Improving Competence in Clinical Ethics Consultation: 
A Learner’s Guide

American Society for Bioethics and Humanities Clinical Ethics Task Force
### The American Society for Bioethics and Humanities Clinical Ethics Task Force

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Introduction: Why this Guide?

Need for this Guide. If you are reading this, you probably already know only too well that the cases brought for clinical ethics consultation are often complex and emotionally charged. You also know that consultations are often requested as a last resort when members of a health care team, patients or family members are in conflict, and their differences seem almost beyond resolution. From informed consent, decision-making capacity, and confidentiality to end of life decisions, the ethical issues raised come inextricably bound up with, among other things, medical, legal and psychosocial issues. To be able to address these complex, multifaceted ethical issues under the time pressures of the clinical setting requires more than good intentions and enthusiasm; it requires particular knowledge and skills (Aulisio, 1999). It was with this in mind that the American Society for Bioethics and Humanities (ASBH) published its report Core Competencies for Health Care Ethics Consultation in 1998 (SHHV-SBC Task Force, 1998). The report focused on knowledge and skill areas the task force deemed central to health care ethics consultation (“core competencies”). Since the report was released it has been the subject of a special issue of The Journal of Clinical Ethics (1999), a Consensus Statement in the Annals of Internal Medicine (Aulisio, Arnold and Youngner., 2000), and a book from The Johns Hopkins University Press (Aulisio, Arnold and Youngner, 2003). Over 10,000 copies of the report have been sold, a testament to the need the report aimed to address.

In the years since Core Competencies was published, however, new data concerning clinical ethics consultation in the US has come to light. Over 81% of all hospitals now have an ethics consultation service of some kind (in contrast to less than 1% of hospitals identified in a 1981 study (Youngner, et al. 1983)), while 100% of hospitals with 400 beds or more, federal hospitals, or hospitals that are members of the Council of Teaching Hospitals have ethics consultation services (Fox, 2002). It is now estimated that over 35,000 are involved in performing over 15,000 clinical ethics consultations each year in U.S. hospitals. Individuals doing clinical ethics consultation come from a wide variety of personal and professional backgrounds, with physicians (36%), nurses (30%), social workers (11%), chaplains (10%), and administrators (10%), making up the over 97% of those who do ethics consultation at hospitals in the USA. Clinical ethics consultation is most often done by small teams (68%), as opposed to full committees (23%) or individual consultants (9%) (Fox, 2002). Despite this dramatically increased level of activity and expanding circle of participants, 95% of people involved in doing clinical ethics consultation in the USA have not completed a fellowship or graduate program in bioethics (Fox, 2002), and the vast majority of ethics committee chairs report feeling “inadequately prepared” for their responsibilities (McGee, et al., 2001).

Purpose of this Guide. This Guide was developed in recognition of the current state of affairs in clinical ethics consultation in North America, not as an endorsement of that state of affairs. We understand that this includes not only a lack of formal education and training on the part of many involved in ethics consultation, but also a lack of educational and training programs specific to clinical ethics consultation (Aulisio and Rothenberg, 2002). Born out of this need, this Guide is designed, first and foremost, to build on Core Competencies (SHHV-SBC Task

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1 For the purposes of the survey, “ethics consultation” was defined as “A service provided by a committee, team or individual to address ethical issues involved in a specific, active clinical case.”
Force, 1998) by helping those currently involved in clinical ethics consultation to take up a self-education program specific to it, a self-education program that will help to develop and improve basic knowledge and skill in ethics consultation. By “self education,” we do not mean solitary, unguided, or undirected education. Indeed, many of the strategies for achieving the learning objectives laid out in the different content areas of this Guide are strategies that involve the participation of others. We also include learning strategies throughout that entail traditional educational means such as “taking a course,” “doing a supervised practicum,” or even inviting outside experts for continuing ethics education, while acknowledging that these traditional educational means may not be equally accessible to many within our intended audience. This leads to a second reason for adopting the Guide approach. While we hope that this Guide will be helpful to its primary audience, those involved in various capacities in actually doing clinical ethics consultation in health care settings, we also hope that this Guide will speak to a secondary audience, i.e., universities and academic medical centers with strong clinical ethics programs, so that they might develop specific ethics consultation education and training programs that are widely accessible to those who might benefit from them.

We intend this Guide as a “next step,” and we mean this in several ways. First, this is a next step in building on the Core Competencies report (SHHV-SBC Task Force, 1998), as it offers specific objectives and learning strategies to achieve the competencies laid out in that report. We also hope that this Guide is a “next step” in what will be ongoing education efforts. That is to say, we know this will not be the final text you will read as you seek to improve your competence in clinical ethics consultation. Therefore, we are providing you with a long list of learning strategies, of other places to learn and of other conversation partners. We also wish to emphasize that we are not taking a position, for or against, on certification or other types of credentialing for those involved in doing clinical ethics consultation in various capacities. Though this debate may need to be revisited in the future, our aim in taking this “next step” is to recognize the needs of those currently involved in ethics consultation and, at least in part, to address those needs. In addition, to move the conversation along we have deliberately left “silences” in which we ask you, the reader, to supply the “answer.” This means that there will be places in this Guide where we will be asking you to write something about your own experience, and we will ask you keep a record of your responses. One purpose of these exercises is for you to create a notebook of your own thinking and work, one that can be shared with others and then used as a springboard for more conversation; yet another “next step.” We also hope that this will create a venue for reflective analysis of your own evolving perceptions of your role. In this way, your use of the guide will make it a living archive of your professional development that can be revisited over time to see how your reflections and practices have changed.

More About the Project’s Origins. Clinical ethics consultation as a practice emerged from a variety of sources and takes a variety of forms. For many of the authors of this Guide, an organization called the Society for Health and Human Values was the first place we met and began to think and talk about the work we were called to do, this new practice of clinical ethics consultation. Prompted by these discussions, a separate society for the practitioners of clinical ethics consultation was founded, called the Society for Bioethics Consultation. These two groups spearheaded the SHHV-SBC Task Force on Standards for Ethics Consultation that produced the above referenced report, Core Competencies for Health Care Ethics Consultation (SHHV-SBC Task Force, 1998). In 1998, the two organizations merged, joined by a third, newer organization, the American Association of Bioethics, to form the American Society for Bioethics
and Humanities (ASBH). It was the ASBH that then adopted and published Core Competencies (SHHV-SBC Task Force, 1998). In 2000, the president and board of the ASBH established a Task Force on Clinical Ethics Consultation (Zoloth, 2001) to build on the Core Competencies (SHHV-SBC Task Force, 1998). This initiative was conceived as part of a larger discussion about the future of the field of bioethics and took on a number of different tasks. In 2003, thanks to the generous support of The Greenwall Foundation and under the leadership of Task Force Co-Chairs, Susan Rubin and Mark Aulisio, the project which resulted in this Guide commenced.

More about the Authors and the Intention of this Guide. We, the authors of this Guide, are a group of bioethicists from a wide variety of disciplines who have been acting as clinical ethics consultants for many years, nurturing, experimenting, and reflecting on the field of clinical ethics consultation as it has grown and developed. For the last two decades there has been a robust conversation about how to do the work of clinical ethics consultation. The authors of this guide have all worked at the bedside as ethical dilemmas arise, and have listened to and learned from the people who must live out the choices that are the subject of our advice. We have also learned from one another. Over the years, this conversation has grown to include a literature about how to provide clinical ethics consultation, how to apply and evaluate different methods, and how to learn to do this work more effectively. This Guide is an opening into that broader conversation for the health care professional who has volunteered or been recruited to be a member of an ethics committee, or for the person who will participate in clinical ethics consultation. We intend the guide as a tool to improve your knowledge base and skill set for dealing with the types of ethical issues that are brought for clinical ethics consultation in your institution. In our work, we have confronted questions about how to address the issues you face in clinical ethics consultation, and we have noted that many of the bioethics educational offerings available to you are about bioethical issues such as cloning, stem cell research, or other interventions most likely not directly relevant to the more common issues you face in your work in clinical ethics consultation. Finding good and systematic training can be a challenge. This Learner’s Guide is an attempt to begin to fill that gap and to provide a road map for improving competence in performing clinical ethics consultation.

Structure and Design of this Guide. This Guide is designed to enable the learner to begin the work of improving and maintaining competence in clinical ethics consultation. The Guide is divided into three discrete content domains—Domain I: Core Knowledge (which is further subdivided into three subtopics: Introduction to Clinical Ethics, Core Ethical Issues Involving Adult Patients, and Core Ethical Issues Involving Minors); Domain II: Process Skills in Performing Ethics Case Consultation; and Domain III: Responsibilities of Ethics Consultants.

Each section of the Guide (with the exception of Domain II) has been uniformly formatted for ease of use, with each domain being further divided into discrete topic areas. Within each topic area, the subsections are: Introduction, Topic Area Outline, Learning Objectives and Strategies, and References. Domain II is sub-divided in a slightly different format, with the subsections as follows: (general) Introduction, Topic Area Outline, Topic Area sub-sections with integrated Objectives and Strategies, and (general) References. Our intention is to identify the core topics we think are essential for improving competence to perform clinical ethics consultation and to suggest focused learning objectives and concrete strategies for approaching mastery of those topics. In other words, rather than functioning as a definitive
textbook on clinical ethics consultation, the Guide is deliberately designed to be used as a road map for learning for prospective learners and educators alike.

Just as we know you will use the guide in different ways, we know that people learn in different ways. For that reason, we have intentionally included a wide variety of learning strategies. We know that some people work best with directed readings, some by having conversations with others, some by seeing these skills in action and having a chance to practice them. The guide is designed to accommodate these different learning styles. The guide can also be utilized by either working systematically from the beginning to the end or going directly to the parts that address the immediate needs of your committee or consultation team, with the understanding that the references and guidance on other areas will be available to you over time.

The Guide will need to be updated over time: you as a reader are invited to be a part of this. We fully expect that new literature, new data, and new resources will emerge that we will want to incorporate. We also want to acknowledge that even though we are recommending specific readings and resources based on our survey of and familiarity with the current literature, we cannot nor would we want to claim that this is a definitive or exclusive list of readings or resources that would be relevant and helpful in improving competence in clinical ethics consultation. Furthermore, we do not claim that the strategies for achieving a particular learning objective are exhaustive (there are, of course, many possible strategies for achieving most learning objectives), that every learning strategy is applicable to every prospective learner (e.g. some strategies refer to "the ethics committee at your institution" - if you do not have an ethics committee the strategy will have to be suitably modified or may not be applicable at all), or that the resources suggested are the best or only resources available (e.g., where only one book, chapter, or journal article may be listed). Rather, what we offer here are a wide variety of materials that one or more of us have found helpful in our own clinical ethics consultation activity.

We began the development of the guide with explicit acknowledgement and appreciation of the fact that there are competing models of clinical ethics consultation (single consultant, small team, and full committee) and differing perceptions of what the primary task of clinical ethics consultation actually is (facilitation, mediation, etc.). In this document, we do not explicitly or implicitly endorse a particular model for ethics consultation. In fact, task force members were selected in part for their representation of diverse perspectives. Though we as authors come from very different perspectives and take very different approaches to clinical ethics consultation, our goal was to identify concrete strategies for mastering the core knowledge and skills that we could all agree are necessary for the competent performance of ethics consultation.

Likewise, we developed the guide in full recognition of the varying contexts in which clinical ethics consultation is practiced (in rural, urban, and suburban settings; in academic medical centers and local community hospitals; in long term care settings and community health organizations, etc.) and with full awareness that the kinds of ethical dilemmas faced, the resources available, and the types of institutional policies in place will be variable across settings. Our goal was to develop material appropriate to the specific contexts and needs of you the learners, with recognition that some adaptation to setting might be necessary.

On a related point, at many places in this guide we recommend seeking local expertise if you can, from local academic and legal scholars. We recognize that this may be more challenging for some than others, depending upon your available local resources, but we want to stress that we believe it is important not to do the work of clinical ethics consultation in isolation,
but rather to seek appropriate expert guidance and counsel as needed, and to make efforts to link your work at the local level with the broader field of bioethics from which clinical ethics consultation emerged.

Finally, we want to note that there are variations in the law across states and counties on some of the issues addressed in this guide. Thus, it would be prudent to seek specific legal guidance to clarify the legal standards in your particular location. And, as should be obvious, this guide is not intended to offer legal advice of any kind.

We hope that you find this Guide to be helpful and thank you for your interest in improving competence in clinical ethics consultation.
References


Topic Area Outline

I. What is Ethics?
   A. Ethics and morality as a family of related concepts
   B. Sources of moral guidance and authority
   C. Methods of resolving moral disputes

II. Relevance of ethics in the clinical setting
   A. Sources of ethical issues in clinical contexts
   B. Using ethical theory and method
   C. Different professional disciplines and clinical ethics consultation

III. Historical development of clinical ethics and ethics consultation
   A. Emergence of contemporary ethics consultation
   B. Quinlan case
   C. JCAHO standards
   D. State legal issues and ethics committees and consultation

IV. Roles and goals of clinical ethics consultation
   A. Scope, limits and goals of ethics consultation
   B. Clinical ethics consultation vs. other services
   C. Clinical ethics consultation and the ethics committee
   D. Clinical ethics consultation and other ethics activities
   E. Role confusion

V. Clinical ethics consultation: models, tools and procedures
   A. Individual, small team, and full committee models
   B. Theoretical bioethics and ethics consultation
   C. Identifying strengths and weaknesses of ethics consultation services

Topic 1: What Is Ethics?

Introduction

Ethical issues, in health care, business, government, science, and the military, are among the most prominent and widely debated issues in America today. Almost daily, newspaper headlines and television news programs feature a fresh story about moral conflict, moral failure, and occasionally, moral heroism, in some area of great public interest. Ethics is not an esoteric or mysterious subject, but a part of our daily lives. If asked, however, to give a concise definition of ‘ethics’, most of us would be at a loss, at least initially. The terms ‘ethics’,
‘morality’, ‘ethical’, and ‘moral’ are in fact understood and used in a number of distinct but related ways.

Health care settings present their own unique sets of ethical challenges. The practice of clinical ethics consultation has emerged to address some of these challenges. When they seek the assistance of ethics consultation, patients, families, and clinicians may bring with them a particular understanding of what makes something an ethical issue or how a moral problem should be resolved. Those doing clinical ethics consultation must, therefore, be aware of different uses of ‘ethics’ and ‘morality,’ different sources of moral guidance or authority, different methods of resolving moral disputes, different types of ethical theory, and the difference between ethics and related areas such as law and etiquette.

Learning Objectives and Strategies

Upon completing study of this topic, learners should be able to:

1. Explain how the terms ‘ethics’ and ‘morality’ refer to a family of related concepts.
   a. Find definitions of ethics and/or morality offered in three of the references (Arras, Steinbock, London. 1999; Beauchamp, 2003; Harris, 2001; Solomon, 2004; Weston, 2001). Discuss the similarities and differences among these definitions.

2. Identify a variety of common sources of moral guidance or authority.
   a. Discuss sources of moral guidance with colleagues (e.g., religious texts and traditions, US Constitution, lessons from history, moral intuitions, community standards, professional codes, family traditions, philosophical texts or traditions) and create a list of the variety of sources of moral guidance or authority.
   b. Either by drawing on your clinical ethics consultation experience or through constructing hypothetical cases, describe three ethics consultation scenarios in which one or more of these common sources of moral guidance may be relevant.

3. Describe several approaches to ethics, and explain the difference between ethical discourse (a systematic approach to ethics) and related areas such as etiquette or custom.
   a. Read chapter one of Applying Moral Theories (Harris, 2001) and identify the difference between factual, conceptual, and normative issues (including different types of normative issues, i.e., legal, ethical etc.) and/or read chapters one, two and three of A Practical Companion to Ethics (Weston, 2001) and complete the “For Practice and Thinking” exercises at the end of each chapter.
   b. Read “Ethical Theory and Bioethics” (Beauchamp, 2003) and/or “Normative Ethical Theories” (Solomon, 2004) and identify major similarities and differences between the theories discussed.
   c. Contact a local college or university and invite a member of its philosophy or religious studies department to provide a brief introduction to philosophical or theological ethics.
   d. Analyze a case from your recent experience in light of two of the theories referred to in 3b above.
e. Read a column from “The Ethicist” in the NY Times Magazine and analyze the nature of the ethical justification for the advice given.

f. Using a sample case, identify the factual or descriptive claims, conceptual claims, and normative claims presented.

**Resources**


**Topic 2: Relevance of Ethics in the Clinical Setting**

**Introduction**

Over the past thirty years, the practice of clinical ethics consultation has emerged in response to the needs of patients, families, and clinicians for assistance in addressing the ethical issues they encounter in obtaining and providing health care. In the US and Canada, hospitals and other health care institutions are the only settings where clinical ethics consultation is routinely available. What is so distinctive about ethical issues in these clinical settings that they have stimulated the growth of clinical ethics consultation?

Clinical ethics issues are, first of all, often issues of great importance in the lives of the interested parties. The consequences of illness and of health care decisions, including healing, death, suffering, disability, and disfigurement, are among the most significant of life events. Not only are these issues of great personal import, they are often complex and difficult to resolve. They may involve complicated concepts and factual information, unavoidable uncertainty about consequences, and deep-seated value differences. Because of both their importance and their complexity, patients and families may seek advice about ethical issues from their clinicians. Clinicians, in turn, may strive to provide informed and well-reasoned responses to such requests for advice as part of their professional responsibility to serve the best interests of
their patients. When solutions to ethical problems prove elusive, patients, families, or clinicians may seek the assistance of ethics consultants in identifying, analyzing, and evaluating possible solutions.

In addition to understanding the importance of ethics in clinical settings, ethics consultants must also be aware of its limitations. They must recognize, for example, that good solutions to moral problems depend not on ethics alone, but on a variety of things, including accurate factual information, effective communication skills, and the insights and contributions of a wide variety of professionals. Those doing clinical ethics consultation must also realize that even the most thorough ethical analysis of a difficult moral problem may not produce a single “correct” solution, but may identify a range of acceptable moral options from which those with decision-making authority may choose.

Learning Objectives and Strategies

Upon completing study of this topic, learners should be able to:

1. Identify and articulate some of the sources of ethical issues in clinical contexts and discuss how different personal, professional, institutional, social, cultural, or religious commitments may incline individuals toward different solutions to clinical ethics problems.
   a. Read “Meeting the need: ethics consultation in health care today” (Aulisio, 2003) and identify the factors that the author claims jointly create a need for ethics consultation in contemporary health care.
   b. Read the same short narrative from one of the books listed below (Barnard, Towers, Boston, Lambrinidou, 2000; Selzer, 1998; Tolstoy, 1960; Zaner, 2004). Have each person involved in ethics consultation or on the ethics committee at your institution briefly present what he or she believes to be the core ethical issues raised by the narrative, and compare and contrast the different core ethical issues each person has identified.
   c. Have each person involved in ethics consultation or on the ethics committee at your institution present the most recent version of a colleague’s (not of their profession) professional code of ethics and identify the core values it expresses. See “Ethical Directives” (2004) for a collection of professional codes of ethics.
   d. Read your institution’s mission statement and discuss its ethical dimensions with those involved in ethics consultation or on the ethics committee at your institution.
   e. Determine whether your institution has a formal statement of ethical principles or code of ethical behavior. If so, review and analyze this document. If not, discuss with colleagues whether the institution should develop such a document.
   f. Identify and list the policies at your institution that have important ethical dimensions.
   g. Invite representatives from social, cultural and religious groups in your community to discuss the implications of their traditions for health care decision making. Ask each representative to bring a text or other document from which they draw core values.

3. Use ethical theory and method to help to identify, clarify, and analyze clinical ethics issues.
a. Read the introduction and one case discussion from *Life and Death Decision Making* (Brody, 1988). Consider how the ethical issues presented in the case are addressed by the theories and methods presented in the introduction.
b. Invite a clinical ethicist with training in moral philosophy and/or religious ethics to guide a discussion on the central ethical theories characteristic of these disciplines.

