Session 11. Institutional Ethics Committees

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Overview
Beginning in the 1960s with decisions about who should get kidney dialysis, suggested by courts in the 1970s, required by the Baby Doe regulations in the 1980s, and proliferated in response to Joint Commission accreditation requirements in the 1990s, institutional ethics committees (IECs) are now mainstays of hospitals in the United States. Most have a traditional charge to provide education, policy review, and consultation, but the specific practices of IECs vary among different institutions. It is helpful to understand the form and function of IECs to use them best in practice.

This module will discuss the functions of IECs and the roles they play in health care institutions, as well as their usefulness in patient care and policy development. 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.

Instructor’s Guide
- Case Summary
- Alternate Cases
- Learning Objectives
- Suggested Reading for Instructor
- Further Reading
- Case Discussion
- Conclusions and Suggestions

Case Summary
Tommy was 3 years old when he was hit by a car resulting in severe traumatic brain injury (TBI). Two weeks into his pediatric intensive care unit (PICU) stay, Tommy’s parents were presented with the option to forego life-sustaining treatment. After a few days of reflecting and discussing the issue, they 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 forgoing life-sustaining treatment was warranted. With more intensive therapy, Tommy was able to breathe without the ventilator, 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, physical and occupational therapists working with Tommy, as well as nurses and social workers from the PICU who came to visit him in rehabilitation, believed they saw slight but noticeable improvements in his cognitive status—possible tracking, smiling, and reacting to
some stimuli. The entire unit, as well as these PICU staff members, is concerned about the ethics of what the parents are suggesting.

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

Alternate Cases
1. Diagnosed with biliary atresia at 3 months, Jamie’s parents reluctantly agree to a Kasai procedure to temporarily mitigate 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 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. The liver specialist who has just admitted Jamie to the hospital believes that the parents’ decision is unacceptable, and she calls the IEC hoping to convince the committee that the transplant should be pursued over the parents’ objections.

  - What role should the IEC play?
  - Who should be involved in the IEC discussions?
    - Should Jamie’s primary care physician be notified?
    - Should the parents be involved?
    - Should legal counsel be present?

2. Mary Jo, a child who is chronically disabled, has had trouble gaining weight even on full-feeds at home and in the hospital. Her “Is and Os” are often unexplainably negative. Also, her percutaneous endoscopic 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 her “messing with” Mary Jo’s feeds. Policy requires that the IEC review the case before he can proceed.

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

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

**Suggested Reading for Instructor**
[http://aappolicy.aappublications.org/cgi/content/full/pediatrics;107/1/205](http://aappolicy.aappublications.org/cgi/content/full/pediatrics;107/1/205). Accessed May 13, 2011

[http://cpj.sagepub.com/content/46/9/771.extract](http://cpj.sagepub.com/content/46/9/771.extract). Accessed May 13, 2011


**Further Reading**


[http://jama.ama-assn.org/cgi/content/abstract/290/9/1166](http://jama.ama-assn.org/cgi/content/abstract/290/9/1166). Accessed May 13, 2011

**Case Discussion**
*What do you know about the prognostics of TBIs and the interests or values of the parents and family? In light of that knowledge, is forgoing life-sustaining treatment an option that should be offered at this time?*

It is often said that good ethical reasoning begins with good understanding of the medical facts. The emphasis here, then, should be on beginning with good clinical knowledge in relationship to the determination of what options are materially relevant to consider.

Of course, ethical reasoning also takes a good understanding of personal, social, and institutional factors as well. Be careful not to set up a false dichotomy between medically relevant information and ethically relevant considerations. No medical “fact” is understood in a vacuum; they are interpreted in light of one’s personal, professional, and cultural influences.

*The option for forgoing life-sustaining treatment 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
IEC? If you agree with either, is this still worth calling the IEC about? Are there any concerns about taking the step to call for IEC involvement?
Explore here why ethics consultations might or might not be triggered. Discuss barriers to or concerns about contacting the IEC. In what ways do personal opinions or institutional pressures act on the decision to call for a consultation?

