

critical access hospital
ETHICS COMMITTEE
RESOURCE GUIDE



**WILLIAM A. NELSON AND
BARBARA A. ELLIOTT**

WITH CONTRIBUTIONS BY:

Ruth B. Purtilo,
Jacqueline J. Glover,
Karen E. Schifferdecker
and Charles E. Gessert

critical access hospital
ETHICS COMMITTEE
RESOURCE GUIDE

William A. Nelson, PhD

Director, Rural Ethics Initiatives;
Associate Professor, Community and Family Medicine,
Dartmouth Medical School

Barbara A. Elliott, PhD

Professor, Department of Family Medicine and Community Health,
Medical School Duluth, University of Minnesota

with contributions by:

Ruth B. Purtilo
Jacqueline J. Glover
Karen E. Schifferdecker
Charles E. Gessert



FORWARD

THE CRITICAL ACCESS HOSPITAL ETHICS COMMITTEE RESOURCE GUIDE

was created in recognition of the important role critical access hospitals (CAH) play in providing quality health care to millions of Americans living in rural settings. CAHs, like all hospitals, frequently encounter ethical challenges, ranging from individual patient care issues to much broader issues, including the economic survival of small rural health care facilities.

Historically, very little recognition has been given to the important and complicated ethical conflicts that occur within rural health care contexts, often as a result of rural health care disparities and the dynamics of small communities. Dr. Nelson, in conjunction with his colleagues focusing on rural ethics issues, has brought needed attention to the many ethical challenges faced daily in rural health care practices.

One useful resource for addressing ethical issues that occur within a CAH is an ethics committee. The necessity and value of ethics committees have long been recognized, and for this reason ethics committees are included in the Joint Commission standards. Effective ethics committees can provide clinicians, patients, and administrators with important insights and assistance when encountering ethics conflicts – insights that can ultimately affect the quality of patient care. An ethics committee will not necessarily have the “answer,” but can assist health care professionals, as well as patients and family members, reason through issues and resolve conflicts. Unfortunately, for various reasons, ethics committees are less likely to exist in CAHs, compared to non-rural facilities.

The authors, Drs. Nelson and Elliott, have developed this practical *Guide* to assist CAH leaders in developing this effective and useful resource for patients, clinicians and administrators in rural health care facilities. The *Guide* is based on the available research and real-life examples that highlight the challenging and all too familiar ethics conflicts common to rural settings.

Critical Access Hospital Ethics Committee Resource Guide

Copyright © 2012 Trustees of Dartmouth College, Hanover, New Hampshire

Dartmouth Medical School's Department of Community and Family Medicine and the authors are pleased to grant use of these materials, without charge, providing that appropriate acknowledgement is given. Any alterations to the documents for local suitability are acceptable. All uses of the *Guide* are limited to personal use and not for resale.

William A. Nelson, Barbara A. Elliott with contributions by: Ruth B. Purtilo, Jacqueline J. Glover, Karen E. Schifferdecker and Charles E. Gessert
Cover and text design by Three Monkeys Design Works

Funded by the U.S. Department of Health and Human Services, Health Resources and Services Administration, Federal Office of Rural Health Policy through a Cooperative Agreement with the National Rural Health Association, (Grant # U16RH03702).

In order to foster dissemination of this practical resource, the *Guide* is available on the Internet. The authors hope that rural providers and administrators from across the United States will be able to take the concepts and suggestions presented here and apply them to their own organizations in order to improve both the quality of patient care, and clinician, administrator, and community satisfaction.

Alan Morgan, MPH
Chief Executive Officer
National Rural Health Association
Washington DC

ACKNOWLEDGEMENTS

WE WANT TO ACKNOWLEDGE THE ENCOURAGEMENT AND SUPPORT that rural health care professionals from throughout the United States have offered in the development of this practical resource for critical access hospitals (CAH).

We want to thank the members of our advisory committee for their interest and helpful suggestions in the drafting of this *Guide*; they have influenced us throughout this journey. The advisory committee included members of the Coalition for Rural Health Care Ethics: Drs. Jackie Glover, Tom Townsend, Lisa Anderson-Shaw, Craig Klugman, and Ruth Purtilo. Additionally, we want to acknowledge members of the Vermont Rural Network, guided by Ms. Cindy Bruzzese, for their feedback and helpful suggestions. For example, at one discussion regarding the *Guide*, members of the network urged us to add a chapter providing the basic steps necessary to create an effective ethics committee, so as to serve as a basic critical access hospital ethics committee game plan. In response to this suggestion, we created Chapter 2, “Steps for Growing Your Ethics Committee.”

In addition, Drs. Sandy Stover and Jon McDonagh shared wisdom from their experiences practicing in CAHs in Minnesota and Alaska, as did chaplains Ana Beier and Sarah Lund. There is no doubt that this *Guide* has been strengthened by their input.

We want to recognize our colleagues at Dartmouth Medical School and the University of Minnesota in the development of this *Guide* as well. We particularly want to express thanks to colleagues in the Department of Community and Family Medicine in New Hampshire, and the Department of Family Medicine and Community Health in Minnesota, and their department chairs, Drs. Michael Zubkoff and Ruth Westra. These individuals continue to foster outstanding learning environments for the next generation of rural primary care physicians.

We want to acknowledge that several chapters in this *Guide* are adapted from chapters in the *Handbook for Rural Health Care Ethics*:

TABLE OF CONTENTS

A Practical Guide for Professionals, authored by Drs. Ruth Purtilo and Jackie Glover. The *Handbook* is available at Dartmouth Medical School's Web site: <http://dms.dartmouth.edu/cfm/resources/rhc/> Additionally, the "Glossary of Basic Concepts in Health Care Ethics" found in the appendix of this *Guide* is adapted from a teaching tool developed at the Medical School Duluth, University of Minnesota by Dr. Elliott and her colleague there, Dr. Charles Gessert.

We especially appreciate Ms. Emily Taylor, an ethics research assistant at the Dartmouth Institute for Health Policy and Clinical Practice at Dartmouth Medical School, for her helpful review of the entire manuscript. We also want to thank Linnea Spelman of Three Monkeys Design Works for her copy editing and expertise in page design. Emily's editing and content guidance, and Linnea's design knowledge and skills, have been invaluable.

This project would not have come to fruition without the National Rural Health Association's (NRHA) support. We want to express our grateful appreciation to the NRHA for funding this project—and for their dedication to ensuring quality health care for rural America. In particular we want to thank Alan Morgan and Amy Elizondo from NRHA and Tom Morris from the Federal Office of Rural Health Policy at Health Resources and Services Administration.

Bill Nelson
Barb Elliott

Introduction

Ethics committees (EC) have a long history of serving as a useful resource for hospital staff addressing ethical challenges. The importance of ethics committees has been recognized in the Joint Commission's "Patient Rights and Organizational Ethics" standards, which stipulates that member organizations must have a "mechanism for addressing ethical conflicts."

Despite the importance of ethics committees to all hospitals, they are mostly found in large urban tertiary care centers. Small rural health care facilities, especially critical access hospitals (CAH) are less likely to have ethics committees. A traditional EC consists of different health care professionals who meet regularly to address hospital policies, such as a resuscitation policy; to develop educational programs and materials; and to provide ethics case consultation. Such a robust agenda can be a challenge to CAHs. As a result, small rural hospitals are less likely to have ECs in place to assist staff members who confront ethics issues; this creates a disparity in the proportion of urban-rural hospitals accredited by the Joint Commission.

This *Guide* is intended to aid critical access hospital administrative and clinical leadership staff in the development of an ethics committee—an effective and useful resource for improving patient care.

The Flex Monitoring Team (based at the University of Southern Maine) conducted a national telephone survey of 450 randomly selected critical access hospitals. The survey covered a wide variety of questions concerning hospitals' community benefit and whether the CAH had a formally established ethics committee. To supplement the basic question regarding the presence of ECs, respondents were asked whether access to additional ethics resources would be of interest.

A total of 381 CAHs responded to the structured telephone survey, yielding a response rate of 85%.¹ Survey respondents were located in 45 states. Two hundred thirty (60%) of the respondents indicated that their CAH had a formally established ethics committee. By comparison, the frequency of ECs in larger, non-rural settings is nearly 100%. More than two-thirds of the rural respondents without ECs indicated a need for additional local ethics resources. These findings identified a potential concern: just as the limited access and availability of rural health care services are associated with worse health status when compared to urban settings, the limited access and availability of ethics resources may be impacting the quality of care provided in rural settings. The study suggested that CAHs could benefit from guidance in developing ethics resources, including ethics committees.

Challenges to Ethics Committees in a Rural Context

Many challenges exist for hospitals in rural settings, several of which are related to the hospital's size and to the rural context itself. Although some contextual differences exist among various rural communities, rural life, in general, is characterized by limited economic resources; reduced health status of patients and clinicians; limited availability of, and accessibility to, health care services; dual and overlapping provider-patient relationships; distinct cultural and personal values; and increased clinician stress in the health care setting. These characteristics can create hurdles in creating an active and effective ethics committee, and can influence EC deliberations.

Nelson summarizes the obstacles for implementing more traditional ethics committees in rural settings in a 2006 article in *The Journal of Rural Health*.²

Challenges to Implementing Traditional Ethics Committees in Rural Settings

- Lack of multidisciplinary professionals
- Difficulty, or even impossibility, conducting regular meetings for a small staff with limited time and multiple responsibilities
- Lack of ethics knowledge and skills on the part of health care providers
- Limited opportunities for relevant ethics training
- Lack of effective training materials that focus on rural ethics conflicts
- Lack of regulatory incentive: rural hospitals are less likely to be reviewed by the Joint Commission on Accreditation of Healthcare Organizations
- Overlapping relationships among patients, clinicians, administrators, and ethics committee members

Using the *Critical Access Hospital Ethics Committee Resource Guide*

To address the need for the development of CAH ethics programs, and the obstacles that may present themselves in this process, we have created this *Critical Access Hospital Ethics Committee Resource Guide*. The *Guide* provides practical information for CAH clinicians and/or administrators seeking to develop an EC. The *Guide* is also applicable for those CAHs that already have an ethics committee, but where the members and/or institutional leadership believe that the committee could enhance its effectiveness.

The *Guide* begins with a foundational chapter focusing on the important role ethics plays for individual health care professionals and hospitals. The chapter offers helpful information in recognizing and addressing ethics conflicts in a thoughtful, reflective manner. Chapter 2 offers the reader a brief outline of the fundamental steps required in building an effective ethics committee. The remaining chapters provide more detailed information on specific topics for the committee's development, including—an EC's purpose and functions; various EC structural models; suggested knowledge base and skill sets

for EC members; various approaches to case consultation; a review of recurring rural ethics issues; strategies for preventing commonly encountered ethics issues; and a list of available ethics resources for additional assistance in preventing ethics issues.

We suggest that the reader carefully studies the first two chapters of the *Guide* in order to learn more about developing an effective ethics committee. The reader should then review those subsequent chapters most relevant to his or her organization's current needs.

We welcome feedback or observations about the *Guide*: whether or not it has been helpful, and how it might be improved. Please feel free to contact us:

William Nelson william.a.nelson@dartmouth.edu
Barbara Elliott bellott@d.umn.edu

References

1. Nelson WA, Rosenberg MC, Mackenzie T, Weeks WB. The presence of ethics programs in critical access hospitals. *HealthCare Ethics Committee Forum* 2010; 22: 267-274.
2. Nelson W. Where is the evidence: a need to assess rural ethics committee models. *J Rural Health* Summer 2006; 22(3):193-195.

CHAPTER 2

Steps for Growing Your Ethics Committee

This *Guide* offers practical suggestions for the development of an effective critical access hospital (CAH) ethics committee. Although no two CAH ethics committees will ultimately look identical, there are some basic characteristics that are essential for an effective committee. One characteristic is the support of administrative and clinical leadership. Without such support, an ethics committee (EC) is less likely to be effective and respected throughout the organization.

Ethics committees require careful thought, planning, and time for implementation. This *Guide* is intended to assist in the process of developing a new committee as well as in strengthening an existing committee.

We offer the following ten basic steps (see box) for the development of an effective ethics committee in a CAH. The steps are placed in appropriate specific order, although the flow may need to be altered for a specific location, and additional steps may exist for a particular facility. We believe these steps are essential for achieving an effective ethics committee.

Needs Assessment

Begin by assessing the need for an ethics committee. Such an assessment can be facilitated by anyone on the hospital staff using a staff-wide survey, although more informal discussions with the staff can be more effective in small hospitals. Informal discussions can explore the questions noted below and have the additional benefit

Ten Steps for Growing Your Ethics Program

1. Needs assessment
2. Initial leadership decision to create an ethics committee
3. Identify the ethics committee leader
4. Identify ethics committee staff
5. Draft committee purpose and activities documents
6. Seek approval of the committee's purpose and activities
7. Discuss the committee's purpose and activities throughout the hospital
8. Develop and pursue a committee self-education program
9. Implement committee activities
10. Periodically review the committee's activities

of providing an opportunity to discuss the importance of recognizing and addressing ethics conflicts and other roles of ethics committees. Whichever assessment mechanism is chosen, the following questions should be explored:

- Do clinical and administrative staff encounter ethics issues or conflicts?
- Do staff ever feel a need to discuss an ethics situation with a competent resource?
- Would the CAH benefit from ethics practice guidelines regarding clinical and administrative practices?
- Is there a need to foster ethics education throughout the hospital?
- Would a specific in-house resource be useful to staff and patients in addressing ethics challenges?

If the responses to the above assessment questions are “yes,” or at least, “I think so,” strongly consider the development of an ethics committee at your CAH.

Initial Leadership Decision to Create an Ethics Committee

Assuming the assessment suggests a need for an ethics resource, the early steps in the creation of an EC can move forward. The needs

assessment, combined with administrative leadership's recognition of the importance of an ethics-grounded organizational culture and practices, is key to the development of an ethics committee. Therefore attaining the hospital's leadership support is essential for the process to move forward.

- Obtain executive agreement that an ethics committee can serve as a useful resource; and
- Inform the Board and other key leaders that an ethics committee is being developed.

Identify the Ethics Committee Leader

A successful ethics committee needs an effective leader. The leader or chair of the committee must:

- Be respected throughout the organization
- Be committed to the committee's mission
- Have available (ideally, dedicated) time to perform committee functions
- Possess a basic level of knowledge and skills in health care ethics

Some facilities may decide to have co-chairs. Divided leadership can work well, as long as the co-chairs work well together and are equally committed to creating an effective committee.

Identify Ethics Committee Staff

The committee chair, in collaboration with clinical and administrative leadership, needs to identify hospital staff members to participate in the ethics committee's work. Because of the nature of ethics committees, membership should be multi-disciplinary, and include physicians, social workers, nurses, clergy, and administrators. If available, other health care professionals are appropriate.

Some characteristics of ethics committee members who will help to create and maintain an effective EC include:

- Commitment to the importance of ethics in today's hospital activities
- Basic understanding of health care ethics
- Willingness to grow in health care ethics knowledge and skills
- Time to participate in the committee's various functions

Draft Committee Purpose and Activities Documents

Once the committee chair and members have been identified, they will need to draft documents that describe the committee's purpose and activities. This may take multiple forms—some hospitals use by-laws or charter statements plus policy and procedure documents, and others have more informal methods of defining the committee's role in the hospital setting. In any case, some basic elements that need to be established and included in defining the committee's purpose and activities include:

- Clear statement of purpose
- Specific description of the committee's activities, such as ethics education, drafting and/or reviewing ethics practice guidelines and policies, and case consultation
- Frequency of regular committee meetings
- Description of the committee's functions, such as how does a staff member or patient access the committee and what are some examples of common ethics challenges that may be appropriate for the ethics committee
- List of committee members and chair(s)

Seek Approval of the Committee's Purpose and Activities

After the committee document specifying the EC's purpose and activities has been drafted, it should be presented to the organization's leadership for formal review and approval. The organization's

leadership should also designate whether the EC is becoming part of the medical executive structure or reporting directly to the Board of Directors. This decision results in the need to add a reference to the ethics committee in the hospital Charter or by-laws.

Discuss the Committee's Purpose and Activities Throughout the Hospital

After formal approval of the committee is achieved and a basic plan is developed to disseminate information about the committee, the committee members should begin sharing information regarding the purpose and activities of the committee with the entire staff. The clinical and administrative leadership should also be involved in this task to demonstrate their commitment and support for the committee's role and importance. Some potential approaches for presenting the committee to the staff and patients include:

- Staff meetings
- Hospital-wide town hall meeting
- Staff newsletters, Web site, and/or electronic communications
- Patient booklets
- Bulletin board posters

Develop and Pursue a Committee Self-education Program

The committee members should develop and implement a coordinated self-education effort to foster their knowledge and skills in health care ethics. Some practical suggestions for self-education are:

- Establish dedicated self-education time during every committee meeting
- Distribute readings from the health care ethics literature and request that the hospital library obtain several basic health care ethics books and subscribe to ethics journals
- Seek support for members to participate in regional or statewide training programs, especially training activities that have a rural ethics focus

Because committee members can always gain new knowledge and enhance their ethics reasoning skills, the committee's self-education process should be ongoing.

Implement Committee Activities

Once the committee's purpose and activities documents have been approved and the committee members have attained a basic level of competence, the committee can begin to implement its designated activities.

Periodically Review the Committee's Activities

Ideally, EC members should review their activities periodically and, when appropriate, make any needed changes to the committee's activities and membership. The review process can include the use of formal, yet simple, short survey instruments. For example, following each ethics consult, a brief survey could be given to the person(s) requesting the consult. Members of the committee can also solicit feedback from clinical and administrative staff in focus groups or in more informal conversational settings. The key is to collect information to ensure that the ethics committee is providing a useful role in promoting quality patient care.

CHAPTER 3

Role of Ethics for Rural Hospitals and Professionals

The purpose of this chapter is to review how ethics is integrated into day-to-day hospital culture and patient decision-making, in addition to our larger society and culture. The chapter, based on the writings of Dr. Ruth Purtilo,¹⁻⁴ also includes material that offers an introduction to the discipline of ethics—its concepts, and application. This information provides a foundation for the educational needs of committee members and for conversations with hospital staff who ask, “How do we determine what is right or wrong in our profession?”

Fortunately, health care professionals are generally able to rely on common sense and lessons from past experiences to provide the moral traction sufficient to address the minor ethics issues they encounter in practice. When decisions regarding care serve the patient’s best interest and are consistent with personal values and society’s moral guidelines, a clinician can usually conclude that the chosen course of action was morally correct. Occasionally, however, providers encounter decision points regarding care where personal and professional values collide. This leaves them with unsettled feelings regarding the “right” or “proper” course of action. In these cases, where doubt is present, ethics becomes an essential tool in determining which course of action is best.

ACKNOWLEDGEMENT

This chapter is adapted from: Purtilo RB. The Ethical life of rural health care professionals. In Nelson, WA, ed. *Handbook for Rural Health Care Ethics: A Practical Guide for Professionals*. Hanover, NH: Dartmouth College; 2009; available at <http://dms.dartmouth.edu/cfm/resources/ethics/>

Providers have heard many times before: “This is the moral and ethical thing to do.” Oftentimes the terms “moral” and “ethical” are used interchangeably. Although they are deeply related, they are not synonymous. As an ethicist, Dr. Ruth Purtilo has pointed out morality is the sum of attitudes, conduct, and character traits that describe how humans in a particular setting have agreed to live so that everyone can exist in harmony.³⁻⁴ Morality helps delineate basic shared values and goals. Beauchamp and Walters describe morality as “certain things [that] ought or ought not to be done because of their deep social importance in the ways they affect the interests of other people.”⁵ An individual’s morality becomes integrated into his or her identity as the individual grows, absorbing the influence of parents, mentors, the media, social norms, and other diverse sources.

Ethics is “a systematic study of and reflection on morality. It is ‘systematic’ because it is a discipline that uses special methods and approaches to examine moral situations; it is also ‘reflective’ because it consciously calls into question assumptions about existing components of our moralities.”⁶

Health care professionals, however, do not live in a social vacuum; the profession understands that its members are expected to conform to certain moral expectations of themselves, their patients, and society; and to reconcile those expectations. Various health professions have a morality of their own, one expression of which is in the professional code of ethics. In sum, a health professional has at least three realms of morality: personal, professional, and societal; and whenever he or she makes a patient care decision as a professional all are present.

Dr. Purtilo shares the following story,³ focusing on the personal, professional, and societal moralities that a provider, Dr. Simmons, encountered within one relationship:

Dr. Kim Simmons was very excited about being invited into the rural group practice. During her hiring interview with the group, she found the team of physicians, nurses, technologists, therapists, and others, compatible with her own commitment to high-quality health care. She told them that she had grown up in a small town in another state, and, although she had enjoyed the opportunity to attend medical

school in a large metropolitan center, she had realized at the end of her residency, that she wanted to return to practice in a rural area. The group was impressed with her enthusiasm, and with the several academic and humanitarian awards she had received during her training. They offered her the job, which she accepted.

After a short time on the job, Dr. Simmons accidentally misdiagnosed the asthma symptoms of one patient, Mr. Ortega, as a temporary allergic response attributable to a high pollen count. She remembered being exhausted on the evening that Mr. Ortega came in, and feeling relieved that he was just another person reacting to pollen. She wanted to be available to serve at a community church supper that evening. When asked if he had ever had such a reaction before, Mr. Ortega said no. But when Mr. Ortega returned two months later, again complaining of difficulty breathing, it dawned on Dr. Simmons that she should probe further. She was aware that the allergy medication she had prescribed probably had not done Mr. Ortega any harm, but also that untreated asthma can have severe and sometimes fatal consequences. The doctor conducted additional tests that confirmed Mr. Ortega's asthma. She found herself uncertain about whether to tell him that she had misdiagnosed him two months earlier, because she knew from experience that acceptance of new young doctors in a rural community was slow and that word traveled quickly. "Why am I hesitating?" she asked herself; "I am an honest person!" She concluded that part of her hesitance stemmed from not wanting to disturb the trust she felt she was building with Mr. Ortega and his ethnic community, many of whom had been suspicious of the "white doctors" and therefore had failed to come for care. To further complicate things, Dr. Simmons felt an increasing need to hold on to patients who might otherwise go to a larger facility 30 miles away.

Some of the moral considerations that Dr. Simmons faced in this encounter are easy to identify: her personal morality counseled her to do her duty well, honestly, and fairly; her professional morality required competent patient care, as well as created concern as to

how disclosing her mistake might affect this patient and others; and the morality of the community or the society required her to consider perceived barriers to care.

The competing moral considerations in this story can be navigated with the help of ethical reasoning. Ethical reasoning identifies the various moral considerations, reflects on them using appropriate ethical tools, and works toward resolution. An ideal outcome of the process would be one that is described as "the moral and ethical thing to do."