4. Explain how the resolution of clinical ethics problems is not the exclusive domain of any one discipline.
   a. Ask each person involved in clinical ethics consultation at your institution to describe a case in which the person’s particular professional training led him or her to a unique ethical insight or argument.
   b. Have each person involved in ethics consultation or on the ethics committee at your institution describe a case in which the person’s particular professional training limited his or her perspective on the ethical issues in the case.
   c. Read one of the narratives from *Conversations from the Edge* (Zaner, 2004) and list three different professional or disciplinary perspectives that may contribute to the ethical resolution of the case. Reread the story, imagining that you are a particular character in the narrative (e.g., patient, nurse) and identify how that perspective can contribute to the ethical resolution of the case.

**Resources**


Topic 3: Historical Development of Clinical Ethics and Ethics Consultation

Introduction

Health care professionals have been concerned about ethical issues since the earliest days of their professions. Broad social attention to health care ethics is quite recent, however. For many years, ethics was seen as a topic best left to the realms of philosophy and religious studies, to be spoken about publicly only in churches and in the lecture halls of academia. With the social and cultural upheavals of the 1960s, however, ethics came into the social spotlight, including ethical considerations in health care. For over 30 years now, political leaders, health care professionals, scholars, teachers, and the public have discussed a variety of moral issues in health care.

Beginning in the 1970s, medical schools began to employ philosophy and religious studies professors to teach formal courses in ethics within the medical curriculum. These ethics scholars worked with their clinical colleagues in both academic and clinical settings, and the first descriptions of clinical ethics conferences and ethics consultations began to appear in an emerging literature of the new field of bioethics. The New Jersey Supreme Court, in the famous 1976 right-to-die case of Karen Ann Quinlan, advocated the use of “ethics committees,” though it appeared to assign to these committees the medical task of confirming the attending physician’s prognosis in end-of-life cases. In the 1980s, the federal “Baby Doe” regulations recommended that “infant care review committees” assume the role of reviewing decisions to limit life-sustaining treatment of handicapped newborns as an alternative to intervention by federal investigators. In 1986, the Society for Bioethics Consultation (SBC) was officially established; later, the SBC merged with the Society for Health and Human Values and the American Association of Bioethics to form the American Society for Bioethics and Humanities (1998). In 1991, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) adopted new patients’ rights standards that required hospitals seeking accreditation to establish mechanisms to address ethical issues in patient care. With generous grant support from the Agency for Health Care Policy and Research, a conference on the Evaluation of Ethics Case
Consultation in Clinical Ethics convened in September 1995 to explore the goals of ethics case consultation and develop evaluation methodology for ethics case consultation. The widely discussed 1998 report of a joint task force of the Society for Health and Human Values and the Society for Bioethics Consultation offered a definition of ethics consultation, recommendations on the consultation process, and a listing of the knowledge and skills necessary for effective clinical ethics consultation.

**Learning Objectives and Strategies**

Upon completing study of this topic, learners should be able to:

1. Describe the emergence of contemporary ethics consultation within the clinical setting and the impact of social forces on clinical ethics practice.
   a. Read and discuss “A Chronicle of Ethical Events: 1940s to 1980s” (Jonsen, 2000). List the major events identified and discuss their significance.
   b. Read the classic article “They decide who lives, who dies” (Alexander 1962). Compare and contrast its description of how the Admissions and Policy Committee functioned with your own experience of how ethics committees should function.
   c. Read “She said, he said” (Rubin and Zoloth-Dorfman, 1996). Identify some of major similarities and differences in the approaches to the practice of clinical ethics consultation described in that article.
   d. Read “Clinical Ethics” and “Ethics Committees and Ethics Consultation” entries from the *Encyclopedia of Bioethics* (Post, 2004)

2. Explain how the understanding and function of clinical ethics consultation has developed since the Quinlan case introduced the notion of “ethics committees.”
   a. Read “Comas: Karen Quinlan and Nancy Cruzan” (Pence, 2004), or watch “The Death of Nancy Cruzan” (PBS Video, 1992). Discuss how these classic cases contributed to the evolution of ethics committees.
   b. Read “Letting Impaired Newborns Die” (Pence, 2004) and discuss the impact of the Baby Doe regulations on the development of ethics committees.

3. Discuss how legal precedents and accreditation standards have influenced the response to ethical issues in the clinical setting.
   a. Read “Procedures for Review of Decision-Making” (President’s Commission, 1983) and the Patient Self-Determination Act (1990) and identify three ways that these may have shaped your institution’s policies.
   b. Compare and contrast the current JCAHO ethics standards (available at http://www.jcaho.org/) with those issued in 1992-93 (JCAHO, 1993). Discuss and reflect on social, political and cultural changes during this time period.
   c. Invite a lawyer familiar with health law and bioethics to discuss legal cases in your state in which ethics committees and/or consultation have been involved.
   d. Read the description of legal cases naming ethics committees or consultants in “The structure and process of ethics consultation services” (Fletcher and Moseley, 2003). Discuss the potential legal implications of providing clinical ethics consultation.
Resources


**Topic 4: The Roles and Goals of Clinical Ethics Consultation**

**Introduction**

The practice of clinical ethics consultation has become a standard way for hospitals to, in the language of the JCAHO, “address ethical issues in providing patient care.” There are, however, many ways to address ethical issues, and it is essential to give greater specificity to the roles and goals of clinical ethics consultation. Without such specificity, clinical ethics consultation may be easily misunderstood or confused with related activities within the hospital.

Generally speaking, the goal of clinical ethics consultation is to assist the interested parties in addressing an ethical issue that arises in patient care. This assistance may take a variety of forms. For example, it may involve helping the parties understand the moral problem, relevant concepts and facts, alternative courses of action, and their likely consequences. It may involve helping the parties to communicate with one another more effectively. It may involve helping the parties to evaluate moral reasons for different alternatives and to achieve agreement on a course of action.

Individuals offering clinical ethics consultation should be careful to distinguish clinical ethics consultation from other practices in the hospital with which it might be confused, including medical consultation, risk management, compliance, and even organizational ethics consultation. Though there may be areas of overlapping interest and cooperation among these practices, their primary goals are clearly different. In contrast to clinical ethics consultation’s focus on achieving defensible solutions to clinical moral problems, medical consultation services
provide medical information, risk management programs protect the institution from liability, and compliance programs promote institutional adherence to legal standards, and organizational ethics consultation offers guidance on moral issues that arise in the management of health care institutions.

**Learning Objectives and Strategies**

Upon completing study of this topic, learners should be able to:

1. Describe the scope, limits and goals of clinical ethics consultation in their institution.
   a. Read pp. 3-10 of *Core Competencies for Ethics Consultation* (ASBH, 1998) and compare and contrast these statements of the scope, limits and goals of clinical ethics consultation to your own institution’s policy.
   b. Read three articles that offer different approaches to clinical ethics consultation (Agich, 2001; Aulisio, 2003; Bliton and Finder, 2002; Engelhardt, 2003; Moreno, 2003; Walker, 1993) and identify important points of similarity and difference with respect to ethics consultation’s scope, limits and goals.

2. Discuss the similarities and differences between clinical ethics consultation and other services whose roles may overlap with ethics consultation.
   a. Invite the directors of programs and services such as risk management, pastoral care, consultation liaison psychiatry, compliance, quality assurance, legal affairs, utilization review, patient advocate or ombudsman, and palliative care to meet with you. Ask them to describe the scope, limits and goals of their services. Compare these with those of your clinical ethics consultation service.

3. Explain the relationship between clinical ethics consultation and the ethics committee at your institution.
   a. Review any policies and procedures that govern clinical ethics consultation and the ethics committee at your institution.
   b. Read two articles on ethics committee successes and failures (Lo, 1987; Fleetwood et al., 1989; McGee, 2001).

4. Discuss the relationship of clinical ethics consultation to other ethics activities such as education or policy review.
   a. Make a list of and categorize the types of cases that have come to clinical ethics consultation in your institution, and identify any discernable patterns. Prepare an educational program for your institution on one or two of the salient recurring ethical issues.
   b. Construct a model policy designed to address one of the above ethical issues in a systematic way.
   c. Read “Teaching ethics on rounds: the ethicist as teacher, consultant, and decision-maker” (Glover, Ozar, Thomasma, 1986), and discuss the different roles of ethics in the clinical setting.
5. Identify several role confusions that can emerge in the practice of clinical ethics consultation.
   a. Read a sample clinical ethics case from the *Journal of Clinical Ethics* or *Hastings Center Report* and identify role-specific duties, responsibilities, and limits for each health professional in the case. Distinguish these role-specific duties from those of persons doing clinical ethics consultation.

**Resources**


Clinical ethics consultation services can be structured in several different ways, and those providing ethics consultation can make use of a variety of different theoretical tools and procedures. For example, individuals, small teams, or entire ethics committees may provide clinical ethics consultations. These different structural models for ethics consultation have different advantages and drawbacks. Awareness of their advantages and drawbacks can enable hospital officials to choose the model or models best suited to the needs and resources of their institution and to specific consultation requests.

Individuals involved in providing clinical ethics consultation may make use of a number of approaches to theory and method in bioethics. The first-formulated of these, the principle-based approach of Beauchamp and Childress, was soon joined by a case-based approach proposed by Jonsen and Toulmin, a unified theory approach offered by Gert, Culver, and Clouser, and several virtue-based approaches drawn from Aristotle and from feminist discussions of the virtue of caring.

Clinical ethics consultation services must make a variety of important decisions about the procedures they will follow. They must, for example, decide who will have access to the consultation service, who will be notified about a consultation and invited to participate in it, what the format of consultation meetings will be, how consultations will be documented in patient medical records and elsewhere, and how consultations will be evaluated.

Learning Objectives and Strategies

Upon completing study of this topic, learners should be able to:

1. Describe the advantages and disadvantages of individual, small team, and committee models for providing clinical ethics consultation.
   a. Using a sample case, discuss with colleagues how individuals participating in clinical ethics consultation in each model might handle the case.
   b. Read “Models for ethics consultation: Individual, team, or committee” (Rushton, Youngner, Skeel, 2003) and discuss the strengths and weaknesses each model.
2. Discuss with colleagues the contributions different methodological approaches to ethics consultation such as principialism, casuistry, virtue-based ethics, narrative ethics, phenomenology, and feminist ethics make to ethics consultation."
   a. Read several sections of *Method in Medical Ethics* (Sugarman, Sulmasy, 2001), and “Listening or Telling” (Zaner, 1996). Describe how each of these approaches might be helpful in analyzing a clinical ethics case.

3. Identify important strengths and weaknesses of your institution’s clinical ethics consultation service.
   a. Gather four or five ethics consultation policies from other institutions and compare them to your institutional policy.
   b. Invite persons who have utilized the clinical ethics consultation service at your institution to give feedback on the strengths and weaknesses of service.
   c. Ask persons from clinical areas who rarely request ethics consultation to give input on why they rarely request consults.

**Resources**


Domain I: Core Knowledge
B. Core Ethical Issues Involving Adult Patients

Topic Area Outline

I. Decision-making capacity (DMC)
   A. Concept, attributes and common misunderstandings of DMC
   B. Methods for assessing DMC
   C. Assessment of DMC as controversial
   D. DMC and ethics consultation

II. Informed consent
   A. Concept, foundations and common misconceptions of informed consent
   B. Necessary conditions of informed consent
   C. Scope and limits of recognized exceptions to the informed consent requirement
   D. Informed consent and ethics consultation

III. Surrogate decision making
   A. Concept and foundations of surrogate decision-making
   B. Moral and legal criteria
   C. Moral and legal standards and process when standards are violated
   D. Surrogate decision making and ethics consultation

IV. Advance care planning and advance directives
   A. Concept and foundations of advance care planning
   B. Legal considerations in your jurisdiction
   C. Complexities of advance care planning

V. End-of-life decision-making
   A. Common end-of-life treatments and conditions
   B. Central moral concepts
   C. Legal and policy issues
   D. Major controversies surrounding end-of-life treatment decisions
   E. Ethics consultation and moral problems in end-of-life care

VI. Privacy and confidentiality
   A. Definition of privacy/confidentiality and applicable laws, regulations and policies
   B. Importance in the clinical setting
   C. Challenges and promotion of privacy/confidentiality
   D. Respecting privacy/confidentiality in the ethics consultation process
VII. Pregnancy and perinatal issues
   A. Moral status of the fetus and scope of maternal decision-making
   B. Conflicting obligations and ethical challenges of pregnancy termination
   C. Conflicting obligations and ethical challenges of pregnancy management
   D. Conflicting obligations and ethical challenges of labor and delivery

VIII. Dealing with “difficult” patients: professional and institutional responses
   A. Labeling of and attitudes regarding patients who frustrate health care providers
   B. Factors contributing to patient behavior
   C. Ethical challenges and strategies to overcoming barriers to treatment adherence

IX. Negotiating difference and accounting for context
   A. Culture and health care
   B. Personal cultural identity and the ethics consultation process
   C. Institutional demographics and community resources
   D. Demographic profile of the patient population
   E. Demographic profile of the health care professionals

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**Topic 1: Decision-making Capacity**

**Introduction**

Judgments about decision-making capacity (DMC) are pivotal in health care, since they determine the ability of patients to participate in choices about their care. Clinicians should, therefore, understand the concept of DMC and how to assess it. Many patients clearly have the capacity to make health care decisions, and others, such as unconscious patients, clearly lack this capacity. In still other cases, clinicians may be uncertain or disagree about whether a patient has sufficient capacity to make a particular health care decision. When a patient’s DMC is in question, clinicians may seek ethics consultation. Thus, individuals participating in clinical ethics consultation should also understand the concept of DMC and the implications of a finding that a patient has, or does not have, capacity to make a health care decision. Individuals offering clinical ethics consultation should be prepared to help health care providers and families understand the moral implications of DMC and resolve disputes or questions about DMC.

DMC is a complex concept, since it is based on four abilities: (1) the ability to express a choice, (2) the ability to understanding relevant information, (3) the ability to appreciate the significance of that information for one’s own situation, and (4) the ability to engage in basic reasoning regarding treatment options (e.g., offering reasons for and against options; engage in basic means-end reasoning). The term ‘competence’ is often used synonymously with ‘decision-making capacity’, but ‘competence’ also refers to a judicial determination that is different from clinical assessments of DMC. There is no simple algorithm for determining DMC—since the capacity necessary to make a decision varies with the complexity of the choice, DMC must be assessed relative to the decision at hand. Clinicians and those offering ethics consultation must strive to avoid a number of commonly held misconceptions about DMC, as, for example, the view that any patient with cognitive impairment or mental illness lacks DMC.
Learning Objectives and Strategies

Upon completing study of this topic, learners should be able to:

1. Explain the concept, attributes, and common misunderstandings of DMC.
   a. Read chapters two and three of *Assessing Competence to Consent to Treatment* (Grisso and Appelbaum, 1998). Make sure you understand and can articulate to colleagues the answers to the following questions:
      i. What is meant by ‘decision-making capacity’?
      ii. What are the four essential attributes of DMC?
   b. Invite a judge or attorney to make a presentation to the group involved in ethics consultation or on the ethics committee at your institution about the legal process of competence adjudication. Then, discuss how the clinical concept of DMC differs from the judicial concept of competence.
   c. Read “Ten Myths about Decision-Making Capacity” (Ganzini, Volicer, Nelson, Fox, and Derse, 2004) and, with colleagues, discuss examples from your experience of common misconceptions about DMC.

2. Describe examples of acceptable and unacceptable methods for assessing DMC.
   a. Read “The Psychometric Properties of the Competency Interview Schedule” (Bean, Nishisato, Rector, and Glancy, 1994) and “The MacCAT-T: A Clinical Tool to Assess Patients’ Capacities to Make Treatment Decisions” (Grisso, Appelbaum, and Hill-Fotuhi, 1997). Practice using one of these DMC assessment tools on a friend. (This strategy is not intended to make those who participate in clinical ethics consultation formal evaluators of DMC, but rather to give them a basic idea of how such evaluations are performed.)
   b. Arrange to observe at least two clinical assessments of DMC performed by physicians or clinical psychologists and discuss whether and how well each of the four essential attributes of DMC was assessed.

3. Describe how assessment of DMC can be controversial.
   a. Read “Competence and Incompetence” (Buchanan and Brock, 1989) and “Patient Decision-Making Capacity and Risk” (Wicclair, 1991). With colleagues, debate the pros and cons of these two conflicting perspectives on DMC assessment.

4. Illustrate through case examples how clinical ethics consultations can depend on appropriate assessment of DMC.
   a. Devote an ethics committee meeting or other gathering of interested persons to a discussion of three clinical cases that pose difficult moral questions about DMC.
   b. Write up an ethical analysis of a clinical case relating to DMC and get feedback from colleagues.

Resources


**Topic 2: Informed Consent**

**Introduction**

Since its introduction into American case law almost 50 years ago, informed consent to treatment has become a central moral and legal right of patients. Health care professionals must, therefore, understand the doctrine of informed consent and be able to obtain effective consent to treatment from their patients. A legally and morally sound informed consent must satisfy three necessary conditions. First, the patient must have decision-making capacity. Second, the patient must be given relevant information about the proposed treatment in language he or she can understand. Third, the patient must give consent to the treatment voluntarily, without coercion or duress. There are a number of recognized exceptions to the informed consent requirement, in emergencies, when the patient is unable to give consent, when the patient waives consent, when information disclosure would harm the patient, and for public health reasons.

Patients, families, or clinicians may be uncertain or may disagree about whether the necessary conditions for a valid informed consent have been satisfied or whether an exception to the consent requirement applies in a particular situation. In such cases, they may seek clinical ethics consultation. Individuals participating in ethics consultation must, therefore, be familiar with the doctrine of informed consent and with the scope and limits of the consent requirement.
Learning Objectives and Strategies

Upon completing study of this topic, learners should be able to:

1. Explain the concept, moral and legal foundations, and common misconceptions of informed consent.
   a. Review two overview articles or chapters on informed consent. Read chapter 2 of *Informed Consent: Legal Theory and Clinical Practice* (Berg, Appelbaum, Lidz, and Parker, 2001) and “Informed Consent” (Brock, 1987). Make sure you understand and can articulate to others the answers to the following questions:
      i. What is meant by “informed consent”?
      ii. What are the three necessary conditions for an adequate informed consent?
      iii. What moral values and principles are fostered by informed consent?
      iv. What are the legal concepts upon which informed consent is based?
   b. Read “Legal and Ethical Myths about Informed Consent” (Meisel and Kuczewski, 1996) and discuss examples from your experience of common misconceptions about informed consent.
   c. Talk to a mental health professional about the role of informed consent in patients who are involuntarily committed.

2. Explain what is required to satisfy each of the necessary conditions of informed consent.
   a. Arrange to observe at least two clinical encounters in which informed consent was obtained and discuss the following questions to determine how well each of the necessary conditions was met:
      i. Did the patient have DMC?
      ii. What types of information were given to the patient?
      iii. How much information was given to the patient?
      iv. How well did the patient understand the information?
      v. Was the patient’s consent voluntary?
      vi. What factors may have compromised the voluntary nature of the patient’s consent?
   b. Determine which standard for information disclosure for informed consent applies in your jurisdiction. You may accomplish this by, for example, consulting with your hospital’s attorney, obtaining a copy of your state’s informed consent statute, contacting a local law school’s health law department, or reviewing an article that discusses how informed consent applies in your area.
   c. In a group of individuals involved in ethics consultation or on the ethics committee at your institution, discuss the standard that applies in your jurisdiction and make sure you understand how it differs from the standards that apply in other jurisdictions. Discuss the pros and cons of different legal and ethical standards for information disclosure.
   d. Explore the difference between informed consent for a one-time procedure and informed consent for an ongoing plan of care in a long-term physician-patient relationship.
colleagues, discuss the difference between permissible and impermissible influences on the patient’s voluntary consent to treatment.

3. Describe the scope and limits of recognized exceptions to the informed consent requirement.
   a. Read chapter 4 of *Informed Consent: Legal Theory and Clinical Practice* (Berg, Appelbaum, Lidz, and Parker, 2001). Make sure you understand the following exceptions: emergencies, patients who lack DMC, patients who waive consent, public health requirements, and therapeutic privilege. Practice explaining what each of these exceptions means and when it applies.
   b. Review an article that explores one or more controversies related to exceptions to informed consent. Read “Ignorance is Bliss? Ethical Considerations in Therapeutic Nondisclosure” (Berger, 2005) and discuss, with colleagues, in a journal club format.

