethics committee do?

In some cases, situations pose problems that set precedent or require wider institutional actions. Ethics committee, then, may attempt to develop or promote system-based protocols or policies to handle these issues. In the case of Tommy, the staff caring for Tommy or the ethics committee may want to follow up in the coming months with staff debriefings to deal with lingering ethical concerns and “moral distress.” Furthermore, the ethics committee may want to work with staff in the PICU to develop protocols to address differences among staff or to handle better “hand-off” issues when new attending physicians take over the ongoing care of a patient.

Conclusions and Suggestions

Finally, ethics committees may organize forums for education, whether about specific issues in caring for patients or in light of the development of policies with significant ethical content. The point is that although the ethics committee is most often associated with case reviews/consults, many committees play much wider roles in their institutions, and it is helpful to familiarize yourself with the full extent of functions the committee performs. Also, the AAP Committee on Bioethics¹ has its own list of 6 recommendations regarding IECs that might be helpful to review and implement where appropriate.

Reference

American Academy of Pediatrics, Committee on Bioethics. Institutional ethics committees. *Pediatrics*. 2001;107(1):205-209

This instructor's guide is part of a collection edited by Douglas S. Diekema, MD, MPH, FAAP; Steven R. Leuthner, MD, MA FAAP; Felipe E. Vizcarrondo, MD, MA, FAAP on behalf of the American Academy of Pediatrics Committee on Bioethics and Section on Bioethics.

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