As the reader moves through this chapter and others, it might be helpful to break the idea of "reflection" into three components, so that ethics becomes a tool for the health care provider. The forms of ethics reflection include:

- **Recognition** of morality in its three realms within the context of everyday practice (personal, professional, societal)
- **Reasoning** about the conflicts that might move an ethics issue into the category of an ethics problem or conflict
- **Resolution** seeking to evaluate and propose potential solutions

We find the forms of reflection so fundamental that we think of them as the three "Rs" of ethical deliberation—ultimately making ethics useful in practical situations. In this chapter, the major focus will be on what Dr. Ruth Purtilo calls the first two "Rs." The third "R" is addressed in Chapter 8.

How Ethics Can Be Useful To Rural Professionals and Committee Members

In learning to recognize the moral dimensions of a situation, it is helpful to distinguish ethics issues from ethics conflicts.

Ethics Issues

Ethics issues are questions of morality that are embedded within situations that deserve reflection. This reflection helps to ensure that the

decision-maker is on a path consistent with the correct moral direction or disposition. The process that Dr. Simmons engaged in during her first meeting with Mr. Ortega illustrates this. In their first encounter, she was a reflective practitioner, acting consistently with her personal morality, consciously aware that in spite of her fatigue, she had a professional moral duty to treat him competently and humanely. She was pleased to be able to keep her societal commitment at the church supper as well.

Ethics Issues Include Several Related Components

- **Ethical Distress** – Recognition of what is right, but the inability to act on it
- **Ethics Conflicts** – Multiple options for action are presented and selecting and acting on any one will compromise the other
- **Locus of Authority** – The individual with the ultimate moral authority in a situation must be determined

In Dr. Simmons's situation, her confidence was shaken when Mr. Ortega returned after two months and she realized she had diagnosed his condition incorrectly. This moment also raised serious questions about the relative weight of each of the three realms of morality in her relationship with Mr. Ortega. In short, Dr. Simmons was beginning to encounter an ethics conflict.

Ethical Distress

Ethical distress occurs when the decision-maker knows what should be done to uphold his or her personal moral values, as well as to support the patient's and society's values and goals, but external constraints keep him or her from accomplishing this. The constraints may come from scarce resources, policies, laws, or other sources. Scarce health care resources (*e.g.*, personnel, equipment, time, space, money) are common reasons for such distress in rural health care environments. Ethical distress may occur when the wishes of patients or their families differ from what the medical team considers sound clinical practice, or when the health care team doubts that the family

is reflecting the patient's true wishes. In Dr. Simmons's case, we have no clear indication that she had this type of ethics problem.

The presence of "ethical distress" (also referred to as "moral distress") can be a helpful trigger highlighting that more attention may be needed in a situation. In the case of Dr. Simmons, she tuned in emotionally to the fact that she may have made an incorrect initial diagnosis on Mr. Ortega, and one that also may have been hasty.

Ethics Conflicts

Ethics conflicts occur when the decision-maker is confronted with more than one right (or wrong) course of action that honors personal, professional, and societal morality, but acting in accordance with one will compromise the other(s). For example, rural practitioners often face ethics conflicts regarding confidentiality. Providers must adhere to a professional moral dictum that honors well-documented confidential patient information. At the same time, however, the nature of the close web of families, neighbors, and the community as a whole may make sensitive information recorded on a patient's medical record public knowledge.

Dr. Simmons identified an ethics conflict during her deliberation following the return of Mr. Ortega. Both her personal and professional moral compasses directed her to be honest about her mistake. Still, she feared this disclosure would have a negative effect on the complex relationships that she and the group's facility have with Mr. Ortega and his community. She also knew that if enough patients were siphoned off to the competing facility down the road, her office might be forced to close, leaving many of the already underserved patients without health care access.

Locus of Authority Conflicts

Conflicts with locus of authority issues, like those experienced by Dr. Simmons, are not unique to the rural situation. However, when they arise, the long-standing and long-established practices of the rural community are likely to prevail as acceptable courses of action over hard and fast policies that prevail elsewhere. This type of conflict shifts the attention of those considering the appropriate course of

action, to a focus on who has the morally authoritative voice in the situation. For example, in situations where it is uncertain how to proceed with treatment, the opinion of a clinician who has served the area for years likely will trump the judgment of a new clinician. This might occur even though the health care team and/or an objective outside reviewer may believe the new clinician is more equipped to make the call.

Locus of authority questions also arise in medical decision-making among ethnic populations. With the increasing ethnic and religious diversity in many rural communities, the health care provider may be confronted with customs that seem foreign and contrary to the customary rural practices. Dr. Simmons's case did not suggest whether she had considered consulting anyone for insight regarding concerns on the basis of Mr. Ortega's ethnic community. She had assumed it was up to her to decide whether to admit her mistake, as she had seen herself as the sole team member involved in the situation. However, it may have behooved Dr. Simmons to research the existence of morally authoritative figures in Mr. Ortega's population, as they may have been able to provide insight regarding the potential outcomes of her decision.

Learning to recognize these three major components of ethics issues provides clinicians with an ethics tool that can be useful when recognizing or encountering an ethics situation. It can assist the clinician with assessing the roles of his or her own personal morality, professional morality and the morality of the community.

Ethical Reasoning When Competing Moral Values Exist

Following the recognition of an ethics problem, clinicians should engage in the second "R": ethical reasoning about the problem. Several ethical principles are used widely in medical and professional ethics circles to help professionals reason about the moral components in a given situation. These principles are often viewed as conceptual tools, which are helpful in reasoning through the particularities of a situation. The ethical principles are defined below and described in more detail in the sections that follow.

These principles are especially useful when a physician recognizes a potential ethics conflict and needs conceptual tools to help sort out

Definitions of Basic Ethics Principles

- **Autonomy** implies that an individual has the final say in decisions affecting his or her well being, even at times of life-and-death decision-making.
- **Beneficence:** Beneficence from the root *bene*, meaning good, implies that health professionals must prioritize acting in the patient's best interest.
- **Nonmaleficence** is the stringent moral claim on health professionals not to put a patient in harm's way.
- **Fidelity and Veracity:** Fidelity is from the root *fides*, faithfulness; Veracity is the devotion to truth. In the patient-clinician relationship, faith and truth create trust.
- **Justice** helps clinicians make moral choices when one claim for resources trumps others, based on relative degrees of merit, contribution, or need among people or groups.

or reason about what is happening. For example, when the principle of justice cannot be accomplished because of policy constraints, a clinician experiences ethical distress. An ethics conflict exists when a patient's autonomous choice of care conflicts with a physician's best judgment about what will prevent harm. Thus, conduct according to one principle would preclude also honoring the other. Taken alone, each principle is worth honoring, but particular situations can put a professional between a rock and a hard place; when two ethical principles directly collide, an ethics conflict exists.

A detailed deliberative process is required to move from reasoning at this level to possible resolution of an ethical problem. Such a complete process is presented in Chapter 8. However, this chapter offers professionals an opportunity to familiarize themselves with the most frequently used ethical principles in health care.

Autonomy

Autonomy implies that an individual has the final say in decisions affecting his or her well being, even at times of life-and-death. In western societies (and especially in America), where independence of

thought and action is considered the norm, the term “self determination” is commonly used. Clinicians also demonstrate “professional autonomy” when making informed and accountable decisions for their patients. A patient’s autonomy may be expressed through his or her own words, or through surrogates in instances when the patient can’t personally express his or her informed preferences. One caveat regarding traditional interpretations of patient autonomy as a reliable ethical principle: There are native cultures, as well as other groups of people, who use communal standards for decision-making. This is particularly important in rural communities where new ethnic and religious groups are becoming more prevalent against the backdrop of individualism.

Beneficence

The term beneficence derives from the Latin root *bene* meaning good. In common health care ethics and health care usage, this term implies that actions by health professionals and others must be conducted with the patient’s interests as the top priority. Some scholars suggest the definition of beneficence has at least three components: doing good, preventing harm, and removing harm.⁷ Health care teams today are faced with heightened ethical distress, due to limited resources and other constraints on what they believe would support care consistent with the patient’s best interests. Also, a patient’s informed preferences may sometimes differ from the ideas of health professionals or ethics committees about how to best help patients and prevent or remove harm. As a result, the ethical principle of beneficence is often in conflict with the other ethical principles. When Dr. Simmons weighed the benefits of disclosing her mistake against the benefits of withholding it, she was making a beneficence-based deliberation.

Nonmaleficence

Nonmaleficence is the stringent moral claim on health professionals not to put a patient in harm’s way. This principle can also be in conflict with other principles. Take the simple example, not uncommon in rural settings, where good clinical judgment suggests moving a patient to a distant tertiary-care facility for life-saving interventions that are not available locally. Not to do so, the professional may argue,

would make him or her an agent of potential harm to the patient. However, viewed from the larger social fabric of the patient’s life in this dire circumstance, to remove the patient from his or her local support network also causes harm. Though Dr. Simmons did not face this particular conflict of nonmaleficence, it is likely one she faces regularly in her moral life as a health professional, as it is very common in the rural health care setting.

Fidelity and Veracity

Fidelity comes from the same Latin root, *fides*, as faithfulness. Veracity is the devotion to truth. In the patient-clinician relationship, faith and truth combine to create trust. Both terms reflect the notion that honoring the reasonable expectations of a relationship is a good thing. Understandably, Dr. Simmons was concerned about any course of action that may involve withholding the truth about her mistake from Mr. Ortega. Our common moral intuition and historical reflection reinforce the idea that faith and truth support human life. Still, the ethics conflict that arises when conveying the truth also carries the possibility of harm, and Dr. Simmons came face-to-face with that concern.

Justice

Justice is the principle that suggests that moral claims for resources may not be equal in moral weight. The concept of justice provides criteria regarding how to make moral choices when one claim for resources trumps others. Some common criteria include relative degrees of merit, contribution, or need among people or groups. Justice is different from the other principles insofar as the unit of consideration is a group or population with similar characteristics, rather than an individual. An example would be the ethical distress that a doctor may face if he or she is unable to offer effective treatment to a child with a rare metabolic disorder, because his or her organization’s policies did not support the cost of treatment. That same clinician or ethics committee then faces an ethics conflict when considering whether to support expensive life-saving treatment for an individual, knowing that the drain on a limited pool of financial resources would harm future patients.

These basic ethical principles are included in the classic ethics theories and are embedded in health professional codes of ethics. For a fuller discussion of these ethical principles see Beauchamp and Childress's book *Principles of Biomedical Ethics*.⁵

Applying these various ethical principles to one's work can help to highlight the basic ideas about harm and good, right and wrong, but this list is by no means exhaustive. For example, the moral concept, "do your duty," as reflected by Bernard Gert in his book *Common Morality*,⁸ relates to one's duty as a member of a particular profession. This has been referred to as professional ethics or group-specific ethics. If one elects to be a member of a particular health profession, such as nursing, occupational therapy, or health-care administration, he or she should accept and abide by the ethical standards and guidelines of that profession.

Weighing Ethical Principles

Ethics questions arise when two or more ethics principles are in conflict with each other. Two ethics theories that describe approaches for weighing principles against each other are deontology and utilitarianism. Both theories offer a guide for resolving ethics conflicts.

Deontology, from the Greek root *deon* meaning duty, calls on rules, laws, or norms to help guide us when weighing possible courses of action. This approach does not provide hard-and-fast rules about which principle or law is the most binding, but merely suggests that agents have certain moral "duties" they should abide by, depending on the situation. Historically, the field of medical ethics has placed high priority on health care providers' duty to do no harm (nonmaleficence); American culture tends to prioritize our common duty to respect each other's autonomy.

The utilitarian approach, from the Latin root meaning utility or usefulness, weighs options by considering which course of action will bring about the best overall outcome for the largest population: the greatest good for the greatest number. This "good" is not just moral, but positive, in terms of its widely considered consequences.

Another essential component in a determination of an ethical course of action is the moral character of the decision-maker. In addition to ethics principles and theories, it is important to consider the character traits of clinicians, administrators, and others who are involved in the reflection and decision-making. A decision-maker's respect for human life, commitment to competence, compassionate disposition, patience, sympathy, honesty, trustworthiness, kindness, humility, and fairness may all affect the course of action he or she chooses. Which character traits did Dr. Simmons exhibit as she moved through the visits with Mr. Ortega? Are there other traits that might have been helpful, or were there some that were a hindrance? These types of questions are useful in the process of ethical reasoning. Ethical tools for reasoning are described below.

Ethical Tools for Reasoning

- Ethical principles link personal moralities or values with specific situations. They can also enhance reasoning about ethics issues/problems.
- Ethics theories such as deontology and utilitarianism highlight the importance of considering duty and outcomes.
- Character traits of decision-makers help position them for morally "right" action.

Rural health care professionals and ethics committee members can use these tools to navigate ethical situations and reflect on their own ability to provide ethically-grounded care.

References

1. Purtilo RB. Rural health care: the forgotten quarter of medical ethics. *Second Opin.* Nov 1987;6:10-33.
2. Purtilo R, Sorrell J. The ethical dilemmas of a rural physician. *Hastings Cent Rep.* Aug 1986;16(4):24-28.
3. Purtilo RB. The ethical life of rural health care professionals. In Nelson, WA, ed. *Handbook for Rural Health Care Ethics: A Practical Guide for Professionals.* Hanover, NH: Dartmouth College; 2009.
4. Purtilo R. *Ethical Dimensions in the Health Professions.* 4th ed. Philadelphia, PA: Saunders; 2005.
5. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics.* 5th ed. New York, NY: Oxford University Press; 2001.
6. Purtilo R. *Ethical Dimensions in the Health Professions.* 4th ed. Philadelphia, PA: Saunders; 2005:15-16.
7. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics.* 5th ed. New York, NY: Oxford University Press; 2001:293-312.
8. Gert B. *Common Morality: Deciding What to Do.* New York, NY: Oxford University Press; 2004.

CHAPTER 4

Purpose and Activities of Critical Access Hospital Ethics Committees

The purpose of this chapter is to identify the purpose, activities and membership for ethics committees (EC) in critical access hospitals (CAH). When the decision is made that a hospital should form an EC, and the leadership for the committee identified, the next steps are committee development and implementation. At this point, it is important to identify how the EC fits into the hospital's organizational structure, and to add a statement to the hospital's by-laws or charter regarding its line of report. This step officially creates the committee within the hospital structure and identifies how the committee participates in hospital activities. After this is completed, additional work may be needed to describe how the EC functions within the hospital setting, which can be done using policy and procedure documents. The ethics committee should be formally organized and recognized as a committee within the context of the facility, with a defined purpose and specific assigned activities.

Ethics Committee: Purpose

A CAH forms an EC as part of its administrative and clinical effort to enhance the quality of patient care because the presence of ethics issues frequently undermines patient care and staff morale. Providing health care is a moral process—dealing with decisions that dramatically and fundamentally affect the lives of others. Therefore, an ethics committee's specific purpose is to serve as a forum to promote and clarify ethics practices throughout the hospital setting to ultimately enhance the quality of patient care.¹⁻³

CAH documents describing the ethics committee should begin with a clear statement regarding its purpose. The lack of a clear statement of purpose can create confusion for both the committee members and the staff.

Sample Ethics Committee Purpose Statement

The committee, composed of a multi-disciplinary group of health care professionals with knowledge and skills in applied ethics, serves as a forum to promote and clarify ethical practices throughout the critical access hospital setting in order to enhance the quality of patient care.

The EC can produce a clear statement of purpose by making use of its diverse membership of professionals whose variety of ethics skills, knowledge, and insights are a valuable resource. An example of a hospital statement of EC purpose is noted in the box above.

Ethics Committee: Activities

To achieve the stated purpose, the EC facilitates many activities that should be specified in appropriate hospital documents.³ Traditionally, these activities include education regarding ethics issues, clinical case

Committee Activities

- Educate ethics committee members, the hospital, and the community
- Consult with hospital staff regarding difficult clinical and administrative ethics cases, making recommendations when appropriate
- Review and create hospital policies and procedures
- Develop and propagate ethics practice guidelines to decrease the presence of future ethics conflicts
- Regularly evaluate the work of the committee to maintain quality of services

consultation, and review of policies.¹⁻³ We suggest two additional activities be specified as committee responsibilities: that the committee actively work to reduce identified recurring ethics conflicts, and that the committee's work be regularly evaluated to maintain its quality.

ECs provide educational efforts to members of the committee and hospital staff regarding ethics issues. They can also provide educational opportunities for patients and families, as well as members of the local community. This topic is addressed with detail in Chapter 7.

ECs also review ethics issues relating to specific patient care decisions (both prospective and retrospective cases) and act as a liaison with other agencies dealing with these issues. Providing clinical case consultation is a significant area of focus for an EC.¹⁻³ To accomplish this activity, individual committee members need basic training in ethics knowledge and skills, and the EC should work to provide these educational opportunities.^{2,3} The committee should also develop a clear process for handling ethics consultations.^{1,3} This topic is addressed more fully in Chapter 8, where documentation to establish a consultations service is included, with a suggested deliberation process.

ECs serve the hospital by collaborating in the development of policies that encompass medical ethics issues (decision-making processes, DNR policies, etc.). Through the review of cases and policies, EC members are positioned to recognize needed changes in policies and hospital systems to prevent the recurrence of ethics conflicts. In this way, ECs also serve as a resource for the administration in maintaining and improving the quality of care delivered to patients and families.⁴⁻⁷

Maintaining hospital policies also relates to the committee's activity of creating practice guidelines or additional policies to address ethics issues that the committee identifies as recurrent. Through their ongoing review of hospital experiences (clinical and administrative) the committee can become aware of circumstances that repeat themselves. When these issues are identified, changing the system to prevent them happening again is another way the quality of care for patients and families is strengthened. This is discussed further in Chapter 9.

EC activities can also include self-evaluation and marketing; these functions are described in more detail in Chapters 11 and 12. These activities enhance the validity of the committee for the hospital; self evaluation allows the committee to investigate its effectiveness and directly improve its activities. This process is only possible when the purpose statement and designated activities are clearly understood within the hospital setting.

Ethics Committee: Composition

Ethics committees are composed of employees from the hospital's multiple disciplines, and the committee members ideally represent the region's cultural and ethnic diversity. The hospital leadership must identify how members are appointed to the committee (such as by the hospital Chief of Staff if the committee reports to the medical executive staff, or by the administrator if it is part of the Board structure), how long each appointment continues, and whether a person can be reappointed. The total size of the committee should be determined (this depends on the size of the staff and their interest—usually a committee has five or more members in the least), as well as the other disciplines that will be represented on the committee. Usually, an EC includes representatives from social services, pastoral care, nursing services, and others services as deemed appropriate in the setting. An administrator and hospital attorney may choose to be *ex officio* members in order to participate in appeals regarding patient care decisions or other legal issues (more details regarding membership are addressed in Chapter 6).

Conclusion

This chapter specifically describes the purpose, activities, and membership for ethics committees in CAHs. When the decision is made to form an EC, identifying how the EC fits into the hospital's structure and participates in its business is crucial; it prepares the community for the committee's activities. These steps are essential for creating a successful setting where the committee's work can be accomplished.

References

1. AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, 7th ed. New York, NY: McGraw Hill, 2010.
2. Lo B. *Resolving Ethical Dilemmas: A Guide for Clinicians*, 4th ed. Baltimore, MD: Lippincott, Williams &Wilkins, 2009.
3. Post LF, Blustein J, Dubler NN. *Handbook for Health Care Ethics Committees*, Baltimore, MD: The Johns Hopkins University Press, 2007.
4. Nelson WA, Neily J, Mills P, et al. Collaboration of ethics and patient safety programs: opportunities to promote quality care. *HEC Forum*. 2008; Mar;20:15-27.
5. Opel DJ, Brownstein D, Diekema DS, et al. Integrating ethics and patient safety: the role of clinical ethics consultants in quality improvement. *J Clin Ethics*. 2009; Fall;20:220-6.
6. Nelson WA, Gardent P, Shulman E, Splaine M. Preventing ethics conflicts and improving healthcare quality through system redesign. *Quality and Safety in Health Care*. 2010;19:526-530.
7. Anderson CA. Ethics committees and quality improvement: a necessary link. *J Nurs Care Qual*. 1996; Oct;11:22-8.

CHAPTER 5

Model Ethics Committee Structures

This chapter describes committee structures that can support an ethics committee (EC) in accomplishing its designated purpose and activities. Several approaches or models are workable, but for a critical access hospital (CAH) setting, we recommend the establishment of a full or traditional ethics committee, as it allows for rich discussions and informed recommendations. Once established and functioning, the EC's members can determine how to divide up responsibilities, while being considerate of member's schedules. In this chapter, the traditional ethics committee model is first described, followed by alternate approaches.

Traditional Ethics Committee Model

As presented in Chapter 4, the activities of the EC include education, consultation, and policy work. In some settings, where resources are more limited, a committee's focus may only be on improving care for in-patients; in other settings, the focus may be broader, in that the EC's educational efforts extend beyond the hospital to include out-patient questions, and/or the policy work advisory to the hospital's governance structure. In any case, an interdisciplinary group of five or more professionals generally makes up the committee. Together they undertake the work of the committee.

A primary activity of ECs is providing consultation regarding clinical dilemmas associated with particular patients' care decisions.¹⁻⁵ In the traditional committee model, the full committee is engaged in the review of the case and advisory process. (This process is detailed in

Chapter 8.) In a setting where the committee is relatively new to ethics consultation, or where there are few consults each year, the whole committee approach to consultation is recommended, as it makes use of the diversity of perspectives and expertise amongst the committee members and ensures thoughtful discussion before a recommendation is reached.

Education is another activity that ECs regularly perform.^{2,5} The EC must educate its own committee members, as well as employees of the hospital (this topic is further discussed in Chapter 7). Each educational effort that strengthens the knowledge and skills of committee members also improves the committee's value to the hospital; it is recommended that every committee meeting include an educational component for the group. Committee members can sign up to lead an educational session when it fits with their schedule—in this way every committee member has the chance to teach as well as to learn. In addition, the hospital benefits when ethics committee members bring new information and insights into their work settings. These educational efforts can be informal (each committee member teaching when they return to their practice sites), or formal (meeting presentations.) In this way, the quality of care at the hospital is strengthened, and the expertise of all practitioners is enhanced.

The third task routinely assigned to an EC is reviewing policies and protocols to assure that the hospital's approach to care is appropriate and does not create dilemmas at an organizational level.^{2,5} Hospitals have identified people and groups whose responsibility it is to keep the policies consistent, up to date, and complete. When the EC offers its help or collaboration in review (or creation) of policies, the committee's expertise extends to all hospital departments. Common policies that benefit from EC involvement include those addressing advance directives, brain death, Do Not Resuscitate and No Intubation orders, forgoing life-extending treatments, etc. Again, having all committee members participate in this development or review assures that the breadth of the interdisciplinary group's skills, knowledge, and wisdom are available to the process.

Other activities either specifically assigned to the EC, or which can emerge as the committee performs its work, include systems-level or organizational considerations. Such efforts can foster a preventive ap-

proach to ethics conflicts. Often these considerations become evident to committee members through their work in the more traditional activities of the EC.