4. Illustrate through case examples how clinical ethics consultations can turn on issues of informed consent.
   a. Devote an ethics committee meeting or other gathering of interested persons to a discussion of three clinical cases that pose difficult moral questions about informed consent.
   b. Write up an ethical analysis of a clinical case relating to informed consent and get feedback from colleagues.

**Resources**


**Topic 3: Surrogate Decision Making**

**Introduction**

When patients lack decision-making capacity, others must make needed treatment decisions on their behalf. Moral and legal criteria have been established for determining who should serve as surrogate decision-makers for such incompetent patients. Moral standards have also been developed to guide the choices of surrogate decision makers. Although surrogates enjoy broad moral and legal decision-making authority for the patients they represent, their authority is not unlimited. When a surrogate decision appears clearly contrary to the previously expressed wishes or best interests of the patient, clinicians may have a responsibility to challenge that decision by invoking institutional and legal measures for patient protection.

Clinicians may be uncertain, in particular situations, who should serve as surrogate decision maker for an incompetent patient. Or, they may be uncertain whether or how to seek to override a surrogate decision they deem to be inappropriate or harmful to the patient. In such cases, clinicians may seek ethics consultation. Those participating in clinical ethics consultation must, therefore, understand criteria for appointment of surrogate decision makers, the scope and limits of surrogates’ authority, and procedures for challenging surrogate decisions.

**Learning Objectives and Strategies**

Upon completing study of this topic, learners should be able to:

1. Explain the concept and the moral foundations of surrogate decision making.
   a. Review an overview article or chapter on surrogate decision-making. Read chapter 2 of *Deciding for Others: The Ethics of Surrogate Decision Making* (Buchanan and Brock, 1989) or “Substantive and Procedural Principles of Decision-making for Incapacitated
Patients” (President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1982). Make sure you understand and can articulate to others the answers to the following questions:

i. What is meant by “surrogate decision making”?
ii. What values or principles are fostered by surrogate decision making?

2. Describe the moral and legal criteria for choosing a surrogate.
   a. Discuss with colleagues the factors that may influence appropriate surrogate selection, including individual preferences, family and social structures, cultural norms, and legal standards.
   b. Drawing on the facts of the Schiavo case, stage a debate with others involved in ethics consultation or on the ethics committee at your institution pitting her husband’s moral claims to serve as surrogate decision maker against those of her parents.
   c. Determine the legal process governing surrogate selection that applies in your jurisdiction. You may accomplish this by, for example, consulting with your hospital’s attorney, obtaining a copy of your state’s statute pertaining to health care surrogates, contacting a local law school’s health law department, or reviewing an article that discusses how surrogate decision makers are selected in your area.

3. Explain the moral and legal standards governing surrogate decision making and how to proceed when these standards are violated.
   a. Make sure you understand and are able to articulate the following:
      i. The three moral standards for surrogate decision making
         --The patient’s previously stated explicit wishes
         --Substituted judgment
         --Best interests
      ii. When one standard takes precedence over the others
   b. Arrange to observe several clinical encounters in which a surrogate is discussing health care decisions for a particular patient. Identify which of the three moral standards is being used in each case.
   c. Determine the legal standards governing the surrogate decision-making process in your jurisdiction. You may accomplish this by, for example, consulting with your hospital’s attorney, obtaining a copy of your state’s statute pertaining to health care surrogates, contacting a local law school’s health law department, or reviewing an article that discusses the surrogate decision-making process in your area.
   d. Read “CPR in Hospice” (2003) and “What about the Family?” (Hardwig, 1990). Discuss with colleagues when and how a surrogate’s decision should be challenged and when it should not be challenged.

4. Illustrate through case examples how clinical ethics consultations can turn on issues of surrogate decision making.
   a. Devote an ethics committee meeting or other gathering of interested persons to a discussion of three clinical cases that pose difficult moral questions about surrogate decision making
   b. Write up an ethical analysis of a clinical case relating to surrogate decision making and get feedback from colleagues.
Resources


Topic 4: Advance Directives

Introduction

Due to mental or physical incapacity or illness, patients may lose the ability to participate in decisions about their treatment. Advance directives can give patients a measure of control over treatment decisions, especially near the end of life, even after they have lost decision-making capacity. Through a process called advance care planning, individuals can learn about options for care, engage in thoughtful discussion about these options with family members and health care providers, formulate and express their wishes in an advance directive, and increase the probability that their wishes will be honored in the appropriate circumstances.

Statutes in most states recognize two main types of advance directives. The first type, often called living wills or instructional directives, describes treatments that patients would or would not want in specific circumstances, such as terminal illness, persistent vegetative state, or severe mental illness. The second type, often called health care powers of attorney or proxy directives, designates a person to serve as a patient’s health care agent when the patient is no
longer able to make health care decisions. These two types of advance directives may be combined in a single document. The specific format and wording of statutory advance directives varies from state to state. It is important to note that, unlike most living wills, most health care power of attorney documents authorize health care agents to make health care decisions for the patient whenever the patient is unable to make them, and thus are not limited to decisions about end-of-life care.

Clinicians have a moral and legal responsibility to pay attention to advance directives as an expression of patient wishes. They may, however, be unsure whether the wishes expressed in an advance directive apply to a specific treatment decision or whether a patient’s health care agent has the right to make a particular treatment decision for that patient. In such situations, clinicians may seek the assistance of an ethics consultant. Ethics consultants must, therefore, be familiar with the moral foundations and limitations of advance directives and with the application and interpretation of advance directives in specific situations.

**Learning Objectives and Strategies**

Upon completing study of this topic, learners should be able to:

1. Explain the concept and the moral foundations of advance care planning.
   a. Read two overview articles or chapters on the topic, “Putting Advance Care Planning into Action” (Teno and Lynn, 1996) and “Improving Care at the End of Life: How Advance Care Planning Can Help” (Moskop, 2004). Make sure you understand and can articulate to others the answers to the following questions:
      i. What is meant by “advance care planning?”
      ii. What values or principles do advance care planning foster?
      iii. What is the difference between advance care planning and advance directives?
      iv. What are the common types of formal and informal advance directives?
      v. What are the strengths and weaknesses of each type?

2. Explain the legal considerations relating to advance directives in your jurisdiction.
   a. Obtain a copy of your jurisdiction’s statute(s) pertaining to advance directives and study it carefully. Make sure you understand and can articulate the answers to the following questions:
      i. What are the requirements for a legally valid (verbal and written) advance directive?
      ii. When, how, and by whom should advance directives be implemented?
      iii. How may they be revoked?
      iv. Is the health care agent (or other surrogate) required to follow the patient’s treatment preferences as specified in the advance directive?

3. Explain some of the complexities surrounding advance care planning.
   a. Engage in the advance care planning process and prepare an advance directive for yourself, or review your existing advance directive. Answer the following:
      i. Did you designate a health care agent? Why or why not?
ii. If applicable, whom did you designate as your health care agent? What factors influenced this decision?

iii. If you designated a health care agent, did you give your agent specific instructions regarding your treatment wishes? Are you confident that your surrogate will carry out your instructions?

iv. Did you provide specific written instructions for treatment decisions? Why or why not?

v. If applicable, what instructions did you give? What factors influenced your choice?


As a group of individuals involved in ethics consultation or on the ethics committee at your institution, discuss some examples from your experience that illustrate the following problems:

i. Vague or inconsistent advance directives

ii. Conflicts between advance directives and family wishes

iii. Conflicts between advance directives and provider preferences and/or standards of care

C. Read “Quality-of-Life and Non-Treatment Decisions for Incompetent Patients: a Critique of the Orthodox Approach” (Dresser and Robertson, 1989). Discuss the potential conflict between respecting a patient’s previously expressed wishes and promoting the patient’s current best interests.

3. Illustrate through case examples how clinical ethics consultations can turn on issues of advance care planning or advance directives.

a. Devote an ethics committee meeting or other gathering of interested persons to a discussion of three clinical cases that pose difficult moral questions about advance directives.

b. Write up an ethical analysis of a clinical case relating to advance care planning and get feedback from colleagues.

Resources


7. Lynn J. Why I do not have a living will. *Law, Med & Health Care.* 1991;19(1-2):101-

8. *Making Choices* (video recording). Distributed by Gundersen Lutheran Medical Center, La Crosse, WI.


Topic 5: End-of-Life Decision-Making

Introduction

Dilemmas in end-of-life care are among the most common and difficult moral problems confronting patients, health care professionals, and ethics consultants. Conflicts about care near the end of life have a variety of causes. Patients, surrogates, or clinicians may, for example, not understand the capabilities or the limitations of medical technologies and so may base decisions on inadequate or false information. Patients, surrogates, or clinicians may, due to fear, denial, guilt, suspicion, or grief, refuse to accept the fact of impending death and so insist on treatments whose burdens outweigh their benefits. Patients, surrogates, and clinicians may hold very different beliefs about the importance of prolonging life or relieving suffering. Based on their different beliefs, attitudes and values, patients, surrogates, and clinicians may embrace different goals for care near the end of life. When goals or preferences for end-of-life care come into conflict, any of the interested parties may seek clinical ethics consultation. Those participating in ethics consultation must, therefore, be familiar with treatment choices near the end of life, common conflicts in end-of-life care, and approaches to analyzing and resolving those conflicts.

Learning Objectives and Strategies

Upon completing study of this topic, learners should be able to:

1. Explain common end-of-life treatments and conditions.
   a. Read “Withholding and Withdrawing Life-Sustaining Therapy” (American Thoracic Society, 1991). Make sure you understand and are able to articulate:
      i. The definition of life-sustaining treatment
      ii. The various types of life-sustaining treatments
      iii. The concepts of palliative care and hospice care
   b. Visit with clinicians in various clinical settings to observe and discuss the nature, risks, benefits, and alternatives to various life-sustaining treatments including:
      i. Mechanical ventilation (including tracheostomy, portable ventilators)
      ii. Dialysis (including hemodialysis and peritoneal dialysis)
      iii. Artificial nutrition and hydration (including central venous lines, TPN, PPN, g-tubes, j-tubes, NG tubes)
      iv. Cardiopulmonary resuscitation (including ACLS, DNR orders)
   c. Visit a hospice patient, either at home or in an institution, and talk to him/her about perspectives and concerns about their end-of-life care. Alternatively, talk to a family caregiver of a patient who has died recently and ask about their impressions about their care their loved one received near the end of life.
d. Talk to a palliative care clinician about difficulties in defining terminal illness and in predicting the progression or outcome of a particular patient’s illness.

e. Read and discuss “Guidelines for the Determination of Death” (Medical Consultants on the Diagnosis of Death to the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1981), “Medical Aspects of the Persistent Vegetative State” (The Multi-Society Task Force on PVS, 1994), and “The Minimally Conscious State: Definition and Diagnostic Criteria” (Giacino, Ashwal, Childs et al., 2002). As an alternative, invite a neurologist to describe neurological criteria for the determination of death, persistent vegetative state, and minimally conscious state.

f. Arrange to observe an examination to determine if a patient meets neurological criteria for death.

g. Arrange to observe an examination of a patient in a persistent vegetative state.

3. Explain central moral concepts in end-of-life care.

a. Make sure you understand and can articulate the meaning of:
   i. physician assisted suicide
   ii. euthanasia
   iii. palliative sedation

b. Describe the differences between the following pairs of concepts and tell whether you think those differences are morally significant (you can review discussions of these concepts in the report of the President’s Commission [President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983]):
   i. killing and letting die
   ii. intended and foreseen consequences (including double effect)
   iii. ordinary and extraordinary means
   iv. active and passive euthanasia
   v. withholding and withdrawing treatment

c. Discuss with colleagues clinical cases that highlight each of these concepts and moral distinctions.

4. Describe legal and policy issues in end-of-life decision making.

a. Review your institution’s policies on ethical aspects of end-of-life care, e.g., limiting life-sustaining treatment, DNR orders, futility, brain death. For each policy, identify five “Frequently Asked Questions” that clinicians or patients are likely to ask, and prepare clear written responses to each. Get feedback on your responses from an experienced ethics colleague.

b. Read and discuss with colleagues “Legal Myths about Terminating Life Support” (Meisel, 1991).

c. Determine the legal standards governing end-of-life decision making in your jurisdiction. You may accomplish this by, for example, consulting with your hospital’s attorney, contacting a local law school’s health law department, or reviewing an article that discusses end-of-life decision making in your area.

d. Read “Comas: Karen Quinlan and Nancy Cruzan” (Pence, 1995). Discuss the historical significance and legal precedents of the Quinlan and Cruzan cases.

5. Describe the major controversies surrounding end-of-life treatment decisions.
a. Read two articles on medical futility, including one that defends the concept (Schneiderman, Jecker, and Jonsen, 1990) and another than critiques the concept (Helft, Siegler, and Lantos, 2000, Rubin, 1998, or Truog, Brett, and Frader, 1992). Debate with individuals involved in ethics consultation or on the ethics committee at your institution the pros and cons of permitting physicians to unilaterally limit life-sustaining treatment on the basis of medical futility.

b. Discuss with colleagues the controversy about the role of quality of life judgments in limiting life-sustaining treatment.

c. Read at least three articles describing different religious and secular arguments for and against the use of artificial nutrition and hydration, and the use of palliative sedation, in dying patients. Discuss in a group with individuals involved in ethics consultation or on the ethics committee at your institution.

6. Illustrate through case examples how clinical ethics consultations can help to clarify moral problems in end-of-life care.

   a. Read “Ethics and Palliative Care Consultation in the Intensive Care Unit” (Aulisio, Chaitin, and Arnold, 2004) and explore the difference between clinical ethics consultation and palliative care consultation.

   b. Devote an ethics committee meeting or other gathering of interested persons to a discussion of three clinical cases that pose difficult moral questions about end-of-life care.

   c. Write up an ethical analysis of a clinical case relating to end-of-life care and get feedback from colleagues.

Resources

1. Achtenberg B. Caring at the End of Life (video recording). Distributed by Fanlight Productions, Boston, MA.


8. *End of Life/Palliative Education Resource Center (EPERC)*. (Website offers a variety of educational materials and other resources.) Available at: http://eperc.mcw.edu/. Accessed August 18, 2005.


17. *On Our Own Terms: Moyers on Dying in America* (video recording, four-part series). Distributed by Films for the Humanities and Sciences, Princeton, NJ.


**Topic 6: Privacy & Confidentiality**

**Introduction**

On the most basic level, privacy entails the right of patients to control access to their person. This includes access to their physical bodies as well as access to personal information. The right to privacy also recognizes the inherent vulnerability of patients and the sensitivity of health information. In the context of health care, this vulnerability includes strangers sharing physical spaces and the opportunity for strangers to witness the most intimate circumstances and/or overhear the most intimate of personal conversations. In health care, personal information is stored in and communicated through a wide variety of media, including medical charts, research databases, electronic charts, appointment reminders, staff meetings, and bedside rounds. Breaches of a patient’s confidentiality or privacy can result in harms, such as widespread knowledge of a patient’s health status, embarrassment, feelings of violation, and discrimination based on stigmatized diseases. Breaches of privacy in the clinical setting may take various forms, including: patient exposure during examinations or procedures; discussing sensitive issues in settings where other patients/families can eavesdrop on the conversation; hallway consultations between clinicians; and giving people outside the “circle of care” access to a patient’s medical record. Thus, protection of patients’ privacy is essential to cultivating trust in the therapeutic relationship. However, protection of patients’ privacy has become more difficult in recent years due to the increasing complexity of the healthcare system, and the large number of people now involved in caring for individual patients.

A distinction is often made between “privacy” and “confidentiality.” Maintaining “privacy” entails restricting access to personal health information, while maintaining “confidentiality” entails determining how information should be appropriately shared for the purpose of providing health care. Patients’ personal information is protected through both federal regulations (such as HIPAA), and state legislation. While there is some variation, in
general, federal and state laws require express consent for disclosure of health information to non-healthcare officials. Nevertheless, confidentiality and privacy are valued differently in different cultural contexts and clinical settings. In most cases, individual patients should be empowered to determine what information is shared and with whom. This includes clarifying with the patient how much health information should be shared with a substitute decision-maker if a patient is temporarily incapacitated. At the same time, there are specific instances when ethics and the law support contravening privacy, such as situations of suspected abuse or neglect of a child or a dependent adult. In such cases, staff may experience a conflict between the duty to protect patient privacy and the duty to protect vulnerable persons and may therefore seek clinical ethics consultation.

Individuals who participate in clinical ethics consultations are sometimes involved in cases where patients or families want health information withheld from third parties, such as insurance companies or employers, or want information removed from the medical record. In addition, by virtue of offering clinical ethics consultation, individuals are often privy to confidential information about hospital staff members. Thus, individuals participating in clinical ethics consultations must consider their obligations to protect patient and staff privacy in the consultation process.

Learning Objectives and Strategies

Upon completing study of this topic, learners should be able to:

1. Define confidentiality/privacy in healthcare, and identify applicable laws, regulations and institutional policies.
   a. Read several articles that use the concepts of privacy and confidentiality (Reed, 2001; Furrow, 1998; Boleyn-Fitzgerald, 2001; Murphy, 1998; Case 2003; Gostin, 2001). Discuss with colleagues the diversity of meanings of these terms in these articles and the relationships between them. How you would explain these concepts to patients, families and health care providers? Come up with working definitions of these terms for your consult service.
   b. Seek the input of your institution’s compliance officer to identify and discuss statues and regulations relevant to confidentiality/privacy, such as HIPAA. Read your institution’s current confidentiality/privacy policies and assess their adequacy in light of these regulations. Review how patients are informed of their right to privacy and how their information may be used. Discuss with colleagues how consent to utilize private information is obtained from patients.
   c. Review legal exceptions to maintaining patient confidentiality/privacy and the appropriate responses to these situations, specifically the “duty to warn.” (Allison, 1998; Bok, 1983; Buckner and Firestone, 2000).

2. Explain why privacy and confidentiality are important in the clinical setting, and the harms that may result from breaches of them.
   a. Review articles by Moskop et al. (2005) on confidentiality in the emergency medicine setting. Watch an episode or two of ER and identify different ways in which confidentiality/privacy are compromised. What harms could potentially be caused by
these infractions? Discuss how frequently similar infractions happen in your own institution.

3. Describe behaviors or actions that respect, promote, diminish, or violate patient rights to privacy and confidentiality in health care settings.
   a. Make a list of the types of information that are considered confidential/private in health care. Do an environmental scan of two particular clinical settings (i.e. an office, ward or unit) where patient information is kept, discussed or used. How private is the information? How does it circulate? Who has ready access to it? Who has legitimate access to it? Identify practical ways that health care providers can promote the privacy of information and physical privacy. Read and discuss with colleagues an article on physical privacy (Mendelson, 2003).
   b. Ride your institution’s elevators, or sit in the cafeteria or a busy clinic waiting room for half an hour. Observe how much confidential/private information is inappropriately shared. How could healthcare providers better safeguard private information? Invite patients and families to share their experiences and concerns regarding privacy and confidentiality with your consultation group. Read and discuss with colleagues the adequacy of different procedures for safeguarding private information (Ubel, 1995).

4. Identify dilemmas and challenges that arise in protecting confidentiality and privacy.
   a. Discuss with colleagues the multiple obligations of the health care provider regarding the use of patient information. Identify circumstances in which health care providers might be asked to conceal patient information (for example, from the family or record). Invite a psychiatrist or mental health advocate to discuss the mental health regulations regarding privacy and analyze specific cases. With individuals involved in ethics consultation or on the ethics committee at your institution, read and discuss an article on confidentiality and mental health (Cordess, 2001).
   b. Discuss with your compliance officer how privacy regulations or practices may vary with specific clinical issues, including HIV, reproductive medicine or genetic testing. Read an article that addresses this issue (Anderlik, 2000; Laurie, 2001; Lee, 1998; Rand, 1998).
   c. Read articles about cultural and contextual influences on privacy/confidentiality (Kalavathy, 2000; Lindenthal, 1985; Sanci, 2005). Brainstorm examples of how cultures differ in terms of privacy concerns, and how healthcare providers might respond.