In this case, the health care workers called for an IEC consultation.

Were they right to call for a consultation?
Should an IEC consultation have been called for? Were these particular health care professionals overstepping their authority in doing so?

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

Conclusions and Suggestions
What is an ethics committee?
Most IECs are developed as mechanisms to handle ethically challenging issues in a hospital or other health care institution. The membership of an IEC typically is composed of institutional staff members—physicians, nurses, social workers, chaplains, administrators, and sometimes legal counsel (the latter 3 groups are not always included because of conflict of interest concerns). Many employ community or unaffiliated people as well to serve as a check on institutional bias and provide greater insight. When available, someone educated in philosophical 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 Joint Commission accreditation requirements calling for a mechanism to handle ethical concerns in the institution, IECs traditionally serve 3 functions within the institution.

- Review and develop institutional policies.
- Educate staff in the institution.
- Provide consultations and case reviews.

Not all IECs perform all 3 functions. Some institutions have a separate ethics consultation service, while other IECs may do little to no policy review or other organizational ethics activities—these may be done by other committees or by a compliance or ethics officer in the institution.

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

What does an ethics committee consultation look like?
Consultations may occur in 3 general ways.
1. **Singular consultant:** Here an individual (hopefully well trained) is tasked (by the institution or the IEC) with consulting. That person will take calls and respond as needed. This process allows for maximum expediency and flexibility but a minimum of perspective.

2. **Small team consultation:** Some institutions use a small team (typically 3 to 5 persons from the larger IEC) to consult. This process provides a bit less flexibility and expediency than the single consultant model but, in turn, provides more perspectives.

3. **Full committee consultation:** Here at least a quorum of the entire IEC meets to discuss an ongoing case. Needless to say, this is the least expedient and flexible approach, but it maximizes the perspectives brought to bear.

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

**What does an ethics committee consultation try to accomplish?**

There are different philosophies that IECs live by in relation to consultations. 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.

Obviously, there can be overlap in fulfilling these objectives. It is important to know what your IEC consultation (or your ethics consultation service) attempts to accomplish and with what methods. Further, you may want to make sure that the IEC representatives have an understanding of the unique aspects of pediatric care and decision-making.

While in most cases IECs have no decision-making authority, they may make recommendations addressing their view of the ethically best decisions available. In such cases, patients, families, and physicians are typically not bound to those recommendations, but it should not be ignored that IEC recommendations do carry some amount of moral authority. Also, some institutional policies may give a determinative role in decision-making to IECs for specific situations. For example, a policy on the use of covert video surveillance in cases of suspected patient condition falsification (ie, Munchausen syndrome by proxy) may require that before the surveillance can be implemented, the IEC review and sign off on its use for the case at hand.

**Who may call for a consultation?**

The answer to this question depends entirely on the ethics consultation policy of your institution. However, most institutions allow for consultations to be called by a wide variety of people—not simply attending physicians or unit directors but almost anyone in the institution, including patients and family members (in fact, this breadth is recommended by the American Academy of Pediatrics [AAP] Committee on Bioethics). Again, there may be some limits specific to your institution.

**Do ethics committees really help? If so, how?**
Research indicates that IEC consultations can provide help for institutions, practitioners, patients, and families. For institutions, consultations 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 consultations 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 precedence or require wider institutional actions. Institutional ethics committees, 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 IEC may want to follow up in the coming months with staff debriefings to deal with lingering ethical concerns and moral distress. Furthermore, the IEC may want to work with staff in the PICU to develop protocols to address differences among staff or to better handle handoff issues when new attending physicians take over the ongoing care of a patient.

Finally, IECs may set up 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 while the IEC is most often associated with case reviews and consultations, many IECs play much wider roles in their institutions, and it is helpful to familiarize yourself with the full extent of functions the IEC performs. The AAP Committee on Bioethics has its own list of 6 recommendations addressing IECs that might be helpful to review and implement where appropriate.

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