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A RURAL PERSPECTIVE ON MODERN BIOETHICS

by

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Presented in partial fulfillment of the requirements

for the degree of

Doctor of Philosophy

The University of Montana

August 2001

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A Rural Perspective on Modern Bioethics

Director: Ken Lockridge



For nearly thirty years, hospitals have been encouraged to provide bioethics services to patients, families and staff members. That encouragement is evidenced by federal legislation such as the Patient Self Determination Act, various legal opinions, and the standards developed by the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) and the American Hospital Association. In spite of such encouragement, little has been known about the bioethics-related services that exist in rural healthcare settings, the ethical issues that complicate healthcare decision making in rural settings, or how those issues are resolved. The bioethics enterprise has strongly encouraged the use of two specific models for bioethics services - ethics committees and case consultation - but the efficacy of those approaches has not been substantiated in rural environments.

This work responds to that overall research deficit by examining the ethics of healthcare in rural America. The examination begins with an historical critique of the construction of modern bioethics and its institutional establishment. That critique, in turn, provides the backdrop for a multi-method exploration of the ethics-related dilemmas, needs, and practices that are experienced by those who live in rural areas. This exploration involves nine separate studies that were conducted among healthcare providers, patients, family members and community leaders who live in rural communities. The data from these studies suggest that the models for bioethics services that have been developed in urban and academic settings do not meet the needs of rural residents. Further, the findings suggest the need for both an expanded definition of bioethics as well as the development of integrated models for bioethics services that better accommodate the moral and cultural context of health care in a given community.

PREFACE

Hilda Hensen¹ serves as director of nursing in a rural hospital, an institution where she has worked for nearly fifteen years. Hilda has high expectations for the kind of care that should be provided. She notes that patients expect to be treated as though they were family members. And they have a right, she suggests, to feel that way. The hospital is closely tied to the community. Community members raised the revenue to fund the hospital, poured the concrete footings, laid the floor boards, and painted the walls. “This is not a world,” she explains during an interview, “where we can turn people away like they do in the big city hospitals. This is a world where people are tight and everybody is a little bit of kin.” This a world of connections; there are few secrets on Main Street.

Throughout the interview, Hilda offered comments such as “in our town, everybody knows everybody” and “people value their own.” Certainly, there is an expectation of self reliance in this community, but so too the realization of interdependence. She explained that: “people care about each other because they *have* to. And sometimes they have to *rely* on each other and not just care about each other.”

While Hilda offered many positive comments about the interconnectedness of her community, she also noted that the level of ‘connectedness’ that is commonly expected in rural settings can be hard to incorporate into a patient’s healthcare plan. In recent years, the shortages of staff, equipment, and supplies have taken a heavy toll. Organizational practices have also changed and to an extent, some of the new protocols discourage dialogue. For example, reports at the shift changes are often taped. Most nurses work in

three or more departments on a daily basis.² Most of the nurses who provide direct patient care in Hilda's hospital have not received much academic training.³ With such limitations, patients do not always receive the quality of care that they expect. Hilda knows that a lack of quality care is a serious cause for concern because if patients and families do not trust the level of care that is provided, they will leave the county when seeking healthcare. A decision to seek care elsewhere can have serious financial consequences for the local hospital.

Hilda also noted that the familiarity and the sense of communal responsibility, so pervasive in a small rural community, make it is hard to separate herself from her work. "I am the nurse," she explains, "when I leave the hospital, get into my car, and go to the grocery store or go to church." She is frequently on call, and sometimes feels an obligation to work even when she is not scheduled to do so. "If I hear there's been an accident, I usually head for the hospital - sometimes before I am even called. Who else can they call? We depend on each other." Hilda discussed these problems in an articulate manner, but was not sure any of them could be termed "ethical" in nature.

After participating in the interview for more than an hour, Hilda noted that the kinds of cultural differences that emerge in rural communities can be "emotionally distressing." She recalled a recent incident in which a young, first time mother experienced a long and difficult labor. Throughout the labor and birth, the young woman begged the nurses for medication to quell the pain. Pain relief was certainly available, but the woman's husband told the nurses that the Bible explicitly adjourned: "In pain shall you deliver your young." His wife, he insisted, must not be offered any pain relief. Hilda

and the other hospital staff who were working that night accepted the husband's directive and coached the young woman as best they could. Everyone involved in the situation endured a long and stressful night; the young woman had a very difficult time coping with the pain.

Hilda and the other nursing staff were irritated with the husband, but they did not discuss the situation with either the husband or his wife. Hilda expected that life would be "easier for the woman in the long run" if the nurses obeyed her husband. She thought that perhaps she was doing the young woman a favor. Though not personally acquainted with either the patient or her husband, Hilda was familiar with their Church and she knew the minister. The minister and the husband would have been angry had the Church's teaching been circumvented. Further, there was little doubt that both would be informed if pain medication was accepted. "There are so few secrets in this town" explained Hilda. Hilda also explained that accepting pain medication could have made life extremely difficult for the young woman; she may have been ostracized by her family and members of the congregation when she returned home. In fact, when the new mother was discharged, the day after the birth, she thanked the nurses; she said she was grateful that they could be "trusted" and had done nothing to place her or her family in jeopardy.

After relaying the incident, Hilda paused for a moment, and noted again that cultural diversity can be challenging. Neither she nor other members of the hospital staff talked to one another about the incident that night nor have they explored the issue in the intervening weeks. Hilda characterized the incident as one of those every day, bed-side problems that are part of hospital life. At the close of an interview that lasted nearly two

hours, she asked: “Would you call that an ethical issue? Did I do the right thing?”

There is no simple answer to Hilda’s question. To find a response, we need to look both backward and forward. We need that backward glance to understand how the ethics of healthcare has emerged as a discipline, and how that emergence has shaped our collective understanding of moral dilemmas and encouraged the development of ethics-related services. And then we need to move forward and consider how the discipline of bioethics can respond to the increasingly complex cultural, historic, political, and economic issues that complicate the provision of healthcare in rural areas. This dissertation responds to that challenge.

The first chapter discusses the social, political, and intellectual environment that led to the birth of bioethics as a discipline. That discussion involves not one, but three separate stories about the genesis of the field. Chapter Two examines the formal, ethics-related services and approaches that became institutionalized in hospitals when the academic discipline of bioethics moved into the clinical setting. In particular, the second chapter discusses and critiques the two dominant models, ethics committees and case consultation, that have been developed to provide formal services to patients, families and healthcare providers. Chapter Three presents a series of nine research studies that have been conducted in rural communities. The studies provide a way to contrast the expectations of the field of bioethics with the realities of rural healthcare. Chapter Four discusses the implications of the rural studies and, in particular, the issues that make adoption of the models and approaches developed in urban settings unlikely and unsuitable in rural areas. Chapter Five discusses the value of an approach to bioethics

that is based on rural experiences and is inclusive, contextual, and process driven as opposed to exclusive, academic and formalized.

At times this narrative describes problems that developed in rural healthcare settings. The names that are used in all of the case studies, stories and examples are fictitious. In addition, the stories are based on comments and examples obtained from a 12-state area and so any reference to real persons is not intended and should not be inferred.

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CHAPTER I

THE BIRTH OF BIOETHICS: WHOSE VOICE, WHOSE VISION

The director of nursing in the small rural hospital agreed to participate in an interview. She did, however, express some reservations; she could not imagine what she could offer if the topic of the conversation was “bioethics.” Bioethics seemed like an academic subject, an area of study more suited to college classrooms than to rural hospitals. After talking for nearly an hour, she noted that her *personal* values sometimes raised unsettling questions. When problems developed, she was not always sure what she should do. She recounted several experiences that had recently proved troubling, such as caring for a drunk driver who killed a popular member of the small community, asking local families to consider organ donation, or withholding information about a terminal diagnosis from a patient. “I struggle with those kinds of issues,” she noted. “But is that bioethics? I am not sure that I know what bioethics really is.”