5. Identify how to respect confidentiality/privacy in the clinical ethics consultation process.
   a. Reflect on a recent ethics consultation performed by your service (or imagine a hypothetical case). What type of patient information was gathered in the consultation process and in what context was this information shared? Who authorizes access to patient information? In light of hospital policy and federal/state regulations, is an ethics consultant empowered to access the patient record without explicit consent? In what other ways can patient privacy be breached in the consultation process? With colleagues, read and discuss an article that addresses this issue (Davis, 1991; Parker, 1998; Rogers, 2003).
   b. Perform a privacy/confidentiality audit of clinical ethics consultation documents and records with your compliance officer or other appropriate individual or office in your institution. How is confidential information recorded? How are records stored and who has access to them? How are cases described in educational events or consultation
reports? Strategize ways to safeguard confidentiality in the consultation process (i.e. not recording patient names/numbers in reports; limiting attendance to those directly involved in the case; reading a confidentiality statement at the beginning of the consultation, etc.).

c. Discuss with colleagues the pros and cons of accepting “anonymous” consultation referrals from staff (i.e. the staff person doesn’t wish to be identified as the person who called for a consultation). What are your obligations to protect the confidentiality of information shared by staff in the clinical ethics consultation process?

Resources


**Topic 7: Pregnancy & Perinatal Issues**

**Introduction**

Pregnancy represents a unique situation in life, the circumstance of one human existing within and totally dependent on the body of another human for a period of several months. The uniqueness of pregnancy makes it difficult to talk about ethical issues in value-neutral language. For example, the term “fetus” emphasizes the dependence of one entity on the other, while simultaneously de-emphasizing the bond women usually have with their unborn children. The term “baby” on the other hand, connotes a separate individual, and evokes an emotional reaction that may overshadow the interests of the woman who harbors the growing child. Similarly, the term “viability” can indicate a developmental milestone at which the baby can survive outside the womb, or the likelihood of a particular pregnancy resulting in a healthy baby.

Ethical issues in pregnancy are often characterized as “maternal-fetal conflicts.” This label, however, polarizes the complexity of circumstances in which pregnant women must weigh their own best interests and those of others including their current and future children. “Maternal-fetal conflict” also ignores the web of relationships in which pregnancy occurs, including the interests of fathers, family members and society in the outcome of a pregnancy. Some authors de-emphasize the uniqueness of pregnancy by focusing on the similarity between pregnancy and parents’ moral relationship with their born children, in order to highlight the moral obligations men also have to their children.

Pregnancy is also distinctive in health care in that it is not an illness, but a biologically normal process occasionally attended by serious health complications. It is also a process that takes place within the bodies of women only.

Health care providers sometime request ethics consultations in order to help define their obligations to the pregnant woman/family and the fetus/baby. Does the physician have one patient or two patients? How should the interests of each be balanced? What strategies might help health care providers forge a working partnership with the pregnant woman? Examples of ethical issues in pregnancy sometimes encountered by ethics consultation team members include: termination of pregnancy; early delivery for mother’s health or fetus’ health; refusal of blood transfusions and other treatments in pregnancy, labor and delivery; advance directives in pregnant patients; and obligations to refer to other institutions for certain procedures not offered by local institutions (such as abortion or sterilization).

**Learning Objectives and Strategies**

Upon completing study of this topic, learners should be able to:
1. Identify the major ethical positions regarding the moral status of the fetus and the appropriate scope of maternal decision-making.
   a. Compare and contrast the three articles by Chervenak et al. (1996), Harris (2000) and Mahowald (1992). Identify and analyze different arguments surrounding the characterization of the fetus as patient and the scope of maternal decision-making. Share with friends or family the various usages of key terms in the literature and observe their reactions to these terms.
   b. Invite an obstetrician and maternal child/health nurse to present an ethically troubling case from their practice. Analyze their use of language and identify the values embedded and contested in categories such as “baby”, “fetus”, “maternal-fetal conflict”, “viability”, “mother”, and “patient”. Share with friends or family the various usages of these terms by health professionals and observe their reactions.
   c. Invite a panel of local religious leaders or institutional chaplains to present, compare and contrast their faith perspectives on the question of the moral status of the fetus at different points in the pregnancy.
   d. Identify and understand how the mission of your organization, and its religious affiliation (if any), influences options and procedures for pregnancy care. Discuss the moral status of the fetus and obligations to pregnant women with your Director of Mission Services or other relevant person in leadership.
   e. Examine popular pregnancy magazines and on-line pregnancy resources (such as e-pregnancy) for characterizations of the maternal-fetal relationship. In addition, review and critique the chapter “An Egalitarian Overview” (Mahowald, 1993) as an example of a feminist discussion of “maternal-fetal conflicts.”
   f. Invite a health lawyer to discuss the legal issues surrounding living wills for pregnant women in your state (if applicable). Review and discuss with colleagues an article that addresses this issue (Frader, 1993; Lederman, 1994).

2. Describe the nature of conflicting obligations and ethical challenges associated with pregnancy termination, for example in labor induction of the near-viable fetus, prenatal diagnosis, maternal health considerations and selective reduction. Describe the legal and cultural context of abortion in your institution and your state.
   a. Discuss with a health lawyer the legal context of abortion in your state, as well as current reporting requirements and practices. Analyze the definitions of “abortion”, “termination” and “induced labor” in laws and regulations.
   b. Review the ACOG standards, “Ethics in Obstetrics and Gynecology” (www.acog.org) regarding abortion and handling maternal-fetal conflicts. Review and discuss your institution’s policies and procedures for termination of pregnancy.
   c. Watch a movie on abortion such as If These Walls Could Talk, Citizen Ruth or Vera Drake. Discuss with your ethics colleagues your reactions to the film and your own personal beliefs regarding abortion and the status of the fetus. Examine how attitudes toward abortion in your group and in these films are shaped by personal experiences, cultural context and the legal environment.
   d. Read chapters of the book Liquid Life by William LaFleur and compare and contrast Japanese perceptions of the status of the fetus and attitudes toward abortion to those of North America.
3. Describe the nature of conflicting obligations and ethical challenges involved in the management of pregnancy, including potential conflicts between maternal health needs or behaviors and fetal well being (e.g., for example, for pregnant women with mental illness, addictions, cancer, cardiovascular problems, traumatic injuries or violent domestic situations).
   a. Read and discuss with colleagues articles that present the arguments for and against prosecuting women whose health behaviors endanger their fetuses (Jos et al., 1995; De Ville, 1998; Annas, 2001; Parks, 1999; Randall, 1999.)
   b. Invite a lawyer to discuss legal issues regarding pregnancy management in your jurisdiction, such as advance directives for pregnant patients and legal definitions of parents (biological parent vs. genetic parent vs. person the mother is married to) and the implications for decision-making.
   c. Read the McCullough (2002) article on pregnant patients with schizophrenia, and outline the argument and possible approaches.
   d. Read and discuss at least two articles pertaining to ethical issues involved in decisions surrounding fetal treatments in utero (Chervenak, 2003; Bliton and Zaner, 2001; Tauer, 2002).
   e. Invite someone from your OB/GYN clinic to discuss cases involving maternal health needs and pregnancy management.

4. Describe the nature of conflicting obligations and ethical challenges surrounding the management of labor and delivery, including: refusal of or demand for treatments or diagnostic testing, sterilization at delivery, the paternal role in decision-making, elective c-section, and competency/consent issues.
   a. Read an article on the AC case (Orona 1994). Read the ACOG position statement on maternal-fetal conflict and court ordered c-section. With individuals involved in ethics consultation or on the ethics committee at your institution, take sides and debate whether the judge in the AC case should have ordered a c-section.
   b. Invite an OB/Gyn and labor/delivery nurse to describe one of their most challenging cases in labor/delivery and outline the strongest arguments on each side for intervening on behalf of the fetus or honoring the mother’s wishes.
   c. Read literature on refusal of and demand for various treatments/diagnostic tests in labor and delivery (i.e. tox screening, fetal monitoring, epidural) (Burrows, 2001??; Cahill, 1999; Marsh, 2001). Compare the arguments in e-Pregnancy on-line magazine with the ACOG position statement regarding elective c-sections. Identify the various ethical claims made in these articles.
   d. Read and analyze articles that address the impact of labor and delivery on the decision-making capacity of women and review articles that contrast the claims of maternal and paternal treatment refusal (Brooks and Sullivan, 2002; Goldberg, 2003).
   e. Read Murray (1996) and discuss parallels between parental decisions for born and unborn children. Discuss the advantages and disadvantages to emphasizing parental rather than maternal decision-making.
Resources


Introduction

While the intent of health care is to promote patient well-being, one side-effect of seeking health care is surveillance; that is, patients’ lifestyles, relationships and moral choices that in most other circumstances would be considered private matters come under scrutiny in the clinical setting. For example, a morbidly obese patient having a routine procedure may be criticized for not following a prescribed diet. A terminally ill adolescent may cause a scandal among staff by having her boyfriend “sleep over” in her hospital bed. Staff may struggle with how to respond to a patient who uses profanity or uses street drugs. Patients who exhibit behaviors clinicians perceive as disrespectful, threatening, abusive, hateful or just interfering with optimum health, effective treatment or the routines of clinical care, are labeled as “difficult.” “Difficult” patients may challenge the professional identities, standards of practice and social norms of health care, as well as the deeply held values of clinicians.

“Difficult patients” are frequently labeled by health care providers as “noncompliant.” Compliance and noncompliance are objectionable terms because they suggest an undesirable model of the physician-patient relationship. That is, the terms suggest that the physician unilaterally determines and tells the patient what is best, and the patient’s job is to comply. This paternalistic connotation is contrary to many contemporary ethical ideals such as that of shared decision making between physician and patient. The alternative label “adherence” is not much better as it emphasizes following a predetermined plan. The terminology of “patient self-care” is emerging in the literature and while this falls prey to many of the same conceptual problems as “compliance” and “adherence” it may connote that some patient actions that do not conform to a medical treatment plan might be attempts by patients to promote their own well being. Thus, it is a less judgmental terminology. It might be argued, in fact, that “noncompliance” is simply an extreme manifestation of patient autonomy.

Ethics consultations regarding noncompliance are often triggered by healthcare professionals’ feelings of frustration, anger or helplessness when patients don’t “follow orders.” Patients may be late for appointments or miss them altogether, not fill prescriptions for medications, or partake of personal habits that exacerbate their illnesses, e.g., smoking, consuming tobacco, or not altering eating behavior. For various reasons, particular patients come to be identified as “noncompliant” or “irresponsible” while most patients do not, despite the fact that few patients are completely adherent to their treatment regimens.

Consultations regarding “difficult patients” will often involve finding the reason for the patient’s self-care plan. These range from socioeconomic barriers to self-care, such as lack of transportation or funds to buy prescribed medications, to mental illness, to the bewildering complexity of a patient’s treatment regimen, to genuine value conflicts between the physician and patient regarding what is best for the patient. Thus, clinical ethics consultations involving concerns of noncompliance will often explore exactly what about the particular patient has caused this issue to surface, whether it is social stigma, cultural misunderstanding, personality conflicts, or some other factor that has caused the physician-patient relationship to fracture. In this way ethics consultation may be an opportunity for clinicians to engage in reflective practice.
around their expectations of patients and their attitudes toward patient lifestyle choices. In general, the goal of these consultations is to restore the physician-patient relationship to a partnership of caring.

Persons requesting clinical ethics consultations will sometimes frame noncompliance as an issue of resource allocation. They may suggest that scarce resources are being inappropriately used for patients on whom they will be wasted, owing to noncompliance. However, resource allocation concerns are seldom a good basis on which to make recommendations in a particular case. The focus should first be on removing barriers to adherence or negotiating a plan of self-care that will be helpful to the patient. Decisions regarding the allocation of scarce commodities such as organs are best made according to systematic criteria at the institutional level, not arbitrarily in a particular case.

Those participating in clinical ethics consultations should be aware that support and understanding for frustrated providers is often among the most valuable services they offer. However, individuals participating in clinical ethics consultations should be vigilant as frustrated staff may call an ethics consult regarding a noncompliant patient with the expectation that the ethics consultation will function to “enforce” concurrence with the medical treatment plan or to convince the patient to comply. Clinical ethics consultation may also be requested in response to questions regarding the ethical parameters for ending a therapeutic relationship, including the clinician’s duty to not abandon patients.

**Learning Objectives and Strategies**

Upon completing study of this topic, learners should be able to:

1. Analyze the language used to describe patients who frustrate health care providers and the values, attitudes and beliefs inherent therein.
   a. Review and discuss with colleagues articles by Scofield (1995) and Sawyer (2003). Make a list of the terms you have heard and from the article that describe “difficult” patients. Analyze the judgments, values and assumptions embedded in these terms.
      i. Read the Coleman and Frank companion articles (1992). Think of a case from your own practice in which these labels have emerged. Reconstruct the case from the patient’s perspective. Reflect on how your values and position framed your perception of the patient’s behavior.
   b. Reflect on ways in which your life or habits do not conform to a medical ideal and the reasons for this. Reflect on any personal experiences of being labeled non-compliant or “difficult” in the health care context. What was motivating your behavior and choices? How did your health care providers respond? How would you have preferred them to respond?

2. Recognize factors that put patients at risk of being labeled difficult or noncompliant.
   a. Review the Brock article (1990) and discuss three different explanations for behavior that would otherwise be labeled difficult or non-compliant. (Burry, 1999)
b. Read and discuss with colleagues an article that identifies strategies and techniques that help patients overcome obstacles or barriers to their self-care (Schlenk, 2004; Daly, 2003; Toljamo, 2001; Kyngas, 1998).

c. Arrange a meeting with nurses and allied health professionals to discuss their perceptions of unit practices and policies that contribute to labeling patient non-compliant/difficult. Ask them to imagine they are a patient and to identify unit practices, clinical routines, institutional policies or physical features of their unit that would frustrate them or their family members. Identify institutional resources for helping to deal with difficult patients or family members (i.e. security, “oasis rooms”, chaplains, etc.).

3. Identify the ethical challenges health care providers may face in caring for “difficult” or “noncompliant” patients and strategies to help patients overcome barriers to treatment adherence.
   a. Review the article by Gunderman (2000) and discuss arguments for and against setting limits on treatment based on “compliance”.
   b. Read Harris (1999) and Groves (1978) and evaluate the institutional responses to the “impossible patient.” Discuss strategies to help patients overcome barriers to adherence.
   c. Review professional codes of ethics regarding professional obligations to noncompliant patients and identify ethical obligations in terminating a therapeutic relationship with a patient.
   d. Read the Orentlicher (1991) article and consider the legal ramifications of denying treatment. Invite hospital legal counsel to participate in the discussion of the article and the issue of abandonment.
   e. Discuss with colleagues the articles by Larkin (1998) and Glannon (1998).

Resources


Topic 9: Negotiating Difference and Accounting for Context

Introduction

Over the past decade, “cultural competence” or “cultural sensitivity” has been touted as integral to effective (and ethical) patient care. Cultural diversity may be perceived as a greater challenge in health care today not because of a real increase in the diversity of America (which has always been a culturally diverse country), but because of the emergence of patient autonomy as a leading principle of biomedical practice. Health care providers today are expected to educate patients about their options, engage them in conversations about their values and motivations, and enable patients to make their own treatment choices based on their unique understanding of their best interests. This process of education and partnership is undoubtedly more challenging when patients and caregivers do not share a common language, worldview or belief system.

Anthropologist Clifford Geertz, in his classic definition of culture, says that culture encompasses the ethos, ethics and worldview of an identified community. It is common for people to perceive culture as something other people have or inhabit, in contrast to our own worldview that we claim as simply “reality.” In the context of healthcare, identifying a patient as a member of a particular culture (i.e. Chinese or Mennonite or Black) is usually done to highlight the patient’s difference from an imagined norm (i.e. white, English-speaking, middle-class), without recognizing the cultural values embedded in these ideas about what constitutes “normal.” The notion that culture is something possessed by “them” and not “us” can be reinforced by cultural competency training which tends to focus on how to treat patients of different cultures, without recognizing that healthcare professionals are themselves a culturally diverse group, and that the structure and practice of biomedicine is its own culture. “Culture” is often used interchangeably with other markers of difference, such as ethnicity or race or religion, and is commonly portrayed as a risk factor for poorer health outcomes or noncompliance.

It is not uncommon for individuals participating in clinical ethics consultations to be told that the “problem” in a particular case is the patient’s cultural beliefs or identity, only to find it is the health care provider who is struggling to reconcile her personal moral beliefs with her professional obligations to the patient. Individuals participating in ethics consultations have an obligation to recognize how their own cultural identity influences how they perceive, analyze and negotiate ethical dilemmas. They also have a responsibility to recognize how their own expectations and assumptions may hinder free and creative communication with persons from different cultures.

Individuals participating in clinical ethics consultations should be attentive to the use of cultural labels (both officially in the medical record and informally amongst staff) within their institution, and avoid stereotyping patients based on these labels. For example, knowing that a patient self-identifies as Catholic, and that the official doctrine of the Catholic Church forbids abortion and euthanasia, does not enable the consultant to make assumptions about the values and choices of Catholic patients. How a patient understands and expresses the norms of her culture is influenced by other aspects of her identity, such as: gender, economic status or class, immigration status, sexual orientation, marital status, clan, religious identity, birth order, age, etc.
Because of this intra-cultural diversity, individuals participating in clinical ethics consultations need not develop distinctive strategies for doing consults with “ethnic” patients (aside from learning to work with a translator). Knowing a patient’s cultural identity should be a signpost or a springboard for further discussion; it is not a definitive map of the patient’s identity, beliefs or moral commitments. Individuals participating in clinical ethics consultations should focus their efforts on discerning the values of the particular patient or family involved in the dilemma. By the same token, they should be wary of utilizing cultural “leaders” or “experts,” such as priests or chiefs. While some patients may welcome the support of a religious or cultural leader, others may feel coerced to conform to traditional customs against their wishes. Ultimately, patients and families should take the lead in initiating consultations with community leaders.

While individuals participating in clinical ethics consultations should resist the urge to define patients rigidly according to their cultural identities, they do need to recognize that patients belonging to visible minorities face real barriers in accessing quality medical care. These barriers include inadequate translation services to facilitate informed consent, increased rates of medical indigence or under-insurance, racism leading to misdiagnosis or inappropriate treatment, etc. Patients who have experienced these barriers may mistrust health care professionals, compounding communication challenges. Ethics consultation may provide an opportunity to help build trust between socially disadvantaged or marginalized patients and the health care system. In addition to health care access and informed consent, “cultural cases” in clinical ethics consultation typically involve issues such as truth-telling (where families want to withhold the diagnosis or prognosis from the patient), identifying appropriate surrogate decision-makers, and making accommodations for religious rituals or alternative therapies in the clinical setting.

Learning Objectives and Strategies

Upon completing study of this topic, learners should be able to:

1. Explain the complexity of the concept of culture as it pertains to health care, including the risks and benefits of labeling patients according to their cultures.
   a. Read chapters 4, 5 and 6 in *A Cross-Cultural Dialogue on Health Care Ethics* by Coward and Ratanakul (1999). How do these authors define culture? How do these definitions differ from our conventional usage of the term “culture”? How would you explain the concept of culture in these articles to a friend or colleague?
   b. Read Fadiman’s *The Spirit Catches You and You Fall Down* (1997), along with Taylor’s companion article “The Story Catches You and You Fall Down.” How much of the conflict in this story can really be blamed on cultural differences, and how much is due to other factors (personality, professional norms, mistrust, etc.)? Discuss with colleagues how you would respond if you were consulted about this case.

