

Medical Ethics with Parent Collaborators

In education about medical ethics, small group discussions with patients or parents put a human face on ethical decision-making in healthcare settings. In one approach to these discussions, parents who have faced very serious medical decisions for their infants or young children share the stories of their children's medical crises and describe decisions they have made. They then offer the learners an opportunity to ask probing questions about the families' experiences and the parents' struggles with difficult decisions and ethical quandaries. Parents can explain how physicians have supported them in making decisions and discuss the learners' future approach to supporting parents in similarly difficult medical circumstances. Parents also provide a perspective on long-term rewards and challenges for children and families after an intense or critical medical experience.

Goals

1. To introduce medical students to ethical issues in medicine and the reasoned approaches that can be used to address ethical issues.
2. To help enable medical students to identify ethical issues in case examples.
3. To illustrate how viewpoints sometimes differ between parents, physicians, and other healthcare professionals when ethical issues arise regarding children in medical settings.
4. To provide an opportunity for medical students or residents to discuss with parents the issues and decisions that arise when infants or very young children experience severe medical problems.
5. To listen respectfully to parents' perspectives about their experiences and decisions concerning their children in serious medical circumstances.
6. To develop appreciation for the contribution parents can make to ethical discussion and analysis by sharing their narratives.

Objectives

Medical students or residents will:

- Listen respectfully to parents' narrative descriptions of their children's critical medical challenges.



- Ask parents questions about their experiences in order to develop an understanding of the parents' viewpoints.
- Engage in dialog with parents and fellow students about ethical issues and difficult decisions that arise for very young children and their parents in serious medical circumstances.

Curricular Context

"Ethics is about right and wrong, not about who decides. The right question is, 'How do participants arrive at truth, at a decision' It's about the process of arriving at ethical decisions, not just who makes the decisions."

—a parent-advisor

At the Uniformed Services University, medical students in their second year of medical school take a semester-long course in bioethics. The course provides an introduction to ethical questions and challenges that arise in serious medical circumstances and a series of small group discussions about cases that raise issues of medical ethics. As part of the three-hour introductory session for this course, parents who have faced serious medical challenges and decisions with their infants or very young children tell their children's stories and discuss their perspectives and decisions with small groups of students. With slight modifications of goals and objectives, similar discussions can provide powerful insight for medical students or residents at any point in their educational careers.

Description of the Activity, with the Role of Parent-Advisors

As an introduction to a course in bioethics, conversations with parents may be preceded by a short lecture about ethical analysis and a film that illustrates some of the complex decisions and ethical challenges that arise in medicine. The lecture may cover the underlying principles of ethical analysis and various approaches to ethical deliberation, with an explanation of how parents' stories can apply to each. It becomes easy for the learners to see how parents' personal stories provide understanding about ethics that cannot be supplied with descriptions of principles considered in the abstract alone.

"The subject matter is so engaging and has direct application... It's so important to put a human face on some of these challenging discussions."

—a parent-advisor

7. Medical Ethics with Parent Collaborators

APPROACH TO ETHICAL ANALYSIS	CONTRIBUTION OF PARENTS' STORIES
<ul style="list-style-type: none">• Traditional analysis with reasoning from abstract principles.	<ul style="list-style-type: none">• Parents' narratives illustrate principles in the context of medical experiences.
<ul style="list-style-type: none">• Reasoning from decisions made in similar cases, as occurs in legal analysis.	<ul style="list-style-type: none">• Parents' experiences provide real-life cases for discussion.
<ul style="list-style-type: none">• Ethical analysis from the care perspective, which emphasizes the interpersonal relationships of the people involved.	<ul style="list-style-type: none">• Parents describe their relationships with their children, families, physicians, and other healthcare providers.
<ul style="list-style-type: none">• The narrative approach, with its emphasis on learning as much as possible about the people involved in a situation by gathering detailed descriptions.	<ul style="list-style-type: none">• Parents provide spoken narratives and opportunities for learners to ask questions to understand details.

One film that provides a powerful example of ethical challenges parents may face is *Dreams and Dilemmas*.¹ This film documents the story of very premature twins from the time of their caesarean delivery through the death of one twin, a very complicated hospital stay, and the time six months later when the second twin goes home to face an uncertain future with significant disabilities. After the film, small group discussions between one parent and six or seven learners provide an opportunity for medical students to hear parents tell their own stories. Students ask questions that help them understand parents' viewpoints about ethical issues, their role as a parent, and the roles of physicians, social workers, chaplains, and others who interact with them during critical medical times. Students in each small group are provided with a list of the sample questions that are also provided to the parents.