Certainly the problems encountered by the nurse seem to fit a nutshell description of bioethics - “the study of the moral principles and values that accompany medical treatment and research.”⁴ But some commentators, especially those trained in traditional philosophy would disagree with that assessment. They suggest that the issues encountered by the nurse, and indeed by most healthcare providers, more specifically meet the realm of moral psychology or moral anthropology as opposed to ethics.⁵ Albert Jonsen, a highly respected philosopher, may not specifically assign the issues to either of

those two categories, but he also defines bioethics quite narrowly, noting that it is a *systematic* study of the moral dimensions of the life sciences and that “a systematic study necessarily is carried out by *scholars* dedicated to thinking, writing and teaching about a subject.”⁶

Thus, a question that seems on the surface quite simple - “is that bioethics?” - is actually rather complicated. In part, the difficulty in articulating a clear definition of bioethics relates to what Albert Jonsen calls the “moral archeology” of the field. Bioethics has historic connections to ancient Greek medicine, medieval Christian medicine and traditional moral philosophy.⁷ The Greek physician Hippocrates and his disciples left a “small connection of moral maxims”⁸ for the “craftsmen” who would practice medicine in order to meet their objective of good living.⁹ Present day physicians still swear by the Hippocratic Oath when they graduate from medical school. Christian dogma linked care of the sick to the work of the Good Samaritan and the Good Shepherd.¹⁰ Moral philosophy has long pondered the Hippocratic/Christian paradox that pervades medicine, the balancing of self interest and “good living,” as reasonable utilitarian goals of those who hold medical knowledge, with the deontological obligation to use one’s skills so as to respond to the needs of others.¹¹

Bioethics, however, is also a new enterprise, a post modern phenomenon, created in response to an array of issues like the technological problems posed by modern medicine and rights of self determination for patients. Thus a discussion about bioethics and its relationship to the problems encountered by the rural nurse requires a series of queries, ones that specifically explore the genesis of the modern bioethical discipline, its

move to a clinical setting, and its evolving influence on medical decision making. That backdrop, in turn, provides a framework with which to examine and contrast the personal, clinical, and organizational values, and concerns that shape the provision of healthcare in rural areas. The consideration of these rural issues enriches the circle of inquiry and helps identify the ethics-related resources that might prove most helpful in rural areas. As indicated in the Preface, the five chapters in this dissertation respond to those broad queries.

This first chapter chronicles the birth of bioethics as a discipline. A birth story seems like a reasonable starting point since the rural nurse, quoted in the opening paragraph, wondered if the issues she faced were “bioethical.” The telling of this birth story, however, is not a straightforward matter. Indeed, not one, but three separate stories are used to analyze the factors that have influenced the structure and focus of the discipline. As will become apparent, different storytellers cite the significance of different events. Each perspective offers threads of myth and fact, calling to mind a theme in Lawrence Durrell’s *Alexandria Quartet* - “the angle of vision is everything.”

These different versions of the birth story are useful because each version offers a framework that helps explain the emergence of bioethics as a field, its acceptance as a speciality area within the arc of medicine and research, and its primary institutional services. As will become apparent, the stories share some common threads but the positions of the threads, and the interpretations of different authors, shift according to each tale. Admittedly the use of three different stories might seem a bit confusing and so a metaphor, that of a leviathan will be used to aid the exploration. The use of a whale as

a metaphor when thinking about bioethics, was first offered by Charles Rosenberg, a noted medical historian. In his critique of the discipline, Rosenberg charged that the “bioethical enterprise” has become lodged in the belly of the medical whale.¹² In that critique, Rosenberg also referenced the concerns of the “critics on the Left,” those who question the extent to which the enterprise has offered meaningful services.

As I developed these different stories about the genesis of bioethics, Rosenberg’s metaphor of a leviathan seemed rather apt. I have also borrowed his use of language that has often been associated with politics. Thus in this first chapter, the “bioethical whale” can be studied via three stories, and perspectives that are right, left, and somewhat centrist. The right wing perspective celebrates the birth of a field that is charged with an almost sacred mission, a field poised to respond to the moral dilemmas that accompany healthcare. The left wing perspective chronicles a history of ethical problems that were ignored or minimized; this second story about the birth of bioethics depicts a field more tarnished than pristine. The third story, the centrist position, links the key insights of the previous stories with the historic, economic, cultural and political factors that have shaped the discipline. Thus the third story affirms the value of a broader, more context-oriented framework for the construction of the modern discipline.

The use of metaphors, associated with the whale will continue throughout the body of the work. Those metaphors are useful because they provide a way to envision the role and scope of bioethics in the academic sphere, the institutional sphere, and ultimately, the rural environment. As such, the metaphors help to create a vision for services that respond to the contextual realities that shape healthcare decision making.

The Birth of a Whale

Considering his leadership in the field, his involvement in seminal activities in the formative years of bioethics and his unofficial title as the “Father of Bioethics,”¹³ the philosopher Albert Jonsen’s telling of the tale is hard to question. Indeed Jonsen’s story has become, more or less, accepted wisdom among bioethicists.¹⁴ In his book *The Birth of Bioethics*, he carefully chronicles the people and events that led to the emergence of the modern discipline. In this story, Jonsen celebrates a series of “serious, disciplined and deep philosophical reflections”¹⁵ among male academicians. With a nod to the almost sacred mission of the field, Jonsen notes that: “A trinity of theologians - Fletcher, Ramsey, and McCormick - presided over the birth of bioethics, [and] a quintet of philosophers - Jonas, Gorovitz, Clouse, Callahan, and Toulmin - were also present.”¹⁶ His version of the founding tale is intriguing, both in what it addresses and what it does not.

The whole of the 1960s, Jonsen suggests, was an era of bioethics conferences initiated by philosophers, theologians, and physicians. One of the first of these conferences, Great Issues of Conscience in Modern Medicine, was held in 1960 at Dartmouth. Over the next few years, other conferences followed. At these conferences, the “splendid scholarly panels”¹⁷ and invited participants discussed and debated the moral issues posed by the advances of science. The problems were stated in generic terms and the public, given the “lofty nature of the problems,” was rarely invited to participate in the discussions.¹⁸ Jonsen notes that the early fathers tried to bring substantive philosophical concerns to the emerging field. As they struggled with the classical

distinctions of applied normative ethics, the teleological and deontological approaches that supported problemsolving, they created a mission and an agenda for the new enterprise.

Glenn McGee, a modern student of the field, has observed that this philosophical approach created a somewhat specialized and insular discipline, a field rigorously guarded by physicians and academic philosophers.¹⁹ That orientation is evidenced in Jonsen's text. Participants needed to be recognized as scholars in order to merit invitations to the cloistered conversations. Daniel Callahan, an influential philosopher, the founder of the Hastings Center and colleague of Jonsen's, acknowledged this "intellectual exclusivity" when he noted that his leading problem in the first twenty years at the Hastings Center was persuading the philosophers to sit down with the theologians and to take them seriously.²⁰ Since Callahan created the Hastings Center as an interdisciplinary institute for the study of bioethics issues in 1969, his comment suggests that the intellectual exclusivity was pervasive and long standing. There are other examples of the exclusivity that characterized the field in its early years. Jonsen notes that Ruth Macklin was invited to join the discussions, a "leading woman bioethicist in a field dominated by white males."²¹ Jonsen also notes the significance of The Sanctity of Life conference held at Reed College in 1967 and suggests it "did better [than previous conferences] because the issues were more closely defined and because a proper theologian and a proper philosopher were invited to do some scholarly ethics." In these formative years, healthcare policy analysts, nurses, and allied health personnel were integrally involved in the discussions and conferences, perhaps because the leadership in

the field was still trying to define the legitimate voices in this new interdisciplinary arena.

Jonsen suggests that as the discussions and essays presented at these conferences became more “scholarly,” the frameworks for permanent bioethics centers were established. The centers, in turn, offered “a more disciplined, careful, long range way of working.”²² In 1969 Dan Callahan, a philosopher and editor of the Catholic journal *Commonweal* - along with some fellow academicians - created A Center for the Study of Values and The Sciences of Man; two years later the center was renamed and it has since been known as The Hastings Center. The Kennedy Institute at Georgetown, widely regarded as a premier center for bioethics, opened in 1971. Jonsen notes that one of the Kennedy Center’s great achievements was the establishment of a bioethics research library that contained “641 titles, a valuable index of the available literature for scholarly research.”²³ The Society for Health and Human Values, originally chartered as a closed society, opened to subscriptions in 1972. Jonsen notes that by 1972, the conversation was mature enough to “conceive the epitome of interdisciplinarity, *The Encyclopedia of Bioethics*.”²⁴ The seminal work was authored by Warren Reich.

This version of the founding story continues by noting that the ethical issues discussed by the academicians throughout the 1960s finally reached the ears of congress. In 1968 Senator Walter Mondale decided the time was right for a national debate about the direction of medical science in the United States. He introduced a joint resolution calling for the establishment of a presidential commission. The Senator was attuned to developing issues in biomedical research and was particularly concerned about experimental procedures like organ transplantation.²⁵ Support for Mondale’s resolution,

however, was slender. Scientists who testified at congressional hearings agreed that medical advances could have troubling aspects, but suggested those aspects were often exaggerated.²⁶ The pioneering heart transplant surgeon from South Africa, Dr. Christian Barnard scoffed at the need for a federal commission. In his testimony before Congress, Barnard noted that the public was not qualified to make decisions about the evolving medical issues of the day. Such a commission, he told the Senators, “would be an insult to your doctors” and would so hamper the doctors that they would never catch up with the progress he [Barnard] had made.²⁷ Mondale’s vision of a national commission became a frightening specter of Federal meddling. There was a strong sense that decisions about issues like organ transplantation should be left to those doing the work rather than self-appointed critics.²⁸

In 1971, Senator Mondale tried again to create a presidential commission and was again defeated. Mondale admitted being “frankly taken aback by the spirited opposition of several prominent men in health sciences”²⁹ who adamantly insisted there were no “new issues” to discuss. Since the opposition to a commission was so strong, no action was taken on Mondale’s bill. Mondale, however, was persistent and tried again in 1973. That year he was successful and his efforts led to the creation of the National Commission for the Protection of Human Subjects. That Commission is regarded by Jonsen, and by many bioethicists, as the cornerstone that shaped the foundation for bioethics as a discipline. That interpretation also reflects one of Jonsen’s persistent themes, notably the need to bring the disciplined, structured methodology of ethics to the discussion of medical research and clinical care.