2. Identify your own cultural identities and their potential impact on the process and outcomes of clinical ethics consultations.
a. Read Horace Miner’s “The Body Ritual among the Nacirema” (1965) and discuss with colleagues the experience of having one’s own cultural customs described as foreign and exotic.

b. Create a “map” of your identity, including all the attributes that are important to understanding your values and your place in the world. Discuss in a group how your own cultural identity is distinctive, and what points of tension you feel with the norms of your culture. Reflect on how you feel about being labeled by one aspect of your identity (i.e. “white” or “Catholic”). With colleagues, read and discuss an article that addresses the risks and benefits of categorizing patients according to their cultures (Berger, 2001).

c. Identify at least three ethical issues in health care that are “hot buttons” for you personally (i.e. issues that evoke a strong emotional reaction). Discuss with your group of individuals involved in ethics consultation or on the ethics committee at your institution why these issues are “hot buttons” for you and reflect on the roots of your personal definitions of right and wrong (i.e. your religious upbringing, life experience, community history, etc.). Strategize how you would deal with a “hot button” case in an clinical ethics consultation, including how you would disclose your personal biases and intuitions to your peers and consultation participants. Read and discuss with colleagues an article that addresses these issues (Dagi, 1995).

d. Read Carter (2001), Orr (1995) and Fins (1998) on cultural diversity and ethics consultation. Discuss with your consultation team strategies you might use to ensure all participants’ voices are heard and concerns considered.

e. Reflect on a recent ethical dilemma. How did various health care professionals present this dilemma? How did the patient/family understand the situation? Were any voices missing? How do you account for these different perspectives? Try to identify the cultural and moral values embedded in the process of clinical ethics consultation (i.e. “due process,” democratic decision-making, neutrality, patient autonomy, professionalism, etc.).

3. Understand the demographic profile of the patient population your hospital serves (i.e. economic status, health status, immigration status, ethnicity, race and religion) by utilizing census information or data from satisfaction surveys or patient records. Discuss with colleagues how the patient population of the hospital is or is not reflective of the community in which the hospital is located. Whom does the hospital serve? Who is included and who is excluded and why?

4. Understand the demographic profile of the health care professionals in your hospital. How do the demographics of the patient population compare to the demographics of those who provide care? How might these differences cause conflicts or create opportunities for miscommunication?

5. Identify resources in your hospital and community for providing culturally appropriate care (i.e. translation services; spiritual care; settlement and integration services, etc.).

6. Invite someone from a translation service to discuss the challenges of providing meaningful translation in a medical environment. Practice conducting a patient interview using the
translator. Read and discuss with colleagues an article that addresses strategies for communicating effectively with patients who are illiterate or present communication challenges (Agar, 1998; Kaufort, 1997; Solomon, 1997).

7. Recognize typical cases in clinical ethics consultation involving “cultural issues” and be able to conduct ethics consultations with culturally diverse participants.
   a. Discuss with colleagues the pros and cons of appealing to “cultural authorities” (i.e. priests, elders or experts) regarding issues involving particular patients. In what context would it be appropriate to consult cultural authorities? Invite cultural experts and leaders to a roundtable discussion about the purpose of clinical ethics consultation, their role in that process, and the ethical issues their constituents most frequently encounter in health care.
   b. Identify the challenges minority groups in your community encounter in accessing and receiving health care. Invite minority community leaders to talk with your group about these challenges. Read and discuss with colleagues an article that addresses this issue (Berger, 1998; Blustein, 2002).
   c. Read two articles that discuss truth-telling (Freedman, 1993; Anderlik, 2000). Strategize how your clinical ethics consultation service might respond to families or physicians who wish to shield patients from “bad news”.
   d. To better understand the influence of family configuration on ethics consultation, discuss with colleagues your own family structures and hierarchies. Who is empowered to make decisions about whom in your family? Compare these models of family to the legal hierarchy of substitute decision-makers in your state or province. Strategize how your clinical ethics consultation service would respond if the patient’s cultural “next-of-kin” did not match with the legal definition. Brainstorm ways to help health care professionals deal with diverse family structures and surrogate decision-makers.
   e. Read two articles on cultural justifications (Buryyska, 2001; Dula, 1995; Howe, 1995; Orr, 1997). Strategize how your clinical ethics consultation service might respond when patients/families argue that they are compelled to do certain things because of their religious or cultural identification.

8. Identify the culture of different health care professions, and the challenges to interprofessional collaboration.
   a. Read chapters of Rothman’s Strangers at the Bedside. As a group, discuss how medicine has changed over the past century, including how changing demographics, sociological trends, legal decisions, politics and other factors affect the practice of medicine.
   b. Read chapters 3-7 Intensive Care (Zussman, 1992) and discuss with colleagues the roles, duties and norms of various health care professionals. How do different professions frame and respond to ethical dilemmas? How are their relationships with patients and families different?
   c. Discuss with colleagues how different professionals use different language, tools, and comportment in their interactions with patients and other staff. How are their relationships with patients similar and distinct? What are potential sources of conflict between professional groups, and how might this manifest in the ethics consultation process?
Resources


Domain I: Core Knowledge
C. Core Ethical Issues Involving Minors

General Introduction

Clinical ethics consultation in pediatrics, involving newborns, infants, children and adolescents, is different from ethics consultation with adult patients. Children have different cognitive capacities and they are dependent on their families, and sometimes the broader society, for nurturing and protection. Children do not only “belong” to their families, but also to the broader community who cares about their well-being. Although historically children were viewed as the property of their parents, there is an increasing interest on the part of the state in the welfare of children, as evidenced by attention to public education, neglect and abuse legislation, and other public health initiatives. Health care professionals have obligations to promote the well being of their pediatric patients that are somewhat independent of their obligations to families. They are to promote the “best interests” of their young patients. Professionals and parents share this responsibility to look after the welfare of children. What is truly in the “best interests” of children and who gets to determine it are possible sources of conflict in pediatric ethics, and a source of much pediatric clinical ethics consultation. Many decisions about children are made with a view to the potential of children, laced with uncertainty about how decisions today will influence their adult capacities. Also, decisions in pediatrics are made in the context of perpetually evolving capabilities as children grow and mature and gain more life experience. As children gain capacity to be involved in their own health care decision making, the framework of best interest can be in tension with the growing obligation to respect the evolving autonomy of the child or adolescent. Ethical issues involving adolescents are some of the most challenging issues facing clinical ethics consultation.

A variety of ethical issues emerge in health care decision making for minors. Some of these issues arise at a particular stage of life, e.g., what role should a “mature minor” have in decisions about his or her health care? Others arise in all age groups, e.g., is it ethically justifiable to forgo medically provided artificial nutrition and hydration? Even where issues are relevant across the spectrum, however, they may need to be addressed differently at different stages of a minor’s life. Therefore, this section begins with a general framework, followed by subsections devoted to particular stages of life. In this section, as elsewhere in this curriculum guide, end-of-life issues receive a great deal of attention, since they constitute a large majority of requests for clinical ethics consultation.

Topic Area Outline

I. General framework for minors and decision-making
   A. Concept of a minor
   B. Decision-making models: adult vs. minors
   C. Best interest standard for minors
   D. Moral/legal standards for granting health care decision-making authority to minors
   E. Scope and limits of parental authority and responsibility
F. Scope and limits of health care professional authority and responsibility  
G. Cultural/religious beliefs and practices and the health care of minors  

II. Ethical issues involving newborns and critically ill infants and newborns  
A. Factors that guide or complicate decision-making in the delivery room  
B. Baby Doe regulations  
C. Futility  
D. Forgoing hydration and nutrition  
E. Decision-making in the PICU  

III. Ethical issues involving chronically ill infants, children and adolescents  
A. Decision-making in pediatric long term care/rehabilitation/home care  
B. Advance care planning in pediatrics  
C. Forgoing hydration and nutrition  
D. DNRs in the school setting  
E. Sterilization of minors with developmental disabilities  
F. Justice and access to resources for the chronically ill  
G. Ethical challenges to complementary and alternative medicine  

IV. Ethical issues involving adolescents  
A. Decision-making with adolescents  
B. Mature minor vs. emancipated minor  
C. Confidentiality and privacy  
D. The adolescent’s authority to make specific health care decisions  
E. Advance care planning with adolescents  

Topic 1: General Framework for Minors and Decision Making  

Introduction  

Health care decision making for minors differs in an obvious and important way from health care decision making for adults. Adults are presumed, without significant evidence to the contrary, to have the capacity to make health care decisions for themselves, and caregivers must secure their informed consent to treatment. In contrast, minors are presumed not to have the capacity to make their own health care decisions, and, with limited exceptions, do not have the legal authority to consent to their own treatment. Instead, authorization to treat minors must be provided by their parents or legal guardians. Parents and guardians have broad discretion in choosing health care for children, but they are expected to act in the best interests of the children and to conform to legal standards prohibiting abuse and neglect of children. As mentioned in the General Introduction above, this attention to the well-being of children is called the “best interest” standard. But as children grow and mature and their capacities evolve, commentators recommend informing them about their medical condition and its treatment and including them in treatment decisions. Adolescents have limited rights, under various state statutes, to give their own consent to treatment in specific situations.  

Caregivers may be uncertain who may give consent or permission for treatment of a minor, or they may have serious reservations about a treatment decision made by a parent or guardian. In such cases, they may seek clinical ethics consultation. Individuals participating in
ethics consultation must, therefore, be able to identify appropriate decision-makers for minors, and must be familiar with standards governing treatment decisions for minors.

**Learning Objectives**

Upon completing study of this topic, learners should be able to:

1. Define the concept of a minor.
   a. Invite your health care institution’s legal counsel and local clinicians who work with adolescents (physicians, physician assistants, nurse practitioners, nurses, psychologists, social workers, chaplains) to provide you with an in-service program on your state and federal laws defining the legal status of minors, the process of medical decision-making for minors, and the clinical applications of these laws.
   b. Read relevant sections from English and Kenney (2005), and discuss with colleagues
   c. Compare and contrast the legal definition of a minor and decision making related issues, with the ethical views of minors and decision making put forth in Kopelman and Moskop (1989). Sections II and III of the book are most relevant to this topic.

2. Explain the difference between decision-making models for adults and for minors.
   a. Invite an ethicist or other professional knowledgeable about important differences and similarities between models for decision making involving adults and minors to do an educational session on this topic.
   b. Read “Minors” (Buchanan, 1989) and discuss the challenges of applying this framework in different practice areas.
   c. Read one or more of the articles by Boyd (1998), Sartain (2000), or Forsner (2005) and describe five common features of children’s experience of illness and hospitalization.

3. Define the “best interest” standard and describe its foundations, limitations and application to minors.
   a. Read a classic description of the best interest standard (President’s Commission, 1982) and the article by Howard Brody (1988) and discuss with colleagues the meanings of best interest and challenges in applying this standard.
   b. Do a retrospective review of an ethics consult in which you or your colleagues were involved that raised questions about the notion of “best interest.”
   c. Interview a pediatric clinician (physician, physician assistant, nurse practitioner,) to discuss the role that the “best interest” standard plays in his or her practice.

4. Identify moral and legal standards for granting minors the authority to make health care decisions for themselves.
   a. Read and discuss with colleagues, “Informed consent, parental permission, and assent in pediatric practice” (AAP, 1995) and Ross (1997). Identify compelling arguments for and against granting minors decision making authority.
   b. Read “Children and Moral Agency” (Mahowald, 1993) and discuss the implications of children’s moral agency for pediatric practice.
c. Invite an expert in public health (perhaps someone from the public health department, school or local sexually transmitted infections or adolescent health or addictions clinic) to discuss the public health basis for minor’s legal authority under state and federal public health statutes to make certain types of health care decisions, including reproductive health, mental health, and addiction.

5. Identify the scope and limits of parental (guardians, foster parents, etc.) decision-making authority and responsibility for minors.
   a. Read “Persons with severe mental retardation and the limits of guardian decision making” (Veatch, 1986) and discuss with colleagues the scope and limitations of guardian decision making authority.
   b. Read “Informed consent, parental permission, and assent in pediatric practice” (AAP, 1995) and describe and critique the roles of professionals and parents. Invite parents of chronically ill children to comment on this framework.

6. Identify the scope and limits of health care professional authority and responsibility for patients who are minors.
   a. Invite clinicians from child protective services (either hospital or county-based services) to discuss the concept and application of medical neglect.
   b. Read and discuss with colleagues, “Family centered care” (AAP, 2003) and contrast with statements from parents (Anderson, 1995), and “Miracle Kid” (The New Yorker, 1999).

7. Describe significant cultural and religious beliefs and practices relating to the health care of minors, such as the status and role of children, family structure and decision-making authority, and children’s religious experience.
   a. Describe the values and assumptions routinely made in your institution regarding the nature and make-up of a “difficult” family.
   b. Write up an ethical analysis of a clinical case relating to minors and health care decision making that includes cultural/religious questions. Get feedback from colleagues about how to appreciate and value the cultural and religious beliefs of the family, and how to address potential conflicts with the beliefs and commitments of the involved health care professionals.
   c. Devote an ethics committee meeting or other gathering of interested persons to a discussion of three clinical cases that pose difficult moral questions about cultural and religious beliefs and minor’s health care. Read and discuss with colleagues an article that addresses these issues (May, 1995 and Sheldon, 1996).
   d. Invite a member of a cultural or religious group that holds beliefs that raise questions about health care for minors, such as a Jehovah’s Witness or a Christian Scientist, to address your committee or group to discuss their views.
   e. Read and discuss with individuals involved in ethics consultation or on the ethics committee at your institution, “Religious objections to medical care” (AAP, 1997). Discuss possible counterarguments to this important policy statement.
   f. View the video, "Man Alive: Choice for K'aila" (Canadian Broadcasting Corporation, 1992) and discuss with colleagues the role of the professionals and parents.
Resources


**Topic 2: Ethical Issues involving newborns and critically ill infants and children**

**Introduction**

Ethical issues commonly arise in the determination of the intensity of treatment for newborns and critically ill infants and children. Decisions include resuscitation in the delivery room, transfer of infants and children to the Intensive Care Unit, the level of care while in the ICU, and transfer from home to the hospital. Professionals and parents struggle to determine how much technology is appropriate based on a poor prognosis for life or quality of life, weighing what is to be gained with what the infant or child has to suffer to realize the gain. Historically, the dialogue about the treatment of newborns has been influenced by a focus on the role of disability in the determination of “best interests.” Until developments in surgery and pediatrics made it possible for infants with severe prematurity and other congenital anomalies to survive for longer periods with more severe problems, most of these infants died. Professionals had much discretion in determining what treatments to offer. Open public debate began with the landmark article in 1973 by neonatologists Duff and Campbell, discussing cases where treatment was withheld from certain newborns. Debate has evolved through the passage of so-called Baby Doe legislation aimed at preventing the non-treatment of newborns based on disability, and the incorporation of Baby Doe language into state child abuse statutes. Ethics consultations may be called to assist the team or the parents of critically ill infants and children in determining a range of morally acceptable choices about life-sustaining technologies.

**Learning Objectives**

Upon completing study of this topic, learners should be able to:

1. Describe the factors that guide or complicate decision-making in the delivery room.
   a. Meet with the medical directors of obstetrics and gynecology (or Labor &Delivery), neonatology (or pediatrics) to discuss institutional policy and practice regarding
resuscitation decisions for the delivery room and the factors that guide these decisions. Read the statement on, “The initiation and withdrawal of treatment for high risk newborns” (AAP, 1995) as background.

b. Review delivery room cases from the literature (Robertson, 2004) and cases from your own state or province and institution, and discuss the values implicit in decision-making. Contrast the Robertson article with Paris’ commentary (Paris, 2005). Also, review responses to the Robertson article (Wocial, 2005; Akeson, 2005; Silverman, 2005; Goldworth, 2005; Harrison, 2005; Cater, 2005; Miller, 2005) and his counter-responses (Robertson, 2005).

c. Describe the framework for decision making in the Neonatal Intensive Care Unit (NICU) and its justification. Read two classic articles (Walters, 1988) and Deciding to Forego Life-Sustaining Treatment, Chapter 6 (President’s Commission, 1983), about decision making for seriously ill newborns, and discuss the key factors that should be considered in decision making for this population. Ask clinicians in your nursery to present challenging cases to which you can apply this decision-making rubric. Include in your discussion the ways that this decision-making rubric highlights different features of the cases.

d. Read Walters’(1988) discussion on the dying of “Baby Andrew”and compare and contrast this account with “Miracle Kid” (New Yorker, 1999) and “Parent’s Perceptions” (Anderson and Hall, 1995) regarding the parents’ perceptions of the appropriateness of treatment and their child’s best interests. Invite parents to share their experiences with making difficult decisions for their critically ill infants.

3. Describe the Baby Doe regulations, their origins, impact, and limitations.

a. View the Video “Better Off Dead?” (Frontline, November 20, 1984) and discuss whether and how “Baby Doe” regulations have had an impact in your state. Invite your hospital legal council or another legal resource to join this discussion.

b. Invite NICU / PICU clinicians to read and discuss the “Ethics and the care of the critically ill infants and children” (AAP, 1996). Discuss the various roles of parents, clinicians, ethics committees and the courts in decision making for critically ill infants.

c. Read the articles by Kopleman, Irons, and Kopelman (1988) and Kopelman (2005), and discuss with colleagues the impact that the Baby Doe regulations have had on the care of critically ill infants.

d. Read and discuss with individuals involved in ethics consultation or on the ethics committee at your institution the overview article, “From the Johns Hopkins Baby to Baby Miller: what have we learned from four decades of reflection on neonatal cases?” (Paris, 2001).

4. Identify key issues associated with the concept of futility.

a. View the video “Better off Dead” (Frontline, 1984) and in your discussion with colleagues, compare and contrast the different views of the parents and clinicians involved.

b. Read the article, “From Baby Doe to Baby K: Evolving Challenges in Pediatric Ethics” (Glover and Rushton, 1995). Describe the emerging themes in decision making. Invite parents to share difficult experiences they have had in being advocates for their children.
c. Read “Ethics and the Provision of Futile, Harmful, or Burdensome Treatment to Children” (Nelson and Nelson, 1992), and discuss with colleagues the cases in the article. Apply the reasoning to cases provided by clinicians in your own institution. Identify possible counterarguments to the positions argued by the authors.

d. Contrast the views in the above article to the ones found in “The Rise and Fall of the Futility Movement” (Helft, Siegler and Lantos, 2000).

5. Identify key issues of forgoing the medical provision of hydration and nutrition

a. Read “Forgoing Medically Provided Nutrition and Hydration in Pediatric Patients” (Nelson, Rushton, Cranford, Nelson, Glover, Truog, 1995) and discuss with colleagues the various cases in the article.

b. Read “Withholding Nutrition from Seriously Ill Newborn Infants: A Parent’s Perspective” (Miraie, 1988), and invite parents to talk about difficult end-of-life decisions involving forgoing the medical provision of hydration and nutrition.

c. Invite a chaplain or other person familiar with faith traditions to review various faith traditions’ views on hydration and nutrition.

d. Read the case of Baby T (Paris, 1991), and discuss with colleagues the withdrawal of nutrition and fluids from this neurologically devastated infant.

6. Describe the framework for decision making in the Pediatric Intensive Care Unit (PICU) and its justification.

a. Read and discuss with individuals involved in ethics consultation or on the ethics committee at your institution a classic formulation of decision making in the PICU (Frader and Thompson, 1994).

Resources


**Topic 3. Ethical Issues Involving Chronically Ill Infants, Children, and Adolescents**

**Introduction**

Although many of the ethical issues faced by clinicians and caregivers involve treatment decisions when infants and children are critically ill and are hospitalized, many distinctive ethical issues also arise in the daily care of chronically ill infants, children and adolescents. Caregivers and clinicians face difficult issues of access to services and the accompanying ethical issues of distributive justice. Pediatric caregivers and families face issues of advance care planning and how the use of technologies for sustaining life similar to those faced by and for adult patients. Those doing clinical ethics consultation may be asked to assist in difficult decision-making involving when to write Do Not Resuscitate orders and/or do not hospitalize orders. Decisions about the medical provision of hydration and nutrition can be especially difficult in the home care or nursing home setting.

**Learning Objectives**

Upon completing study of this topic, learners should be able to:

1. Describe a framework for decision making in pediatric long term care/rehabilitation/ home care and its justification.
   a. Invite clinicians from a pediatric long term care facility or from a home care agency that serves pediatric patients to discuss with individuals involved in ethics consultation or on the ethics committee at your institution cases that raise ethical issues and how they approach decision making in such cases.
   b. Read and discuss with colleagues the articles by Lantos (1992) and Kohrman (1994) about ethical issues in the care of chronically ill children.
   c. Invite parents of chronically ill children to describe their views about the roles of parents and professionals in caring for them.