Various Ethics Committee Models

Alternate Models to the Traditional Committee Structure

- Dividing the traditional committee into sub-committees or teams
- Designating an ethics expert
- Linking institutional ethics committees through a network or academic center
- Forming a multi-facility ethics committee (MFEC)

Sub-committees or Teams as Part of the Traditional Model

The traditional committee group can also configure its membership to address the variety of tasks that are delegated to the group. Some ECs create subgroups within the committee-of-the-whole, assigning differing tasks to the sub-committees. In a setting with a limited number of committee members, each person may not be expected to participate substantively in all of the designated committee activities. For example, in a committee of six members, two might be assigned to the education efforts, three to the consultation process, and two members to policy work. Each group would do their subcommittee work and bring summaries to the larger committee when decisions or consultations are needed. Another model calls for small groups with specific assignments to each of the tasks. Advantages of this approach are that the people who are most qualified (*e.g.*, have the needed knowledge and skills) work in their areas of expertise, and the smaller group can often respond more quickly. In addition, the smaller number of committee members can seem less intimidating to those they are working with. However, this approach does not have the breadth of expertise or knowledge of the traditional committee model, and it limits the on-going education of the members who are not participating in the task-at-hand.

A Designated, Individual Consultant Model

An alternate approach to the traditional ethics committee model is to select a single person to do the work of the EC.^{1,3,5} In a rural setting, this person then acquires the training and support to become the 'local expert' in ethics. This person becomes the ethics consultant to the hospital and resolves educational, policy, organizational, and case issues as needed and contracted. The consultant can usually provide a more timely response than a full committee, and can bring considerable expertise and training to the setting. A limitation of this model is that any advice or recommendation is seen as (and is) one person's perspective rather than that of a group. Fewer checks and balances exist in this model. The individual consultant may also require a higher level of ethics knowledge and skills than in a group approach where the knowledge and skills are pooled among the committee members.

This model can, however, be useful when creating or further developing a local ethics committee. In these settings, the individual consultant acquires the education and relationships to inform the hospital on ethics issues. Then this local expert's knowledge is passed to members of a developing ethics committee, as it evolves and becomes established. This strategy can be cost-effective for CAHs that are trying to build an ethics committee over time.

A Multi-facility Ethics Committee (MFEC) Model

Often times having a full ethics committee or even an individual consultant is not feasible for small rural or frontier facilities. In these cases, it is possible for multiple facilities to share a single ethics committee. This is known in the literature as a multi-facility ethics committee (MFEC).^{2,4} The multi-facility ethics committee has the potential to be both efficient and effective by sharing ethics expertise and financial support, and by reducing possible duplication of efforts.

Multi-facility ethics committees are created when each facility identifies one or two professionals who are willing to work together in their commitment to sharing their ethics knowledge and skills with people from other facilities to create an ethics committee resource for their institutions. These members join together with those from other hospitals and select a chair or co-chairs of the committee. Each

participating institution provides modest financial support for their representatives and for the operation of the committee. Because of geographical distances between facilities, meetings can be conducted by conference calls or video-conferencing.

The MFEC can sponsor educational activities for its members and for staff at the participating institutions. An additional function of a MFEC may be proactively reviewing organizational practices and policies of the participating institutions.

The MFEC model is particularly plausible where there is an existing relationship among institutions. Our experiences include programs in central West Virginia and Northern Minnesota. In one setting, three counties have worked closely together to start an ethics committee that serves two small rural hospitals and a number of long-term care facilities. A key ingredient for success in these examples has been the willingness of the top administration at each institution to support the MFEC.

Conclusion

This chapter describes ethics committee structures that can accomplish the committee's designated purpose and activities. A traditional (full) ethics committee is recommended, since it allows for the richest discussions, informed committee work, and provides an effective resource for the hospital. This traditional model can also consist of subcommittees, with specific roles for groups of members. When the traditional model is not feasible, identifying an individual to serve the CAH as the ethics expert, or partnering with regional facilities to create an ethics committee, are valid options.

References

1. Glover, JJ. Doing ethics in rural health care institutions. In: Nelson WA, ed., *Handbook for Rural Health Care Ethics: A Practical Guide for Professionals*. Hanover, NH: Dartmouth College; 2009.
2. Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, 7th ed. New York, NY: McGraw Hill; 2010.
3. Lo B. *Resolving Ethical Dilemmas: A Guide for Clinicians*, 4th ed. Baltimore, MD: Lippincott, Williams & Wilkins, 2009.
4. Nelson WA. Where is the evidence: A need to assess rural ethics committee models. *J Rural Health*. Summer 2006;22(3):193-195.
5. Post LF, Blustein J, Dubler NN. *Handbook for Health Care Ethics Committees*, Baltimore, MD: The Johns Hopkins University Press, 2007.

CHAPTER 6

Rural Ethics Committee Membership

The purpose of this chapter is to describe the variety of member characteristics that are important in the creation of an effective ethics committee (EC) for a critical access hospital (CAH), including the members' skills and knowledge.

An interdisciplinary ethics committee includes members who can accomplish the committee's designated purpose and activities. Those who are appointed to the EC need to be motivated, able to make a time commitment, and ideally, skilled and knowledgeable. First, a committee leader is recruited and appointed, and his or her ethics education is prioritized. Then, additional committee members are appointed, their education is prioritized, and eventually the committee's development as a group becomes sufficient for accomplishing activities.

Selecting Committee Leadership

The selection of a person to lead the ethics committee is a crucial step in a committee's success. Ideally, the person has both the respect of colleagues, as well as ethics expertise (although having ethics knowledge is less important than having personal and professional skills that will keep the committee and its work running smoothly). In cases where the chair is not yet an ethics "expert," he or she would need to pursue on-going ethics education, and initially have access to a professionally trained ethicist. Ethicists in regional centers and large academic centers can be approached to serve in this role. They may be available for phone calls or even to travel to the CAH for meetings

and educational sessions. If this approach is considered, the hospital will need to pay the consultant for these services and extend the Board insurance to cover him or her while working at the CAH.

The EC leader should be well respected within the institution, committed to an extended tenure as chair of the committee, and an effective communicator.¹⁻³ He or she should be able to present concerns respectfully and persuasively, so they are understood when there are difficult recommendations or observations that need to be made, such as recommending changes in hospital procedures, the need to hire additional skilled staff, or lobbying for educational funds for the committee.

Committee Member Selection

The interdisciplinary group that makes up an EC generally includes physicians, nurses, social workers, clergy, administrators, and other health professionals.^{2,3} The hospital legal counsel can participate as needed in an *ex officio* role because of possible conflicts of interest; they have information that can clarify legal ramifications that weave into ethics considerations. A community representative may also be part of the group in order to bring the "patient's" voice into the committee's work. When identifying a community person, often a current or past hospital board member, local businessperson, or local clergy are considered. People in these positions have skills that can add to the information and knowledge base of the hospital-based committee members, as well as provide a direct connection to the community for marketing and support.

Common Professions of Committee Members

- Physician
- Nurse
- Social worker
- Clergy
- Quality Improvement professional
- Community member
- Legal counsel
- Administrator

In smaller settings, the committee may be as few as three or four people, although five or six may be a more effective number depending on the anticipated tasks. The committee membership should also reflect the ethnic and cultural diversity of the patients served by the hospital.³ This is important because a number of ethical concerns arise from differences in religious and cultural expectations.

Personal characteristics are important in selection of committee members, in addition to members' ethics knowledge and skills. Those who are selected to be part of the committee should also be respected for their interpersonal skills, clinical judgment, and willingness to hear and consider a variety of viewpoints. Since some of the discussions can become emotional, the capacity to deal with disagreements and tolerate broad differences is important. Each person—whether professional or community-based—needs to commit to both self-education and maintaining confidentiality.

Committee Member Commitment

People who join an ethics committee commit to work together over a period of time. The hospital invests in these individuals' growing knowledge and skills, so they can become not only skilled, but wise. With time, this training and experience mature. Also, as people work together, they come to know and count on one another's skills. The on-going discussions in ethics settings involve personal values and difficult issues, allowing members to develop an understanding and trust of other committee members' perspectives. Without this level of trust, discussions and insight are limited.

Those who become part of the ethics committee also need to be exquisitely sensitive to confidentiality.³ Living and working in a rural setting where there are multiple overlapping relationships and contacts, this sensitivity is essential. In fact, there are times when a committee member needs to step away from a case or situation because the personal or work-related relationships overlap and can impact the ability to participate objectively.

Time commitment is an additional issue. Much of an ethics committee's work is 'on-call,' as the group responds when cases, policy, or organizational issues arise. Because of the importance of the com-

mittee's work to the organization, members who participate in the EC must have the support of the administration to put the additional time into this work. They should also be compensated for their (over-)time.

Core Competencies for Ethics Committee Members (ASBH Report)¹

In order for an ethics committee to function and fulfill its purpose, each committee member should possess a basic level of knowledge and skills (including clinical and administrative understandings) in ethics in order to accomplish the committee's tasks. The ultimate goal is for patients, families, surrogates, health care providers, and administrators to be able to trust that the EC members are competent to offer the needed assistance. When a committee is first established, becoming trained in these areas reassures other hospital employees that the committee members bring these competencies, not just personal opinions, to their work.

Each member brings different strengths to the ethics committee based on his or her professional background, life experience, and personal qualities. In order to participate fully in committee work, committee members need to supplement their other backgrounds to add the skills needed for effective committee work. The American Society for Bioethics and Humanities has produced a summary of the *Core Competencies for Health Care Consultation*, which describes the skills needed to participate in an EC. In each category, these skills can be basic or advanced skills: basic skill is defined as the ability to use the skill in common and straightforward situations; advanced is defined as the ability to use the skill effectively in more complex cases.

Knowledge Competencies for Committee Members¹

- Moral reasoning and ethical theory
- Typical bioethical issues and concepts in hospital settings
- Relevant health care systems and legal regulations
- Institutional policies and clinical practices
- Beliefs and perspectives of populations served
- Relevant codes of ethics and conduct

Moral Reasoning and Ethical Theory

Possessing knowledge about moral reasoning and ethical theory as they relate to committee work includes understanding at least the basics presented in Chapter 3 regarding differences between morality and ethics; the ethics principles, and the alternate approaches to resolving ethics conflicts. Additionally, having knowledge about the steps needed to accomplish the ethical reasoning process (one approach is described in Chapter 8) is important to this set of information.

Common Bioethical Issues and Concepts

Knowledge of typical bioethical issues and concepts in hospital settings is also a core competency for participating in an EC. Typically, these issues especially include concerns related to end of life care, decision-making, and reproductive health. In a larger sense, these issues and concepts include truth-telling, surrogacy, informed consent, and competency/capacity. A more complete list of these concepts is included in the Glossary at the end of this Guide.

Local Health Care System and Legal Regulations

Understanding relevant health care systems and legal regulations is also important for members of an EC. For example, understanding how medical care is reimbursed; what a CAH can do and who they serve; how transportation between facilities happens; and the role of social services and mental health care, is important when resolving specific issues.

Knowledge About the Hospital's Policies and Clinical Practices

Having knowledge about the hospital's policies and clinical practices allows EC members to recognize ethics issues when they emerge—policies and practices provides the contextual background for all ethics issues. Also with this knowledge, committee members can recognize when policies and practices are not serving patients and families well and can work with the hospital at an organizational level to revise them.

Knowledge of the Beliefs and Perspectives

Knowledge the beliefs and perspectives of the populations that are served at the hospital is essential to working as part of an EC. This information holds the values and beliefs that become the substance of ethical dilemmas: when values conflict, decisions are needed that prioritize one set of values over a set of equally compelling issues. Without this knowledge, a member of an ethics committee cannot fully perceive or understand the ethics conflict.

Relevant Codes of Ethics and Conduct

Relevant professional codes of ethics and conduct also provide important background information for ethics committee members. When there are disagreements about how to proceed, treat, or otherwise serve patients and families, the commitments made through professional codes of conduct (which were often conferred as 'oaths' upon graduation from school) provide strong direction for professionals.

Areas of Expertise Essential to Ethics Committee Members

Skills for Ethics Committee Members¹

- Ethics assessment skills
- Process skills
- Interpersonal skills
- Evaluative skills

Ethical Assessment Skills

Ethical assessment skills include the ability to gather relevant data, assess the dynamics of the case (including power relations, racial, ethnic and religious issues), and distinguish the ethical issues from the clinical, legal, and institutional concerns. Assessment skills also include being able to recognize the values that are in conflict (including those of the EC members), and to clearly articulate the ethical issue(s) that are involved in the conflict.

Process Skills

Process skills are needed to respond to a committee request and include the ability to identify resources that are needed to reflect upon, respond to, or resolve the concern (e.g., which providers, family members, etc., are involved; library or internet searches; etc.) Process skills also include the ability to communicate the findings and recommendations to the others involved in the case; and to document the consultation clearly and thoroughly in the patient's record. Identifying any institution-level concerns that the conflict has raised is an additional process skill.

Interpersonal Skills

Interpersonal skills are critical to every aspect of EC work. These skills include the ability to listen to, and communicate with, all involved parties; to educate the involved parties regarding the ethical dimensions of the concerns; to clearly describe the views of various parties; and to enable communication among those who are involved. These skills actually allow communication around barriers that otherwise keep the conflict from being resolved.

Evaluative Skills

Finally, committee members need evaluative skills to be able to critically analyze the uncertainty or conflict present in an ethics issue. Committee members should be able to access relevant resources, knowledge, and arguments, and then identify and justify a range of ethically acceptable options and their consequences. Knowledge of common ethics issues and concepts is also useful in encountering ethics cases, as are the skills to recognize and use moral reasoning and ethics theory in considering the options.

These skill sets are essential to the functioning of the EC. When consulted, committee members need to obtain relevant information; interview the stakeholders involved in an issue; assure that the voices of all are heard, especially those of the patient and family; explain, facilitate, and when appropriate, mediate solutions; and document the process appropriately. Beyond the consultation process, committee members are also asked to view the larger picture of the hospital

setting, so that the issues might be prevented in the future through policy and procedural changes. These functions are addressed in more detail in Chapter 8.

New Committee Members Over Time

These skills need to be acquired by new members who are added to the EC over time. New member orientation to the committee's work should include personal mentoring, a reading list that includes background pieces to complement the skills the member brings through their professional training, and an opportunity to routinely ask questions of the committee. Additionally, an agenda item for each committee meeting should include an educational piece, even if brief, to continue the education of current members, as well as newer members.

Conclusions

This chapter describes the variety of skills, knowledge, and personal characteristics that are important in ethics committee members.

References

1. ASBH Core Competencies resource materials available through: <http://www.asbh.org/publications/content/edguide.html>
2. Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, 7th ed. New York, NY: McGraw Hill, 2010.
3. Post LF, Blustein J, Dubler NN. *Handbook for Health Care Ethics Committees*, Baltimore, MD: The Johns Hopkins University Press, 2007.

CHAPTER 7

Ethics Education Activities in Critical Access Hospitals

The purpose of this chapter is to suggest practical approaches for the ethics committee (EC) when fostering ethics education in the critical access hospital (CAH) and beyond. Ethics education should begin with the self-education of the committee members followed by sharing knowledge with staff throughout the facility. Once education activities are established within the facility, they can be extended to community members. This will help to raise the community's understanding of typical issues faced in health care; to expand the community's awareness of the role of the hospital-based ethics committee; and to hear the community's values by way of their responses to the educational topics.

Committee Member Self-Education

As an ethics committee becomes organized and begins its work in a CAH, it is important that committee members are educated both individually and as a group. The hospital needs to be supportive of these activities in order to create a resource that can serve patients, the hospital, and the community. There are many ways this education can occur. It is often useful to identify an ethics leader and allow that individual to obtain the initial training. This leader can then serve as an educator to other committee members. This allows committee teamwork to be established early, and to continue building as the group matures.

Committee members can educate themselves independently, or with ethics committee colleagues as a group, using the available ethics literature or attending ethics education conferences.¹⁻⁵ They may also

choose to engage in more formal health care ethics certificate and degree programs. Regardless of the method, the key is that each committee member should acquire the knowledge and skills described in Chapter 6 to accomplish the committee's work.

Resources for the self-education of committee members are described below, and several specific resources are included in the Appendix of the *Guide*. Appendix I offers a brief list of resources.

Ethics Resources and Networks

- Ethics literature and Web-based resources
- Professional clinical or administrative colleagues
- Health care ethicists
- Professional organizations
- Ethics committee networks
- Academic-based ethics programs

Rural Ethics Literature and Resources

To successfully manage a broad spectrum of ethics challenges in rural practices, committee members need to acquire a basic understanding of health care ethics, including an awareness of basic ethical standards of practice. Ethical standards can be found in a wide variety of profession-specific sources including textbooks, the American College of Physicians Ethics Manual,⁶ professional codes of ethics, and various position papers on a wide variety of ethical concerns. The end of this chapter includes a list of strong resources to use when beginning this process; the end of this *Guide* provides an expanded bibliography. Many ethics centers have created useful Web sites that offer a wide range of resources that can be accessed as well.

Networking with Professional Colleagues

In addition to developing ethics-related knowledge and skills, rural health care professionals can develop a network of colleagues, who can be consulted to provide support or advice regarding ethics challenges. Seeking the perspective of clinicians or administrators outside

the immediate situation can provide the rural provider with insight, clarity, and supportive advice.

Collaborating with Professional Organizations

In addition to collaborating with colleagues and ethicists, CAH ethics committee members can foster linkages with national and state professional organizations that may have a rural focus. These linkages can help to enhance educational opportunities for committee members, by providing the opportunity to network with contacts. These contacts can provide an opportunity to engage with others on topics of concern in rural health care delivery, including the ethical challenges inherent to rural practice. With these contacts, rural health care professionals can actively participate in national professional organizations that establish standards of care to ensure that a rural perspective is heard. Rural health care providers can also work with such organizations to advocate for adequate rural health care resources.

Networking with Ethicists

CAHs can identify health care ethicists to provide them with consultation and local training. Despite the general lack of trained ethicists living or working in rural settings, many are available through the telephone, email, Internet, or telehealth programs. Developing contacts with ethicists and clinicians can alleviate any potential sense of isolation for the CAH. As mentioned in Chapter 5, larger health systems in the region usually have ethics programs, and their ethicists could participate in this network and perhaps serve as a resource for the CAH ethics committee. Additionally, the American Society of Bioethics and the Humanities (ASBH) is a large professional society that focuses on scholarship and teaching on health care ethics issues. The ASBH Web site offers a directory of members by state that can be accessed to help identify a nearby member. ASBH has established a formal affinity group on rural bioethics that meets at a scheduled time during the ASBH annual meeting.

Identifying Ethics Committees Networks

Ethics committee members should identify if a state-based ethics network is available in their area. Some networks are rural-focused, such

as in Northern Minnesota, Vermont and West Virginia. Even the State ethics networks that are not rural-focused can be useful resources for CAH ethics consultants and committee members; existing networks often provide ethics education programs, as well as opportunities to meet, share experiences, and reflect on cases.

If a state-based ethics committee network does not exist in your state, you may want to consider developing one, especially among the CAHs. Helpful guidance for forming a regional or state ethics network can be found in Chapter 16 of the *Handbook for Rural Health Care Ethics: A Practical Guide for Professionals*. The chapter is titled, "Developing Rural Ethics Networks." The *Handbook* is also available free of charge on Dartmouth Medical School's Community and Family Medicine Web site: <http://dms.dartmouth.edu/cfm/resources/rhc/>

Accessing Academic-based Ethics Centers

CAH ethics committee members can identify and use academic-based ethics centers and Web sites that provide ethics resources. These Web sites can serve as valuable sources of information, resources, and material. Many of these Web sites are listed in this *Guide's* bibliography. In addition to ethics-focused sites, there are several outstanding general rural resources, including the Rural Resources Center (RAC) and the National Rural Health Association (NRHA). Both organizations have comprehensive Web sites.

Local CAH-wide Education

Following self-education, EC members should look to provide continuing education for clinicians, staff and administrators at their CAH. Some of this education can be related to policy and procedures that the committee has been involved with or developed; other efforts can provide forums for discussion of recent difficult or uncertain situations. These discussions may be 'Lunch and Learn' sessions. Committee members may also serve as speakers or panelists for continuing education of hospital employees; this can build community, establish expectations, and inform others of the committee's approaches to challenging situations.

Community Ethics Education

The EC can provide an important connection to the community at large. Ethics committees work to incorporate community values into decisions; in order to do this; they need to be in close connection with the community in order to understand their values. For example, providing facility or community-based programs, such as at churches, regarding advance directives or other end-of-life care concerns, allows community members to begin the conversation about personal preferences at the end of life. Presentations about organ donation to groups of young adults can prepare them for the opportunity to become a donor when they obtain their driver's license—or help them to better understand what becoming a donor entails. These CAH or community-based presentations provide education to community members, and they also allow the committee members to learn about the community's concerns and values. These important insights can then become woven into the committee members' in-hospital work.

The National Rural Bioethics program, based in Missoula, Montana, has facilitated community forums using the Readers Theater approach. A Readers Theater is designed to provide education and to stimulate informed conversation. The Readers Theater technique was developed and pioneered at East Carolina School of Medicine, where actors read a story line that describes problems that develop when providing health care. The scripts can be based on various common ethics issues encountered in rural settings, and participants may try on different roles. As described in the National Rural Bioethics Project's Educational Resources Web site,⁷ "incidents are described in the voices of physicians, nurses, hospital administrators, patients, families, and clergy. An administrator or physician may read a nurse's or a patient's lines, a patient may assume the physician's role. After the reading, the actors and audience engage in a discussion of the issues and themes." It has been noted that the scripts have been well-accepted by a wide variety of rural audiences and health care providers, and have provided a way to talk about ethics issues. Potential scripts can be found on the National Rural Bioethics Web site.⁷

CAH ethics committee members can also develop pamphlets or other handouts describing their ethical standards of practice to comple-

ment the discussions. Pamphlets on various topics can be made available in clinic and hospital waiting rooms, or given to patients during one-on-one visits.

Conclusion

Ethics education is critical to the effectiveness of the EC. Education of the committee members is an ongoing process and should never be minimized. The education of the committee can then be shared with the CAH's staff and the local community. There are many rural ethics resources that can be accessed by the committee members. In Appendix I of this *Guide*, there is a very brief selected bibliography that EC members will find useful.

References

1. American Society for Bioethics & Humanities' Core Competencies Update Task Force. *Core Competencies for Health Care Ethics Consultation: The Report of the American Society for Bioethics and Humanities (2nd Ed.)*. Glenview, IL: American Society for Bioethics & Humanities; 2011.
2. Society for Health and Human Values–Society for Bioethics Consultation. *Core Competencies for Health Care Ethics Consultation: The Report of the American Society for Bioethics and Humanities*. Glenview, IL: American Society for Bioethics Consultation; 1998.
3. Aulisio MP, Arnold RM, Youngner SJ. Health care ethics consultation: nature, goals, and competencies. *Ann Intern Med*. 2000;133:59-69.
4. Orr RD, Shelton W. A process and format for clinical ethics consultation. *J Clin Ethic*. 2009;20:79-89.
5. Smith ML, Sharp SS, Weise K, Kodish E. Toward competency-based certification of clinical ethics consultant: a four-step process. *J Clin Ethic*. 2010;21:14-22.
6. American College of Physicians. *Ethics Manual (Fifth Edition)*. http://www.acponline.org/running_practice/ethics/manual/ethicman5th.htm
7. The National Rural Bioethics Project <http://www.umt.edu/bioethics/>

CHAPTER 8

A Model Process for Ethics Deliberation and Consultation

The traditional purpose and activities of an ethics committee (EC) include offering consultation in difficult clinical and management cases, as well as assisting with ethics education, participating in policy development, and (increasingly) being instrumental in hospital quality improvement efforts. The purpose of this chapter is to describe how hospital procedures can be drafted to allow clinical consultation, and to suggest a deliberative approach that an ethics committee can use when they are asked to consider and make recommendations regarding an ethics issue.