Mondale deserves credit for persistence, but timing was also on his side.

According to Jonsen, two particular research studies received press attention and called into question the moral compass provided by medical researchers. One issue involved research conducted by the Public Health Service in the small, rural Alabama town of Tuskegee. In July of 1972, the New York Times described a research study in which “human beings with syphilis were induced to serve as guinea pigs, [and] have gone without treatment for the disease.”³⁰ The article noted that the men were poor, black, and uneducated; they were never told that they had the disease nor were they told they were research subjects. Instead, the men were told they had “bad blood” and should have medical examinations - some of which involved painful spinal taps. Even when penicillin became available, the men were offered no treatment. The Public Health Service even made an arrangement with the local draft board to keep the subjects off the list of draftees needing treatment.³¹ As of 1969, as many as 100 men in the research protocol had died of syphilis; others had serious syphilis-related problems.

As the New York Times dissected the story, the ethics of experimentation was propelled into public view. When the study was initiated, the causative agent, the stages of the disease and the complications were all known to science.³² The investigators were simply trying to learn more about the complications that characterized the final phase of the disease. The Public Health Service hired Eunice Rivers, a black nurse and a person trusted by the black community so as to enhance legitimacy and prospects for continuity. After the New York Times published a story about the study, a Centers for Disease Control (CDC) spokesman characterized the research as a legitimate experiment

involving “medical matters and clinical decisions.”³³ Mondale and other members of Congress, however, were troubled, and their concerns kept interest in a potential presidential commission alive.

Less than a year after the Tuskegee revelations, another research problem surfaced, and the call for a federal commission was renewed. In April of 1973, the National Institute of Health (NIH) released a recommendation from an advisory panel that outlined the use of newly delivered live fetuses for medical research. The fetuses, delivered intact due to late abortions, could be briefly maintained while studies were done.³⁴ Scientists who supported the use of these “tissues” suggested that there was nothing unethical about it. One scientist noted that the babies would die anyway.³⁵ Eunice Kennedy Shriver, and other members of the Kennedy family, hotly contested the moral legitimacy of such studies and led a series of public protests that embarrassed the NIH and forced Congressional action. Both the Senate and the House began discussions about legislation that would provide the parameters for research. Senator Ted Kennedy, Chair of the Committee on Labor and Welfare, initiated the Senate hearings. Though issues related to the use of fetal tissue helped focus attention on research ethics in general, Senator Kennedy’s concerns more specifically involved genetic manipulation and neurological or pharmacological modifications of behavior.³⁶

Kennedy threw his political weight behind Mondale and on June 28, 1973, Public Law 93-348 created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. On December 3, 1974, the eleven member commission was sworn into office; Albert Jonsen was one of the Commissioners. Jonsen

described the commission as a group of strangers, all but two from the academic world. The meetings were long and tortuous, shaped by the congressional mandate to identify the ethical principles that should underlie research with human subjects. No other commission, according to Jonsen had ever received such a charge.³⁷ But he also noted that never before had thinkers, concerned with the issues of medical ethics and research, been so prepared for such a mandate. To meet the “call for ethical principles,” the commissioners held a retreat at the Belmont House, a conference center of the Smithsonian Institute. The group became known as the Belmont Commission and they quickly established their ethical principles.

The subgroup working on ethical principles initially suggested seven. The list was interesting: respect individual freedom, benefit individual research subjects, benefit other individuals and groups present and future, minimize harm to subjects, minimize consequential harm to others, attend to distributive justice and compensating justice, and protect the weak and the powerless. There was much discussion as to whether those principles were universal; the notion of compensation was particularly questioned. One commissioner complained that such a list was not “crisp enough” and the list of principles was eventually narrowed to three - beneficence, freedom, and justice.³⁸ The Commissioners appeared to be satisfied with the abbreviated list, and overall the commission was regarded to be remarkably successful in meeting its mandate. In terms of process, the commissioners proceeded in an issue by issue, case by case manner, consistently applying the universal principles that would shape authoritative guidelines.

The primary product of the Commission, the Belmont Report, dealt with three

specific areas of concern: “a distinction between research and practice, a discussion of the three basic ethical principles [noted above], and remarks about the application of these principles.”³⁹ The report was published in 1979. It created the conceptual framework that, according to many commentators, has since governed the ethics of research with human subjects.⁴⁰ The report acknowledged that rules are often inadequate to cover complex situations, but still indicated that research protocols must incorporate three ethical principles: respect for persons, beneficence, and justice.⁴¹ The applications of the principles included considerations such as: informed consent, risk/benefit assessment, and selection of subjects for research.⁴²

To a considerable extent, the Belmont Report created an agenda for bioethics. This new discipline was perceived as practice-oriented, an enterprise expected to solve or at least ameliorate insistently visible problems.⁴³ This practice-oriented approach was an important consideration since the distinctions between research and the practice of clinical medicine were becoming less clear.

As the legislative mandate for the Commission approached its expiration date, Senator Kennedy sponsored a bill to create a new commission: The President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. In effect, this action reestablished and upgraded the Belmont Commission. However, the mission of this new Commission was somewhat vague, its purview moving from research activities to medical care of the dying and even to health care access. The manuscript entitled “Deciding to Forego Life-Sustaining Treatment” is regarded as its most successful effort.⁴⁴ This report outlined the standards for hospital-

based ethics committees. The publication of these standards formally moved the discipline of bioethics into the healthcare system. The transition to the hospital environment, and the implications of that transition, will be addressed in detail in the following chapter.

Thus Jonsen sketches a seamless and well integrated chronology of a field's emergence and response to the moral problems that accompany medicine and research. It is not, as he notes, a Big Bang, but rather a steady progression through a period of philosophical reflection, to an era of conferences, to the development of Centers, to the creation of national commissions, and finally to the implementation of clinical ethics services in hospitals throughout America. This birth story has an almost sacred aura. There was the earlier reference to the "trinity of theologians" who presided at the birth of the enterprise. Jonsen notes that the word bioethics was "canonized" in a Library of Congress' catalogue that described an article by the philosopher Dan Callahan.⁴⁵

This new discipline was exclusive and academic in orientation. Its maturity was marked by its ability to address substantive philosophical concerns through the structured methodology of ethics. These methodologies, or formal processes of argumentation, were modeled at the elite conferences and outlined in texts authored by the giants in the field - Beauchamp and Childress, Veatch, Englehardt, Pellegrino, and Thomasma.⁴⁶

There were some basic assumptions that justified the use of these formal processes of argumentation. At the outset, philosophers believed that ethical problems, regardless of their variety or context, had basic common features that are based on theories and principles. The theories were based on the duties and obligations that stem

from normative philosophy. The principles of beneficence, non-maleficence, justice, and patient autonomy provided a methodology that linked action to theories. Autonomy, a term loosely associated with several ideas including privacy, voluntariness, self mastery, freedom to choose, and responsibility for one's choices,⁴⁷ seemed to be a particularly important value, given the research issues that clouded the Tuskegee studies.

The theoretical approaches and principles that emerged in those formative years were easily transplanted into graduate programs and medical school curricula. When Robert Veatch conducted a study in 1972, he found that 56 of 94 medical schools reported that ethics was only taught within other courses.⁴⁸ Veatch's study led to a series of national initiatives, and Jonsen reports that medical ethics is now an established part of medical education.⁴⁹

The forefathers also helped to establish the relevance of bioethics services in the clinical environment. Jonsen notes that physicians who had access to bioethics resources began to appreciate the assistance that could be provided by persons like Ruth Macklin, the philosopher referenced earlier in this text. As a result, formal bioethics services were developed in hospitals throughout the country.

A Nurse Revisited

Without doubt, Jonsen perceives the birth of bioethics as a cause for celebration. And indeed, when the accomplishments of the field are seen through his eyes, they are noteworthy. But the question posed by the rural nurse at the outset of this chapter still calls for an answer. The nurse found it hard to ascertain the connection between her

experiences at the bedside and the discipline of bioethics. She asked if the issues she encountered would be viewed as “bioethical.” A quick and clean answer was elusive at the start of the chapter, and as the first story of the genesis of bioethics comes to a close, the answer to her question remains elusive. Jonsen offers a story that is long and detailed; he skillfully acknowledges key people, key events, and key processes used for decision making. However, the connections between the “serious, disciplined and deep philosophical reflections”⁵⁰ described by Jonsen, and the every day, bedside problems faced by the rural nurse are not readily apparent. Jonsen underscored the discipline’s mission to delineate substantive philosophical concerns; the nurse was concerned about the every day dilemmas. Jonsen emphasized the importance of systematic study by those “scholars dedicated to thinking, writing and teaching about a subject.”⁵¹ The rural nurse needed practical resources that would help her identify and respond to problems. Jonsen extolled the creations of bioethics libraries and centers, journals, books, and consultants. The rural nurse had never received any training in bioethics, had no access to resources and was not certain that she would recognize ethics-related issues if they developed in her healthcare setting.