2. Describe a model for advance care planning in pediatrics.
a. Read and discuss with colleagues “Advance Care Planning for Children with Special Health Care Needs: A Survey of Parental Attitudes” (Wharton, Levine, Buka, Emanuel, 1996). Invite parents of chronically ill children to share their views on the issues surrounding advance care planning, including timing of discussions, relevancy of written documents, and communication across institutions, e.g. with EMS.
b. Invite pediatric clinicians who work with HIV patients or oncology patients to read and discuss “Preliminary Study of a Values-History Advance Directive Interview for a Pediatric HIV Clinic” (Wissow, Hutton, Kass, 2001) and the commentary by OJ Sahler (2001). In particular, discuss the barriers to having such discussions and strategies for overcoming these barriers.

3. Identify key issues of forgoing the medical provision of hydration and nutrition in pediatric long-term, rehab, and home care.
   a. See resources and strategies under hydration and nutrition above.
   b. Discuss with individuals involved in ethics consultation or on the ethics committee at your institution the particular issues of the providers in home care, rehab and long term care regarding forgoing hydration and nutrition.
   c. Invite a pediatric hospice clinician to explain the impact of the medical provision and withdrawal of hydration and nutrition on chronically ill children.

4. Identify key issues of Do Not Resuscitate orders in schools
   a. Read and discuss with individuals involved in ethics consultation or on the ethics committee at your institution, “Do Not Resuscitate Orders in Schools” (AAP, 2000). Pay particular attention to the different perspectives of school officials, pediatric clinicians and families.
   b. Invite a clinician from a local home care and/or hospice organization that service a pediatric population and a school official to discuss current policies.

5. Identify the key issues of the sterilization of minors with developmental disabilities.
   a. Read and discuss with individuals involved in ethics consultation or on the ethics committee at your institution, “Sterilization of Minors with Developmental Disabilities” (AAP, 1999).
   b. Invite a legal resource person to describe and discuss your state’s statute regarding sterilization and its clinical application.

6. Describe issues of justice and access to resources for the chronically ill.
   a. Read and discuss with individuals involved in ethics consultation or on the ethics committee at your institution, “Justice, Fair Procedures and the Goals of Medicine” (Daniels, 1996).
   b. Invite social workers and case managers and families who deal with getting services for chronically ill children to share their views of the challenges they face.

7. Identify the ethical challenges surrounding the use of complementary and alternative medicine.
   a. Read your institution’s policy and other relevant professional society position statements e.g., The American Medical Association, The American Academy of Pediatrics (AAP,
2001) on the use of complementary and alternative medicine and discuss the implications for clinical ethics consultation.

**Resources**


**Topic 4. Ethical Issues Involving Adolescents**

**Introduction**

Ethical issues involving adolescents are among the most difficult. Clinicians and family caregivers often struggle to balance obligations to provide care with respect for the developing
autonomy of adolescents. Adolescents are often not legally empowered to make health care decisions, except in certain limited circumstances, but they often have developed strong values and preferences regarding their treatment that clinicians must not simply ignore. The concepts of assent and of mature and emancipated minors have been developed to help sort out obligations to adolescent patients. Adolescents are not children, nor are they completely adults. They are maturing in many ways—physically, psychologically, sexually, socially, and spiritually. They often engage in risky behaviors, including sexual activity, smoking, and taking drugs, and suffering adverse consequences, without the experience and development to help them manage these behaviors and their consequences. Clinicians and caregivers struggle to protect adolescents, while at the same time being respectful of their developing capacities. Clinical ethics consultations often involve questions about the capacity of adolescents, what decisions they may make, and what to do in the event of conflict between adolescents and their families or clinicians.

Learning Objectives

Upon completing study of this topic, learners should be able to:

1. Describe the evolving framework for decision making with adolescents, and its justification.
   a. Read and discuss with individuals involved in ethics consultation or on the ethics committee at your institution, “Minors’ Rights in Health Care Decision Making” (Center for Practical Bioethics, 1995). Compare and contrast this account with “Informed Consent, Parental Permission and Assent” (AAP, 1995).

2. Distinguish between the concepts of a “mature minor” and an “emancipated minor.”
   a. Read relevant sections from State Minor Consent Laws: A Summary (English and Kenney, 2003) and discuss with colleagues.
   b. Invite an expert in public health (perhaps someone from the public health department, school or local sexually transmitted infection or adolescent health or addictions clinic) to discuss the public health basis for minors’ legal authority under state and federal public health statutes to make certain types of health care decisions.

3. Recognize the confidentiality and privacy rights of adolescents.
   a. Read and discuss with individuals involved in ethics consultation or on the ethics committee at your institution, “Confidential Health Services for Adolescents (AMA Council on Scientific Affairs, 1993).
   b. Read and discuss with colleagues, “Counseling the Adolescent about Pregnancy Options” (AAP, 1998). Invite a legal resource person to identify the legal requirements in your state.
   c. Read and discuss with colleagues, “Contraception and Adolescents” (AAP, 1999). Invite clinicians working with adolescents to share their views on local policies and procedures.

4. Describe an adolescent’s legal authority to make health care decisions regarding reproduction, mental health, substance abuse and sexually transmitted infections, and the moral rationale for that authority.
a. Invite an expert in public health (perhaps someone from the public health department, school or local sexually transmitted infection or adolescent health or addictions clinic) to discuss the public health basis for minor’s legal authority under state and federal public health statutes to make certain types of health care decisions.

b. Read relevant sections from *State Minor Consent Laws: A Summary* (English and Kenney, 2003) and discuss with colleagues.

c. Invite your health care institution’s legal counsel and local clinicians who work with adolescents (MDs, PA, NP, RN, psychologists, social workers, chaplains) to provide you with an in-service on your state’s and federal laws defining the status and process of medical decision-making for minors and the clinical applications of these laws.

5. Articulate a strategy for advance care planning with adolescents.

a. Read and discuss with individuals involved in ethics consultation or on the ethics committee at your institution, “Implications of the Patient Self-Determination Act: Guidelines for Involving Adolescents in Medical Decision Making” (McCabe, Rushton, Glover, Murray, Leiken, 1996). Invite clinicians who work with adolescents to discuss the suggestions in the article and current practice at your institution.

b. Read “Mature Minors and End-of-Life Decision Making: A New Development in Their Legal Right to Participation” (Badzek and Kanosky, 2002) and discuss with colleagues the role of adolescents in the advance care planning laws in your state.

c. Read “The Use of Advance Directive with Adolescents” (McAlliley, Hudson-Barr, Gunning, Rowbottom, 2000) and invite clinicians who work with adolescents, parents, and adolescents to discuss the barriers and strategies for involving adolescents in advance care planning.

**Resources**


Domain II: Process Skills in Performing Ethics Case Consultation

Introduction

Clinical ethics consultation can mean many different things to different people, ranging from an informal conversation with a colleague who wishes to “run a case by you” to a far more detailed and formal process. This section will focus on formal case consultations. These are distinguished by the fact that the clinical ethics consultation entails taking responsibility for gathering information and making recommendations or endorsing as ethically acceptable an agreed upon course of action. It is not simply accepting information as presented by a single party who frames the question to be answered as often happens in so-called “curbside consults.” (Participants in clinical ethics consultation should be aware of the hazards that can come from such informal consultation.) Ethics consultation requires taking responsibility for reconstructing the case and interpreting information. This interpretive process often requires critically considering the information provided. It may require redefining or recasting the problem originally presented. In order for the process to culminate in recommendations, certain cognitive activities will be performed, including analyzing the information and responding to the problem. Sometimes these steps are explicit and discrete, other times they are implicit in the work of the clinical ethics consultation.

Formal consultation can occur in a variety of formats. Regardless of the format, we believe that ethics case consultation requires certain information gathering, analytic, facilitation, and communication skills. Not all skills are used in all consultations or equally employed in all formats. Nevertheless, any particular consultation might require these skills and a person who regularly participates in consultations should develop them.

Individuals participating in clinical ethics consultation need to be aware of any personal and professional biases that may influence their work in ethics consultation. One must develop skills in identifying and managing personal and professional biases. For example, an individual’s religious beliefs or cultural norms can affect his or her evaluation of options. An individual’s professional background may affect how patient advocacy or risk management considerations manifest in the consultation. (Domains IA and III provide strategies for identifying and managing personal and professional biases.) Although participants in clinical ethics consultation come from a variety of constituencies, the proper role of ethics consultation is to advocate for an unbiased robust process and not to privilege the needs and agenda of any one party.

Other sections of this Learner’s Guide address core knowledge for clinical ethics consultation. For the present purposes, we assume that anyone performing ethics case consultations will have developed the requisite knowledge of content required by the kinds of cases they encounter. This section focuses on the skills necessary to guide the process of consultation in whatever format that might take or whatever issues it may involve.

All the skills discussed in this section should enable those doing clinical ethics consultation to perform tasks commonly associated with ethics consultation. These tasks may occur in a variety of orders, and not all consultations may involve all elements. They include:

- Effectively navigating in the clinical setting in order to accomplish the tasks demanded by ethics consultation.
- Gathering information (a multi-part task utilizing the medical records and appropriate interviews) and assessing the appropriateness of the case for ethics consultation, i.e.,
determining if the case falls within the scope of the ethics consultation service (and referring the case to an appropriate resource if deemed outside the scope of ethics consultation.)

- Evaluating, interpreting, and analyzing the information.
- Fostering communication among the parties to the consultation or facilitating a meeting of the principals and understanding of each perspective; assessing options for moral acceptability; and assisting the parties to identify and think through ethically acceptable options.
- Promoting implementation of an ethically acceptable plan of action by identifying responsibilities, documenting agreements and points of consensus the principals achieve in the meeting and/or documenting recommendations or ethically acceptable options.
- Soliciting feedback and implementing quality assurance measures.

In what follows, we will outline a variety of skills needed for each part of this approach to consultation. We have made an effort to focus on skills and skill-building materials applicable to a broad range of formats and models for conducting ethics case consultation.

The skills that follow parallel the process skills outlined in the Core Competencies document (pp. 13-16). That is, the process skills in question concern developing techniques and judgment that foster appropriate information gathering, facilitating the exchange of information among potentially conflicting parties, sorting through the ethically acceptable options available, and defining an appropriate plan of action. This section builds upon that report by focusing on the skills and techniques needed to achieve the outcomes it highlighted.

We will emphasize two general models for developing, refining, and practicing skills for conducting case consultations:

1. An apprentice model – One observes consultations as they are conducted by a skilled consultant and/or conducts consultations under the supervision of a mentor. The mentor and trainee engage in debriefing and feedback of shared consultation activities aimed at promoting the correct actions and sound understanding of the reasons for particular actions.

2. Simulation model – One practices role plays or case simulations and receives structured feedback in an effort to sharpen communication, facilitation, and mediation skills.

The tasks associated with effectively leading an ethics case consultation require a number of general skills. These tasks need to be practiced directly in order to gain proficiency. Thus, those who will perform ethics case consultation will need three things to gain or sharpen their competence:

1. Opportunities to practice the tasks and skills
2. A method of evaluating performance
3. Feedback on performance

Topic Area Outline
I. Orientation to the clinical setting
   A. Roles, scope of practice, routine of care
   B. Medical terminology
   C. Info recording & communication

II. Information gathering and assessment
   A. Identification of relevant parties to the ethics consultation.
   B. Data gathering
   C. Eliciting perspectives
   D. Identification of the ethical issue or conflict; Referral skills to related professionals

III. Evaluating, interpreting & analyzing information
   A. Narrative reconstruction
   B. Issue clarification; option identification & analysis

IV. Facilitating communication and identifying ethically acceptable resolutions
   A. Meeting skills, e.g., inclusion & introduction of relevant parties, role and goal explanation, etc.
   B. Interpersonal skills, e.g., eliciting information, views, and values; clarification of concepts
   C. Identification of relevant ethical norms and standards
   D. Negotiation and summary skills

V. Implementation
   A. Summarizing findings and recommendations
   B. Identification of responsibilities
   C. Debriefing
   D. Record keeping

VI. Feedback & quality assurance
   A. Seeking feedback
   B. Peer review mechanisms

**Topic 1: Orientation to Clinical Setting**

**Introduction**

All who do clinical ethics consultation will need to be able to navigate within the clinical environment, across different specialties. This will require understanding of the roles and scope of practice of various kinds of caregivers, trainees, and students, learning about the routines of clinical care (e.g., various types of “rounds” performed by services), and the ways in which information is recorded and communicated among health care professionals.

**Learning Objectives & Strategies**

Upon completing study of this topic, learners should be able to:

1. Identify the roles, scope of practice, routines of care of various kinds of clinicians, trainees, and students.
a. Arrange to shadow three different types of clinicians for a work day
b. Attend several different multidisciplinary team meetings and rounds in a variety of clinical areas and identify the different contributions that different professionals make (including who dominates, who is marginalized, what information is emphasized or de-emphasized).
c. Arrange to observe the activities at three different nursing stations and identify clinician interaction patterns
d. Read and discuss articles by Storch (1999) and Emanuel and Emanuel (1992). Compare and contrast the moral relationships between physicians and nurses.

2. Explain basic medical terminology used, common diseases seen, and standard treatments offered at your institution.
   a. With a group of colleagues involved in ethics consultation, develop a list of common medical terms and abbreviations commonly arising in case consultations. Define and discuss these terms and abbreviations.
   b. Create and maintain a glossary for use in ethics consultation practice.
   c. Identify resources available for clarification of medical terminology and abbreviations at your institution. Some of these resources are available on the web free of charge. For instance, see:
      - The CancerWEB Project (University of New Castle). Available at: http://cancerweb.ncl.ac.uk/omd/
   d. Review patient education material regarding common diseases and treatments for major clinical areas at your institution.

3. Describe how information is recorded and communicated among HCPs.
   a. Arrange to do several mentored chart reviews in different clinical settings and identify where and how different professionals record their observations.
   b. Review a chart with an ethics consult note from a previous consultation and identify how consultations are recorded in charts at your institution.
   c. Arrange to observe three shift change reports in different clinical areas and identify how information is communicated from one shift member to the next shift member.
   d. Attend multidisciplinary rounds and observe inter-professional communication (as suggested above); including nurse-physician.

General strategies for achieving each of the specific objectives above include the following:
   a. Arrange opportunities for clinical observation and guided reflection with a clinical preceptor.
   b. Clinical Practica or clinical rotations – These courses are increasingly offered by Master of Arts Programs in bioethics and combine clinical observation with precepting by clinicians. Some focus on familiarity with the clinical setting in general. See, for instance:
      - http://www.pitt.edu/~bioethic/progoffMA.htm#Top
      - http://www.cwru.edu/med/bioethics/masrequirements.htm
   Other practica focus directly on supervised consultation skills. See, for instance:
Topic 2: Information Gathering and Assessment

Introduction

Ethics case consultation requires accomplishing certain tasks in an initial stage prior to conducting a case conference. This initial information-gathering stage should be an active and dynamic process in which the individual performing the consultation interprets, assesses and analyzes the accumulating information and identifies the need for additional information.

For instance, a physician might state that he or she is requesting an clinical ethics consultation because a family is conflicted in its treatment goals for a patient. The person conducting the consultation must gather a variety of information beginning with the decision-making capacity of the patient. This information will guide whether the question to be answered remains the same as the physician stated it or whether the next step is the determination of the appropriate surrogate decision maker. Interviewing the appropriate surrogate and other parties to the case will determine if further conversation and/or mediation is needed or whether the problem has resolved as review of the perspectives of parties to the case either helped them to come to agreement or uncovered a pre-existing consensus among them. At each step, analysis of the information being gathered points to the next step in the information gathering process. This analysis implicitly involves knowledge of such matters as informed consent, decision-making capacity, identification of surrogate decision makers, and the role of interpersonal family dynamics in surrogate decision making. However, as these analyses are implicit within the information gathering, the case may have initially appeared to be more straightforward than it actually was. Nevertheless, such analyses are provisional and open to reinterpretation as the case progresses.

In order to perform ethics case consultations, persons conducting the consultation must be able to gather the primary data regarding the reason for the ethics case consultation, identify relevant issues surrounding the consultation, and reconstruct the perspectives of the principals to the case.

Learning Objectives & Strategies

Upon completing study of this topic, learners should be able to:
1. Identify the relevant parties who may provide information about the medical, psychosocial, and ethical issues surrounding the ethics consultation.
   a. Procure and review the policies of your institution related to informed consent and surrogate decision making and use these to identify who has the primary decision-making authority in the case.
   b. Review the portions of this Learner’s Guide related to informed consent, surrogate decision making, and decision-making capacity.
c. Review three previous ethics consultations at your hospital with the persons who conducted the consultations. Ask from whom they gathered the main information about the case and how they identified the interested parties.

d. Gather several persons who conduct ethics case consultation, perhaps in the context of your institution’s ethics committee, and read two or three cases from an ethics casebook (Kuczewski and Pinkus, 1999). Ask the persons who conduct consultations who they might first contact in their information-gathering process.

e. Construct a prima facie approach you can use for information gathering, e.g., begin with the patient and potential surrogate decision makers, explore perspective of attending physician, follow cues provided regarding other parties to the cases, e.g., significant personal relationships of the patient, perspectives of other health care professionals involved in the patient's care, etc.

2. Gather data from a medical chart including medical and social information, and perspectives of varying consultants and health-care providers (HCPs):

   - Medical - This includes the patient’s diagnoses, prognosis, symptoms, and types duration and effects of treatments.
   - Nursing – This includes caregiving needs, such as feeding, toileting, wound care, tracheostomy care, level of functioning and participation in care, etc.
   - Social – Family structure/dynamic, financial concerns, documented treatment and decision making preferences, etc.
   - Spiritual/pastoral care – Patient's belief system, understanding of ultimate concerns, e.g., illness, death, etc.

   a. Read a medical chart of a patient who has been hospitalized for at least three days. Be sure to examine the admitting note, advance directives section, and progress notes. Summarize the medical information, the nursing information, and the social information. Review your summary with a physician, a nurse, chaplain, and a social worker each of whom is involved in the patient’s care. Ask them if you have accurately summarized the information. If you omitted or misinterpreted significant information, re-examine the chart and note where this information is recorded.

   b. Arrange to observe a person experienced in providing ethics consultation as she reviews and summarizes a patient’s medical record. Note how she approaches the chart and to what sections she pays special attention. Pay particular attention to how she checks her understanding with particular parties to the consultation.

3. Elicit the perspectives of health care professionals and of patients, surrogates, their families, or persons in significant personal relationships with the patient. These discussions are meant to help the parties to the consultation to see alternative constructions of the situation and points of view, to identify conflict of values and interpretation, and to build trust. As a result, the skills needed to elicit the perspectives of the parties will include being able to:

   - ask open-ended and specific questions to elicit the information relevant to the issues or questions involved in the case
   - engage people who are reluctant to talk to you
   - elicit facts and opinions without being judgmental; typical facts important to these discussions include patient’s diagnoses, length of illness, religious &
cultural background & affiliation, family structure, social structure, education, employment, significant family illnesses, and other facts made salient by the perspective of the patient, family or health-care provider

• respond appropriately to emotions expressed by interviewees
• discern patient values from charts, HCPs, and interviews
• help individuals clarify their values, intentions, and narratives
• help individuals articulate their unasked questions and concerns and to express their assumptions and beliefs about the case
• help compromised individuals to freely express themselves.

• a. Asking appropriate questions for a clinical ethics consultation can be fostered by using any of several checklists or guides to gathering pertinent information for an ethics consultation. Guides are available in J. C. Fletcher, R. Boyle, Introduction to Clinical Ethics, (2nd ed) pp. 23-24, and A. R. Jonsen, M. Siegler, W. Winslade, Clinical Ethics, (5th edition); or at the Department of Veteran’s Affairs National Center for Ethics website: www.va.gov/integratedethics/download/Ethics_Consultation_Primer.pdf.

b. Interviewing skills can be developed through an apprenticeship with an established ethics consultant in which the apprentice observes interviews and conducts them under close supervision of the mentor.

c. One can develop appropriate attitudes and an understanding of interviewing objectives by reading books that outline an open-ended constructivist approach to gathering information from the perspectives of the various parties as well as understanding the emotional component of such conversations (Douglas F. Stone, Sheila Heen, Bruce Patton, 2000).