Consultation Procedures

In hospital settings, where ethics committee consultations are available, identified hospital procedures for accomplishing these consults should exist. These steps are specific to each setting, and depend on both the unique people and procedures involved. It is important that these steps are recorded so that the committee's work can be evaluated for effectiveness. Included below is an example of how a hospital can describe its consultation process. In this example, the charge nurse is the common pathway to communicate a request for an ethics consult.

ACKNOWLEDGEMENT

This chapter is adapted from: Glover, JJ. Doing ethics in rural health care institutions. In: Nelson WA, ed., *Handbook for Rural Health Care Ethics: A Practical Guide for Professionals*. Hanover, NH: Dartmouth College; 2009; available at <http://dms.dartmouth.edu/cfm/resources/ethics/>

Hospital Consultation Procedure Example

- Requests for consultation may be initiated by the patient, family, attending physician, other health care providers, or any person having a significant relationship with the patient.
- When a request arises, the charge nurse contacts the ethics committee member on call (usually the chair of the Ethics Committee) to begin the consultation.
- The ethics committee member on call reviews the request for appropriateness. If appropriate for consultation, the committee is convened.
- The committee reviews the case and proceeds as follows:
 - ◆ Discusses issues that initiated the consultation including medical, family, economic, psychosocial, spiritual, legal and ethical dilemmas.
 - ◆ Clarifies options, including the ethical justification or rationale for each option.
 - ◆ Selects appropriate options to recommend.
- The ethics committee communicates its recommendations to the appropriate involved parties.
- A summary statement is placed in the patient's medical record Progress Notes by the ethics committee member on call.

Committee Deliberation Process

Ethics analysis is part of everyday clinical and management decision-making, but in more complex or troubling circumstances, a more formal mechanism for ethics deliberation is necessary.¹⁻³ In these settings, the issues are reviewed using a decision aid. This approach allows the committee members to reflect on the competing values that created the ethical distress and conflict. A committee can also use this review process retrospectively to gain experience and prepare themselves to perform consultations when the EC is still in early development.³

The goals of this deliberative process are to assure that all ethics issues are adequately identified and understood; that the perspectives of all relevant stakeholders are heard; and that ultimately, a course of

action that is ethically justifiable is chosen.¹ The deliberation process pushes committee members to carefully name and review all potential courses of action and their appropriateness for addressing the ethics conflict. In most cases, the EC only makes recommendations to the traditional decision-makers (the clinicians and patient/family/surrogate), and the clinician and patient make the ultimate decision. Several models for ethics decision-making are available in the literature, but all share some of the basic components or steps that are highlighted below in a process adapted from Dr. Glover's chapter, "Doing' ethics in rural health care institutions." (In: Nelson WA, ed., *Handbook for Rural Health Care Ethics: A Practical Guide for Professionals*).¹

Process for Committee Deliberation

- **Step 1:** In plain words, what is the ethical question that needs addressing? (These are "should" and "ought" questions.)
- **Step 2:** What are the relevant facts?
- **Step 3:** What are the concerns, values, and preferences for each of the relevant parties (separating patient, family, clinicians, etc., perspectives)?
- **Step 4:** What is/are the conflict(s) among values?
- **Step 5:** What are the options; what can be done to address the ethical question?
- **Step 6:** Make a choice among the options; include a discussion of how to proceed along this course of action.
- **Step 7:** Justify your choice. Give the reasons to support your recommendation, referring to the values in Step 4 and the ethics guidelines that are at stake.
- **Step 8:** How could this ethics issue have been prevented? Should any facility policies, guidelines, or practices be revised to diminish the presence of this ethics issue in the future?

Case Study

This section of the chapter offers a case study followed by a case analysis applying the suggested deliberative process.

The O'Donnell family has ranched in the Sweetwater Valley since the 1850s. "It's what my grandfather left us," says Sam, "and I don't plan to let him down." There's nothing easy about this life—too much snow in the winter, not enough rain in the summer. On eight sections of land, Sam and his sons put their cattle out to graze, grow hay, and if they're lucky and get the moisture, harvest some wheat. "In a good year, we make a buck, and in a bad year, we lose two, but we're here and we're not going anywhere else," says Sam. The little hilltop cemetery on the edge of his property quietly underscores Sam's statement. Fenced with barbed wire, it's the resting place for Sam's grandparents, his parents, his uncles and others who worked this land over the past 150 years.

When Dr. Richardson moved to this ranching community about five years ago, Sam O'Donnell was one of the first people he met. Since then, Dr. Richardson has provided medical care to Mr. O'Donnell, Mrs. O'Donnell and their sons. He attended the festivities at the ranch when the O'Donnell's son was married, and just last year, he delivered the rancher's first grandchild.

When Mr. O'Donnell arrives at the emergency room with chest pain and shortness of breath, he admits to "being a little slow this spring." But it's been a cold spring, he explains, and long hours have been spent protecting the new calves. He'd be grateful, though, if he could get something for this pain and the "funny, sick feeling" he's had for the past few weeks that doesn't seem to be passing. He came to the emergency room because he was in town and it was a convenient stop before returning back out to the ranch.

Dr. Richardson examines Mr. O'Donnell and is frankly concerned. He suspects serious heart disease, and explains to the rancher that he needs more tests. "You need to go to the city," says Dr. Richardson. He carefully explains the tests that

will be done, and the procedures that might be needed. "I've heard of those by-passes," says Sam O'Donnell. "And I know Pete, my neighbor, had an angioplasty; that was the beginning of his troubles. He died anyway, but not before he had more surgery and a lot more bills." Mr. O'Donnell says he'll go home and think about the whole situation. He and his wife don't have health insurance, and there's nothing they can sell right now to pay for a lot of medical care. "The boys can take care of the ranch," he says. "And they'll take care of their mother, and she'll have a home. My grandson can grow up knowing he has a place. But if I ransom this place to pay for a heart, well, there won't be much left for anyone to live for."

"I expect that we can keep this between us," says Sam O'Donnell. "My wife is just glad I stopped to check in with you about it. I'm not going to have her choose between life for me or life for her boys." The rancher does not indicate exactly what he will tell his wife, their sons, and his friends. Dr. Richardson is pretty sure that Mr. O'Donnell will just attribute his difficulties to hard work—and nothing that a little rest can't cure—and expects that his wife will accept the story.

Case Summary

Dr. Richardson is a primary care physician who has been taking care of the O'Donnell family since coming to the rural community five years ago. Sam O'Donnell is a rancher who presents to the emergency room where Dr. Richardson diagnoses symptoms of coronary artery disease and recommends further evaluation and treatment at a distant health care center. Mr. O'Donnell refuses to go to the other medical center for further assessment and treatments, and does not have savings or medical insurance. Mr. O'Donnell does not want to 'ransom his place' and possibly leave his family destitute to pay for medical care, when he may die anyway. Mr. O'Donnell wants Dr. Richardson to tell his wife that he is fine.

Case Deliberation Process

Step 1: What are the ethical questions?

As is typical in rural settings, there are several overlapping ethical questions raised by this case. Each of them carries implications for the other questions:

- What are Dr. Richardson's ethical obligations to Mr. O'Donnell; what should he tell him?
- What are Dr. Richardson's obligations to Mr. O'Donnell's family? What should he tell them? If they ask Dr. Richardson directly, what should he tell them?
- What are Dr. Richardson's obligations to the community?

Step 2: What are the relevant facts?

Medical facts: Mr. O'Donnell has been experiencing chest pain and shortness of breath since the spring; Dr. Richardson suspects coronary artery disease after the rancher's physical examination in the emergency room; Dr. Richardson recommends that Mr. O'Donnell "goes to the city" for more tests and possible procedures, which he carefully explains; Mr. O'Donnell says that he will go home "and think about the whole situation." Dr. Richardson anticipates that Mr. O'Donnell will need a lot of support during this illness, with or without additional treatment.

Medical insurance: Mr. O'Donnell and his wife don't have health insurance; there is nothing that they can sell to pay for medical care.

Confidentiality request: Mr. O'Donnell asks Dr. Richardson to keep this information between them—not to tell his wife; Mr. O'Donnell doesn't say exactly what he will tell his wife, sons and friends; Mr. O'Donnell is concerned that his wife will have to choose between life for him, or a future for their boys.

Beliefs and experience: Mr. O'Donnell's friend had angioplasty and "that was the beginning of his troubles. He died anyway...with more surgery and a lot more bills."

Context: Sam O'Donnell's ranch has been in his family since the 1850s; Dr. Richardson moved to this ranching community about five years ago; Mr. O'Donnell was one of Dr. Richardson's first patients; Mr. O'Donnell's wife and sons are also Dr. Richardson's patients. The additional facts that need to be gathered:

- How long has Mr. O'Donnell been experiencing his symptoms? How urgent is his need for further evaluation and treatment?
- How far away is "the city"?
- Are there alternative settings or opportunities where he could get tests at reduced costs?
- What does Mr. O'Donnell expect Dr. Richardson to say about his health status? What if his family asks Dr. Richardson specifically about his health status?
- How does this family usually make tough decisions that impact everyone in the family?
- What other sources of support, *e.g.*, other relatives, neighbors, and/or a faith community does Mr. O'Donnell have? His family?

Step 3: What are the concerns, values and preferences for each of the relevant parties?

Mr. O'Donnell's values center around his family's financial well being—he wants to preserve the family ranch and not incur large medical bills that could put the financial viability of the ranch at risk. He is concerned enough about his health to visit the doctor and seems to be well connected to his wife, as he has come to see the doctor at her request, but he ultimately wants to protect her from his health information. Sam O'Donnell also values privacy—even from his family. He wants Dr. Richardson to keep their conversation confidential.

Dr. Richardson's professional values include providing appropriate state of the art care and promoting Mr. O'Donnell's well being by offering him further evaluation and treatment of his suspected coronary artery disease. Other values include truth-telling: making sure that Mr. O'Donnell has enough information to make an informed decision to accept or refuse further testing (*e.g.*, respecting his autonomy), and not lying to Mr. O'Donnell's family if he is asked direct questions

(Dr. Richardson may also consider it "lying by omission" if he accepts that Mr. O'Donnell may tell his family something that is not true, and he does not correct the misinformation they have received.) Trust is at stake in Dr. Richardson's relationship with Mr. O'Donnell due to this confidentiality issue, but trust is also at stake in his relationship with the O'Donnell family, and the community. Justice is obviously an important value for Dr. Richardson, too. He is concerned that it wouldn't be fair to keep the family uninformed and thus less able to help their father through his illness or treatment. Justice is evident in another way as well: Dr. Richardson treats Mr. O'Donnell at an emergency room, even though the rancher doesn't have insurance; Dr. Richardson wants to offer the same level of care to Mr. O'Donnell as he does to his other patients who do have insurance. Dr. Richardson also has compassion for Mr. O'Donnell and his predicament—he wants to help Mr. O'Donnell get any needed services without sacrificing his family's ranch.

We can assume that **Mr. O'Donnell's wife** values her husband's health and well being; she is the one encouraging her husband to see Dr. Richardson. We don't know anything about how this family makes important decisions, but it doesn't seem that shared decision-making and openness are priorities, at least for Mr. O'Donnell, since he is planning to make this decision privately and independently.

Step 4: What is/are the conflicts among values?

There are several conflicts raised between the values observed in Step 3. Overall, Dr. Richardson's clinical dilemma arises from the conflict between his desire for promoting Mr. O'Donnell's well-being and respecting Mr. O'Donnell's desire to make his medical decisions independently and privately. Dr. Richardson wants to respect Mr. O'Donnell's decisions, but not at the expense of compromising his patient's care by being untruthful to his family.

Contextual ethics issues also play into the clinical concerns raised here and add complexity. They include:

1. Mr. O'Donnell's choice to spare his wife a decision, that he thinks she should not have to make, raises both autonomy and justice issues within their relationship: is

this fair to her? Learning how this family makes tough decisions may be important information for resolving the ethics issues.

2. Also, Dr. Richardson's relationship with the other members of the O'Donnell family, who are also his patients, and his relationship with his other patients in this rural community are also at stake: If people believe that Dr. Richardson failed to diagnose and treat Mr. O'Donnell's problems, will they still trust Dr. Richardson to provide their care in the future?

Step 5: What are the options? What can be done to address the ethics questions?

The clinical question that needs to be addressed is how Dr. Richardson should respond to Mr. O'Donnell's request not to say anything to his wife/family. The options listed here are ethically appropriate to varying degrees (see discussion in Step 7).

1. Dr. Richardson could do as Mr. O'Donnell requests, but with one caveat: he could tell Mr. O'Donnell that if his family asks, he will direct them to talk with Mr. O'Donnell; Dr. Richardson will not lie to Mr. O'Donnell's family.
2. Dr. Richardson could agree to do as Mr. O'Donnell requests, but with one caveat: he could tell Mr. O'Donnell that if his family asks, he will answer their questions honestly, because he will not lie to Mr. O'Donnell's family.
3. Dr. Richardson could try to persuade Mr. O'Donnell to allow a discussion about these care decisions between the doctor, Mr. O'Donnell and Mr. O'Donnell's wife.
4. Dr. Richardson could try to convince Mr. O'Donnell to get further tests by finding alternate sources of funding for the evaluations.
5. The doctor could call Mr. O'Donnell's wife, tell her of her husband's health issues, and recruit her to talk with Mr. O'Donnell about his health care choices.

6. Dr. Richardson could discharge Mr. O'Donnell from his practice, since the patient is not willing to do what Dr. Richardson is advising.

Step 6: What should the provider do—what is the best choice among the options? Include a discussion of how it would actually be done.

Overall, when faced with ethical distress, the normal first response for any clinician is to consider his or her 'gut reaction' to the question of "What should I do?" However, the complexity of the ethics issues in this case calls for a reflection on the dynamics of the larger situation. This will help to clarify the various relationships and ethical considerations between the issues.

After a thorough ethical deliberation, it seems that the recommended course of action should be for Dr. Richardson to try to convince Mr. O'Donnell to have a discussion about his health status with his wife (Option 3). This would allow all of the involved parties to be fully informed and commit to a common set of goals for the care for Mr. O'Donnell.

Step 7: Justifying your choice, giving reasons to support the decision.

When ethical distress is present in the clinical setting, the various ethics issues need to be addressed and responded to in a clear manner. The recommended course of action should incorporate ethics guidelines/principles and, in rural settings, should take into consideration all secondary ethics issues that may be present outside of the clinical setting.

Option 3: This option honors Mr. O'Donnell's wishes (respects his autonomy) and also encourages Mr. O'Donnell to bring his family in for assistance (builds beneficence while reducing potential harm, by informing those impacted by the decisions; addresses the justice issues of fairness and cost; builds family support). This option also maximizes trust, openness, truthfulness, and a shared understanding of everyone's well being, and is the recommended option.

Options 1 and 2: If Mr. O'Donnell cannot be persuaded to have his wife join in on a discussion regarding his health care decisions, the next best option would be either Option 1 or 2. Both of these options call for Dr. Richardson to set limits in his relationship with Mr. O'Donnell, while at the same time giving him room to honor Mr. O'Donnell's preferences for care. These options also allow him to maintain honesty when communicating with the O'Donnell family. Ultimately, selecting either of these two options maintains a balance between the obligations of the patient and the provider, while also addressing the larger contextual issues involved.

Unfortunately, engaging in either option 1 or 2 will potentially deceive Mr. O'Donnell's family (e.g., they may never ask for more information) and may leave community members with the impression that Dr. Richardson provides less than the standard of care. Additionally, it could be difficult for Dr. Richardson to see Mr. O'Donnell and his family at future appointments, and otherwise around town, while maintaining this secret. To address this issue in the future, as part of the ongoing and continuing care plan, Dr. Richardson might intermittently invite Mr. O'Donnell to involve the rest of his family or maybe a trusted spiritual leader, into his care conversations and decisions. Perhaps over time, Mr. O'Donnell would see the benefits of being more open with his circumstances, as well as the harms associated with keeping his health status a secret.

Options 4 and 5: The ethical appropriateness of options 4 and 5 depends on the nature of the pre-existing relationships between Dr. Richardson and the O'Donnell family. Unless Dr. Richardson knows Mr. O'Donnell and his family very well, options 4 and 5 are not appropriate options, in that they are violations of professional conduct. However, if there is an existing personal relationship between them already, sharing Mr. O'Donnell's prognosis may not compromise confidentiality, based solely on established patterns of behavior in the relationship. However, if there is no established relationship, these options have potential to cause considerable harm (and little benefit) given the contextual issues: family and community dynamics could become public, and trust would certainly be undermined.

Option 6: Although it is ethically defensible, option 6 is the least practical option in that this case occurs in a rural setting. Dr. Rich-

ardson has obligations to provide care for those in his community, and he has built a level of trust in his community. Where would Mr. O'Donnell find care if Dr. Richardson did not provide it? Although Dr. Richardson does not have an unqualified obligation to provide care, Mr. O'Donnell's refusal to undergo additional evaluation and involve his wife in decision-making do not provide an adequate justification to fire Mr. O'Donnell as a patient, given the difficulties of finding other health care providers in rural settings.

Step 8: How could this ethics issue have been prevented?

The important ethics issues of this case are confidentiality, truth-telling, decision-making, and trust. It is important for all physicians to communicate to their patients and staff the importance of respecting a patients' needs and requests, as long as they do not interfere with honoring other patient's needs and requests. One possible way to communicate this (and to prevent ethics issues that may arise from not communicating it) is to have written information available, and conversations with all (new) patients, that speak to these issues and their importance. It might be easier for Dr. Richardson to keep Mr. O'Donnell's wishes private if he had previously spoken with the O'Donnells about this.

Consensus and Conscience in Ethics Deliberation

Ethics committee members reading this discussion may disagree with our analysis of this case. Such disagreement is not a bad thing—in fact; it is a necessary part of ethics deliberations. Confronting counter-arguments and responding to them makes an accepted reasoning stronger. Good reasoning is based on sound information and is supported by respect for differing values, the ranking of competing values, and by the prioritization of ethics guidelines and principles. Disagreement over how to balance differing values is the most difficult aspect of any ethics deliberation. Resolution ultimately requires the skills of respectful attention, patience, and open inquiry.

Although a comprehensive and careful process of ethics decision-making usually results in consensus, deep disagreement can still exist. The responsibility of those working as part of (and with) an ethics committee is to ask that each involved member be thorough

and clear-thinking, challenge assumptions, and strive to resolve disagreements.

Conclusions

This chapter describes a deliberative approach that can be used when performing ethics consults, and suggests how hospital procedures can be drafted to mitigate and resolve the ethics issues creating these consults.

References

1. Glover, JJ. Doing ethics in rural health care institutions. In: Nelson WA, ed., *Handbook for Rural Health Care Ethics: A Practical Guide for Professionals*. Hanover, NH: Dartmouth College; 2009
2. Lo B. *Resolving Ethical Dilemmas: A Guide for Clinicians*, 4th ed. Baltimore, MD: Lippincott, Williams & Wilkins, 2009.
3. Post LF, Blustein J, Dubler NN. *Handbook for Health Care Ethics Committees*, Baltimore, MD: The Johns Hopkins University Press, 2007.

CHAPTER 9

Anticipating and Preventing Recurring Ethical Challenges

The purpose of this chapter is to briefly introduce an emerging role for ethics committees (ECs): the application of the concept of preventive ethics. In addition to the traditional functions of ethics committees, there is growing interest in a preventive ethics function to address recurring ethics conflicts and issues.

The need for a preventive ethics approach grows out of the recognition that recurring ethics conflicts can have a detrimental effect on critical access hospitals (CAH). Ethics conflicts can affect a patient's quality of care, the hospital staff, and the facility's reputation. The negative impact of ethics conflicts is recognized as undermining staff morale, diverting staff time, increasing job turnover, and negatively affecting the organization's culture.¹⁻⁴ In addition, analysis of the economic costs of ethics conflicts identified several cost categories related to the ethics conflicts—organizational operational costs, legal costs, marketing and public relations costs.⁵⁻⁷

Preventive ethics is a systems-oriented approach for addressing recurring issues, frequently applying quality improvement thinking and methods, in order to decrease the likelihood of recurrent ethics con-

ACKNOWLEDGEMENT

This chapter is adapted from: Nelson WA, Schiffedecker KE. Practical strategies for addressing and preventing ethical issues in rural settings. In Nelson, WA, ed., *Handbook for Rural Health Care Ethics: A Practical Guide for Professionals*. Hanover, NH: Dartmouth College; 2009; available at <http://dms.dartmouth.edu/cfm/resources/ethics/>

flicts.⁸⁻¹² A recurring ethics issue is one that involves different patients, at different times, in different settings, but raises the same basic ethics conflict—such as disagreement over whether a treatment is futile in end-of-life care. It also can be a recurring management issue such as actions or decisions that potentially create a conflict of interest.

Strategies for Preventing Ethics Conflicts

There are several constructive strategies that ECs in CAHs can engage in to proactively address ethics conflicts and potentially decrease their frequency.

Constructive Strategies for Preventing Ethics Conflicts

- Develop and propagate CAH policies and practice guidelines to avoid recurring ethics conflicts
- Collaborate with various facility departments and programs to identify and address ethics conflicts
- Expand ethics training among clinical staff in rural settings
- Enhance ethics awareness in rural communities through public forums and discussions

There are two fundamental strategies for implementing a preventive ethics approach in CAHs. A preventive approach to ethics conflicts can be employed by an EC in conjunction with its other activities. As discussed earlier in this *Guide*, a common activity for ECs is to have an ethics consultation service that assists staff in addressing challenging clinical cases with ethics conflicts. This approach tends to be reactive—a response to a current conflict. This traditional reactive approach to complex and challenging ethics conflicts can be helpful to the involved parties. However, this reactive approach also has several potential concerns. First, responding to an ethics conflict occasionally requires a rapid response that is not always available in CAHs. Second, time limitations of committee members can affect the availability of ethics consultants and committee members, and thus preclude a thoughtful review of the conflict. And third, the traditional reactive process tends to accept that ethics conflicts are frequently

recurring and ignore the reality that ethics conflicts take a toll on the CAH, and can be addressed proactively.