The Underbelly of the Whale

The second story about a birth of bioethics is not so much a disputation of Jonsen’s well-integrated chronology as it is a critique of its central accomplishments. Jonsen and the other forefathers may have created a thriving enterprise, but in the process, important moral principles and values were ignored or minimized. When one considers

the series of events that color this second story, the rural nurse's confusion about the relationship between her problems and the field of bioethics is not surprising.

The critics who offer this alternative tale suggest that the enterprise of bioethics is noteworthy, not for the "more disciplined, careful, long range way of working"⁵² so admired by Jonsen, but for its accommodations, the careful delineations that kept the field at the margins of important medical and moral dilemmas. The field of bioethics claims to represent medicine's cultural identity, but ironically it manages and perpetuates "a system often in conflict with that idealized identity."⁵³ According to the medical historian Charles Rosenberg, the critics on the "Left" charge that:

Bioethics is no more than a kind of hegemonic graphite sprayed into the relentless gears of bureaucratic machines so as to quiet the offending sounds of human pain. Its ethical positions are, in terms of social function, no more than a way of allaying social and legal criticism, and are merely the self reproaches of ethically-oriented physicians. Bioethics has [traditionally] focused too narrowly on the visible problematic instance - on the plug being pulled or not pulled, on the organism being cloned or the cloning interdicted - and avoided consideration of less easily dramatized policy debates and mundane bedside dilemmas..... it is not surprising that in a bureaucratic society we have created a cadre of experts and a body of knowledge to provide a soothing measure of humanity, certified and routinized.⁵⁴ (Rosenberg 1999, 42).

The comparison of the discipline to hegemonic graphite certainly seems to suggest that key pieces of the bioethics legend should be reconsidered. The historian Tina Stevens appears to agree with that assertion. She describes the discipline, not as the spontaneous creation sketched by Jonsen, but rather "a recent expression of a centuries-long cultural legacy of American ambivalence toward progress."⁵⁵ The founding fathers are described, not as a "a trinity of theologians and a quintet of philosophers"⁵⁶ but rather as a self-selected group of individuals and practitioners who "maintained that society was

unprepared to answer the moral questions posed by novel technologies.”

Since society was so unprepared for the new moral dilemmas, the services of this self-selected group were desperately needed.⁵⁷ Thus technical experts emerged to solve the problems associated with technologies. The services they offered did not, suggests Stevens, challenge authority. Rather, the bioethics movement aided authority, constricted potentially threatening avenues of inquiry, and thus allowed medical science and research to proceed on course.⁵⁸ This “elision of the political into the ethical,” muted the voices of those who were too critical of biomedicine and independent oversight was compromised.⁵⁹

The field of bioethics was able to secure institutional legitimacy because bioethics “had proved far less threatening to existing social arrangements than the changes demanded by more radical, and more popular, social critics of the sixties.”⁶⁰ Some of the post war geneticists who called for ethical scrutiny hoped to avoid social and moral disquietude; others hoped that the involvement of bioethicists would “stave off the possibility of more virulent external control of various eugenic proclivities and proposals.”⁶¹ When the search for moral quietude was combined with “professional medicine’s desire to protect itself from the legal liabilities of conducting medical research,”⁶² the moorings for the modern discipline were firmly established.

Over the past thirty years, the “road taken” has proved profitable for the enterprise of bioethics. As Rosenberg notes, the “cadre of experts” has enshrined its heroes and villains and commemorated its sacred places.⁶³ The field maintains a “publishing activity worth millions of dollars; it is embodied in chairs and centers, institutional

review boards, presidential commissions, universities, law schools, medical schools, hospitals, and in media coverage.”⁶⁴ Pharmaceutical and biotechnology corporations need bioethicists and are willing to give ethicists “gifts, contracts, honoraria, consultation fees and stock options.”⁶⁵

These achievements, however, have not come without cost. As a condition of acceptance, says Rosenberg, bioethics has taken up residence in the belly of the medical whale.⁶⁶ Echoing this refrain, the philosopher Carl Elliot notes that bioethics has become an institutional phenomenon; it has “attached itself to hospitals and medical centers, feeding off the revenue and controversy that medicine generates.”⁶⁷ Elliot learned first hand how uncomfortable these institutional liaisons can become. He served as a co-editor when the Hastings Center Report published some papers that criticized the way prozac is prescribed and marketed. Eli Lilly, the pharmaceutical giant that markets prozac subsequently withdrew its sizable annual contribution to the Hastings Center.

To more fully evaluate the arguments of those who offer this less laudatory perspective about the origins of the field, we must retrace our steps and consider some events that received little or no attention in Jonsen’s version. These events suggest that from the beginning, bioethicists have failed to respond to emerging concerns. To some extent, that failure stems from precisely what Jonsen celebrates - the discipline’s philosophic roots. Bioethics has been largely shaped by Anglo-American analytic philosophy⁶⁸ and those roots have typically removed or isolated value assumptions from the institutional, technical, and conceptual realities that characterize medicine.⁶⁹ For example, philosophers who, in the 1950s and 60s, followed logical positivism envisioned

only two meaningful types of inquiry, empirical investigations into matters of fact and conceptual discussions of meanings.⁷⁰ Since philosophy was *not* an empirical discipline, it had to be seen as conceptual. This analytic orientation, however, has decontextualized bioethics and separated theory from practice.⁷¹ When operating in this mode, “analytic philosophers become naive agents of larger powers by asking the questions and framing the analysis in ways that serve these powers by leaving them assumed and unexamined.”⁷²

Thus in the formative years of the discipline bioethicists, as noted by Stevens, were “more apt to discuss ‘man’s’ confrontation with an ineluctable process, a process politically disembodied from its productive sources.”⁷³ As a result, Nussbaum suggests that whole tracts of inquiry were relegated to the outer darkness.⁷⁴ Moral and political philosophy existed only in a reduced form - studying the meanings of moral terms and the force of ethical language.⁷⁵

This second story about the birth of bioethics is supported by data from several sources, including a government committee, a prominent philosopher, and a well-respected author. Admittedly, sources like the Clinton Advisory Committee on Human Radiation Experiments and Eileen Welsome’s exhaustive volume *The Plutonium Files*, were not created to specifically chronicle the birth of bioethics as a field. Those sources, however, uncover the research environment that prevailed in the field’s formative years and to that extent, they portray a field that clothed itself in the mystique of academia and minimized the reality of a moral crevasse. While the discipline was carefully crafting a philosophic, academic agenda in one wing of a university, scientists and researchers were subjecting uninformed and unsuspecting human subjects to painful and life threatening

research studies in another. Enthused with form, theory, and brilliant argumentation, the emerging field of bioethics failed to recognize the underbelly of the leviathan.

What follows, then, is not so much a “second story” about the birth of bioethics as a series of scarcely recognized events that received little attention when they occurred or in Jonsen’s version of the founding myth. Eileen Welsome discovered the underbelly in 1987 when she was working on an article for a local New Mexico newspaper. She was interested in some toxic waste sites, near her community; supposedly they held the carcasses of radioactive animals. She drove to Kirtland Air Force Base and asked to read some files so she would know more about the kinds of studies that had been performed on the animals. At the close of what seemed like an unproductive day, she noticed a footnote about a human plutonium experiment. She was amazed when she saw the reference and at least initially wondered if she was the first to stumble on this piece of information.

Welsome, however, was not the first to write about human plutonium experiments. Her research indicated that a Washington, D.C. publication, *Science Trends*, had published an article about the plutonium injections in 1976. In addition, issues related to the injections were discussed during a congressional hearing in 1976 and a report about the injections was published in 1986.⁷⁶ The 1976 publication and the congressional hearings, 10 years distant from one another, received little attention from the media or from the growing cadre of bioethicists. The lack of attention deserves consideration, especially since the 1976 article in *Science Trends* would have been published when the Belmont Commission was still in session.

Welsome was intrigued by what she read and worked on the story intermittently for the next few years. During those same years, her newspaper began filing Freedom of Information requests with the Department of Energy. In 1993, the Albuquerque Tribune published a three-day series, authored by Welsome, that described for the first time a series of plutonium experiments and the people who had endured them. In December of that year, the Secretary of the Department of Energy, Hazel O'Leary called a press conference to express her shock at the revelations. She announced a declassification of documents and a new policy of openness and candor.