4. Identify the ethical question, issue, or locus of conflict that prompted the request for consultation and determine whether a case falls within your scope of practice. If not, you should be able to refer the case to appropriate other resources such as risk management, quality assurance, social work, pastoral care, palliative care, or other related disciplines.

a. Review three previous clinical ethics consultations at your hospital with the persons who conducted the consultations. Identify the ethical issue in terms of at least one of the sections of this Learner’s Guide.

b. Interview three persons experienced in ethics case consultation. Ask them to recall a case that they referred to other appropriate resource persons, to explain their thought process in making that discernment, And to recount the conversation that took place in making the referral.

c. If your facility does not yet have a mechanism for ethics consultation but is considering developing one, ask proponents of the mechanism what kinds of cases they think ethics consultation might address. Try to identify topics in this Learner’s Guide under which they fall. If you cannot find such topics, talk with persons from risk management, social work, patient relations, pastoral care, and other areas to determine whose expertise might best address such cases.
Topic 3: Evaluate, Interpret & Analyze Information

Introduction

When a request is made for clinical ethics consultation, the person making the request usually describes the case and suggests what the ethical issues or questions are. Sometimes this person even suggests what he or she believes to be the correct solution to the problems as he or she perceives them. Of course, this account is the perspective of one party to the consultation and is likely to be incomplete. As a result, it is necessary for the person conducting the consultation to begin an information gathering process as described in the previous section.

The result of the information gathering process is likely to be that several different perspectives emerge. Each of the involved parties may frame the issues and questions differently. A good consultative process is likely to lead to each party gaining a fuller appreciation of the perspectives of the others and may result in a course of action that addresses areas of overlapping concern among the parties.

As the person conducting the case consultation gathers information, it is important that he or she identify each of the emerging perspectives and analyze the options to address the issues that have emerged. This process enables the person conducting the consultation to think creatively about options he or she might raise or recommendations that he or she might make that could potentially produce consensus on a course of action. And, it also is an opportunity to determine if any of the courses of action being suggested by the parties are not ethically acceptable. This kind of interpretive and analytic exercise is an important part of preparing to conduct a case conference or to make recommendations.

Learning Objectives & Strategies

Upon completing study of this topic, learners should be able to:

1. Identify or reconstruct competing accounts of the case using information from the different participants and identify salient variations among the accounts and perspectives.
   a. Shadow an experienced ethics consultant during a case. Review the case in progress explaining the perspective of each party to the case. Tell the story of the case from each perspective. Note how underlying concerns shift among perspectives. Compare your understanding with that of the experienced consultant. Determine ways you can check your understanding regarding the perspectives of persons that remain unclear.
   b. Review three cases in ethics casebooks that explicitly highlight the different perspectives of the different parties to the case (Mark G. Kuczewski & Rosa Lynn Pinkus, An Ethics Casebook for Hospitals, Practical Approaches to Everyday Cases, Georgetown University Press, 1999.) Note and discuss with experienced ethics consultants and ethics committee members the differences in perspectives among the parties, or gaps in the understanding of any of the perspectives. Identify ways that a person conducting a consultation could check his or her understanding regarding the perspectives of persons that remain unclear.

d. View two movies that highlight the difference between the patient’s perspective of illness and the physician’s understanding of disease, e.g., Wit (2001), The Doctor (1991). Analyze these movies with experienced ethics consultants and ethics committee members and identify ways to bridge these gaps among perspectives.

2. Clarify the issues in the case identifying a broad preliminary range of ethically acceptable options.
   a. Shadow an experienced ethics consultant during a case. Review the case in progress, explaining the perspective of each party to the case and noting the wishes and needs of each party as you understand them. Identify at least three possible ethically acceptable courses of action that might address the wishes of the parties. Compare your understanding with that of the experienced consultant.
   b. Review three cases in ethics casebooks that explicitly provide outcomes to the cases and possible alternative endings (e.g., Mark G. Kuczewski & Rosa Lynn Pinkus, An Ethics Casebook for Hospitals, Practical Approaches to Everyday Cases, Georgetown University Press, 1999). After reading each case, identify at least two possible ethically acceptable courses of action. Compare your suggestions to those provided by the book.
   c. Follow the procedures in the two learning strategies above. But, add at least one ethically unacceptable option that you could imagine one of the parties to the consultation requesting. Write down what you would say to this suggestion. Show your written statement to an experienced ethics consultant and ask him or her to critique it for the accuracy of your ethical reasoning and for the sensitivity it would express to the person making the suggestion.

**Topic 4: Facilitate Communication and Identify Ethically Acceptable Resolutions**

**Introduction**

In some cases, the initial fact gathering activities involved in case consultation will foster communication among the parties to the consultation or clarify the facts for them. As a result, the initial activity may lead directly to resolution or may make the recommendations clear and ready to be entered in the medical record. In other cases, a case conference may be in order. In some situations, the person taking the lead in the clinical ethics consultation facilitates the meeting and either directly carries out or cues the participants in the following steps. In other situations, the person who conducts the consultation attends a care conference run by the attending physician or another member of the health-care team. In this latter instance, the person taking the lead in the
ethics consultation should monitor the conference and prompt for any of the following tasks should they be omitted, for this to qualify as a formal clinical ethics consultation.²

The tasks associated with running or effectively participating in a case conference require a number of general skills including active listening, reflective listening, re-interpretation of points of view or positions, and ability to summarize narratives and points of view. However, the specific tasks are likely to need to be directly practiced in order to gain proficiency.

**Learning Objectives**

Upon completing study of this topic, learners should be able to:

1. Introduce oneself properly, explaining what an ethics consultation is and what a person taking the lead in the consultation does, the purpose and limits of the consultation, the authority (or lack thereof) of the person conducting the consultation and his or her recommendations, and the relationship between the ethics consultation mechanism and the health-care facility. (See Domain III)
2. Ensure that all relevant parties have been invited and encouraged to participate.
3. Ensure all parties are introduced and explain their respective roles.
4. Explain the goals and process of the meeting and what the parties to the consultation can expect from the process. Seek affirmation from the parties to the consultation to pursue these goals or modify them in response to feedback.
5. Elicit the medical facts from the health care professionals and facilitate clarification of the medical facts for the patient and family.
6. Elicit the views and values of the principals regarding the issues in question in the case ensuring that all participants have the opportunity to express their opinion. Prompt creative thinking in regard to ethically acceptable options.
7. Facilitate understanding of each perspective through techniques such as reflective listening, asking clarifying questions, and summarizing viewpoints.

**Learning Strategies for Objectives 1-7**

a. Role play an ethics case conference and solicit feedback on your effort in conducting the consultation. Evaluating an clinical ethics consultation can be a matter of asking a series of simple or simple questions about specific aspects of the performance of the ethics consultant. Such questions can be guided with a sample template such as [http://bioethics.lumc.edu/onlinema/Ethicsconsult_template.htm](http://bioethics.lumc.edu/onlinema/Ethicsconsult_template.htm)

² It should be noted that these differences in procedure may be determined by the needs of the case but may also issue from the particular model being used by the person taking the lead in conducting the ethics consultation. That is, some models emphasize making recommendations, others facilitating communication through a case conference. Clearly the model employed will sometimes determines which steps are deemed appropriate at which stage.
b. Videotape a simulated ethics consultation and self-assess one’s performance based on a template of questions as described above.

c. Keep track of feedback on your responses to challenges posed by other parties to the mock consultation (in a & b above) and note things you did that worked well and those that didn't. Vary the ways persons play the roles in the cases and how you respond to each kind of role and personality.

d. Conduct an ethics case conference under the supervision of an experienced consultant and receive feedback on the specific tasks of the case conference.

e. Asking appropriate questions for an ethics consultation can be fostered by using any of several checklists or guides to gathering pertinent information for an clinical ethics consultation. Lists are available in: J. C. Fletcher, R. Boyle, *Introduction to Clinical Ethics*, (2nd ed) pp. 23-24, and A. R. Jonsen, M. Siegler, W. Winslade, *Clinical Ethics*, 5th edition.)

**Learning Objectives (continued)**

Upon completing study of this topic, learners should be able to:

8. Interpret relevant institutional policies, professional standards or other ethical constraints regarding possible options.

9. Highlight the ethical considerations in a case and facilitate discussion of them.

10. Identify, analyze and set aside ethically unsupportable options. Make recommendations concerning ethically acceptable options. (In some models of case consultation, the consultation ends with options defined and recommendations issued. In other models, the person conducting the consultation continues as follows to facilitate consensus and a plan of action among the parties.).

**Learning Strategies for Objectives 8 – 10**

a. Shadow an experienced ethics consultant during a case. Identify and review relevant institutional policies and professional society codes of ethics after the case. Compare the resolution to the case to the frameworks provided in the policies and codes.

b. Shadow an experienced ethics consultant during a case. Identify and review relevant topics in this Learner’s Guide after the case, e.g., if the case involves issues of decision-making capacity, review that section of the guide. Compare the resolution to the case to the frameworks provided by relevant portions of the guide.

c. Practice explaining the relevant institutional policies, professional society codes of ethics, and relevant portions of this Learner’s Guide in layperson’s terms. Receive feedback from a variety of types of persons such as ethics committee members.

d. Review three cases in ethics casebooks that explicitly provide outcomes to the cases and possible alternative endings (e.g., Mark G. Kuczewski & Rosa Lynn Pinkus, *An Ethics Casebook for Hospitals, Practical Approaches to Everyday Cases*, Georgetown University Press, 1999). After reading each case, identify at least two possible ethically acceptable courses of action. Compare your suggestions to those provided by the book.
e. Follow the procedures in the learning strategies above. But, add at least one ethically
unacceptable option that you could imagine one of the parties to the consultation
requesting. Write down what you would say to this suggestion. Show your written
statement to an experienced ethics consultant and ask her to critique it for the accuracy of
your ethical reasoning and for the sensitivity it would express to the person making the
suggestion.

**Learning Objectives (continued)**

Upon completing study of this topic, learners should be able to:

11. Identify areas of agreement & disagreement.
12. Negotiate areas of disagreement as possible and identify ethically appropriate or ethically
acceptable options, noting resolutions as developed and explaining the available courses of
action when agreement is not possible.
13. Summarize the results of the conference and review with the parties the agreed upon plan of
action and who will implement each part of the plan.

**Learning Strategies for Objectives 11 – 13**

a. Negotiation skills can be developed through an apprenticeship with an established ethics
consultant in which the apprentice observes negotiations and conducts them under close
supervision of the mentor.
b. Acquire mediation skills by pursuing formal mediation training courses such as those
offered by:
   i. The Harvard Law School Program on Negotiation. Available at:
   ii. The Division of Bioethics at Montefiore Medical Center. Available at:
mediation techniques in a role play from the book (pp. 139-185) Evaluate the
effectiveness of these techniques.

**Topic 5: Implementation**

**Introduction**

Persons conducting ethics case consultation are facilitators and advisors. When they are
facilitating the ethics consultation, they should have no formal patient care responsibilities in the
case. As a result, their main responsibilities in bringing closure to a case involve summarizing
results and recommendations, clarifying the responsibilities of the parties to the consultation, and
creating appropriate documentation—not implementing the resolution per se. Furthermore,
persons who do clinical ethics consultations should develop and participate in mechanisms that
allow for feedback from others who participated in the consultation to promote quality assurance and improvement and establish a mechanism for accountability.

While the role of persons who conduct consultations is strictly advisory and facilitative, the consultant’s responsibilities during the implementation phase are very important. Properly summarizing and documenting the results of the consultative process is likely to exercise an influence on the parties to the consultation and to promote adherence to any agreements achieved. In addition, as clinical ethics consultation and patient care are both processes, it is possible that additional aid will be needed from those conducting the consultation in the immediate or near future as circumstances evolve. Follow-up procedures and skillful documentation are very helpful should the need for further clinical ethics consultation services arise.

**Learning Objectives & Strategies**

Upon completing study of this topic, learners should be able to:

1. Summarize findings, conference results, and recommendations in the medical record and/or in the institutionally sanctioned medium for recording the consultation.
2. Clearly identify responsibilities of each party to implement the conclusions reached.

**Learning Strategies for Objectives 1 & 2**

a. Arrange to observe a skilled consultant during the implementation phase of the consultation, paying particular attention to the processes of writing notes and recommendations in the medical record.

b. Review three cases in the records of an ethics case consultation mechanism or service. Locate and analyze the clinical ethics consultation note.

c. Role play a case consultation or read about one in a casebook. Write the entry you would make in the medical record. Seek feedback from experienced ethics consultants.

**Learning Objectives & Strategies, continued**

3. Arrange to observe the implementation process (i.e., see what happened) and debrief parties to the consultation as needed or appropriate. Indicate availability for further consultation or involvement as needed.

a. Observe an experienced ethics consultant during the implementation phase of the consultation, paying particular attention to follow-up and debriefing conversations.

b. Role play an ethics case consultation. Include a part in which debriefing conversations several days after the consultation are played.

4. Keep consultation records for analysis by appropriate peer reviewers and colleagues to promote quality improvement.
a. Arrange to observe an experienced ethics consultant during the implementation phase of the consultation, paying particular attention to the processes of completing the consultation records. Ask the health-care providers involved in the case how helpful the chart note was and whether further information should have been included.
b. Review the records of three ethics case consultations. Analyze the records and ask an experienced ethics consultant to review the parts of the record including the chart note, and to explain their importance
c. Role play a case consultation or read about one in a casebook. Write the entry you would make for the consultation records. Seek feedback from experienced ethics consultants.

**Topic 6: Feedback & Quality Assurance**

**Introduction**

It is important that persons conducting clinical ethics consultation develop structures for peer-, self-, and client criticism. That is, feedback should be elicited on a regular basis from the interested parties who were involved in the consultation. The person taking the lead in the consultation should also create records that allow for ongoing and long-term evaluation of the performances of those conducting ethics case consultation.

**Learning Objectives & Strategies**

Upon completing study of this topic, learners should be able to:

1. Seek feedback from the parties to the case following resolution of the case.
   a. Develop short "customer satisfaction" survey for ethics case consultation. Consult with quality assurance experts at your facility for strategies on how to utilize the instruments.
   b. Arrange to attend relevant clinical meetings, e.g., mortality & morbidity conferences, nursing conferences, where a case on which you consulted is discussed.
2. Participate in appropriate peer review mechanisms of your consultations, provide justifications, and consider criticism.
   a. Attend an ethics committee meeting where a case consultation is reviewed.
   b. Shadow an experienced ethics consultant and attend an ethics committee meeting where one of the case consultations you observed is reviewed.
   c. Perform an ethics case consultation under the supervision of an experienced ethics consultant. Present your case consultation at an ethics committee meeting.
   d. Videotape a simulated ethics consultation and show the tape at an ethics committee meeting for feedback.

**Resources**


Domain III: Responsibilities of Those Engaging in Ethics Consultation

Introduction

Clinical ethics consultation raises a number of crucial considerations regarding responsibility, e.g., to whom is one responsible, for what is one responsible, or what is the extent of such responsibility? The issue of responsibility in the context of clinical ethics consultation requires clarity regarding the role of the individual participating in ethics consultation (as distinct from other roles) and the power differentials within the particular institutional setting. Attention to power and responsibility in ethics consultation will lead to the creation of accountable, transparent practices.

Topic Area Outline

I. Scope and limitation of the role
   A. Scope of authority in primary institutional role vs. ethics consultation
   B. Misperceptions and misuses of the role of ethics consultation
   C. Explaining the role of ethics consultation within your institution to others
   D. Appearance, comportment, interpersonal skills and the ethics consultant
   E. Power and the ethics consultation

II. Conflicting interests and commitments
   A. Underlying values and commitments and interests
   B. Competing obligations

III. Challenges of the role: the experience of providing ethics consultation
   A. Boundaries and moral weight of ethics consultation
   B. Distinctions between moral uncertainty, moral dilemmas, moral distress and moral residue
   C. Experience of marginalization

IV. Responding to “unethical” practice
   A. Integrity and unethical situations
   B. Disclosure and transparency in ethics consultation

V. Evaluation and accountability of the ethics consultation service
   A. Accountability in the ethics consultation process
   B. Strengths and weaknesses of various evaluation strategies
   C. Errors in the ethics consultation process

Topic 1: Scope and Limitation of the Role

Introduction
Most people who participate in clinical ethics consultation have other roles within their health care institutions. Accordingly, and as previously addressed (Topic 4, Domain 1A), it is important that those performing ethics consultation distinguish that role from those other institutional responsibilities. This demands recognizing the boundaries and limits of the ethics consultation role. Perhaps more importantly, those fulfilling ethics consultation roles must be sensitive to the ways in which it not only may be understood by others within the institution (including patients and families, physicians and nurses, administrators, etc.), but may in fact wield an authority not similarly wielded in one’s other institutional roles. As a result, attention may be required to ensure that, when in the role of performing clinical ethics consultation, one knows how to avoid abuses of that power.

In this section, learners will consider the role of clinical ethics consultation in their institution. Learners will explore the institutional authority associated with this role and why it must be distinguished from the authority associated with individuals’ primary institutional roles (administrator, chaplain, nurse, physician, etc.). This section examines some common misunderstandings about, and possible misuses of, the role of ethics consultation, consideration of the power associated with ethics consultation—and potential (even if unintended) abuses of such power. In addition, learners will review ways in which appearance, comportment, and interpersonal skills influence both the reception and effectiveness of ethics consultation. In light of all of these issues, learners will also develop a clear and concise description of the role that may be used when telling others (including patients and families) what this role entails.

Learning Objectives and Strategies

Upon completing study of this topic, learners should be able to:

1. Differentiate between the scope of authority of one’s primary institutional role (e.g., administrator, chaplain, lawyer, nurse, physician, social worker) and that of clinical ethics consultation.
   a. Write a brief description of your primary role in the institution, specifically the tools, practices, authority and character associated with that role. Read the policy/guidelines/protocol which governs the role of clinical ethics consultation within your institution (if there is none, develop one). Compare and contrast your primary role to that of ethics consultation.
   b. If possible, discuss with a professional colleague the similarities and differences between your clinical ethics consultation roles other roles you have in the institution. Identify how these roles might get confused or be experienced as in conflict. Strategize ways to remain clear in your role as ethics consultant, and avoid role confusion (e.g. keeping a reflective journal of consults; debriefing; etc.).

2. Identify misperceptions regarding, and possible misuses of, the role of clinical ethics consultation in general.
   a. Read, “Bioethics as Secular Priesthood” (MacDonald, 2003), “Character and Ethics Consultation” (ASBH, 1998), and “Character and Ethics Consultation: Even Ethicists
Don’t Agree” (Baylis et al., 2003), and discuss with colleagues the arguments for and against the notion that individuals participating in ethics consultations must be held to a higher standard in terms of their character, comportment and practices, by virtue of their role.

b. In a discussion with professional colleagues, identify common presumptions (accurate or otherwise) regarding the role of ethics consultation, such as being the “moral police” or serving as a “moral exemplar” or responsible for “fixing the institution.”

c. Discuss with others who provide ethics consultation several different kinds of requests for help or support that would be inappropriate for ethics consultation (i.e. human resources issues; clinical practice or patient safety issues) and how you might find other ways to ensure these issues are addressed.

3. Describe and explain the role of ethics consultation within your institution to both institutional insiders and individuals from outside the institution—for instance, patients and families.

a. Review the communication tools (e.g., brochure, poster, web site) that your institution uses to publicize the ethics consultation service (if there are none, develop some).

b. Ask a range individuals (patients, family members, nurses, physicians, social workers, pastoral care ministers, directors of clinical services, administrators, community/civic leaders, etc.) to write a brief description of their understanding of the role and activities of ethics consultation.

c. Review all the summary statements and assess how others perceive the role and activities of ethics consultation, noting any misperceptions or discrepancies.

d. Write down how you would verbally explain the role of an individual who participates in ethics consultation to (1) clinical staff and (2) patients and families. Practice explaining the role of ethics consultation.

e. Devise a feedback mechanism (educational program, individual meetings) by which misperceptions, confusions, and lack of understanding may be systematically addressed in the future.