Despite these concerns, having a competent, effective and available ethics consultation response is essential because ethics conflicts do arise and need to be addressed in a timely way. However, adding a preventive approach to the case consultation process can also be critically important. As part of their role on an EC that performs ethics consults, committee members are in positions to identify the underlying causes of conflicts and suggest corrective actions to decrease potential recurrences in the future. For example, once the case consultation has been provided, ethics committee members, in collaboration with those requesting the consultation, might come to the question during a debriefing session—“this situation happens over and over again, what we can do to prevent it?” Together EC members should begin the process of assessing why the conflict occurred. They might apply a Root Cause Analysis process to the recurring ethics conflict. After getting a better sense as to why the conflict occurred, EC members might propose a strategy to prevent it from happening again, such the development of a practice guideline or an educational activity. An ethics practice guideline is a guide for action that is consistent with ethical standards and the organization’s values. The preventive process is used to focus on improving organizational systems and processes to ensure quality care, and when needed, redesigning systems and practices, rather than focusing on the individuals involved in the ethics conflict.

Preventive thinking can be used in many settings and situations beyond the consultation process. Because many ethics conflicts are not reviewed by the ethics committee, staff can employ the same approach throughout the facility by proactively identifying ethics issues and developing strategies for addressing them.¹³⁻¹⁶ For example, during a physician or nursing staff meeting the question could be asked, “What situations have created ethical uncertainty or conflict this past week? Is the conflict a new or recurring issue? Did it create uncertainty regarding how best to respond to the issue?” The noted ethics issues can then be prioritized, and systematically and thoughtfully discussed to create an ethically-grounded, proactive response. Then, the resulting guideline can be shared in an attempt to address similar circumstances in the future.

Another strategy to promote a preventive ethics approach is through community outreach programs. CAH ethics-related policies, such as privacy and confidentiality policies can be shared as part of an education forum. The community outreach effort can provide helpful information to community members by enhancing their understanding of the CAH’s fundamental values. If there are questions about the CAH’s values and practices, questions can be addressed in an atmosphere of open communication.

Developing and Propagating Ethical Standards of Practice

Whether a recurring ethics issue is identified in conjunction with a formal ethics consultation or in staff discussions, a thoughtful systems-oriented process should be employed to develop a proactive response. Both applications of the proactive approach to ethics conflicts should apply five basic steps.

The process starts by identifying the recurring ethics issue, such as during the debriefing following the ethics consultation or in a staff meeting. For example, a member of the EC could meet with the Head of Human Resources, or a Vice President of Operations, and ask the question, “What are some of the recurring ethics issues that you or your staff has recognized that create distress or conflict?” Once the ethics issue(s) are identified the EC can systematically and thoughtfully discuss the identified ethics issues with other health care professionals with interest in the issue. For example, if the identified issue is an end-of-life issue the group might consist of additional staff. This process is similar to a quality improvement initiative. In fact much of the preventive ethics-thinking correlates with quality improvement efforts-thinking and methods.

This preventive ethics group would then study the recurring issue, draft a plan such as practice guideline or an educational initiative, share the guideline or implement the training, and assess whether the guideline or training has helped to reduce the occurrence of the ethics issue from becoming a conflict. If the guideline or training has been less than effective, the approach will need to be reviewed and revised.

A Proactive Approach to Ethics Conflicts

- Identify the recurring ethics issues that create conflict or uncertainty
- Study the ethics issues in a systematic, systems-oriented manner
- Develop ethics practice guidelines to assist clinicians and executives on handling the conflict when it is recognized again
- Integrate the guideline into the organization's culture so that all staff is aware of the guidelines and the rationale behind it
- Review the guideline to determine if it is adequately addressing the ethics conflict and decreasing its recurrence over time

A proactive preventive process that leads to the development of ethics practice guidelines may seem like extra work, but it has the advantage of creating an environment of increased ethical certainty and staff morale—thus avoiding emotionally draining and time consuming ethics conflicts. In the end, practical, anticipatory approaches that capture the skills of the EC members can enhance the CAH's overall culture and quality of care by helping the staff reduce the recurrence of ethics conflicts.

Conclusion

Because the presence of ethics conflicts can undermine the CAH's overall culture and be time consuming to address, ECs should consider implementing a preventive ethics approach to their activities. Such a systems-oriented approach, applying quality improvement thinking and methods, can ultimately contribute to the facility's ability to deliver high quality, cost-effective care.

References

1. Hamric AB, Blackhall LJ. Nurse-physician perspectives on the care of dying patients in intensive care units: collaboration, moral distress, and ethical climate. *Crit Care Med*. Feb 2007;35(2):422-429.
2. Bischoff SJ, DeTienne KB, Quick B. Effects of ethics stress on employee burnout and fatigue: an empirical investigation. *J Health Hum Serv Adm*. Spring 1999;21(4):512-532.
3. Nelson WA. Ethical uncertainty and staff stress. *Healthc Exec*. 2009;24(4):38-39.
4. Schneiderman LJ, Gilmer T, Teetzel HD. Impact of ethics consultations in the intensive care setting: a randomized, controlled trial. *Crit Care Med*. Dec 2000;28(12):3920-3924.
5. Schneiderman LJ, Gilmer T, Teetzel HD, et al. Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: a randomized controlled trial. *JAMA*. Sep 3 2003;290(9):1166-1172.
6. Nelson WA, Weeks WB, Campfield JM. The organizational costs of ethical conflicts. *J Healthc Manag*. Jan-Feb 2008;53(1):41-52; discussion 52-43.
7. Heilicser BJ, Meltzer D, Siegler M. The effect of clinical medical ethics consultation on healthcare costs. *J Clin Ethics*. Spring 2000;11(1):31-38.
8. Nelson WA. Dealing with ethical challenges. How occurrences can be addressed before they happen. *Healthc Exec*. Mar-Apr 2007;22(2):36, 38.
9. McCullough LB. Preventive ethics, managed practice, and the hospital ethics committee as a resource for physician executives. *HEC Forum*. Jun 1998;10(2):136-151.
10. Forrow L, Arnold RM, Parker LS. Preventive ethics: expanding the horizons of clinical ethics. *J Clin Ethics*. Winter 1993;4(4):287-294.
11. McCullough LB. Practicing preventive ethics—the keys to avoiding ethical conflicts in health care. *Physician Exec*. Mar-Apr 2005;31(2):18-21.
12. Chervenak FA, McCullough LB. An ethical framework for identifying, preventing, and managing conflicts confronting leaders of academic health centers. *Acad Med*. Dec. 14, 2008 2004;79(11):1056-1061.
13. Nelson WA, Neily J, Mills P, Weeks WB. Collaboration of ethics and patient safety programs: opportunities to promote quality care. *HEC Forum*. Mar 2008;20(1):15-27.

14. Opel DJ, Brownstein D, Diekema DS, et al. Integrating ethics and patient safety: the role of clinical ethics consultants in quality improvement. *J Clin Ethics* 2009;Fall;20:220-226.
15. Foglia, M. and R. Pearlman. Integrating clinical and organizational ethics: a systems perspective can provide an antidote to the silo problem in clinical ethics consultations. *Health Progress* 2006;87(2):31-5.
16. Nelson WA, Gardent P, Shulman E, Splaine M. Preventing ethics conflicts and improving healthcare quality through system redesign. *Quality and Safety in Health Care*. 2010;19:526-530.

Ethics Committee Evaluation

This chapter describes how ethics committees (EC) and their work can be evaluated to assure the committee is accomplishing its identified purpose and activities. Committees need to be responsible for accomplishing their tasks of case consultation, policy development, education and quality improvement; and be able to demonstrate accountability for their utilization of hospital resources. The purpose of this chapter is to review how evaluations can be done to assess the committee's effectiveness.

An evaluation process begins with a review of the hospital's expectations for the committee's work (presented in Chapters 4, 5, 6 and 8 of this *Guide*).

Issues Addressed when Evaluating an Ethics Committee

- Committee membership (committee structure and member preparation)
- Purpose and activities of the ethics committee (policy, education and consultation outcomes)
- Guidelines for accessing and managing consultations (consultation processes)
- How committee work is accomplished (staffing and workload; committee efficiency)

When establishing an EC, committee expectations are defined and can be written into hospital Charters, policies and procedures. The specified expectations provide the criteria for evaluating the committee's accomplishments, as well as assessing its effectiveness.¹⁻⁴ This may be done in conversation at an annual retreat or at a dedicated committee meeting. For example, perhaps over the past year the committee has been asked to consult on three cases, and to review and refine the hospital's Do Not Resuscitate or No Intubation policy. The evaluation of the EC work would consider how the group accomplished both of these functions during this year. The evaluation might assess how easily and efficiently the ethics committee's structure allowed for completion of these tasks.

Evaluating Ethics Committee Structure

In evaluating the committee structure, it is critical to review how well the EC has accomplished the work it has been asked to do.^{2,4} One of the most often discussed structural concerns of ECs and EC effectiveness is the competency of its members. It is important to ensure that they possess, and effectively apply, the knowledge and skills described in Chapters 6 and 7. The most commonly used method to evaluate the competency of EC members is to ask them to evaluate their own knowledge and skills in specific areas. Once the information is gathered, a plan can be developed and implemented to address any identified gaps.

Evaluating the Consultation Process and Outcomes

Evaluating the EC consultation calls for a review of the interactions between the committee and those they have served. The steps in the deliberation process need to be considered (see Chapter 8), in addition to the quality of the committee's system for requesting a consultation (see also Chapter 8). It is important to identify any root cause(s) or structural gaps that have been recognized in the committee's work (e.g., inability to reach committee members, inadequate policies, lack of funds for training). The evaluation process can include subjective and/or objective measures, and can be based on both narrative and outcome information.⁴

The evaluation of the consultation process assesses how well the members of the committee, and the supporting hospital staff, have followed the specific procedures documented for a consultation process, such as:

- Being timely in response to requests
- Determining if a request is appropriate for ethics consultation
- Notifying individuals involved in the consultation
- Formulating the ethics question
- Reviewing the medical record
- Visiting with involved parties
- Identifying the appropriate decision-maker
- Gathering ethics knowledge
- Facilitating moral deliberation
- Synthesizing and communicating information
- Making recommendations
- Documenting consultations
- Following up with participants
- Identifying underlying systems issues

Since each consultation is unique, it is likely that all of these steps are not completed in each case. However, it is important to review the specific procedures and processes periodically²⁻⁴ to ensure that the approach to the consultation process is appropriate and builds committee effectiveness. Once the evaluation information is gathered, a plan is developed and implemented to address any identified policy or procedure gaps.

Evaluating the outcomes of EC consultations is a separate assessment, and refers to reviewing the decisions the committee has made in their consultations.² Outcomes include not only the positive and negative effects on patients (e.g., whether patients feel that their preferences were honored or ignored), but also the benefits and burdens on the staff and the hospital. Some outcomes are easily measurable (such as morbidity, mortality, and cost), but the relevance of these outcomes is not always clear. Other outcomes are more difficult to measure (such as adherence to ethical standards, patient satisfaction, employee morale, and public trust in the organization), but may be more relevant to the evaluation.

At a minimum, it is important to routinely gather information regarding the satisfaction of participants involved in consultation—patients and their families, as well as employees—and to compare those findings with the committee’s goals.² For example, following every consult a three-question form can be given to the person who requested the consultation. The questions could ask: “On a 1-5 scale: a) was the situation dealt with in a timely way? b) Did the consultation help you understand the nature of the process?; and c) was the input of the ethics committee helpful in resolving the issues?” Again, after the evaluation information is gathered and reviewed, a plan is developed and implemented to address any identified policy or procedure gaps.

Evaluating Access to the Committee

Another important aspect of the EC evaluation is to consider how available the service has been for the population it serves.²⁻⁵ For the committee to be truly accessible, hospital staff and administrators, as well as patients and their families who are authorized to access the service, need to be aware of the service and what it does. At a minimum, it is important to learn whether the potential users of the service are aware that it exists. Another way to evaluate access to the committee is to learn if those who have used the committee’s services have been able to access them easily, find them useful, and feel comfortable using them again in the future.

Evaluating the Efficiency of the Committee

Evaluating the efficiency of an EC requires weighing the benefits of the service it provides, against the resources spent to maintain it, such as money, staff time, and personal/institutional effort. With an increased focus on cost effectiveness and responsible stewardship of limited funds, efficiency is of increasing concern in health care organizations. Cost savings is not the goal of ethics consultation; however, proactive ethics consultations and committee policy work can reduce costs and improve the quality of services within the hospital setting.⁶⁻⁷ An EC’s efforts are designed to provide consistent and timely recommendations that improve the quality of care at the hospital. Assessing the extent to which this has been accomplished is the goal of this part of the evaluation.

Conclusions

This chapter describes how EC and their work can be evaluated to assure the committee is accomplishing its identified purpose and activities. We can evaluate the impact of the committee on patients, hospital staff, and on morale, as well as list its accomplishments. These findings can result in committee changes to further strengthen its work. However, it is important to note that it is difficult to verify whether the ethics committee is making a demonstrable difference in the institution; that is an issue for researchers to investigate at a population level, not one for evaluation at the CAH facility level.

References

1. Cranford RD, Moldow G, Allen EV. Evaluating ethics committees. *The Hastings Center Report*. Sept.-Oct.1989:23-27.
2. Fox E, Arnold RM. Evaluating outcomes in ethics consultation research. *J Clin Ethic*. 1996;7:127-138.
3. Dubler NN, Webber MP, Swiderski DM. Charting the future: Credentialing, privileging, quality, and evaluation in clinical ethics consultation. *Hastings Center Report*, 2009;39(6):23-33.
4. Fletcher JC, Hoffman D. Ethics committees: Time to experiment with standards. *Annals of Internal Medicine*. 1994;120(4):335-338.
5. Hoffman, DE. Evaluating ethics committees: A view from the outside. *The Milbank Quarterly*. 1993;71(4):677-701.
6. Lo B. *Resolving Ethical Dilemmas: A Guide for Clinicians*, 4th ed. Baltimore, MD: Lippincott, Williams &Wilkins, 2009.
7. Nelson WA, Weeks WB, Campfield JM. The organizational costs of ethical conflicts. *J Healthc Manag*. Jan-Feb 2008;53(1):41-52

Support and Marketing of the Ethics Committee

There are several features of effective ethics committees (EC), including leadership support and institution-wide recognition. Because of the importance of this support and the staff's recognition of the beneficial functions of the EC, facility-wide committee communications about the committee cannot be left to chance. This chapter offers a few practical approaches for creating and maintaining support and recognition for the EC and its work.

Since EC members need to address the importance of maintaining support and recognition for the EC, they should develop a plan to foster ongoing support and recognition, and then implement and evaluate the plan. For example, submitting the expected annual written progress reports to the highest board should be augmented by personal quarterly updates from the EC chair to the Chief Operating Officer, medical executive and/or Board of Directors at the critical access hospital (CAH). In this approach the EC's work becomes a point of information and pride for the hospital.

Gaining Administrative Support and Recognition

Administrative and clinical leadership support of the committee is essential. Leaders must demonstrate their support by regularly talking about the importance of ethics in the everyday life of the facility; openly endorsing the committee; and encouraging clinical and administrative staff to make use of the committee's services, accessing them when they encounter an ethical challenge.

Fostering a supportive relationship with CAH staff requires the committee to be in regular communication with leadership. Hospital leadership should be reviewing the work of the committee and describing the positive impact of the committee's functions to the organization, such as how it decreases staff's moral stress, increases patient satisfaction, and reduces the frequency ethics conflicts. Additionally, the leadership can describe how a preventive approach to ethics conflicts can enhance the quality of patient care. The EC leadership also needs to go beyond the submission of a yearly report—the Chair needs to continuously reach out to hospital leaders to ensure that the benefits of an effective EC are clearly understood and appreciated.

Gaining Staff Support and Recognition

Ethics committees also need to gain the acceptance and respect of CAH staff. Even though it is true, committees must “prove their worth.” Additional strategic marketing can be very useful in promoting staff understanding of the important role carried out by the EC. One example of the need for marketing relates to the frequency of EC consultations. In U.S. hospitals, almost all ethics programs have a policy of accepting requests for consultations from anyone involved in a given case; however, individuals encountering ethics conflicts may be unaware of the availability of an ethics consultation service. Some have suggested a correlation between ECs that actively publicize their services and consultation volume. It is important to create opportunities for hospital employees, as well as community members, to learn about the ethics program and its services.

Furthermore, marketing the ethics committee can be helpful in addressing any number of barriers that may promote reluctance to access the committee including perceptions regarding a lack of weekend ethics consultation availability or that the consultation process takes too much time, etc. Staff, and maybe even patients, may believe that requesting an ethics consultation or review may have personal repercussions. Marketing can help to alleviate misunderstandings and create a more realistic understanding of the beneficial roles an EC can play in patient care and hospital morale.

Rural ethics committees may want to consider various strategies for marketing the committee's functions to ensure that staff and patients

and their families are fully aware of its availability and functions. Marketing efforts are closely tied to, and should be facilitated in conjunction with, the committee's education activities.

Steps for Publicizing and Marketing the Ethics Program

- Identify target populations who need to know about the program
- Determine what information staff and patients currently know about the program
- Develop and implement a plan to further inform staff, patients, and the community
- Review the effectiveness of the marketing effort

Identify Target Audiences and their Needs

Ethics committee members must first identify the staff, health care departments, and community groups that need to know about the committee's activities. Each group will benefit from targeted marketing. For example, the emergency room or outpatient clinic staff may need specific information regarding access to the committee “after hours.” Other staff may be concerned with whether there is potential for retribution if they consult the EC. More general audiences may need to learn about what an ethics conflict is and whether identifying an ethics issue means there is something illegal going on.

Assess the Need for Marketing

The next step is to assess what these groups already know about the ethics committee in order to know where the educational and marketing efforts should begin. In addition to using survey forms, ECs can learn the answers to these questions by informally making inquiries with colleagues, staff and patient/families. Gathering this information is crucial and can greatly contribute to the committee members' ability to effectively move to the next step.

If the EC is newly established, creating conversations, pamphlets, or other communications to inform people of the service is also an

important marketing step. On the other hand, if the committee has already been established, this step reviews the existing ethics committee contacts. If a particular segment of the audience is identified as not using the committee, it should be contacted to learn why.

Develop and Implement a Marketing Plan

The ethics committee should develop a multi-faceted marketing plan to inform the CAH staff, patients, and the community about its work. Community education panels and forums can be effective, either focused on advance directives or other topics. Participation in a community health fair may also be successful. Some suggested avenues for marketing include:

- Disseminating an EC pamphlet for both staff and patients
- Including information regarding the EC in patient admission material
- Presenting and discussing the EC's purpose and functions during new staff orientations
- Providing EC information on bulletin boards
- Posting EC information on the hospital's Web site
- Holding staff presentations, such as a grand rounds or "brown bag" lunch discussions
- Organizing an annual ethics conference for the staff and the community, possibly using an outside guest ethics speaker
- Offering community programs or forums, such as discussions on advance care planning
- Discussing the EC's activities during various staff meetings, such as a nursing or medical staff meeting

Assessing the Marketing Plan

Finally, the ethics committee should periodically assess the effectiveness of its marketing and education efforts to determine the impact of current activities and whether additional initiatives should be developed and implemented.

Supportive educational efforts and marketing are essential tools for developing and maintaining an EC. Ethics committee members need to consistently reflect on the questions: how can we grow our relationship with clinical and administrative leadership, and how can it become an expected part of our institution and community? An effective marketing and education program takes planning and implementation time, both of which are necessary for the success of the EC.

Conclusion

The marketing of the EC overlaps with its education activities but they are not the same. Marketing should be employed to foster both support for the committee and recognition of its important role. Since marketing is important to the success of the committee, it should not be left to chance. Applying various basic initiatives, such as regular communication between the committee and facility leadership, discussion of the EC in the hospital newsletter, staff wide discussions, and new employee orientation presentations are just a few approaches to describe the committee and share its impact.

Selected Rural Health Care Ethics Resources

General Ethics Resources

American College of Physicians. Ethics Manual (Fifth Edition). http://www.acponline.org/running_practice/ethics/manual/ethicman5th.htm

Post LF, Blustein J, Dubler NN. *Handbook for Health Care Ethics Committees*. Baltimore, MD: The Johns Hopkins University Press, 2007.

Lo B. *Resolving Ethical Dilemmas: A Guide for Clinicians*. 4th ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2008.

Orr RD, Shelton W. A process and format for clinical ethics consultation. *J Clin Ethic*. 2009; 20:79-89.

Purtillo, R. *Ethical Dimensions in the Health Professions*. Philadelphia: Elsevier Saunders, 2005.

Singer PA, Viens AM, eds. *The Cambridge Textbook of Bioethics*. New York, NY: Cambridge University Press, 2008.

Rural Ethics

Cook AF, Hoas H. Ethics and rural healthcare: what really happens? What might help? *Am J Bioeth*. Apr 2008;8(4):52-56.

Roberts LW, Battaglia J, Smithpeter M, et al. An office on main street: health care dilemmas in small communities. *Hastings Cent Rep* 1999;29:28-37.

Klugman CM, Dalinis PM, eds. *Ethical Issues in Rural Health Care*. Baltimore, MD: Johns Hopkins University Press; 2008.

Nelson, WA, ed., *Handbook for Rural Health Care Ethics: A Practical Guide for Professionals*. Hanover, NH: Dartmouth College Press; 2009; <http://dms.dartmouth.edu/cfm/resources/ethics/>

Selected Web Sites

American Medical Association: Medical Ethics

<http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics.shtml>

AMA Code of Medical Ethics

<http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page>

The American Journal of Bioethics

<http://Bioethics.net>

Center for Practical Bioethics

<http://practicalbioethics.org/>

Rural Ethics Resources

<http://dms.dartmouth.edu/cfm/resources/rhc>

Rural Health Care Ethics Bibliography

Health Care Ethics

American College of Physicians. Ethics Manual (Fifth Edition). http://www.acponline.org/running_practice/ethics/manual/ethicman5th.htm

American Medical Association. *Code of Medical Ethics*. <http://www.ama-assn.org/ama/no-index/physician-resources/2498>.

American Medical Association, Council on Ethical and Judicial Affairs. Opinions on the patient-physician relationship. *Code of Medical Ethics*. <http://www.ama-assn.org/ama/no-index/physician-resources/2498>.

American Medical Association, Council on Ethical and Judicial Affairs. Opinions on confidentiality, advertising, and communications media relations. *Code of Medical Ethics*. <http://www.ama-assn.org/ama/no-index/physician-resources/2498>.

American Medical Association, Council on Ethical and Judicial Affairs. Reporting impaired, incompetent, and unethical colleagues, Opinion 9.031. *Code of Medical Ethics*. <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion9031.page>.

American Psychiatric Association. The principles of medical ethics: with annotations especially applicable to psychiatry. <http://www.psych.org/MainMenu/PsychiatricPractice/Ethics/ResourcesStandards/PrinciplesofMedicalEthics.aspx>.

Bacchetta MD, Fins JJ. The economics of clinical ethics programs: a quantitative justification. *Camb Q Healthc Ethics*. 1997; Fall;6:451-60.

