

Part A: Understanding Grief and Loss in Children and Their Families

Discussion Guide: Ethics at the End of Life: Futility and Care

Learning Objectives for this Section

- 1.5** Describe the ethical principles involved in end of life decision-making (e.g., resuscitation and DNR orders) and discussion of goals of care:
- Develop capacity to identify ethical issues that complicate end of life experiences for patients, families and providers.
 - Discuss a simple method to describe and analyze ethical issues
 - Focus on issues of futility as a common and complex ethical concern
 - Develop strategies to help families and providers discuss and manage futility in a way that will help reduce burden on families and avoid excessive moral distress for providers

Relevant Milestones: PROF1, PROF 2

Introduction

Section A.6 Slideset: Ethics at the End of Life begins with a complex hypothetical case for discussion. Later in the set, examples are drawn from cases reported by pediatric residents. The cases included lend themselves to robust discussion, but learning theory shows that adult learners gain much more from discussion of problems real to their current experience.

Hence this discussion will be most effective if cases known to the learners are used in place of or in addition to the cases included here. This module is not designed to provide a single correct approach to an ethics issue, but it can help identify the set of possible, ethically justifiable responses. The discussion is the real goal.

- When preparing for the presentation it is often helpful to solicit cases from the residents several days ahead. This offers a chance to clarify the details and invite residents to participate as presenters.
- Open the discussion with the case you are using. With slides 7 and 8, engage the group in a discussion of how each of the basic principles of biomedical ethics applies in this case. (What are the issues related to autonomy – how do they manifest? What does beneficence mean here – what is the family/patient’s sense of well-being, what is the medical notion of well-being?, etc.)
 - o It is very helpful to write comments on a board so that everyone can see the range of responses and interpretations of each moral duty. One of the key points is that we all interpret these obligations somewhat differently and our interpretation has a huge impact on our approach.
- Give each participant copies of the ethics case analysis guide to keep. (They may be provided in laminated, pocket size form). These will help them to anticipate the structure of the discussion.

In the slide set, futility is presented as a mismatch between goals of care and therapeutic possibilities. In usual medical parlance, the mismatch is a narrow medical question involving medical goals versus the likelihood of success of a specific clinical intervention. This module expands the idea of goals to include the patient/family goals of care as the primary concern. The goals of care reflect more than the narrow medical issues. Families’ goals may involve social values and religious beliefs, and a more expansive sense of well-being, benefit and harm, than the goals defined by medical options.

Section A.7: Ethics Case Analysis Guide

This guide to identifying and analyzing ethics issues in clinical care was developed by the Program on Ethics in Clinical Practice at the Johns Hopkins Berman Institute of Bioethics. It serves as a framework to help students, residents and faculty engage in an organized discussion of ethics issues. It can also help individuals initiate their own internal assessment of ethics issues in clinical care.

The analysis method uses the Principles of Biomedical Ethics (Beauchamp and Childress) to frame the discussion. These principles are: autonomy, beneficence, non-maleficence and justice. Please note that other approaches to ethics (virtue ethics, ethics of care, communitarian ethics, etc.) are equally valid, and perhaps in some cases even more valid. The principles-based approach is limited but very useful for organizing a conversation. It is also the approach that most students learn in medical schools in the US.

The **Four Topic Method** (see Slide 13) is a revision of the method introduced by Jonsen, Siegler and Winslade in their book *Clinical Ethics*.

The case analysis method starts with a particular question: Why does this case bother you? This is geared to help clinicians define the actual problem before launching into a discussion of what “ought” to happen. The more clearly the problem is articulated, the more effective the analysis.

The analysis continues with an explication of the concerns of the case in terms of the principles approach. Each principle—duty to respect autonomy, beneficence, non-maleficence and justice—is considered with respect to the case at hand. The moral obligations raised by each principle are clarified and the conflicts between those principles become the focus of the ethical question.

Once the question is clear, the **Four Topic Method** is used to organize relevant information. It often happens that some of the apparent ethical conflicts are resolved when morally relevant information becomes more available. A particular example for end of life concerns is clarification of the patient/family goals of care. When we are able to unpack the common and basic “we want everything done” to evoke a rich discussion of the meaning of that desire and the expectations it raises for both families and providers, an seemingly intractable ethics issue might be solved with new strategies for comfort care or a plan for a specific but limited trial of life sustaining therapy.