We ask parents to bring pictures of their children and to arrive prepared to tell the stories of their children's medical histories and the critical medical decisions they have had to make. Parents are also prepared to answer questions such as the following:

1. When and how did you first find out that your child had special needs? OR When and how did you receive your child's diagnosis?
2. What difficult medical decisions have you faced with your child?
3. What were the ethical issues involved in your child's situation? (e.g., whether the cost of the care was justified, whether your child's projected quality of life warranted the level of medical intervention needed to keep him or her alive, whether the pain and suffering of your child was extreme, whether more could or should be done to save your child's life.)



4. What role did medical information, doctors' opinions, and your own values play in your decision-making?
5. What has been the outcome of these decisions for you and your child?
6. Should projections about long-term cost of care and quality of life play a role in these decisions? If so, how?
7. Have you seen any ways in which your decision-making about ethical issues has changed as a result of your experiences with your child?



Medical students and residents gain an appreciation for the viewpoints of different parents when they have an opportunity to hear more than one story, so we provide an opportunity for each small group of students to engage in a discussion with three different parents. After meeting with one group of students for 25–30 minutes, the parents move to a second table and share their stories with another group of students. After 25–30 minutes with this group, they move to a third table to discuss their experiences again. The students ask probing questions and the parents answer candidly. Some parents also share their reactions to the film the group has viewed or paper cases that are in the students' study materials for the course. Sometimes the groups include a faculty member or a healthcare provider from the community as a facilitator.

Outline for an Introductory Session of a Course in Bioethics

1. **Lecture:** Provide an introduction to Ethics and ethical reasoning.
2. **Film:** View a film that conveys one family's experience with critically ill infants.
3. **Large group discussion:** Discuss the film in a large group; prepare learners for active participation in small group discussions with parents.
4. **Small group discussions:** Hear and discuss parents' narratives about their experiences with critically ill, very young children.

Organization for Parents who Participate

When arranging this activity for a large group of medical students or residents, quite a bit of advanced planning is required. At the Uniformed Services University, a class includes about 160 students, so 20 or 30 parents are needed. Email messages or postcards announce the event two to three months beforehand, with follow-up messages for recruitment, reminders of time, date, and place, and thank you notes afterwards. A more detailed packet is needed with instructions for participating and information about logistics such as parking and room location. Since this activity requires a time commitment of several hours and emotional vulnerability while telling difficult stories, a formal thank you letter is also important. Samples of letters and instructions for parents appear in the Appendix.



Preparing Parent-Advisors to Share Experiences that Evoke Deep Emotion

The success of this activity depends in part on careful preparation of parents for their role. The film is particularly difficult for some parents to watch because of the intense emotion evoked by the struggles of the twins and the parents it portrays. Even though this film shows several very sensitive professionals and loving and dedicated parents, viewing the film can be a distressing emotional experience for parents, especially those who have experienced a similar situation. Part of the parents' preparation for the session involves reading a written summary of the film (which appears in the Appendix) and a reminder to bring tissues to the class. The film is also available for previewing by parents before the session. The parents' preparation also includes an introduction to the vocabulary used in the ethics course, since without previous exposure some of the vocabulary can sound harsh and insensitive in the context of their emotions and perspectives as parents.

"During the ethics course sessions, the students always get personal and ask if we were afraid of our child dying, what the child knew, and how siblings were affected."

—Colleen O'Brien, parent-advisor

Each parent participant receives a phone call from a parent staff member to thoroughly discuss the expectations during the small group, the questions students are likely to ask, and possible emotional responses the parents may have to the material and the setting. Following the class session, each parent receives a follow-up call to give them an opportunity to discuss the experience. Despite the challenges of this activity, however, parents, faculty, and students find it a powerful activity that builds important insights about parents, children, physicians, and ethics as experienced in families' lives.

Reference:

1. *Dreams and Dilemmas: Parents and the Practice of Neonatal Care*, a film by Richard Kahn with the Ethics Institute at Dartmouth College. Running time 58:02. Available from Fanlight Productions. 1998.



“I enjoy the Ethics Course as it is a day full of miracles being shared around tables. This session impacts thousands of lives for a lifetime...and all in one day’s work.”

–Sue Fisk, parent-advisor