Bendapudi NM, Berry LL, Frey KA, Parish JT, Rayburn WL. Patients' perspectives on ideal physician behaviors. *Mayo Clin Proc*. Mar 2006;81(3):338-344.

- Bernat JL. "The hospital ethics committee and the ethics consultant" *Ethical Issues in Neurology* 3rd Ed. Lippincott Williams & Wilkins: Baltimore, MD. 2008:109-133.
- Bischoff SJ, DeTienne KB, Quick B. Effects of ethics stress on employee burnout and fatigue: an empirical investigation. *J Health Hum Serv Adm.* Spring 1999;21(4):512-532.
- Callahan D. Bioethics. In: Reich WT, ed. *Encyclopedia of Bioethics*. New York, NY: Simon & Schuster Macmillan; 1995.
- Dubler NN, Liebman CB. *Bioethics Mediation: A Guide to Shaping Shared Solutions; Revised and Expanded Edition*. Vanderbilt University Press; 2011.
- Fox E, Myers S, Pearlman RA. Ethics consultation in United States hospitals: a national survey. *Am J Bioeth.* Feb 2007;7(2):13-25.
- Halevy A, Brody BA. A multi-institution collaborative policy on medical futility. *JAMA.* Aug 21 1996;276(7):571-574.
- Institute of Medicine. Committee on Quality of Health Care in America. *Crossing the quality chasm: a new health system for the 21st century*. Washington, DC: National Academy Press; 2001.
- Jonsen A, Siegler M, Winslade W. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine* (7th Ed.). New York: McGraw-Hill; 2010.
- Mills AE, Rorty MV, Spencer EM. Introduction: ethics committees and failure to thrive. *HEC Forum.* Dec 2006;18(4):279-286.
- Milmore D. Hospital ethics committees: a survey in upstate New York. *HEC Forum.* Sep 2006;18(3):222-244.
- Moreno JD. Ethics committees: beyond benign neglect. *HEC Forum.* Dec 2006;18(4):368-369.
- Nelson WA. Defining ethics. How to determine whether a conflict falls under your ethics committee's purview. *Healthc Exec.* Jul-Aug 2006;21(4):38-39.
- Nelson WA. Dealing with ethical challenges. How occurrences can be addressed before they happen. *Healthc Exec.* Mar-Apr 2007;22(2):36, 38.
- Nelson WA, Gardent P, Shulman E, Splaine M. Preventing ethics conflicts and improving healthcare quality through system redesign. *Quality and Safety in Health Care.* 2010;19:526-530.
- Nelson WA, Neily J, Mills P, Weeks WB. Collaboration of ethics and patient safety programs: opportunities to promote quality care. *HEC Forum.* Mar 2008;20(1):15-27.
- Nelson WA, Weeks WB, Campfield JM. The organizational costs of ethical conflicts. *J Healthc Manag.* Jan-Feb 2008;53(1):41-52; discussion 52-43.

Orr RD, Shelton W. A process and format for clinical ethics consultation. *J Clin Ethic.* 2009; 20:79-89.

Rural Health Care Ethics

- Anderson-Shaw L. Rural health care ethics: what assumptions and attitudes should drive the research? *Am J Bioeth.* Mar-Apr 2006;6(2):61-62.
- Aultman JM. A foreigner in my own country: forgetting the heterogeneity of our national community. *Am J Bioeth.* Mar-Apr 2006;6(2):56-59.
- Bushy A, Rauh JR. Implementing an ethics committee in rural institutions. *J Nurs Adm.* Dec 1991;21(12):18-25.
- Cook A, Hoas H. Are healthcare ethics committees necessary in rural hospitals? *HEC Forum.* Jun 1999;11(2):134-139.
- Cook AF, Hoas H. Where the rubber hits the road: implications for organizational and clinical ethics in rural healthcare settings. *HEC Forum.* Dec 2000;12(4):331-340.
- Cook AF, Hoas H. Voices from the margins: a context for developing bioethics-related resources in rural areas. *Am J Bioeth.* Fall 2001;1(4):W12.
- Cook AF, Hoas H. Re-framing the question: what do we really want to know about rural healthcare ethics? *Am J Bioeth.* Mar-Apr 2006;6(2):51-53.
- Cook AF, Hoas H. Ethics and rural healthcare: what really happens? What might help? *Am J Bioeth.* Apr 2008;8(4):52-56.
- Cook AF, Hoas H, Guttmanova K. Bioethics activities in rural hospitals. *Camb Q Healthc Ethics.* Spring 2000;9(2):230-238.
- Cook AF, Hoas H, Guttmanova K. Ethical issues faced by rural physicians. *S D J Med.* Jun 2002;55(6):221-224.
- Cook AF, Hoas H, Guttmanova K. Not by technology alone ... Project seeks to assess and aid patient safety in rural areas. *Biomed Instrum Technol.* Mar-Apr 2003;37(2):128-130.
- Cook AF, Hoas H, Guttmanova K, Joyner JC. An error by any other name. *Am J Nurs.* Jun 2004;104(6):32-43; quiz 44.
- Cook AF, Hoas H, Joyner JC. Ethics and the rural nurse: a research study of problems, values, and needs. *J Nurs Law.* May 2000;7(1):41-53.
- Cook AF, Joyner JC. No secrets on Main Street. *Am J Nurs.* Aug 2001;101(8):67, 69-71.
- D'Agincourt-Canning L. Genetic testing for hereditary cancer: challenges to ethical care in rural and remote communities. *HEC Forum.* Dec 2004;16(4):222-233.

- Danis M. The ethics of allocating resources toward rural health and health care. In: Klugman CM, Dalinis PM, eds. *Ethical Issues in Rural Health Care*. Baltimore, MD: Johns Hopkins University Press; 71-96.
- Deady KE. Cyberadvice: the ethical implications of giving professional advice over the internet. *Georget J Leg Ethics*. Spring 2001;14(3):891-907.
- Fleming DA. Ethical implications in the use of telehealth and teledermatology. In: Pak H, Edison K, Whited J, eds. *Teledermatology: a User's Guide*. Cambridge: Cambridge University Press; 2008:97-108.
- Fraser J, Alexander C. Publish and perish: a case study of publication ethics in a rural community. *J Med Ethics*. Sep 2006;32(9):526-529.
- Fryer-Edwards K. On cattle and casseroles. *Am J Bioeth*. Mar-Apr 2006;6(2):55-56.
- Glover JJ. Rural bioethical issues of the elderly: how do they differ from urban ones? *J Rural Health*. Fall 2001;17(4):332-335.
- Hardwig J. Rural health care ethics: what assumptions and attitudes should drive the research? *Am J Bioeth*. Mar-Apr 2006;6(2):53-54.
- Having KM, Hale D, Lautar CJ. Ethics committees in the rural Midwest: exploring the impact of HIPAA. *J Rural Health*. Summer 2008;24(3):316-320.
- Henry MS. Uncertainty, responsibility, and the evolution of the physician/patient relationship. *J Med Ethics*. Jun 2006;32(6):321-323.
- Jennings FL. Ethics of rural practice. *Psychother Priv Pract*. 1992;10(3):85-104.
- Kelly SE. Bioethics and rural health: theorizing place, space, and subjects. *Soc Sci Med*. Jun 2003;56(11):2277-2288.
- Klugman CM. Haves and have nots. *Am J Bioeth*. Mar-Apr 2006;6(2):63-64.
- Klugman CM, Dalinis PM, eds. *Ethical Issues in Rural Health Care*. Baltimore, MD: Johns Hopkins University Press; 2008.
- Kon AA, Rich B, Sadorra C, Marcin JP. Complex bioethics consultation in rural hospitals: using telemedicine to bring academic bioethicists into outlying communities. *J Telemed Telecare*. 2009;15(5):264-267.
- Maddalena V, Sherwin S. Vulnerable populations in rural areas: challenges for ethics committees. *HEC Forum*. Dec 2004;16(4):234-246.
- Martinez R. A model for boundary dilemmas: ethical decision-making in the patient-professional relationship. *Ethical Hum Sci Serv*. Spring 2000;2(1):43-61.
- Miller PJ. Dual relationships in rural practice: a dilemma of ethics and culture. *Hum Serv Rural Environ*. 1994;18(2):4-7.
- Moss AH. The application of the Task Force report in rural and frontier settings. *J Clin Ethics*. Spring 1999;10(1):42-48.
- Nelson W. Addressing rural ethics issues. The characteristics of rural healthcare settings pose unique ethical challenges. *Healthc Exec*. Jul-Aug 2004;19(4):36-37.
- Nelson W. Where is the evidence: a need to assess rural ethics committee models. *J Rural Health*. Summer 2006;22(3):193-195.
- Nelson W, Lushkov G, Pomerantz A, Weeks WB. Rural health care ethics: is there a literature? *Am J Bioeth*. Mar-Apr 2006;6(2):44-50.
- Nelson W, Pomerantz A, Howard K, Bushy A. A proposed rural healthcare ethics agenda. *J Med Ethics*. Mar 2007;33(3):136-139.
- Nelson W, Weeks WB. Rural and non-rural differences in membership of the American Society of Bioethics and Humanities. *J Med Ethics*. Jul 2006;32(7):411-413.
- Nelson WA. Ethics programs in small rural hospitals. Ethics committees are essential all healthcare facilities, not just large ones. *Healthc Exec*. Nov-Dec 2007;22(6):30, 32-33.
- Nelson WA. The challenges of rural health care. In: Klugman CM, Dalinis PM, eds. *Ethical Issues in Rural Health Care* Baltimore: Johns Hopkins University Press; 2008:34-59.
- Nelson WA, Pomerantz AS. Ethics issues in rural health care. *Trustee*. Aug 1992;45(8):14-15.
- Nelson WA, Pomerantz AS. Ethics issues in rural health and hospitals. In: Friedman E, ed. *Choices and Conflict: Explorations in Health Care Ethics*. Chicago, IL: American Hospital Publishers; 1992:xii, 209.
- Nelson WA, Pomerantz AS, Weeks WB. Response to commentaries on "is there a rural ethics literature?" *Am J Bioeth*. Jul-Aug 2006;6(4):W46-47.
- Nelson WA, Schmidek JM. Rural healthcare ethics. In: Singer PA, Viens AM, eds. *The Cambridge Textbook of Bioethics*. New York, NY: Cambridge University Press; 2008:289-298.
- Nelson WA, Rosenberg MC, Mackenzie T, Weeks WB. The presence of ethics programs in critical access hospitals. *HealthCare Ethics Committee Forum*. 2010;22:267-274.
- Nelson WA. Health care ethics and rural life: stigma, privacy, boundary conflicts raise concerns. *Health Progress*. 2010;91(5):51-54.
- Nelson WA, Morrow CE. Rural primary care-working outside the comfort zone: commentary by William A. Nelson and Cathleen E. Morrow. *Virtual Mentor*. 2011;13:278-281.

Niemira DA. Grassroots grappling: ethics committees at rural hospitals. *Ann Intern Med*. 1988;109(12):981-983.

Niemira DA, Meece KS, Reiquam CW. Multi-institutional ethics committees. *HEC Forum*. 1989;1(2):77-81.

Niemira DA, Orr RD, Culver CM. Ethics committees in small hospitals. *J Rural Health*. 1989;5(1):19-32.

Ostertag SG, Forman WB. End-of-life care in Hancock County, Maine: a community snapshot. *Am J Hosp Palliat Care*. 2008;25(2):132-138.

Perkins DV, Hudson BL, Gray DM, Stewart M. Decisions and justifications by community mental health providers about hypothetical ethical dilemmas. *Psychiatr Serv*. 1998;49(10):1317-1322.

Purtilo R, Sorrell J. The ethical dilemmas of a rural physician. *Hastings Cent Rep*. 1986;16(4):24-28.

Purtilo RB. Rural health care: the forgotten quarter of medical ethics. *Second Opin*. 1987(6):10-33.

Rauh JR, Bushy A. Biomedical conflicts in the heartland. A systemwide ethics committee serves rural facilities. *Health Prog*. 1990;71(2):80-83.

Roberts LW, Battaglia J, Epstein RS. Frontier ethics: mental health care needs and ethical dilemmas in rural communities. *Psychiatr Serv*. Apr 1999;50(4):497-503.

Roberts LW, Battaglia J, Smithpeter M, Epstein RS. An office on Main Street. Health care dilemmas in small communities. *Hastings Cent Rep*. Jul-Aug 1999;29(4):28-37.

Roberts LW, Dyer AR. *Concise Guide to Ethics in Mental Health Care*. Washington, DC: American Psychiatric Publishing; 2004.

Roberts LW, Johnson ME, Brems C, Warner TD. Preferences of Alaska and New Mexico psychiatrists regarding professionalism and ethics training. *Acad Psychiatry*. May-Jun 2006;30(3):200-204.

Roberts LW, Johnson ME, Brems C, Warner TD. Ethical disparities: challenges encountered by multidisciplinary providers in fulfilling ethical standards in the care of rural and minority people. *J Rural Health*. Fall 2007;23 Suppl:89-97.

Roberts LW, Warner TD, Hammond KG. Ethical challenges of mental health clinicians in rural and frontier areas. *Psychiatr Serv*. 2005;56(3):358-359.

Robillard HM, High DM, Sebastian JG, Pisaneschi JI, Perritt LJ, Mahler DM. Ethical issues in primary health care: a survey of practitioners' perceptions. *J Community Health*. 1989;14(1):9-17.

Schank JA. Ethical issues in rural counselling practice. *Can J Counselling*. 1998;32(4):270-283.

Sriram TG, Radhika MR, Shanmugham V, Murthy RS. Comparison of urban and rural respondents' experience and opinion of ethical issues in medical care. *Int J Soc Psychiatry*. Autumn 1990;36(3):200-206.

Turner LN, Marquis K, Burman ME. Rural nurse practitioners: perceptions of ethical dilemmas. *J Am Acad Nurse Pract*. 1996;8(6):269-274.

Ullom-Minnich PD, Kallail KJ. Physicians' strategies for safeguarding confidentiality: the influence of community and practice characteristics. *J Fam Pract*. Nov 1993;37(5):445-448.

Van Vorst RF, Crane LA, Barton PL, Kutner JS, Kallail KJ, Westfall JM. Barriers to quality care for dying patients in rural communities. *J Rural Health*. 2006;22(3):248-253.

Warner TD, Monaghan-Geernaert P, Battaglia J, Brems C, Johnson ME, Roberts LW. Ethical considerations in rural health care: a pilot study of clinicians in Alaska and New Mexico. *Community Ment Health J*. 2008 2005;41(1):21-33.

Rural Health Care

The uninsured in rural America. *Kaiser Commission on Medicaid and the Uninsured*. <http://www.kff.org/uninsured/upload/The-Uninsured-in-Rural-America-Update-PDF.pdf>. Published 2003.

Agency for Healthcare Research and Quality. Center for Financing, Access and Cost Trends. Medical Expenditure Panel Survey. Washington, DC 2006.

Anderson DG, Hatton DC. Accessing vulnerable populations for research. *West J Nurs Res*. 2000;22(2):244-251.

Baer LD, Johnson-Webb KD, Gesler WM. What is rural? A focus on urban influence codes. *J Rural Health*. 1997;13(4):329-333.

Bailey J. Health care in rural America: a series of features from the Center for Rural Affairs Newsletter. Available at http://www.cfra.org/pdf/Health_Care_in_Rural_America.pdf. Published 2004. Accessed Feb. 23, 2009.

Baldwin LM, MacLehose RF, Hart LG, Beaver SK, Every N, Chan L. Quality of care for acute myocardial infarction in rural and urban US hospitals. *J Rural Health*. 2004;20(2):99-108.

Baldwin LM, Patanian MM, Larson EH, et al. Modeling the mental health workforce in Washington State: using state licensing data to examine provider supply in rural and urban areas. *J Rural Health*. 2006;22(1):50-58.

Bauer JC. Rural America and the digital transformation of health care. New perspectives on the future. *J Leg Med*. 2002;23(1):73-83.

- Bennett KJ, Olatosi B, Probst JC. *Health Disparities: a Rural-Urban Chartbook*. Columbia, SC: South Carolina Rural Health Research Center; 2008.
- Beresford L, Jones A, Person JL, Regas C. *Providing Hospice and Palliative Care in Rural and Frontier Areas*. Kansas City: National Rural Health Association; 2005.
- Berger J, Mohr J. *A Fortunate Man; the Story of a Country Doctor*. 1st ed. New York, NY: Holt, Rinehart and Winston; 1967:13-15.
- Bigbee JL, Lind B. Methodological challenges in rural and frontier nursing research. *Appl Nurs Res*. 2007;20(2):104-106.
- Bird DC, Dempsey P, Hartley D. Addressing mental health workforce needs in underserved rural areas: accomplishments and challenges. Working Paper # 23. <http://muskie.usm.maine.edu/Publications/rural/wp23.pdf>. Published 2001.
- Blalock SJ, Byrd JE, Hansen RA, et al. Factors associated with potentially inappropriate drug utilization in a sample of rural community-dwelling older adults. *Am J Geriatr Pharmacother*. 2005;3(3):168-179.
- Boffa J. Is there a doctor in the house? *Aust N Z J Public Health*. Aug 2002;26(4):301-304.
- Braden J, Beauregard K. Health status and access to care of rural and urban populations. National Medical Expenditure Survey Research Findings 18. Rockville, MD: AHCP; 1994.
- Brasure M, Stensland J, Wellever A. Quality oversight: why are rural hospitals less likely to be JCAHO accredited? *J Rural Health*. Fall 2000;16(4):324-336.
- Brooks RG, Menachemi N, Burke D, Clawson A. Patient safety-related information technology utilization in urban and rural hospitals. *J Med Syst*. Apr 2005;29(2):103-109.
- Burnum JF. Secrets about patients. *N Engl J Med*. Apr 18 1991;324(16):1130-1133.
- Bushy A, ed *Rural Nursing*. Newbury Park, CA: Sage Publications; 1991.
- Bushy A. Defining 'rural' before tackling access issues. *Am Nurse*. Sep 1993;25(8):20.
- Bushy A. Women in rural environments: considerations for holistic nurses. *Holist Nurs Pract*. Jul 1994;8(4):67-73.
- Bushy A. When your client lives in a rural area. Part I: Rural health care delivery issues. *Issues Ment Health Nurs*. May-Jun 1994;15(3):253-266.
- Bushy A. *Rural minority health resource book*. Kansas City, MO: National Rural Health Association; 2002.
- Bushy A. Creating nursing research opportunities in rural healthcare facilities. *J Nurs Care Qual*. Apr-Jun 2004;19(2):162-168.
- Bushy A. Nursing in rural and frontier areas: issues, challenges and opportunities. *Harvard Health Policy Review*. 2006;7(1):17-27.
- Bushy, A. Rural nursing: practice and issues. American Nurses Association Continuing Education Program module. American Nurses Association: 2004.
- Campbell CC, Gordon MC. Acknowledging the inevitable: Understanding multiple relationships in rural practice. *Prof Psychol Res Pract*. 2003;34(4):430-434.
- Chan L, Hart LG, Goodman DC. Geographic access to health care for rural Medicare beneficiaries. *J Rural Health*. Spring 2006;22(2):140-146.
- Chartbook. Health, United States*. Vol Hyattsville, MD: Centers for Disease Control and Prevention. National Center for Health Statistics Web site. <http://www.cdc.gov/nchs/data/has/has01cht.pdf>.
- Christianson J. Potential effects of managed care organizations in rural communities: a framework. *J Rural Health*. Summer 1998;14(3):169-179.
- Coburn AF, Wakefield M, Casey M, Moscovice I, Payne S, Loux S. Assuring rural hospital patient safety: what should be the priorities? *J Rural Health*. Fall 2004;20(4):314-326.
- Conesa C, Rios A, Ramirez P, et al. Rural primary care centers as a source of information about organ donation. *Transplant Proc*. Nov 2005;37(9):3609-3613.
- Cox J. Rural general practice: a personal view of current key issues. *Health Bull (Edinb)*. Sep 1997;55(5):309-315.
- Crocker J, Major B, Steele C. Social stigma. In: Gilbert DT, Fiske ST, Lindzey G, eds. *The Resource Guide of Social Psychology*. Vol 2. Boston: McGraw-Hill; 1998:504-553.
- Culler SD, Atherly A, Walczak S, et al. Urban-rural differences in the availability of hospital information technology applications: a survey of Georgia hospitals. *J Rural Health*. Summer 2006;22(3):242-247.
- Davis DJ, Droes NS. Community health nursing in rural and frontier counties. *Nurs Clin North Am*. Mar 1993;28(1):159-169.
- Eberhardt MS, Pamuk ER. The importance of place of residence: examining health in rural and nonrural areas. *Am J Public Health*. Oct 2004;94(10):1682-1686.
- Economic Research Service. Rural-urban continuum codes. <http://www.ers.usda.gov/Data/RuralUrbanContinuumCodes/>. Published 2003.

Economic Research Service. Rural children at a glance. *Economic Information Bulletin*, No. 1. <http://www.ers.usda.gov/publications/eib1/eib1.pdf>. Published 2005.

Flex Monitoring Team. CAH Information. <http://flexmonitoring.org/cahlistRA.cgi>.

Fordyce MA, Chen FM, Doescher MP, Hart LG. *2005 Physician supply and distribution in rural areas of the United States*. Seattle, WA: WWAMI Rural Health Research & Policy Centers; 2007.

Fram MS, Miller-Cribbs JE, Van Horn L. Poverty, race, and the contexts of achievement: Examining educational experiences of children in the U.S. south. *Soc Work*. Oct 2007;52(4):309-319.

Gamm LD, Hutchison LL, eds. *Rural Healthy People 2010: A Companion Document to Healthy People 2010. Volume 3*. College Station, TX: Texas A&M University System Health Science Center, School of Rural Public Health, Southwest Rural Health Research Center; 2004.

Gamm LD, Hutchison LL, Dabney BJ, Dorsey AM, eds. *Rural healthy people 2010: a companion document to health people 2010. Volume 1*. College Station, TX: The Texas A&M University System Health Science Center, School of Rural Public Health, Southwest Rural Health Research Center; 2003.

Gamm LD, Hutchison LL, Dabney BJ, Dorsey AM, eds. *Rural Healthy People 2010: A Companion Document to Health People 2010. Volume 2*. College Station, TX: Texas A&M University System Health Science Center, School of Rural Public Health, Southwest Rural Health Research Center; 2003.

Gazewood JD, Rollins LK, Galazka SS. Beyond the horizon: the role of academic health centers in improving the health of rural communities. *Acad Med*. Sep 2006;81(9):793-797.

Gessert CE, Elliott BA, Peden-McAlpine C. Family decision-making for nursing home residents with dementia: rural-urban differences. *J Rural Health*. Winter 2006;22(1):1-8.

Geyman JP, Norris TE, Hart LG, eds. *Textbook of Rural Medicine*. New York, NY: McGraw-Hill; 2001.

Guo G, Phillips L. Key informants' perceptions of health care for elders at the U.S.-Mexico border. *Public Health Nurs*. May-Jun 2006;23(3):224-233.