Soon after O'Leary's press conference, President Clinton appointed the President's Advisory Committee on Human Radiation Experiments. This new committee shared some similarities with the committees that had been formed by previous presidents. Similar to previous governmental bioethics initiatives, the Clinton Committee empaneled premier thinkers in the field of medicine and science and asked them to consider issues that were morally problematic. But aside from the recruitment of highly respected commissioners, the differences between the Clinton Committee and the earlier efforts - the Belmont Commission or the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research - are more pronounced than the similarities. The Belmont Commission, as noted in the previous story, was charged with identifying the ethical principles that should underlie research with human subjects. The Clinton Committee was asked to dig deeper, to move beyond principles and specifically to: (1) uncover the history of human radiation experiments from 1944 through 1974; (2) examine the cases in which the government had intentionally released

radiation into the environment; (3) identify the ethical and scientific standards for evaluating these events and; (4) make recommendations so that such “wrong doing” will not be repeated.⁷⁷

To accomplish that agenda, the Committee chose a methodology that was very different from the academic and more insular orientation employed by earlier federal commissions. Both previous efforts, the Belmont Commission and the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, struggled long and hard in philosophical debates about the basis for moral decision making; commission members held round tables and spirited discussions.⁷⁸ In the 1980s, when the members of the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research were trying to identify the distinctions for forgoing life-sustaining treatment, they discussed a philosophically elegant draft prepared by staff philosophers.⁷⁹ The discussions maintained a very academic focus.

In contrast, Clinton’s Committee moved from closed rooms and paneled halls to more public places. This was not an exclusive enclave; rather, the Committee members actively sought public input. As the philosopher Jonathan Moreno noted, the committee had to reconstruct a “heretofore-secret” history.⁸⁰ All federal agencies were directed to make available *any* documents, either research or clinical, that might further the inquiry. As a result, tens of thousands of separate items and documents that had previously been classified were rolled into committee offices.⁸¹ Sixteen public meetings were held, and subsets of committee members held public forums in cities throughout the country. The

committee received testimony from more than 200 witnesses and conducted interviews with hundreds of professionals who were familiar with radiation experiments. The Ethics Oral History Project was initiated to learn from physicians how research with human subjects was conducted in the 1940s and the 1950s.⁸²

The scope of the committee was considerable, and committee members soon found that the effort to sketch an organized, coherent picture of the research activities conducted over a 40-year period involved a nearly impossible task. The data they needed were not catalogued in the bioethics library at Georgetown, an entity regarded as the temple of the field. As a result, the tale that unraveled would not be clear or straight or linear; some documents were buried, some had been destroyed. As Moreno noted, the federal agencies that had something to do with the questionable research experiments had lost their “institutional memory of sensitive matters from decades before.”⁸³ The committee members could find no clear record of the rules that had guided research before the 1960s and no clear justification for why rules had sometimes been abandoned since then. Though the members of the Clinton Committee studied hundreds of thousands of documents, they still believe the historical record is incomplete. The efforts did document, however, more than 4,000 human radiation experiments between 1944 and 1974. The experiments, as it turned out, involved thousands and thousands of people. Almost without exception, the subjects were poor, powerless and sick.⁸⁴

Some of those morally troubling research activities were still being conducted in the years when Senator Mondale was calling for a national debate and his critics were insisting that decisions should be left to those doing the work rather than self-appointed

critics.⁸⁵ Due to the sheer numbers involved in research activities, the Committee could not possibly review all experiments. Thus it focused attention on representative studies in eight categories and assessed current research practices with an eye toward the development of new policies and regulations.⁸⁶ The eight categories identified by the committee members included the following:

- experiments with plutonium and other atomic bomb materials
- the Atomic Energy Commission's program of radioisotope distribution
- non-therapeutic research on children
- total body irradiation
- research on prisoners
- human experimentation in connection with nuclear weapons testing
- intentional environmental releases of radiation
- observational research involving uranium miners and residents of the Marshall Islands⁸⁷

At the outset, the members of the Clinton Committee realized that the plutonium studies followed patterns that characterized some earlier research efforts. For example, the Committee report notes that researchers were definitely aware of the risks associated with plutonium-related studies. Radioactivity has been a tool of medical research and diagnosis for the more than 100 years and the benefits and the perils of the tool were recognized soon after x-ray was discovered. Indeed the first case of x-ray induced cancer was affirmed in 1904.⁸⁸ By 1925, scientists and government officials recognized the hazards of radium. That year, Dr. Martland, a physician and member of the Newark Board of Health, established the etiology of industrial radium poisoning and the dangers of deposited radium. Because a variety of concerns identified by Martland reemerged when plutonium was studied, his discoveries merit attention.

Martland's research was based on the illnesses he diagnosed among the "radium

girls,” the young women who painted luminescent dials on watches and ingested, on average, about 4000 micrograms of radium in about six months.⁸⁹ His reports indicated that the radium levels in the buildings were high, deposits on clothes were high, and the women - who sometimes used the paint as eye make-up and lipstick - “glowed like ghosts.”⁹⁰ Throughout the 1920s and 1930s, the dial painters lost their teeth, their bones crumbled, open sores could not be cured, and cancers ravaged their intestines.⁹¹

In unsettling ways, the radium industry charted a path that would be systematically followed by those who, years later, worked with plutonium. The radium industry staunchly denied Martland’s claims and used physicians and scientists as well as professional and medical journals to bolster their assertions about the safety of the work. Many physicians and scientists - even ones affiliated with academic institutions like Harvard - worked for US Radium and other radium companies; some scientists refused to testify, while others suppressed evidence. The federal government, hesitant to muzzle an economically and politically powerful industry, renewed the licenses of radium companies until 1977.

So perhaps it is no surprise that in later years, the government was hesitant to muzzle the plutonium initiatives, especially since the research could potentially serve national interests. Like the earlier initiatives that involved radium, the plutonium studies used the expertise of scientific consultants to control knowledge, conceal data, and evade liability. The American scientists who were conducting plutonium studies knew that plutonium could be extremely damaging. In spite of that realization, they wanted to determine tolerance levels. That activity required the use of human subjects. To obtain

human subjects, the Manhattan Project scientists began working with medical faculty at the University of California at San Francisco and later with scientists, physicians, and medical faculty throughout the country. In a study conducted between 1945-47, 18 men, women, and children in hospitals across the country were injected with plutonium. Urine, stool, and blood samples were collected, packed in crates and sent to the Manhattan project in New Mexico.⁹²

Some of the patients were close to death when they were injected; some were mistakenly thought to be mortally ill but would live many years. Some diagnoses were, at the time of the injections, uncertain. Most subjects never knew what had happened to them or why such terrible health-related catastrophes befell them. None of the doctors ever told patients that the *medicine* they received in the hospital was part of a research study designed to measure the effects of plutonium in the system. Most of the subjects died; those who lived were plagued by innumerable physical ailments the rest of their lives. Because there was no evidence that consent had been obtained from those first subjects, the decision was made to maintain the secrecy of the studies.⁹³

Those initial studies were just the tip of the iceberg. As the years passed, plutonium research efforts intensified and thousands of people were used as subjects. Some of the studies chronicled by the Clinton Committee are particularly disturbing. At Vanderbilt University Hospital Prenatal Clinic, for instance, experiments were conducted to assess the rate at which radioactive isotopes crossed the placental barrier. Women who were scheduled for prenatal examinations were given a “special cocktail” of radium laced iron.⁹⁴ During a two-year period, 829 women were given a “little drink” that they

thought was nutritious and beneficial for both them and their babies. At the Fernald School for Boys, researchers from MIT created a Science Club; radioactive iron and calcium was mixed into the oatmeal of the boys who were enrolled.⁹⁵ The studies that have been cited, and a considerable number of additional experiments, were conducted with the assistance of medical doctors who worked in hospital and clinic settings. This complicity has thus blurred forever the thin line that separates research and clinical practice.

A Study in Contrasts

This second story is both important and troubling because it unfolds in parallel with but utterly disconnected from Jonsen's tale of the immaculate conception of the modern bioethical establishment. The scale of the plutonium research far outsize the dimensions of two seminal events that Jonsen notes - the Tuskegee experiments and the NIH regulations about the use of fetal tissue. If the Belmont Committee was as pivotal as Jonsen has suggested, one would have imagined that the 1976 article in *Science Trends* and the 1986 congressional hearings would have ignited public ire and initiated passionate debate among bioethicists. The congressional hearings, for example, documented that at least 700 people had been used involuntarily for research activities.

Perhaps the limited attention given to either the 1976 article in *Science Trends* or the congressional hearing is an indication that by 1986, the bioethics establishment was already constricting its margins and focusing on more narrowly defined, technological problems of clinical medicine such as artificial ventilation, abortion, definition of death,

and organ transplantation. Those kinds of problems are amenable to discussion with normative philosophy's de-ontological or teleological framework. In her critique of bioethics, Stevens quotes David Rothman, a historian who celebrates bioethics' historic commitment to individual rights.⁹⁶ However, when one reads the stories told by either Moreno or Welsome, that commitment to individual rights is blurred; in fact, the rights and interests of the researchers and the economic goals of key industries repeatedly trumped the interests of the patients.