4. Understand how your appearance, comportment and interpersonal skills influence your reception and your effectiveness as an ethics consultant (e.g., gender, ethnicity, formality of dress, white coat)

a. Read your institution’s policy on professional comportment and discuss its implications for clinical ethics consultation.

b. Discuss with colleagues the implications of wearing a white coat, scrubs, stethoscope, and other readily identified professional attire while performing clinical ethics consultation.

c. Identify an ethics consultation that you think may have been influenced by the appearance, gender, ethnicity, etc. of those conducting the ethics consultation and discuss these influences and how they might be appropriately managed.

5. Understand and appreciate the power—and its possible abuse—associated with the role of clinical ethics consultation.

a. Read several foundational articles on the power dimensions of ethics consultation, “Authority in Ethics Consultation” (Agich, 1995) “Reflections of a Reluctant Clinical

b. Discuss with others who provide ethics consultation, or other colleagues, the different reasons why the judgments and actions of those involved in clinical ethics consultation may be misunderstood and misinterpreted by other health care providers, patients, and families, and how such misunderstanding and misinterpretation can lead to (even if unintentional) abuse of power by those involved in clinical ethics consultation.

c. Discuss with others who provide clinical ethics consultation or other colleagues how the potential for abusing institutional power (whether intentional or not) might be limited. Consider both the behavior of individuals involved in ethics consultation and protocols/pathways promoted by your institution.

Resources


**Topic 2: Conflicting interests and commitments**

**Introduction**

Most people who participate in clinical ethics consultation have other roles within their health care institutions. Accordingly, and as previously addressed (Topic 4, Domain 1A), it is important that those performing ethics consultation distinguish that role from those other institutional responsibilities. This demands recognizing the boundaries and limits of the ethics consultation role. Perhaps more importantly, those fulfilling ethics consultation roles must be
sensitive to the ways in which it not only may be understood by others within the institution (including patients and families, physicians and nurses, administrators, etc.), but may in fact wield an authority not similarly wielded in one’s other institutional roles. As a result, attention may be required to ensure that, when in the role of performing clinical ethics consultation, one knows how to avoid abuses of that power.

In this section, learners will consider the role of clinical ethics consultation in their institution. Learners will explore the institutional authority associated with this role and why it must be distinguished from the authority associated with individuals’ primary institutional roles (administrator, chaplain, nurse, physician, etc.). This section examines some common misunderstandings about, and possible misuses of, the role of ethics consultation, consideration of the power associated with ethics consultation—and potential (even if unintended) abuses of such power. In addition, learners will review ways in which appearance, comportment, and interpersonal skills influence both the reception and effectiveness of ethics consultation. In light of all of these issues, learners will also develop a clear and concise description of the role that may be used when telling others (including patients and families) what this role entails.

Learning Objectives and Strategies

Upon completing study of this topic, learners should be able to:

1. Identify values underlying and informing their various commitments and interests.
   a. After having made a list of their own core values and commitments, have each person who performs ethics consultation reflect on several ethically challenging situations faced in their personal life that have helped shape and/or clarify these values and commitments. Discuss several insights regarding these values and commitments which were learned as a result of such situations.
   b. Have one or two persons involved in ethics consultation or on the ethics committee at your institution identify a case (or two) from the past that continues to stimulate reflection concerning conflicting interests and commitments. Ask each person to help identify the values embedded in the case(s) that may underlie the conflicts.
   c. Compare and contrast the values identified for the case(s) with those listed on one’s own values inventory.
   d. Have each person involved in ethics consultation or on the ethics committee at your institution discuss a possible clinical situation in which one might recuse oneself from participating in clinical ethics consultation because of challenges to one’s own personal values, commitments and experiences.

2. Identify and explain competing obligations (i.e. to staff and patients, to individual patients vs. the institution) associated with ethics consultation. Outline the range of, and the strategies for responding to, conflicting interests in clinical ethics consultation for those who perform ethics consultation.
   a. Read several articles regarding the status of different commitments associated with ethics consultation, such as “Insider Trading: Conscience and Critique in Bioethics” (Zoloth-Dorfman and Rubin, 1998), “Throwing a Bone to the Watchdog” (Elliot, 2001),
“Professional Ethicist Available: logical, secular and friendly (Bosk, 1999), “DRAFT: Model Code of Ethics for Bioethics” (MacDonald), and “Bringing Codes to Newcastle” (Freedman, 1989).

b. Based on the various institutional roles one holds, and the experience one has had in those roles, create a list of primary obligations associated with each role. Exchange lists with others who perform ethics consultation in your institution.

c. For the list one now has, identify and discuss any potential conflicts among the obligations listed. Then identify and discuss with colleagues non-role-based values that might support, and that might challenge, the set of obligations listed.

d. Identify and discuss with others involved in ethics consultation or on the ethics committee at your institution different ways in which the conflicts identified above may be addressed (i) individually, (ii) by all members of your institution who have leadership responsibilities for ethics consultation within the institution, and (iii) within the actual process of ethics consultation in which patients, families, and other care providers may also be present.

e. Discuss with colleagues potential conflicts between the three different strategies identified in step (d) as well as the pros and cons of each.

f. Read at least two professional statements on conflicts of interest, such as those published by the American Medical Association (1994), and identify the core values expressed therein. Discuss the implications of these values for ethics consultation practice.

Resources


Topic 3. Challenges of the Role: The Experience of Providing Ethics Consultation

Introduction

The range of ethical considerations encountered in clinical ethics consultation—by those providing ethics consultation, patients and families, primary physicians, nurses, and other involved parties—may be quite broad. Some factors are inherent in the clinical context—for example, uncertainty, continual change, necessary and forced trust. Other factors are closely associated with the dynamics and complexities of the institutional health care setting. Accordingly, clinical ethics consultation will likely entail a diversity of ethical concerns above and beyond those explicitly identified in the initial request for ethics consultation. Identifying the many factors that shape and reflect this diversity of ethical concern may be challenging, especially in the process of the ethics consultation. Clarifying what counts as a “best” option in any given situation, moreover, will be dependent upon which ethical considerations are considered most weighty.

As a result, the diversity and complexity of ethical concerns in clinical contexts invariably leads to situations in which those engaged in clinical ethics consultation may encounter pressure to compromise one set of concerns for the sake of another. This pressure can be especially acute when there is enduring uncertainty and/or serious disagreements among those involved in ethics consultation, e.g., physicians, nurses, patients, family, or between those involved in ethics consultation and broader institutional considerations. Because clinical ethics consultation can have life-altering consequences for care providers, patients, and families, it is crucial that those participating in clinical ethics consultation appreciate the different challenges and experiences that might be encountered in ethics consultation.

In this section, learners will consider a variety of experiential factors associated with ethics consultation practice which highlight the moral dimensions of engaging in ethics consultation. Specifically addressed are such matters as responsibility, uncertainty, moral distress and compromise, and marginalization. Learners will explore these both as they are experienced by the various participants involved in ethics consultation (patients, families, health care providers) and how they may be understood and addressed from within the role of ethics consultation.

Learning Objectives and Strategies

Upon completing study of this topic, learners should be able to:

1. Delineate the boundaries of responsibility associated with clinical ethics consultation and the moral weight associated with taking on such responsibility
   a. Read “Traversing Boundaries” (Bliton and Finder, 2002), “The Least Dangerous Profession?” (Scofield, 1993), and “Voices and Time” (Zaner, 1992). Discuss with
colleagues the experience of “feeling”—or “being”—responsible as occurred in the most recent ethics consultations in which you were involved.

b. Construct a list identifying specific responsibilities associated with ethics consultation in your own institution.

c. For each responsibility listed, describe its scope and limit, then outline 2-3 situations in which each responsibility might arise in the future.

2. Describe the distinctions between moral uncertainty, moral dilemmas, moral distress and moral residue. and identify positive and negative aspects of the notion of ‘moral compromise.’

a. Read “Moral Residue” (Webster and Baylis, 2000) and create a glossary of the “ethics” and “morals” language, including “moral uncertainty,” “moral dilemma,” “moral distress,” “moral residue,” and “moral compromise.”

b. Compare and contrast the core meanings of each term identified.

c. For each major term identified, discuss an ethics consultation experience which exemplifies the core meaning (NOTE: one situation may be used for more than one term). Be sure to discuss whose experience it is, and discuss whether different individuals in the same case could exemplify the same term but have different experiences.

3. Identify and analyze the experience of marginalization as likely experienced by medical, nursing, and other staff, patients/families, and those performing clinical ethics consultation.

a. Have each person involved in ethics consultation identify a case in which at least one of the participants in the situation could have felt “silenced” by the events (that is, unable to speak freely and openly about what was ethically at stake).

b. Identify the factors that could have led to such a feeling of being “silenced.”

c. Identify situations you believe are “obviously unethical,” then discuss factors that could lead individuals involved in such situations to experience the feeling of being “silenced.”

d. Read “She Said/He Said: Ethics Consultation and the Gendered Discourse” (Rubin and Zoloth, 1996) and “Keeping Moral Space Open: New Images of Ethics Consulting.” (Walker, 1993) then discuss what might be done—in individual ethics consultations and institutionally—to prevent or limit the extent of the experience of feeling “silenced.”

Resources


**Topic 4: Responding to “unethical” practice**

**Introduction**

While participating in clinical ethics consultation, individuals sometimes become privy to situations in which clear wrongs are being committed. These may range from errors in medical judgment, to discrimination, to abuses of power, to breaches of confidentiality, or to errors in clinical ethics consultation. Individuals in an institution are typically seen as having some degree of responsibility for appropriately responding to such breaches. However, greater responsibility may be ascribed to those who participate in ethics consultation. Having a clear understanding of the general institutional responsibility is essential; there may, however, be little institutional clarity regarding the extent of the specific responsibilities of those engaged in performing ethics consultation. It is critical that those serving the institution by performing ethics consultation be prepared to respond effectively to clear wrongdoing with recognition of the significance of their doing so within that role.

In this section, learners will consider crucial facets of responsibility in relation to clinical ethics consultation and practices or events clearly demarcated as “unethical.” Learners will begin with an exploration of the practical meaning and implications of integrity, including factors that often inhibit individuals from “doing the right thing.” Next is an examination of obligations to disclose what is going on in such situations, the need to do so in a transparent manner, and the challenges of taking such action within institutional contexts.

**Learning Objectives and Strategies**

Upon completing study of this topic, learners should be able to:

1. Describe how integrity is understood in the context of responding to situations seen as clearly unethical.
a. Identify situations or practices within your institution that you believe all would agree are “obviously unethical.”

b. Discuss with individuals involved in ethics consultation or on the ethics committee at your institution who within the institution is typically seen as being responsible for addressing such situations or practices, including the mechanisms for reporting and following-up.

c. Discuss with colleagues what typically happens when those mechanisms fail, e.g., what happens when no one “steps up to the plate”?

d. Identify factors that might lead individuals knowingly to violate recognized standards, be they legal, safety, professional, etc. Similarly, identify factors that might lead individuals to avoid participating in or enacting typical mechanisms for addressing “obviously unethical” situations or practices.

e. Read the Canadian Bioethics Society’s “DRAFT: Model Code of Ethics for Bioethics” (MacDonald) and discuss with others involved in clinical ethics consultation how such a Code may/may not help in the kinds of situations identified in step (d).

2. Explain the importance of disclosure and transparency in ethics consultation.

a. Read “Who Needs Medical Ethics?” (Satel and Stolba, 2001), “Why Medical Ethicists Don’t (and Won’t) Share Uncertainty” (Scofield, 2000), and “When We Were Philosopher Kings” (Shalit, 1997).

b. Discuss with colleagues how the critiques presented by these authors may be based in legitimate considerations as experienced within your institution.

c. Draft a possible “Reply” to these critiques.

d. Discuss with colleagues how your institution ensures transparency and disclosure regarding ethics consultation.

Resources


**Topic 5: Evaluation and Accountability of the Ethics Consultation Service**
Although clinical ethics consultation services continue to proliferate in healthcare institutions, there is no standard for measuring “good” ethics consultations actually or which consultation models and strategies are more or less effective. Often persons providing ethics consultations assume the process is inherently therapeutic or benign. But like all interventions in health care, ethics consultation can be a positive or harmful experience for participants (e.g., patients, families and staff). Some potential harms of ethics consultation include: breaches of confidentiality/privacy, exacerbation of conflicts, displacement of moral responsibility, and the use of ethics consultation for political ends. Those engaged in ethics consultation must not only clearly articulate their roles and limits; they should have processes in place to review the efficacy of clinical ethics consultation. In addition, ethics consultation, like all social processes, is susceptible to error. The clinical ethics consultation service should have mechanisms for quality control to identify, ameliorate and prevent errors in the consultation process.

In many institutions, accountability for clinical ethics consultation is limited to retrospectively reporting cases to an ethics committee (or hospital leadership) for “review.” However, many ethics committees do not have clear criteria or processes for reviewing cases and providing feedback to those participating in ethics consultations in order to improve services. The literature on strategies for evaluating ethics consultations remains thin. Published studies are idiosyncratic in their methods, participant populations and analytical tactics. Researchers reported utilizing a variety of tools, including surveys, observational studies and interviews. Nevertheless, it is useful to become familiar with this literature in order to create an evaluation strategy best suited to your institution. The process of crafting an effective evaluation strategy must be guided by five fundamental questions:

1. What are the goals, purposes and reporting structures of ethics consultation at your institution?
2. What do you want to learn through an evaluation process?
3. What are the purposes of evaluation? (How do you envisage using the information?)
4. What resources are available to the consultation service to support the evaluation process?
5. Given all of the above, what method(s) of evaluation best suits the clinical ethics consultation service at your institution?

In this section, learners will explore means for ensuring accountability for the activities associated with clinical ethics consultation. This will include developing a process for reviewing consultative activity, addressing error in ethics consultation, and engaging in ongoing quality improvement review.

**Learning Objectives and Strategies**

Upon completing study of this topic, learners should be able to:

1. Understand the definitions and importance of accountability in the consultation process.
a. Familiarize yourself with the policy/guideline/protocol/approach that governs the review of ethics consultation activities for your institution. If none exists, develop a proposal for reviewing ethics consultation activities within your institution.
b. Read several articles addressing evaluation and accountability for clinical ethics in general (see Macrae, 2005 and Leeman, 1997), and ethics consultation in particular (Fry-Revere 1993; Fletcher, 1993; Hoffman, 1993; Tulsky and Stocking, 1996; Fox, 1996; Kelly, 1997; see also the entire special section on Evaluation of Ethics consultation, Journal of Clinical Ethics (1996) 7(2)). Discuss with others involved in ethics consultation or on the ethics committee at your institution the various ways accountability in ethics consultation is defined in these articles.
c. Construct a list comparing and contrasting the suggestions in these articles with the policy/guideline/protocol/approach that governs the review of ethics consultation activities for your institution.
d. Compare and contrast what you have done in part (c) with standards for accountability in your primary professional role.
e. Discuss first with others involved in ethics consultation and then colleagues in your primary professional role how they think about accountability in their primary professional roles versus their role in ethics consultation.

2. Describe the strengths and weaknesses of various evaluation strategies, and identify which evaluations strategies are best suited to your institution.
a. Read several published reports of ethics consultation evaluations using a variety of methods (Orr 1996; White, Dunn, and Homer, 1997; Schneiderman, 2000; Schneiderman, 2003; Kelly, 1997; Heilicser, 2000; Dowdy, 1998; see also www.va.gov/integratedethics/download/Ethics_Consultation_Primer.pdf).
b. Discuss with colleagues the strengths and weaknesses of each method of evaluation employed in these articles. What resources does each method of evaluation require? What does each method of evaluation assume about the purpose and utility of ethics consultation?
c. Answer the five fundamental questions listed in the introduction above, and write a brief report articulating a justification for selecting particular methods of evaluation and review for ethics consultation at your hospital. Share this report with colleagues and institutional leaders for feedback.

3. Appreciate that errors can and will occur in clinical ethics consultation, and thus develop strategies for identifying, reviewing, and correcting such errors.
a. From the book, Margin of Error: The Ethics of Mistakes in the Practice of Medicine (Rubin and Zoloth, 2000), read Rubin and Zoloth’s “Dead Wrong: Error in Clinical Ethics Consultation” (195-216), Bernal’s “Error in Ethics Consultation” (255-272), Bosk’s “Margin of Error: The Sociology of Ethics Consultation” (273-286), and Olick’s “Ethics Consultation and the Law: What is the Standard of Care?” (287-304).
b. As discussed by Bernal, have all those who provide ethics consultation briefly describe in writing an ethics consultation situation in which they were involved in which they believed an ethics consultation error occurred.
c. Using the Bosk article ( Rubin and Zoloth, 2000), discuss as a group whether (and why) each situation described in part (b) is best thought about as the result of organizational structure or the nature of everyday health practices.
d. Develop a procedure by which possible errors in clinical ethics consultations may be reviewed for the sake of improving practice (and not merely error identification or establishing blame).

Resources


**Appendix A**

**Graduate & Health Care Communication Programs that Offer Relevant Course Work**

- Numerous Master of Arts in Bioethics programs offer Clinical Practica or clinical rotations – These courses combine clinical observation with precepting by clinicians. See for instance
  - [http://www.pitt.edu/~bioethic/progoffMA.htm#Top](http://www.pitt.edu/~bioethic/progoffMA.htm#Top)
  - [http://www.cwru.edu/med/bioethics/masrequirements.htm](http://www.cwru.edu/med/bioethics/masrequirements.htm)

- Some MA Programs in bioethics offer courses in which ethics consultations may be directly observed. See, for instance,
  - [http://www.union.edu/Academics/Bioethics/Academics/](http://www.union.edu/Academics/Bioethics/Academics/)

- There are MA programs that offer courses in which consultations are simulated. These courses may be taken or related materials made available on a website for home use, e.g., [http://bioethics.lumc.edu/onlinema/ethicsconsult_SP2004.htm](http://bioethics.lumc.edu/onlinema/ethicsconsult_SP2004.htm)

- For a complete list of graduate Master of Arts programs in bioethics, visit the ‘Resources’ section of the ASBH website ([www.asbh.org](http://www.asbh.org))

- The Department of Veteran’s Affairs National Center for Ethics has valuable ethics consultation resources available at: [www.va.gov/integratedethics/download/Ethics_Consultation_Primer.pdf](http://www.va.gov/integratedethics/download/Ethics_Consultation_Primer.pdf)
• Health-care communication seminars provide opportunities to practice related communication skills such as breaking bad news and negotiating care plans. See http://www.annenberg.nwu.edu/pubs/commed/
  http://www.physicianpatient.org/

Mediation Training Courses

There are numerous educational institutions that offer training in mediation skills. Although these may not directly address health care ethics case consultation, many of the interpersonal skills can be adapted to the consultation schema. Similarly, training in clinical pastoral education (CPE), social work, and other similar disciplines often contain reflective listening and mediation skills training that might be applied to the ethics case consultation service.

• Association for Conflict Resolution http://www.acresolution.org/
• Consensus Building Institute http://www.cbuilding.org/
• Conflict Resolution Services Center http://www.campus-adr.org/CR_Services_Cntr/crservices.html
• International Institute for Conflict Resolution and Prevention http://www.cpradr.org/
• Program for Health Care Negotiation and Conflict Resolution http://www.hsph.harvard.edu/php/pri/phcnr/home.htm
• Health Care Negotiation Associates http://www.hena.net/index.htm
• National Association for Community Mediation http://www.nafcm.org/
• Program on Negotiation at Harvard Law School http://www.pon.harvard.edu/research/main/index.php3
• Professional Mediation Association http://www.promediation.com/
• American Bar Association Section of Dispute Resolution http://www.abanet.org/dispute/
• Stanford Center on Conflict and Negotiation http://www.stanford.edu/group/sccn/

Mediation Information Resource Websites

• http://www.mediate.com/
• http://www.crinfo.org/narrative_mediation/new_developments.cfm