Han GS, Humphreys JS. Overseas-trained doctors in Australia: community integration and their intention to stay in a rural community. *Aust J Rural Health*. Aug 2005;13(4):236-241.

Hart LG, Larson EH, Lishner DM. Rural definitions for health policy and research. *Am J Public Health*. Jul 2005;95(7):1149-1155.

Hart LG, Salsberg E, Phillips DM, Lishner DM. Rural health care providers in the United States. *J Rural Health*. 2002;18 Suppl:211-232.

Hartley D, Bird DC, Dempsey P. Rural mental health and substance abuse. In: Ricketts III TC, ed. *Rural Health in the United States*. New York, NY: Oxford University Press; 1999:159-178.

Health Resources and Services Administration. One department serving rural America: HHS Rural Task Force Report to the Secretary. Published 2002. Accessed Dec. 13, 2008.

Henderson CB. Small-town psychiatry. *Psychiatr Serv*. Feb 2000;51(2):253-254.

Institute of Medicine. Committee on the Future of Rural Health Care. Board on Health Care Services. *Quality Through Collaboration: the Future of Rural Health* Washington, DC: National Academies Press; 2005.

Johnson ME, Brems C, Warner TD, Roberts LW. Rural-urban health care provider disparities in Alaska and New Mexico. *Adm Policy Ment Health*. Jul 2006;33(4):504-507.

Johnson-Webb KD, Baer LD, Gesler WM. What is rural? Issues and considerations. *J Rural Health*. Summer 1997;13(3):253-256.

Kelly KM, Andrews JE, Case DO, Allard SL, Johnson JD. Information seeking and intentions to have genetic testing for hereditary cancers in rural and Appalachian Kentuckians. *J Rural Health*. Spring 2007;23(2):166-172.

Kiser K. Doctoring the old-fashioned way. *Minn Med*. Jan 2006;89(1):8-10.

Kullnat MW. A piece of my mind. *Boundaries. JAMA*. Jan 24 2007;297(4):343-344.

Larson SL, Machlin SR, Nixon A, Zodet M. Health care in urban and rural areas, combined years 1998-2000. *MEPS Chartbook No. 13. AHRQ Pub. No. 04-0050*. [Rockville, MD:] Agency for Healthcare Research and Quality. http://www.meps.ahrq.gov/mepsweb/data_files/publications/cb13/cb13.shtml. Published 2004.

Levin A. Stress of practicing in rural area takes toll on psychiatrist *Psychiatric News*. Dec. 13, 2008 2006;41(9):4.

Link BG, Phelan JC, Bresnahan M, Stueve A, Pescosolido BA. Public conceptions of mental illness: labels, causes, dangerousness, and social distance. *Am J Public Health*. Sep 1999;89(9):1328-1333.

Long KA, Weinert C. Rural nursing: developing the theory base. *Sch Inq Nurs Pract*. Summer 1989;3(2):113-127.

Loue S, Quill BE, eds. *Resource Guide of Rural Health*. New York, NY: Kluwer Academic; 2001.

- Loux SL, Payne SM, Knott A. Comparing patient safety in rural hospitals by bed count. *Advances in Patient Safety: from Research to Implementation*. Rockville, MD: Agency for Healthcare Research and Quality. <http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=aps.section.1319>. Published 2005.
- Malecki E. Digital development in rural areas: potentials and pitfalls. *J Rural Studies*. 2003;19(2):201-214.
- Merwin E, Snyder A, Katz E. Differential access to quality rural healthcare: professional and policy challenges. *Fam Community Health*. Jul-Sep 2006;29(3):186-194.
- Mitchell GW. Rural hospitals: a different take on conflict of interest. *Trustee*. Mar 2008;61(3):30.
- Mohatt DF, Bradley MM, Adams SJ, Morris CD. Mental health and rural America: 1994-2005. An overview and annotated bibliography. Rockville, MD: Office of Rural Health Policy, U.S. Department of Health and Human Services. <ftp://ftp.hrsa.gov/ruralhealth/RuralMentalHealth.pdf>. Published 2007.
- Moscovice I, Rosenblatt R. Quality-of-care challenges for rural health. *J Rural Health*. Spring 2000;16(2):168-176.
- Moscovice I, Wholey DR, Klingner J, Knott A. Measuring rural hospital quality. *J Rural Health*. Fall 2004;20(4):383-393.
- Moszczyński AB, Haney CJ. Stress and coping of Canadian rural nurses caring for trauma patients who are transferred out. *J Emerg Nurs*. Dec 2002;28(6):496-504.
- Nassar ME. Racial and ethnic disparities in health care. *Ann Intern Med*. Jan 18 2005;142(2):153; author reply 153-154.
- National Center for Health Statistics. Table 33. Age-adjusted death rates, by race, sex, region, and urbanization level: United States, average annual 1996-1998, 1999-2001, and 2003-2005. <http://www.cdc.gov/nchs/products/pubs/pubd/hus/updatedtables.htm>.
- National Rural Bioethics Project. Decisions and obligations: "It's a matter of priorities". *Ethics in Rural Healthcare Settings Case Studies*. <http://www.umt.edu/bioethics/ahrq/DecisionsandObligationsCase.htm>. Published 2003.
- National Rural Health Association. Minority and Multicultural Affairs. <http://www.ruralhealthweb.org/go/rural-health-topics/minority-and-multicultural-issues/minority-and-multicultural-affairs>. Accessed Dec 5, 2008.
- National Rural Health Association. How is rural defined? <http://www.ruralhealthweb.org/go/left/about-rural-health/how-is-rural-defined>.
- National Rural Health Association. *Rural Minority Health Resource Book*. Kansas City: NRHA; 2008.
- Norris AC. *Essentials of Telemedicine and Telecare*. New York, NY: J. Wiley; 2002.
- North Carolina Rural Health Research Program, University of North Carolina at Chapel Hill Cecil G. Sheps Center for Health Services Research. Facts about rural physicians. http://www.shepscenter.unc.edu/research_programs/rural_program/pubs/finding_brief/phy.html. Published 1997.
- Ohsfeldt RL, Ward MM, Schneider JE, et al. Implementation of hospital computerized physician order entry systems in a rural state: feasibility and financial impact. *J Am Med Inform Assoc*. Jan-Feb 2005;12(1):20-27.
- Reynolds L. What is rural? http://www.nal.usda.gov/ric/ricpubs/what_is_rural.shtml.
- Ricketts TC. The changing nature of rural health care. *Annu Rev Public Health*. 2000;21:639-657.
- Ricketts TC. Workforce issues in rural areas: a focus on policy equity. *Am J Public Health*. 2005;95(1):42-48.
- Rodriguez MD, Rodriguez J, Davis M. Recruitment of first-generation Latinos in a rural community: the essential nature of personal contact. *Fam Process*. Mar 2006;45(1):87-100.
- Rogers FB, Shackford SR, Hoyt DB, et al. Trauma deaths in a mature urban vs rural trauma system. A comparison. *Arch Surg*. Apr 1997;132(4):376-381; discussion 381-372.
- Rosenblatt RA, Andrilla CH, Curtin T, Hart LG. Shortages of medical personnel at community health centers: implications for planned expansion. *JAMA*. Mar 1 2006;295(9):1042-1049.
- Rosenblatt RA, Hart LG. Physicians and rural America. In: Ricketts III TC, ed. *Rural Health in the United States*. New York, NY: Oxford University Press; 1999:38-51.
- Rosenthal MB, Zaslavsky A, Newhouse JP. The geographic distribution of physicians revisited. *Health Serv Res*. Dec 2005;40(6 Pt 1):1931-1952.
- Rosenthal TC, Fox C. Access to health care for the rural elderly. *JAMA*. Oct 25 2000;284(16):2034-2036.
- Rost K, Owen RR, Smith J, Smith RJ. Rural-urban differences in service use and course of illness in bipolar disorder. *J Rural Health*. 1998;14(1):36-43.
- Rourke LL, Rourke JT. Close friends as patients in rural practice. *Can Fam Physician*. Jun 1998;44:1208-1210, 1219-1222.
- Rudman WJ, Bailey JH, Garrett PK, Peden A, Thomas EJ, Brown CA. Teamwork and safety culture in small rural hospitals in Mississippi. *Patient Safety & Quality Healthcare*. 2006(Nov/Dec).

Rural Assistance Center. Frontier Frequently Asked Questions: What is the definition of frontier? http://www.raonline.org/info_guides/frontier/frontierfaq.php.

Schoenman JA, Mueller CD. Rural implications of Medicare's post-acute-care transfer payment policy. *J Rural Health*. Spring 2005;21(2):122-130.

Schrader SL, Nelson ML, Eidsness LM. Palliative care teams on the prairie: composition, perceived challenges & opportunities. *S D Med*. Apr 2007;60(4):147-149, 151-143.

Schultz CG, Neighbors C. Perceived norms and alcohol consumption: differences between college students from rural and urban high schools. *J Am Coll Health*. Nov-Dec 2007;56(3):261-265.

Seshamani M, Van Nostrand J, Kennedy J, Cochran C. *Hard times in the heartland: health care in rural America*. Washington, DC.: U.S. Department of Health & Human Services; May 23, 2009.

Shreffler MJ. Culturally sensitive research methods of surveying rural/frontier residents. *West J Nurs Res*. Jun 1999;21(3):426-435.

Simon RI, Williams IC. Maintaining treatment boundaries in small communities and rural areas. *Psychiatr Serv*. Nov 1999;50(11):1440-1446.

Simpson C, Kirby J. Organizational ethics and social justice in practice: choices and challenges in a rural-urban health region. *HEC Forum*. Dec 2004;16(4):274-283.

Simpson JL, Carter K. Muslim women's experiences with health care providers in a rural area of the United States. *J Transcult Nurs*. Jan 2008;19(1):16-23.

Sobel SB. Small town practice of psychotherapy: ethical and personal dilemmas. *Psychother Priv Pract*. 1992;10(3):61-69.

Spiegel PB. Confidentiality endangered under some circumstances without special management. *Psychotherapy*. Winter 1990;27(4):636-643.

Stevenson KB, Barbera J, Moore JW, Samore MH, Houck P. Understanding keys to successful implementation of electronic decision support in rural hospitals: analysis of a pilot study for antimicrobial prescribing. *Am J Med Qual*. Nov-Dec 2005;20(6):313-318.

Stockman AF. Dual relationships in rural mental health practice: An ethical dilemma. *J Rural Comm Psych*. 1990;11(2):31-45.

U. S. Department of Health and Human Services, Health Resources and Services Administration. Rural Health Fact Sheet. <http://www.hrsa.gov/about/pdf/orhp.pdf>.

US Department of Health and Human Services. *Tracking Health People 2010*. Washington, DC: US Dept of Health and Human Services; 2000.

Wallace AE, Weeks WB, Wang S, Lee AF, Kazis LE. Rural and urban disparities in health-related quality of life among veterans with psychiatric disorders. *Psychiatr Serv*. Jun 2006;57(6):851-856.

Ward MM, Jaana M, Bahensky JA, Vartak S, Wakefield DS. Clinical information system availability and use in urban and rural hospitals. *J Med Syst*. Dec 2006;30(6):429-438.

Ward MM, Jaana M, Wakefield DS, et al. What would be the effect of referral to high-volume hospitals in a largely rural state? *J Rural Health*. Fall 2004;20(4):344-354.

Warner M, Boudreault M, Fingerhut LA. Suicide trends 1950-2002. Washington, DC: National Center for Health Statistics Web site. http://www.cdc.gov/nchs/ppt/injury/suicide_1950_02.ppt. Accessed Dec. 6, 2008.

Weeks WB, Kazis LE, Shen Y, et al. Differences in health-related quality of life in rural and urban veterans. *Am J Public Health*. 2004;94(10):1762-1767.

Weeks WB, Lushkov G, Nelson WA, Wallace AE. Characteristics of rural and urban cadaveric organ transplant donors and recipients. *J Rural Health*. Summer 2006;22(3):264-268.

Westfall JM, Van Vorst RF, McGloin J, Selker HP. Triage and diagnosis of chest pain in rural hospitals: implementation of the ACI-TIPI in the High Plains Research Network. *Ann Fam Med*. Dec. 13, 2008 2006;4(2):153-158.

Willging CE, Salvador M, Kano M. Brief reports: Unequal treatment: mental health care for sexual and gender minority groups in a rural state. *Psychiatr Serv*. 2006;57(6):867-870.

WWAMI Rural Health Research Center. Rural-urban commuting area codes (version 2.0) <http://depts.washington.edu/uwruca/>. Accessed October 20, 2008.

WWAMI Rural Health Research Center. RUCA Data: Travel Distance and Time, Remote, Isolated, and Frontier. <http://depts.washington.edu/uwruca/ruca-travel-dist.php>.

Ziller EC, Coburn AF, Loux SL, Hoffmah C, McBride T. Health insurance coverage in rural America: chartbook: *Kaiser Commission on Medicaid and the Uninsured*. <http://www.kff.org/uninsured/upload/Health-Insurance-Coverage-in-Rural-America-PDF.pdf>.

APPENDIX III

Rural Health Care Ethics Web Sites

National Rural Health Association (NRHA)

<http://www.ruralhealthweb.org/>

The NRHA Web site provides information about rural health care and its unique challenges and opportunities. It includes a helpful chart differentiating rural from urban health care. The site offers useful links to related publications, policy initiatives, networking opportunities, and NRHA programs.

Rural Assistance Center (RAC)

<http://www.raonline.org/>

The RAC Web site provides a broad range of health and human services information, including funding information, rural health care research, news, and events. The site also offers information guides, maps, state and regional resources, and a directory of experts and organizations that have an interest in rural health.

The National Rural Bioethics Project

<http://www.umt.edu/bioethics/>

The National Rural Bioethics Project Web site at the University of Montana offers results from rural health care research, a helpful resources section, and applicable patient safety information. In addition, the site provides a variety of practical tools that are appropriate for health care providers and staff, patients, and even community members.

National Organization of State Office of Rural Health (NOSORH)

<http://www.nosorh.org/>

The NOSORH site provides a listing of regional and state Office of Rural Health representatives from throughout the United States. Committees that address issues from finance to health information technology are listed, and contact information is provided for each. The site provides a mentoring program and resources for members and non-members.

Veterans Affairs National Center for Ethics in Health Care

<http://www.ethics.va.gov/>

This Web site provides tools for health care professionals aiming to address ethics questions. The site also offers numerous links to VA ethics resources, including material for the Integrated Ethics Program, the National Ethics Committee, and ethical issues like pandemic flu preparedness and response, among others.

University of Pennsylvania Center for Bioethics

<http://www.bioethics.net>

This Web site details the University of Pennsylvania's Bioethics program, including outreach and public service information and Center resources, such as the journal, *The American Journal of Bioethics*. The site covers a broad range of bioethics topics and provides general ethics guidance that is applicable to a variety of bioethics discussions.

American Medical Association: Medical Ethics

<http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics.shtml>

This Web site provides the AMA's Code of Medical Ethics for reference, the declaration of professional responsibility, as well as a virtual medical ethics mentor. The site also includes the AMA's Council on Ethical and Judicial Affairs, the Ethics Resource Center, and the Institute for Ethics.

Applied Ethics Resources on WWW

<http://www.ethicsweb.ca/resources/bioethics/>

This site contains a basic but thorough listing of ethics-related resources including ethics institute and organizations, ethics publications, topics and issues, and other relevant organizations. Noted topics cross a broad range of health care issues.

The American College of Healthcare Executives

www.ACHE.org

The ACHE site provides a variety of services to members, as well as helpful ethics resources that are available to non-members. The resources are very user-friendly and include an ethics toolkit, code of ethics, policy statements, and self-assessments.

**Dartmouth Medical School
Community and Family Medicine**

<http://dms.dartmouth.edu/cfm/resources/rhc/>

This Dartmouth Medical School Web site contains a PDF version of the book, Handbook for Rural Health Care Ethics: A Practical Guide for Professionals. The book is available free via the Web site as one large PDF document as well as by chapter. In addition to the Handbook the Web site provides a PDF document of a useful Training Manual for Rural Health Care Ethics.

AMA Code of Medical Ethics

<http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page>

This Web site provides ethics guidelines for physicians regarding a wide-range of ethics issues.

**Glossary of Basic Concepts
in Health Care Ethics**

Advance Directive: An indication (usually written but may be oral) of the preferences of a patient regarding her wishes for medical care in the future, in the event that she is unable to participate in making decisions (often at the end of life).

Allocation: The apportionment or distribution of health care resources across various populations in need of the resources. Concept can be sub-divided into “micro-allocation” levels (for example, distribution of ICU beds at the level of individual patient) and “macro-allocation” levels (for example, distribution of Medicare resources across the health care services covered by Medicare).

Assent: Children and others who do not have legal or decisional capacity to take part in medical decision-making, assent to participate in care. In these settings, parents or other surrogates provide informed permission for diagnosis and treatment procedures.

Autonomy: A foundational principle of medical ethics, referencing the “right” of adult patients of sound mind to participate in decisions regarding their medical care. More generally, the term is derived from the Greek *auto-* (self) and *nomos* (rule, governance, or law); hence self-rule or self-governance.

ACKNOWLEDGEMENT

The Glossary has been adapted and expanded from a teaching tool originally developed and copyrighted by Drs. Barbara Elliott and Charles Gessert, 2010.

Beneficence: A foundational principle of medical ethics, referencing acting to “do good” for the patient, often interpreted as “acting in the best interests of the patient.” More generally, the term is derived from the Latin *bene-* (well), and *ficere* (to do); hence “to do good,” or acting in a kind way.

Best Interests: The Best Interests standard is one of the standards that may be used in making decisions for a patient when she cannot make decisions for herself. In using the Best Interests standard, the decision-maker chooses what is deemed to be best for the patient, and thus, in the patient’s ‘best interests.’ The Best Interests standard may be compared with the Substituted Judgment standard (see definition below), which is generally used (when possible) in American bioethics.

Brain Death: “Whole brain death” can be understood to mean complete and irreversible loss of all brain function, cortex and brainstem. “Higher brain death” is used by some to refer to loss of function of cortex (consciousness, thought, feeling) when the brainstem is still functioning. “Whole brain death” is accepted by most as a definition of death, per the Uniform Definition of Death Act. [“Any individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made with accepted medical standards.”] Current “accepted medical standards” for “whole brain death” include irreversibility, and absent cortical and brainstem function.

Capacity: As related to “decision-making capacity,” the ability of a patient to participate in medical decision-making. Compare with competence (see below). There are a range of standards for determination of decision making capacity; it is generally accepted that the more risk involved in the medical intervention, the “higher” the standard for capacity that should be used. Proposed “standards” for capacity include (from “lower to higher”) 1) ability to communicate a choice; 2) ability to understand the situation and relevant information; 3) ability to give a reason for the choice. Physicians generally determine capacity, but may need the help of other providers in more complex cases.

Cardiopulmonary Resuscitation (CPR): “Artificial” provision of (or attempts to provide) cardiac and pulmonary function for patients who experience acute cardio-pulmonary failure (arrest). The term CPR also references the protocol used to attempt resuscitation.

Casuistry: Casuistry is an ethical theory that judges moral action based primarily on the precedent of previous cases in similar circumstances. Narrative theory is a prominent example of casuistry.

Competence: Compare with capacity (see above). Competence is a legal concept; competence or incompetence is determined by a judge or court. A determination of incompetence indicates that the person does not have the minimal ability or capacity to perform an act. A judge might rely on a medical opinion from a physician to assist in this determination.

Competing Interest: This term references tension that occurs when there are two concerns that demand the professional’s attention at the same time. In many instances both concerns can be addressed without compromising either. For example, time devoted to patient care cannot be spent on continuing medical education, teaching, clinical research, personal hobbies, or family activities. These competing interests can usually all be accommodated with careful time management.

Confidentiality: In medical ethics, the right of patients to privacy and control over their own medical records and information. In most cases health care professionals are obliged to respect patient confidentiality and to prevent public or inappropriate release of patient information. Exceptions to this include steps necessary to protect patients themselves (for example, in cases of child abuse), or third parties (for example, infectious diseases, impaired drivers, or violence).

Conflict of Interest: This term references circumstances that occur when there are two concerns that focus the professional’s attention at the same time, and attending to one compromises the other. Conflicting interests cannot both be fulfilled; the physician literally cannot advance one interest without setting the other back. For example: giving a continuing education presentation about back pain, while being paid by a pharmaceutical company to talk about their specific pain medication.

Consequentialism: Consequentialist theories are ethical theories that judge moral action primarily based on the consequences of that action; they seek to maximize the utility, or good, of those consequences while minimizing harms. Utilitarian theories are prominent exemplars of consequentialism, and can be either “rule based” or “act based.”

Conservatorship: When a person is deemed incompetent to make decisions for herself, the court may assign another person to be her conservator. At this level of legal supervision, the conservator then is responsible for being the decision maker and for managing the property of the individual (see Guardianship).

Cost-benefit Considerations: The process of making decisions based on how well, or how poorly, an action will turn out (see Consequentialism, above). This approach to decision making summarizes all the benefits of a potential action, compares them to the anticipated negative consequences or costs, and makes a decision to achieve the greatest benefit. A challenge in using this process for medical decision-making is that physicians, patients and policy writers define “benefit” differently.

Decisional/Non-Decisional: Patients who have lost capacity or have been deemed incompetent by the courts are considered ‘non-decisional’ in making medical decisions. People of sound mind and over age 18 are assumed to be decisional.

Deontology: Deontological theories are ethical theories that evaluate moral actions in and of themselves, (largely) independent of their expected consequences. Deontological theories are most often rules-based, with moral actions being judged according to their adherence to rules (for example, “Thou shall not kill”).

Disproportionate Care: Disproportionate care is any medical treatment that either offers no reasonable hope of benefit or is too burdensome for the patient or others, considering the personal, financial, familial, social and spiritual circumstances (*i.e.*, the burdens or risks outweigh the expected benefits of the treatment).

Donation After Cardiac Death (DCD): Also known as non-heart beating organ donation. DCD is a relatively new concept by which patients may be accepted for organ donation after cessation of heartbeat, but before “brain death” criteria (see above) are fully met. In most situations this practice requires careful coordination of many different health care teams and personnel, and is considered by some to be ethically ambiguous.

Do Not Resuscitate (DNR) Orders: An order in a medical record, entered by a health care professional, which indicates that cardiopulmonary resuscitation (CPR) is not to be administered to a patient in the event of cardiopulmonary arrest. In the vast majority of circumstances this order is written only when the DNR is requested or agreed to by a competent patient or surrogate decision maker, after discussion with a health care professional. In some settings health care professionals can make unilateral DNR decisions regarding patients.

Durable Power of Attorney for Health Care (DPOA-HC): The DPOA-HC is a legal designation of a surrogate decision-maker for health care decisions. This designation can be made using a DPOA form prepared with the assistance of an attorney, or by completing the appropriate part of an advance directive. A Durable Power of Attorney (without the health care designation) pertains to decisions regarding property and money; the DPOA-HC pertains to decisions regarding the person: health care and life style. Power of Attorney is a designation that can be invoked at any time; a Durable Power of Attorney is only in force when the patient is non-decisional.