Thus the issues that surface in this second version of the birth chronicle shed a different light on morality and the intersection of science, medicine, and medical research. A comparison of events, noted by Welsome and Jonsen highlight a series of different issues in the formative years of bioethics. Welsome notes that during the years 1964-67, scientists and staff in the Public Health Service and the Atomic Energy Commission were quietly doing follow-up studies among the women who were given the radioactive cocktails at the Vanderbilt Prenatal Clinic. As part of the follow-up protocol the women, some of whom had lost children to cancer, were not told the purpose of the study, other than it involved a study of diet and eating habits.⁹⁷ Jonsen, on the other hand, notes that in 1966 Reed College held the impressive seminar on The Sanctity of Life, a seminar that would bring together people who would become "stars in the bioethical firmament."⁹⁸

Welsome notes that in 1968, *Mother Jones* published an article that described the activities of physicians at Oak Ridge and in particular, their experiments on a child who died.⁹⁹ In 1969 she notes that an article in the *Journal of Epidemiology* suggested a cause

and effect relationship between radioactive cocktails administered to unsuspecting women at Vanderbilt and the deaths of four of their children.¹⁰⁰ In his history of bioethics, Jonsen highlights a series of different issues during those years. The year 1969 was notable because the Hastings Center was organized in New York. The first issue of *The Hastings Center Report* was published in 1971 and included articles such as “Values, facts and decision making.” Welsome notes that in 1971, newspaper reporters were writing about a new series of questionable research studies, ones that involved total body irradiation. Jonsen notes that in 1972 and 1973, stories about the Tuskegee studies and the use of fetal tissues provided political motivation for the Belmont Committee. While the Belmont commissioners were discussing their principles and the theoretical foundations of morality, follow-up plutonium studies were being conducted in Cincinnati and Chicago. Permission for the studies was provided by the Atomic Energy Commission - a government entity - with the caveat that the subjects would not be told about the nature of the studies or the fact they had plutonium in their bodies.¹⁰¹

Jonsen lauds the birth of the Belmont Commission in June of 1973. His text does not, however, mention the significance of an article that was published in *the New York Times* in December of 1973. The article detailed a series of questionable studies that were conducted by the Central Intelligence Agency.¹⁰² The studies involved the use of psychoactive drugs and other chemical, psychological, and biological agents on unsuspecting human subjects.¹⁰³ In the weeks after the stories appeared in the *Times*, subsequent articles revealed that the Department of Defense had also been involved in research activities that were equally troubling and destructive. There was such

consternation and public concern relative to these activities that Congress convened the Church Committee and the President created the Rockefeller Commission.¹⁰⁴ Jonsen notes the significance of the first meeting of the Belmont Committee in December of 1973, but his chronology of the birth story mentions neither the Church Committee nor the Rockefeller Committee. Welsome notes that in 1986, congressional hearings documented a series of human radiation experiments that involved at least 700 people. Jonsen notes that in the 1980s, the new field of bioethics was struggling with the ethical issues involving organ transplantations.

Certainly Jonsen's story about the birth of bioethics cannot be discounted because it fails to fully examine the significance of all of the critical events that have or should have shaped the field. Granted, some of the information chronicled in this second story was not broadly available in the early days of bioethics. And in fairness to Jonsen, he briefly mentions the work of some early philosophers who wrote about controversial issues. In 1969, he notes that the highly respected Hans Jonas wrote an elegant piece, "Philosophical Reflections on Experimenting with Human Subjects."¹⁰⁵ Jonas argued that justifying experiments by considering them a right of society exposes individuals to unacceptable dangers. Jonas also suggested that simply obtaining informed consent was inadequate and that additional conditions had to be met. Subjects must be recruited from those who are most knowledgeable about the research and experiments must be undertaken for adequate cause.¹⁰⁶ But Jonsen does not discuss the Jonas piece in detail, and does not suggest that it shaped or heavily influenced the scope of the discipline.

Jonsen also notes that in 1970, the eminent theologian Paul Ramsey authored a

critical review of the Willowbrook studies that were conducted on children. In 1973, Jessica Mitford published *Kind and Unusual Punishment: the Prison Business*.¹⁰⁷ Mitford describes the dangerous and coercive research conducted behind prison walls. Certainly the work of Jonas, Ramsey, and Mitford received some attention in the early days of bioethics, but bioethicists in general seemed more intrigued with different issues, ones that involved *selective* problems of clinical medicine.

In short, the chasm that separates these two founding stories is substantial. Jonsen's version celebrates the genesis of the field and the people who would become "stars in the bioethical firmament."¹⁰⁸ Led by critics like Stevens, those on the "left wing" see hegemonic graphite. Jonsen applauded the achievement of what he terms interdisciplinarity - the trinity of theologians, the quintet of philosophers, and the conscientious healers. Those on the Left suggest that the voices of outsiders have been constrained, that the "legitimate" voices were carefully groomed and the greater public largely excluded. Jonsen's version celebrates a field that responds to the great moral problems that accompany healthcare. The second story suggests that the enterprise of bioethics is unable and perhaps unlikely to either recognize or respond to serious moral issues, principles and values that require attention.

Perhaps the chasm that separates these two stories can be attributed, in part, to the placement of bioethics within the discipline of philosophy. Jonsen celebrates those ties to philosophy. He appreciates the lofty nature of the moral problems, and the value of "serious, disciplined and deep philosophical reflections."¹⁰⁹ He suggests the discussions about bioethics improved when a proper theologian and a proper philosopher were invited

to do some scholarly ethics.

The philosopher Robert Solomon, however, sees a different angle. He suggests that philosophy tends to display a contempt for action and passion and a disdain for “appeal to the emotions.”¹¹⁰ Heated arguments are considered inappropriate.¹¹¹ Such an orientation, suggests Solomon, means that philosophy may not be the best “home” for bioethics because the hard part of ethics is facing up to the issues, dealing with the politics, and responding to the often violent passions that both issues and politics provoke.¹¹² Solomon suggests that when philosophers marginalize or dismiss the emotions or when they isolate themselves from politically charged situations, they lose the motivational seed from which all action emerges.¹¹³

H. Tristram Engelhardt, another well-respected philosopher, adds a slightly different though equally interesting insight that helps to explain the differences in perspective that separate these two stories. He notes that the structure and the orientation of both the Belmont Commission and the President’s Commission were almost guaranteed to promote a unified, philosophic orientation, a manufacture of moral and philosophic consensus.¹¹⁴ Admittedly, as Jonsen suggests, when the Belmont Commission met there was no single ethical theory to determine moral values. But the committee members had a shared agreement about moral consensus and shared agreement about the approach that would support such a consensus.

There are advantages to having shared agreement, especially, as Engelhardt notes, if one wants to produce usable guidance for healthcare policies, regulations, and guidelines. If such an agenda is anticipated, one has good grounds not to appoint people

with truly foundational moral differences. Individuals who will follow a well articulated, predetermined agenda and disallow considerations that are inconsistent with the assumed understanding of the prevailing vision may prove the safest candidates when selecting chairs for such committees.¹¹⁵ But such selection also means that important issues, differences of opinion, and different world views may not be recognized or validated.

As if to verify that point, this second story seems to suggest that the well articulated, predetermined agenda that emerged in the early days of bioethics remains quite solidly in place today. For the same reasons that early ethicists did not become integrally involved in the problems surrounding the plutonium research, bioethicists today remain at the periphery of discussions about evolving worldwide problems like the drug trials, conducted by pharmaceutical companies in third world countries.¹¹⁶ Similarly, bioethicists are more likely to focus attention on the ethical justifications for a required request for organ donation¹¹⁷ rather than the morality of a system that requires a request for organ donation from all who are near death, but allows the transplantations of those organs only for those who have financial resources.

A Nurse Revisited

The second story opened with the suggestion that some commentators perceive bioethics as a kind of hegemonic graphite sprayed into the relentless gears of bureaucratic machines. The discipline is criticized for its ambiguous social agenda and its mechanistic, technologic orientation. The nurse who was quoted at the beginning of this chapter might be interested in those criticisms. She may still question her ability to

recognize the extent to which ethical concerns develop in her rural hospital. But she may be able to relate - perhaps uncomfortably so - to some of the issues that surfaced in this tale.

The nurse has certainly encountered issues related to patient autonomy and competency; she may have lived in areas where persons were unwitting subjects when nuclear tests were conducted. In recent years, she may have seen the carefully worded advertisements, published in rural newspapers, that seek volunteers for drug and other research studies. If an ethics committee existed in her hospital, a topic like the legitimacy of drug studies might have been raised.

The stories about people who are less informed and less powerful may heighten the nurse's concerns about issues that she faces. In her community, nearly 30 percent of the population is uninsured and many families have limited access to healthcare. Since the passage of a federal rule in 1998, she has had to ask members of these families to consider a request for organ donation when the death of a family member is imminent. "People know me," she explains, "and because we have these relationships, they don't want to say no when I ask them to consider organ donation." That reality leaves her with a nagging discomfort: "The request is a guarantee," she notes, "that those who get the most from the system will get more."