Emancipated Minor: A person who has not yet reached the age of majority, but who is decisional and able to consent for herself due to state law (re: health concerns regarding pregnancy or related issues, mental health and substance abuse concerns), or court action (re: the individual has been declared emancipated).

EMTALA: This acronym references the federal Emergency Medical Treatment and Active Labor Act, which requires hospitals to examine and stabilize a patient who presents to an emergency room for attention to an emergency medical condition—without consideration of insurance coverage or ability to pay.

Ethical and Religious Directives (ERDs): The Ethical and Religious Directives present guidelines for health care services delivered in institutionally based Roman Catholic health care settings. Since they express the Church's moral teaching, the ERD's are also helpful to Catholic professionals engaged in health care in other settings.

Ethicist: A person with specialized training in theoretical or applied ethics; alternatively, one who "broadens and deepens" the abilities of others to be reflective concerning human moral experience.

Ethics: A term with several different meanings a) types of philosophy and/or theology concerned with the nature of morals and moral evaluation (for example, what is right or wrong, virtuous or vicious, and beneficial or harmful); b) the study of the rules, standards, and values related to moral actions and behavior; or c) an adjective describing the morality of a particular moral action.

Ethics, Applied: "Applied ethics" are ethics that analyze moral issues within certain practices (for example, health care ethics, business ethics, environmental ethics), or analyze specific, controversial moral issues such as abortion, euthanasia, or fraud.

Generally speaking, two features are necessary for an issue to be an "applied ethical issue." First, the issue must be controversial in the sense that there are significant groups of people both for and against the issue at hand; second, it must be a distinctly moral issue.

Ethics, Case: An ethics case is an ethics conflict or uncertainty involving specific individuals, such as a patient in a particular situation and time.

Ethics, Clinical: Clinical ethics is the area of health care ethics that focuses on decisions, conflicts, or actions related to the clinical care of patients within the context of the clinician-patient relationship. An example of clinical ethics is the decision related to the removal of an individual patient from life-sustaining treatment.

Ethics, Conflicts: Ethics conflicts occur when there is uncertainty, a question, or a conflict regarding competing ethical principles, personal values, or professional and organizational ethical standards

of practice; for example, when a patient with decisional capacity demands futile treatment. Ethics conflicts also occur when one considers violating an ethical principle, personal value, or organizational standard of practice. When an administrator or clinician violates (or considers violating) established ethics standards, norms or an expectation for conduct.

Ethics, Health Care: Health care ethics focuses on the application of applied ethics concepts and reasoning to the delivery of health care. Areas of study related to, and overlapping with, health care ethics includes bioethics, e.g., the study of ethical controversies brought about by advances in biology and medicine.

Ethics, Issue: An ethics issue is an ethics conflict that is recurring in a series of ethics cases over a period of time. For example, issues related to the withholding or withdrawing of life-sustaining treatment may recur. Ethics issues are generally addressed in policy and procedure changes at an organizational level.

Ethics, Organization: Organizational ethics is the area of health care ethics that focuses on the institution's structure, culture, procedures, practices, policies, mission, and values that ultimately impact patient care. An example of organizational ethics is the creation of institutional guidelines regarding removal of patients from life-sustaining treatment.

Ethics, Reasoning: Ethical reasoning connotes deliberation and explicit arguments to justify particular actions based on moral or ethical analysis. Ethics is the systematic study of, and reflection on, morality—"systematic" because it uses special methods to examine situations, and "reflection" because it calls to question assumptions of existing morals or values, such as customs, habits or traditions. The "ethical thing to do" is defined by a course of action that has been reasoned and reflected upon; why an action is considered right or wrong—e.g., what's the justification for the decision or action? Therefore, ethical reasoning can help lead to the "right" thing to do when ethics conflicts occur.

Ethics, Research: Research ethics is the area of health care ethics that focuses on actions and decisions related to the conduct of research in health care settings, such as informed consent for partici-

pating in research projects, conflicts of interests, the dissemination of research findings, and scientific misconduct. The principles guiding the ethical practice of research have been articulated in the Nuremberg Code, the Declaration of Helsinki and the Belmont Report. U.S. laws and policies require Institutional Review Board (IRB) oversight of human subject research.

Euthanasia: “Actively” and “intentionally” ending the life of a patient perceived to be suffering from a terminal illness or other medical condition for beneficent reasons—for example, by administering a lethal injection. Compare with physician assisted suicide (see below).

Extraordinary Care: See ‘Disproportionate Care’; the two terms were declared equivalent in a 1980 Vatican statement.

Futility: In medicine, the judgment, on scientific grounds alone, that some kinds of medical treatments will be non-beneficial in given circumstances. That is, certain medical interventions may be considered “medically futile,” and therefore some invoke “futility” in arguing that the interventions should not be offered or given to patients. An example might include giving/offering CPR to a patient who is days from death with a terminal malignancy, when survival rates in many studies approach 0%. Others argue, for example, that “futility” depends on one’s perspective, or that “futility” represents a paternalistic (see below) effort to override patient autonomy.

Goals of Care: The goals of medical treatment reference the outcomes of care that are preferred by the patient and shared by the physician. It is important to discuss and agree on the goals, when needed, to negotiate these goals, recognizing that realistic goals of care must be based on truthful discussion of prognosis and careful listening.

Guardianship: When a person is deemed incompetent to make decisions for herself, the court may assign another person to be her Guardian. This person then is responsible to be the decision -maker for the person, including making health care decisions. Note that there are several levels of guardianship, which include those that focus on the person (including health care decisions) and those that include managing the property of the individual (termed conservatorship if the court does not include decisions of the person).

HIPAA (Health Information Portability and Accountability Act): A federal law passed in 1996 that closely regulates patient confidentiality and use of patient medical records, especially the electronic transfer of patient data, beyond the immediate health care team. Health care professionals and institutions are liable for penalties and monetary fines (which may be significant) if violations occur.

Hippocratic Oath: Credited to Hippocrates, the first known oath of the medical profession, written in the 5th century BCE.

Hospice: A philosophy of care for patients (and their significant others) who are in the terminal phase of an illness (“terminal” commonly understood as a life expectancy of six months or less). Hospice care is interdisciplinary, and includes physicians, nurses, social workers, chaplains when desired, counselors, home health aides, volunteers, and so forth. The focus of hospice care is on optimizing “quality of life” (broadly understood to include not only physical comfort, but also emotional, spiritual, social, economic well being) as defined by the patient, rather than focus on treatment of the underlying medical condition. Hospice is similar to “palliative care” (see below), but is generally distinguished from “palliative care” in that hospice care includes few curative therapies.

Hydration: Hydration refers to the fluids used to maintain a body. Hydration can be delivered by mouth, through a nasal-gastric tube, percutaneously through the stomach wall, or intravenously. Hydration is recognized as a medical intervention, and thus can be withheld or withdrawn when it is no longer consistent with the goals of care. Several court cases have established that it is justifiable to withhold or withdraw fluids (and food).

Implied Consent: Any non-decisional patient brought to the emergency department and who is to be treated under the EMTALA is assumed to have consented to treatment; consent for care in these emergency circumstances is implied consent.

Informed Consent: A pre-eminent concept in medical ethics, grounded primarily in respect for patient autonomy. Informed consent requires that a patient or patient surrogate be provided with information regarding a proposed medical intervention, so that she

may consent to, or decline, the intervention. There is some variance amongst authors in medical ethics regarding what constitutes “adequate” informed consent; a more rigorous view would include patient competence, patient voluntariness (no coercion), disclosure of information by the health care professional (including the nature of the intervention, benefits/risks, alternatives, and uncertainties regarding intervention), assessment of patient understanding, and exploration of patient’s preference.

Informed Permission: Parents of minor children give informed permission for medical interventions that will be done for their dependent child(ren); only an individual can give informed consent for care she chooses to receive. A minor child assents to care—a person must be over age 18 to consent (unless emancipated).

Institutional Review Board (IRB): IRBs are boards that oversee human research protections for research that is conducted within facilities/institutions. These boards must be constituted and operated in a manner consistent with federal requirements (the Office for Human Research Protections [OHRP]) and must be registered with the federal OHRP.

Intent: Many medical interventions create positive outcomes while also having the potential to do harm. The combination of these two circumstances is known as the “double effect,” and the ethical interpretation of the outcome is based on the intent of the action. For example, morphine is appropriately prescribed to reduce pain in a dying patient; it may simultaneously also reduce the patient’s respiratory drive, hastening her demise. The use of the morphine may be justified on the basis of the intent to relieve pain, despite the double effect of the treatment.

Justice: A foundational principle of medical ethics concerning the fair and equitable distribution of medical interventions and resources according to what persons are due or owed. The application of Justice may be controversial in that while Aristotle’s “Formal Principle” of justice seems reasonable (“Equals ought to be treated equally, and unequals are to be treated unequally”), it has been difficult for scholars to find agreement on a “material” definition of justice (that is, a definition to give guidance in the allocation of medical resources). Possible “material”

definitions have included “to each according to” a) “need”; b) “effort”; c) “contribution”; d) “merit”; e) “free market”; and f) “equity” (equal shares).

Living Will: One form of a written advance directive, in which a patient clarifies who should be their “surrogate decision-maker” (see below) and/or what types and levels of medical treatment are desired when a patient is no longer able to make decisions on her own (often at end of life).

Medical Error: Medical errors may occur in the assessment, diagnosis, treatment and/or follow up of a medical condition. Medical errors often involve incomplete or inaccurate care; their consequences may be minor or major. Medical errors result in thousands of deaths each year. Traditionally, errors have been attributed to mistakes made by individuals, who may be subsequently be penalized for these mistakes (medical malpractice suits). A newer model for addressing errors attempts to identify the underlying system defect that allowed the opportunity for the error to occur, and then work to redesign the system through quality improvement thinking and methods to prevent the recurrence of the error.

Morality: Morals help to delineate basic shared values; morality usually refers to conduct that conforms to the accepted customs or conventions of a group of people. Morality is learned by children from parents or other adults, and is usually accepted without deliberation. Personal morality is based on common values, traditions, customs, law, intuitions, and faith-based personal beliefs that an individual calls upon for regular guidance in making decisions about what to do or how to behave. It may be seen as a more general term than “ethics,” having to do with a person’s experiences of conflict between right and wrong/good and bad, or with standards regarding right and wrong/good and bad that one learns and/or develops over time.

Moral Reasoning: Moral reasoning is a type of practical reasoning through which one comes to a decision regarding what to do when faced with a moral dilemma. There are different understandings of practical moral reasoning in ethics and medical ethics, but basic elements include first, developing a description of the moral dilemma; second, deciding which ethical principles/concepts/issues are of concern or at stake in the dilemma; third, proposing a solution to the

dilemma; and fourth, offering a defense, rationale, or justification for the suggested solution.

Narrative: The use of narrative in health care ethics is closely related to casuistry (see above). Narrative is the act, process, or an instance of narrating, e.g., telling a story. In the context of health care ethics, narration involves using the patient's life story as a guide to decision-making regarding future interventions and goals of care.

Negligence: Professional negligence is an act or omission by a medical professional in which the care provided deviates from accepted standards of practice in the medical community and causes injury or death to the patient. Medical malpractice is tried in the courts where financial awards may be made to patients who have been injured with negligent acts.

Non-beneficial Care: A term used to reference or describe medical care that does not offer benefit to the patient; this term is also used interchangeably with "futile care."

Non-maleficence: This foundational principle references "doing no harm" in providing medical care to the patient. The concept is attributed to Hippocrates: *primum, non nocere* or "first, do no harm," and the term is from Latin *maleficus*, that is, wrongdoing.

Nutrition: Nutrition refers to the food used to maintain a body, and it can be delivered by mouth, through a nasal-gastric tube, percutaneously through the stomach wall, or intravenously. Nutrition is recognized as a medical intervention, and thus can be withheld or withdrawn when it is no longer consistent with the goals of care. Several court cases have established that it is justifiable to withhold or withdraw food (and fluids).

Ordinary Care: See 'Proportionate Care'; the two terms were declared equivalent in a 1980 Vatican statement.

Organ Donation: Giving organs for use, most commonly to live recipients (although some patients donate their organs or bodies "to science" post mortem, as in anatomy cadavers). Some tissues can be donated from cadavers for use in live recipients as well (for example,

corneas, bone). Some organs can be donated from live persons (for example, partial liver transplantations, or donating one kidney). However, most organ donations are from people who are brain dead (see above), while an increasing number of organs come from "donation after cardiac death" cases.

Palliative Care: Care intended to improve the quality of life of patients by attending to the symptoms of their serious or life-threatening diseases. Quality of life is improved by prevention or treatment of the symptoms of the disease, the side effects caused by treatment of the disease, and the psychological, social, and spiritual problems related to the disease or its treatment. Palliative care may or may not include active treatment of the underlying disease itself. The term is sometimes referred to as called supportive care and symptom management. It is generally distinguished from hospice (see above) by continuing curative efforts and a longer life expectancy.

Paternalism: A term describing professional behavior in which a health care professional makes decisions for a patient (in a "fatherly" way, applying beneficence) without allowing the patient to participate fully in medical decision-making.

Patient-Professional Relationship: This term references the relationship between a patient and her health care professional; it may be a brief one-time encounter, a relationship that develops over many years, or something in between. Many models of patient-professional relationships have been developed, including the Paternalistic model, the Informative model and the Deliberative model; each model describes who has the power in making the decision.

Persistent Vegetative State (PVS): Persistent vegetative state is a disorder of consciousness in which patients with severe brain damage who were in a coma progress to a state of partial arousal rather than true awareness. It is a diagnosis of some uncertainty in that it deals with a syndrome. After four weeks in a vegetative state, (VS), the patient is classified as in a persistent vegetative state (PVS). After a year, it becomes Permanent Vegetative State. Several landmark court cases regarding have examined the circumstances under which care providers may be obliged to keep such patients alive, including: Karen Ann Quinlan, Nancy Cruzan, and Terri Shiavo.

Physician-Assisted Suicide: When a physician actively and intentionally makes the means to commit suicide available to a patient who then follows through with the suicide. For example, writing prescriptions for a lethal drug or combination of drugs, giving explicit instructions on how to take them so as to cause the death of the patient would be considered physician-assisted suicide if the patient follows through and commits suicide. If certain conditions are met, some instances of physician-assisted suicide are legal in Oregon, Washington and Montana, but not in other states in the U.S.

Privacy: This right guaranteed by the U.S. Constitution allows that there are particular aspects of life that are protected from intrusion by government. With regard to medical practice, reproductive care decisions (including abortion) are acknowledged as private decisions, and thus protected from government intervention. Compare with confidentiality (see above).

Professionalism: Medicine is a profession with commitments to its patients and society that are stated in medical oaths and accomplished through (continuing) education. Currently there are three principles at the center of medical professionalism: the primacy of patient welfare; patient autonomy; and the fair distribution of health care resources (social justice).

Proportionate Care: Proportionate care is any treatment that, in the given circumstances, offers a reasonable hope of benefit and is not interpreted as too burdensome for the patient. What offers a “reasonable hope of benefit” to the patient is judged considering the person’s personal, financial, familial, social and spiritual circumstances, and their personal preferences. Generally, a treatment or means is not too burdensome when it offers benefits that outweigh the burdens to the patient.

Proxy: See Surrogate Decision-maker.

Quality of Life: An assessment each person makes for herself, regarding health, life circumstances, and other factors, including degree of desire for aggressive health care interventions. Health care providers should talk with patients regarding their current and desired quality of life when discussing goals of care and planning care.

Risk-Benefit Considerations: In social justice assessments, risk-benefit is an economic consideration. In medical settings, the risk references the physical/functional risk, balanced by commensurate benefits, in light of the goals of care. At a personal level, the question asked by the patient/family is: “Is it worth it for me to...” See also Cost-Benefit Considerations (above).

Risk Management: In medical settings, risk management refers to the hospital/facility efforts that are designed to identify and reduce the probability or impact of unwanted outcomes.

Scope of Practice: Scope of Practice is a term used by state licensing boards to define the procedures, actions, and processes that are permitted for the licensed individual. Scope of Practice is limited by the specific education, experience, and demonstrated competency of the licensed individual.

Shared Decision-making: Shared decision-making describes the decision-making process and ideal outcome of informed patient choice. It refers to the robust communication process between the physician and patient. The physician provides unbiased and complete information regarding all treatment options and information, plus his or her sense of the best way to proceed. For the patient, this process includes discussion of personal factors that might make one treatment alternative more preferable than others. This open, two-way exchange of information and opinions about options, risks, benefits, and values can lead to better understanding and better decisions about clinical management for patient-centered care.

Substituted Judgment: Substituted Judgment is one of the standards used for making decisions on behalf of patients who lack capacity to make their own decisions. A surrogate decision-maker (see below) who uses the Substituted Judgment standard, makes decisions based on what the patient would have wanted, were she able to speak for herself. The Substituted Judgment decision could be based on oral or written advance directives, knowledge of the patient’s values, preferences, goals, and beliefs, and so forth. When using Substituted judgment, the surrogate does not make decisions based on what the surrogate would want if she were in the patient’s situation, nor does the surrogate make decisions based on what the

surrogate wanted the patient to decide. Rather, the patient's wishes, as previously communicated to the surrogate, are to be substituted for the surrogate's wishes when making the decisions. Compare with Best Interests (see above).

Surrogate Decision-Maker: When a person is non-decisional, another person must make health care decisions for her. This person is the Surrogate Decision-Maker (also termed 'Proxy Decision-Maker'). The Surrogate makes decisions using either the Substituted Judgment or Best Interests standards.

Tarasoff: Tarasoff references a 1970's case from the Supreme Court of California that established the 'duty to protect' or 'duty to warn' obligation of a (mental health) professional. It obliges a professional who hears a credible threat of harm to a specific individual to warn the intended victim and assure that the police and/or others who can protect the threatened individual are also informed.

Triage: Triage is the process by which limited resources are distributed. Medical triage is a process of prioritizing which patients will receive care first; under some circumstances medical triage also determines which patients will receive life-saving interventions. Triage is routinely used in busy Emergency Departments, and is important in military medicine and disaster management.

Truth-Telling: Truth-telling is regarded as a virtue in the practice of medicine, and is regarded as integral to the exercise of patient autonomy. However, truth-telling is also nuanced and complex in the practice of medicine. Informed consent is based on the physician-patient exchange of information that is valid and complete. However, many factors impact the ability and desire to reveal (complete) truth—for example; some patients/families may not want full disclosure from the physician.

Tuskegee Syphilis Study: The Tuskegee Syphilis experiment was a clinical study conducted from 1932-1972 in Tuskegee, Alabama. Investigators recruited 399 African-American sharecroppers with syphilis for research related to understanding the natural progression of the untreated disease, in hopes of justifying treatment programs for African-Americans. The 40-year study was ethically controversial, pri-

marily because of deception regarding the research, the lack of consent, and the researchers' failure to treat patients appropriately after the 1940s validation of penicillin as an effective cure for the disease.

Utilitarianism: A sub-type of the consequentialism (see above) ethical theory where judgments are made based on the consequences or outcomes of the proposed decision for the largest number of people. The question to be answered is: what decision would provide the greatest good for the greatest number?

Values: A complex term in morality, ethics, philosophy, and theology. "Value" in a simple sense, is understood as something's worth and references how something is good or appreciated. In philosophy and theology, the term "values" refers to a person's priorities in making judgments. The term can also be applied to an organization's defined priorities, such as values statement.

Virtues: While specific positions in "virtue ethics" vary, virtues are generally seen as habituated character traits or dispositions that govern actions, help to order emotion, and can help to guide conduct. The classic "cardinal virtues" are temperance, courage, prudence, and justice; the "theological virtues" are faith, hope, and love. Recent positions in medical ethics have argued that physicians ought to be virtuous; for example, good physicians should display the virtues of compassion, trustworthiness, and integrity. From the Greek *arête*, meaning "excellence."

APPENDIX V

Authors

William A. Nelson, MDiv, PhD, is an Associate Professor, The Dartmouth Institute for Health Policy and Clinical Practice (TDI) and Community and Family Medicine at Dartmouth Medical School. Dr. Nelson teaches intra-professional courses on health care ethics with a focus on the relationship between ethics, quality and value in today's health care organizations. He is also an adjunct Associate Professor at New York University's Robert Wagner Graduate School of Public Service. Previously he served as the Ethics Education Coordinator for the VA's National Center of Health Care Ethics, which he co-founded.



Dr. Nelson has published over 80 manuscripts. Many of his scholarly and research activities have focused on ethics issues in rural America. In 2009, he edited the *Handbook for Rural Care Ethics: A Practical Guide for Professionals* (Dartmouth College Press). In 2010, he coauthored the *Rural Ethics Training Manual* which is available on the Web site <http://dms.dartmouth.edu/cfm/resources/rhc/>. Dr. Nelson serves as the coordinator of the Coalition for Rural Health Care Ethics. In 2009, he was a Leadership Fellow with the National Rural Health Association.

Dr. Nelson has been invited to deliver hundreds of presentations in the US and internationally. In 2010, he co-edited *Managing Ethically: An Executive's Guide* (Health Administrative Press) and is a regular ethics column contributor to *Healthcare Executive*.

Dr. Nelson is a recipient of the US Congressional Excalibur Award for Public Service and in 2004 received the Department of Veterans Affairs Under Secretary for Health's highest honor, the "Exemplary Service Award." He studied US and international health care policy as a W.K. Kellogg National Leadership Fellow. In 2006, Dr. Nelson was awarded an Honorary Doctorate of Humane Letters from Elmhurst College.

Barbara A. Elliott, PhD, is Professor, Department of Family Medicine and Community Health, at Medical School Duluth, University of Minnesota. She is also an adjunct Professor of Bio-behavioral Sciences, and serves as Affiliate Faculty in the Center of Bioethics, University of Minnesota. She is trained and works as a hospital chaplain. Dr. Elliott chairs and consults with multiple hospital ethics committees, including several in rural settings in the Midwest.



Photo credit: Jeff Frey & Associates

In a rural-focused medical school, Dr. Elliott teaches medical ethics, the health issues of family violence, and spirituality and health care. After investigating how people distribute and share limited resources in multiple settings around the world as a W. K. Kellogg National Leadership Fellow, she has pursued research focused on another justice issue: the health care needs and outcomes of those with limited access to health care. This work has documented the personal, social, and medical outcomes of extending access to health care to the under-served. These efforts have been continuously funded since 1984, resulting in more than 50 peer reviewed articles, an edited

volume, several book chapters, and regular invitations to present at conferences, symposia and meetings.

Dr. Elliott has received many awards and acknowledgements for her efforts. She was recognized as Minnesota's Marvelous Woman of the year in 1995, and has received awards from the Minnesota Medical Association (Stop the Violence Award, 1998), the American Academy of Family Physicians (Research of the Year, 2002), the Chancellor's Award for Distinguished Research (2006), and the University of Minnesota award for Outstanding Community Service (2007).