Before learning about this second story, the nurse may have perceived the "required request" for organ donations as simply a political issue, another government mandate. This second story, however, suggests that such a request has ethical implications. Further, if the nurse thinks about the activities of Nurse Rivers, a person

also trusted by her community, she may feel some unsettling comparisons. At the very least, this second story suggests that bioethics has more connections to the problems that develop in the lives of common people than was apparent in the first story. Overall, however, the discipline of ethics may still seem distant from the daily realities that she encounters at the bedside.

In the Belly of the Whale

The third story that is relevant to the founding of bioethics acknowledges the philosophical foundations and the professional cadre celebrated by Jonsen. The story also acknowledges the moral failings catalogued by Welsome and Moreno, as well as the field's technologic and institutional moorings that Stevens believes have both legitimized and limited medicine's values. Such an acknowledgment, however, suggests that the birth story needs a wider perspective, one that extracts from the previous stories a new focal point for the genesis of the discipline. The focal point for this third tale is based, not on a singular influence like technology or a particular approach like normative philosophy, but on the central importance of context and the long term social, political, economic, religious, and cultural values that have formed our moral sensibilities and our perceptions of appropriate behavior. Thus this third story leans less toward either the adulation of founding fathers or the black hole of cultural conspiracy, and more toward cultural tragedy.

To a considerable extent, the third story illustrates how society's long term values - what Rosenberg calls "context" - provide the sustenance that keeps the

bioethical whale alive. Key to this perspective is the premise that bioethics is, and perhaps always should be, a social and historical enterprise - but preferably one more consciously so. As Rosenberg notes: “Without history, ethnography, and politics, bioethics cannot situate the moral dilemmas it chooses to elucidate.”¹¹⁸

This story incorporates many of the notions that Jonsen offered in the first story. Without doubt, bioethics is a philosophical endeavor and bioethicists have traditionally used the basic theories and systems of normative philosophy to resolve grave questions about healthcare. They have done so, as the philosopher Tristram Engelhardt has noted, by seeking a “single, coherent area of moral and conceptual investigation.”¹¹⁹ Jonsen recognized that mission when he referenced the “lofty nature of the problems” that face bioethicists, the need for reflective and systematic study and the importance of “the necessary vocabulary, grammar, and process of ethical decision making.”¹²⁰

And certainly, suggests this third story, bioethics has served - as critics like Stevens charge - as a “midwife to technologies.” As evidenced by the second story, that role has not always been constructive; it has both “reduced public opportunities for the expression of outrage”¹²¹ and focused on narrowly defined problems. The extent to which issues associated with the definition of death,¹²² organ donation,¹²³ and genetics¹²⁴ command the attention of the field is somewhat indicative of that technologic connection. Also indicative of that connection is the extent to which the field emphasizes the technologic aspects of some issues - the need to scientifically articulate a definition of death and the need to increase organ donations - but places less emphasis on other issues - the culture concerns that counter indicate organ donation or the distributive justice issues

that develop since access to transplantation services is limited to those who have a source for reimbursement.

But emphasizing the singular importance of traditional philosophy or medical technology is inadequate because the story of bioethics is larger and more complex. Value assumptions, suggests Rosenberg, cannot be isolated from contextual realities. Thus bioethicists need to be aware of the gap between “theory and practice, conscious intent, and unforeseeable outcome.”¹²⁵ He argues that bioethics should parallel the historian’s job of cultural reconstruction and that practitioners should seek the “time and place-specific structure of choices as perceived by particular actors.”¹²⁶

According to Rosenberg, discussions that do not consider the context are not very helpful because bioethics is defined by its *context of use*. He notes that: “Questions that can be framed as matters of justice and autonomy are at once questions of control and economic gain. Perceptions of right and wrong, of appropriate standards of practice, constitute de facto political realities - variables in negotiating choices among rival policies as well as in particular clinical interactions.”¹²⁷ In short, healthcare decisions take place in a context of socioeconomic factors, relationships between people, and the feelings those relationships engender.¹²⁸

To some extent, the enterprise of bioethics has failed to recognize the importance of this contextual approach because bioethics is “conservative in important ways.”¹²⁹ Its technological determinism ignores social and cultural influences and its affinity for *individualism* turns it away from social problems.¹³⁰ Such an orientation is problematic, especially when one considers, as Rosenberg notes, that the moral values that suffuse

medicine are historically constructed and situationally negotiated. If the enterprise of bioethics fails to incorporate these broader social values into its theoretical framework, it increases the risk of what has been a characteristic “disconnect” in our healthcare system: a “boundless faith in the power of the laboratory and the marketplace, and a failure to anticipate and respond to the human implications of technical and institutional innovation.”¹³¹ Rosenberg notes:

The new enterprise [of bioethics] has been charged with a difficult and elusive job. We live in a frightened yet interconnected world, a world of ideological and social diversity, of inconsistency and inequity, of change and inertia. We cannot discuss relationships between men and women who differ in power and knowledge without acknowledging those inequities: class, geography, gender, race and education all modify the category patient; economic incentives as well as the institutional and intellectual structures of medicine (such as speciality and organizational affiliation) modify the category physician. A growing awareness of such complexities has made bioethics an increasingly labile and self-conscious enterprise. And perhaps a less confident one as well: articulating and applying a foundational ethical basis for particular social actions no longer seems an easily attainable goal.¹³² (Rosenberg, 1999, 35-36)

Thus this third story about the genesis of bioethics requires a larger net, one that captures our historical responses to health and illness, medicine, and science. Those historic connections can tell us a great deal about bioethics and its relationship to the current system of healthcare. This third story weaves back and forth, selecting pertinent references from both the first and second stories, adding new and seemingly unrelated events, all in an attempt to underscore the importance of context and the tragedies and opportunities that context implies.

Simply stated, modern bioethics arose from deep origins in our attitudes toward health and illness, wealth and poverty, science and progress. Thus its deepest limitations

and potentials only make sense in this larger perspective. In recent years, for example, the enterprise of bioethics has focused some attention on issues related to the allocation of healthcare resources. The development of a national system for the allocation of organs for transplantation serves as a good example of that attention. The allocation of healthcare resources, however, is not a new issue. Allocation was an issue in the 1800s when, as Rosenberg notes, “Class and dependence, as much as diagnosis, determined one’s place in a ‘system’ of healthcare.”¹³³ Medical ideas and practices were widely distributed, but clearly based on conventional moral values.¹³⁴ Some diseases and natural disasters - cholera, plagues, floods, and locust - were perceived as an exercise of God’s will, the temporal means God uses for moral purification.¹³⁵ Likewise, diseases associated with poverty, sin, lechery, gluttony, and alcoholism were associated with moral bankruptcy.¹³⁶

Historically, care would not be provided for diseases associated with moral bankruptcy.¹³⁷ Until the cholera outbreak of 1866, medical opinion was unanimous in agreeing that the intemperate, the imprudent, and the filthy were particularly vulnerable to that disease.¹³⁸ In fact, the history of cholera appeared to indicate that those countries with the fewest Christians were punished most severely.¹³⁹ Slightly more scientific information was available by 1866, but the public still believed that cholera had a religious foundation.¹⁴⁰

Those religious and social values, rather than the traditional framework of normative philosophy, shaped the development of a healthcare system. The *worthy* poor deserved hospital care and the care of physicians.¹⁴¹ A laying-in hospital might admit a

poor mother-to-be but not an unmarried mother-to-be.¹⁴² Letters of recommendation were required in order to be accepted by some hospitals.¹⁴³ At times, a reputable witness needed to verify that a potential recipient, though poor, was of “worthy character.” Hospitals, throughout the 1800s, did not want to be confused with almshouses.¹⁴⁴ Service to the poor also met an important utilitarian goal - it provided a captive audience for the teaching and advancement of medicine.

Ideas about non-maleficence, self-determination, and patient autonomy capture the imagination of present day bioethicists. Those ideas also have a long history. Throughout the nineteenth and early twentieth centuries, there were no clear distinctions between health care and research, so beliefs about class also determined one’s treatment as a research subject. In the 1890s, Franz Boas, an esteemed and well-respected anthropologist and a curator at the American Museum of Natural History, strongly endorsed the polar research activities conducted by the explorer Robert Peary.¹⁴⁵ A number of Peary’s research activities could be viewed as quite harmful to the Native people, but two are notable for their violations of self-determination, non-maleficence, and autonomy.

Soon upon his arrival in the Arctic, Peary convinced several Native people to show him their source for their knives. Peary suspected, based on the writings of earlier researchers, that the source was meteoric iron and if so, he wanted to retrieve it.¹⁴⁶ The Native people, on the other hand, believed the large rocks were a divine gift and harm would occur if the rocks were moved. But Peary found a guide who would take him to this sacred site. He scratched his initials onto the rock and then brought this multi-ton

meteorite back to the United States where it could be placed on permanent display in the American Museum of Natural History.

He also brought six Eskimos to the United States as “specimens” and donated them to the Museum.¹⁴⁷ Dressed in their thick, arctic furs, they were viewed for hours a day by the public. When five of the “Eskimos” died of heat, malnutrition, disease, and neglect, their bones were leached and mounted for display in the museum.¹⁴⁸ Boas’ only published statement on the scientific results of Peary’s studies affirmed the importance and validity of the work: “Many things heretofore unknown have been learned regarding their language, their traditions and their personal characteristics. Casts of their heads have been made for the museum.”¹⁴⁹

Boas is not generally perceived as an insensitive man. Indeed he had a distinguished career in American anthropology.¹⁵⁰ But he was a man committed to scientific discovery and his values were shaped by his professional reading of the ethical “context” of the time. He believed that the Eskimos were an “inferior people”¹⁵¹ and believed the studies that could be conducted would benefit mankind and benefit the American Museum of Natural History.¹⁵² Some might suggest this story about the Eskimo research reflects the activities of individuals but, in fact, the activities well-represented public sentiment about acceptable conduct. Peary’s activities were supported by the Navy, by generous benefactors, and by the public. On the day Peary arrived with his Eskimos, 20,000 people met him at the harbor.¹⁵³ Huge crowds visited the Eskimos when they were on display at the museum.

Certainly throughout the 1900s, there were shifts in public attitude, changes in

expectations of the healthcare system, and changes in beliefs about acceptable conduct. But the scientific, religious, political, and economic factors that linked science and morality remained strong. What is intriguing about the contextual perspective suggested by Rosenberg, Ott, and other historians is that not only do these cultural factors shape the dominant social and cultural values, but they also define and legitimize the narrow, “professional” versions of those values. Thus over time the medical profession, in particular, has come to embody a particular set of moral values and responsibilities as well as the powers associated with those values. This emergence of professionalism, a concept previously associated with European trades, has had a profound impact on the medical establishment and standards of medical care.

That impact and, in particular, the relationships between social and cultural factors and the public, professional, and individual moral codes became more visible as healthcare became more scientific. For instance, the discovery of the bacillus that caused tuberculosis provided support for a hygienic state and regulations that enhanced civic health and social order.¹⁵⁴ Protection of the public was of greater concern than was care of the diseased.¹⁵⁵ Support for a hygienic state and protection of the public are good examples of dominant social values.

Those dominant social values also helped to define and legitimize the narrow *professional* versions of civic health and social order. This new rigorous “spirit of science” was represented by men like George Soper who, in the summer of 1906, investigated a typhoid epidemic in New York.¹⁵⁶ He identified the Irish cook, Mary Mallon, as a carrier of the disease and the “source” of the outbreak. Through Soper’s

knowledge, persistence, and influence, Mary was incarcerated in order to protect society.

All of the social and professional values of the day supported the decision to incarcerate Mary. She was not deemed as particularly “worthy” and so there was no reason to protect her. Like other domestic workers, Mary was considered to be a member of the lower class; her Irishness seemed to contribute to her refusal to accept the authority of the physicians and the legal system.¹⁵⁷ She was blamed for spreading a “loathsome disease.”¹⁵⁸ Soper, snugly wrapped in the mantle of professionalism, fueled the fears of the public by wondering if Mary was mentally disturbed and intent upon spreading “typhoid germs among mothers and babies and doctors and nurses like a destroying angel.”¹⁵⁹ As a final touch, he advised the upper-class society: “We should be careful about how we chose our cooks.”¹⁶⁰ Soper’s personal ethic, the values of the profession and the values of society merged and there was scant notion that Mary should be protected or that her rights were somehow abridged.

A Matter of Context

This third story is helpful because, as Rosenberg suggests, “just as the three principles of value in real estate are location, location, location, for history they are context, context, context.”¹⁶¹ When viewed through the contextual paradigm, clearly ever wider and more tragic social, political, economic, and religious values have helped to shape each of the founding stories recounted throughout this chapter. The dial painters who ingested radium in the 1920s and 30s were poor, working class girls. They were expendable for three reasons: science was interested in experimental medicine and

interesting research problems,¹⁶² radium companies were politically and economically influential businesses, and social class distinctions were held firmly in place by those with power and resources.

The men who were targeted for the Tuskegee Study were all poor, black sharecroppers in a rural country area;¹⁶³ they were not considered as worthy or as valuable as other members of society. Fernald School had, as residents, persons who were mentally disabled; it also had troublesome children and adults, prostitutes, and alcoholics, children from large immigrant families - anyone the judiciary found to be stubborn.¹⁶⁴ In the 1950s, medical and military critics in the Pentagon opposed using the Nuremberg Code as the Department of Defense's human experimentation policy because "they didn't want any written policy that threatened to restrict human experimentation for *national security needs*, or that questioned the *moral integrity* of physicians and commanding officers and their ability to make tough ethical calls."¹⁶⁵ In all of these instances, certain classes of people were perceived as less desirable or more expendable; that status, in turn, determined their treatment status in the healthcare system.

In contrast to those who were deemed less desirable, there was a growing recognition of an elite class of people - not unlike George Soper - who, by virtue of their profession, were more desirable and hence more privileged. These more favored cohorts came to embody a particular set of moral values, responsibilities, and powers. This enthusiasm for the virtues of the "profession," however, failed to calculate the extent to which power, when protected by the aura of professionalism, can be abused. That failure to consider the relationship between power and professionalism has relevance for the

enterprise of bioethics - especially since in recent years, bioethicists have become increasingly interested in championing their own version of professionalism.

An abbreviated chronology of the growth of medical professionalism helps reveal the risks associated with professionalism. In 1851, physicians in the United States were not generally viewed as “professionals;” in fact, there was so little confidence in physicians that 15 states had repealed all legal restrictions upon the practice of medicine.¹⁶⁶ In Iowa, a six-month reading course was sufficient to gain the title of doctor.¹⁶⁷ In 1901, when Mary Rowland applied for a medical license she noted that some of her peers had less formal training than needed. She wrote: “I thought that my patient that day might die from infection because the doctor was so dirty.”¹⁶⁸

By the 1930s and 40s, however, medicine began to provide a “way to make sense, to give form to what is emotional, messy, and unpredictable.”¹⁶⁹ In this more mechanistic world view, the body becomes an object of social control, and patients, as individuals, become subject to a certain kind of judgement.¹⁷⁰ As was indicated by the stories about cholera, the dial painters and Tuskegee, this new world view gave physicians greater levels of control over the medical system. By the 1960s, physicians were perceived as models of probity, and their knowledge and responsibility, as Freidson and Sullivan suggest, ensured that the public would be well served.¹⁷¹

Certainly, the embodiment of values and knowledge within a profession seems like a positive development. That assessment is based on the assumption that certain professions, like medicine, are defined by rigid oaths and codes of conduct that ensure the public will be “well served.” But, as the numerous examples in both the second and third

stories illustrate, the designation of a “profession” may not ensure adherence to any particular moral standards. In fact, the philosopher Robert Veatch suggests that it is difficult to determine what can be reasonably inferred from oaths, codes, or treatises on medical conduct.¹⁷² He notes that there are differences in perspective as to whether the statements are “primarily exhortatory, descriptive, or self protective.”¹⁷³ Veatch suggests that some people view codes as mere guidelines and indeed, that was the position taken by the American Medical Association (AMA) when it revised its *Principles of Medical Ethics* in 1980.¹⁷⁴

The power of codes is further blunted by the fact that, as Al Jonsen has noted, the medical license is protected in American courts as a property right. The property right certainly entails some public responsibilities, but the rights of physicians are often more cherished than the responsibilities.¹⁷⁵ Physicians can conceive their practice as if it were property and offer benefits to those who seek them.¹⁷⁶ Those who seek healthcare enter into a fiduciary arrangement which the physician can fulfill, based on his conditions.¹⁷⁷ Thus bioethicists like Ruth Macklin can cite the importance of “Kant’s famous categorical imperative” and insist that patients should be treated as end in themselves.¹⁷⁸ The provision of healthcare, however, must still accommodate an economic system that views the expertise of the physician as a property right as opposed to a moral responsibility.

Rosenberg’s notion about context becomes quite compelling when one considers the linkage between a property right and a moral responsibility, and the relationship between “professionalism” and what Eli Ginzberg calls the “monetarization of

medicine.”¹⁷⁹ In the years post 1950, at the same time the practice of medicine was becoming increasingly *professionalized*, the money economy began to penetrate nearly all aspects of the medical care system.¹⁸⁰ Doctors had an expanding array of new opportunities to participate in lucrative technological and research-oriented activities.¹⁸¹ With an eye toward such trends, the health economist Marc Rodwin suggests that entities like the AMA or the American College of Surgeons are viewed by some as trade organizations.¹⁸² In an environment so “professionalized” and “monetarized,” the physicians hold most of the power; the patients lack knowledge of how to regain their health; they are dependent on others for care, and are uniquely vulnerable to manipulation.¹⁸³

A society enthusiastic about professionalism and confident about the moral rigor associated with oaths and codes, may be less likely to restrict a wide range of ethically problematic activities like those associated with the plutonium studies or, in more recent years, issues associated with pharmaceutical research. Rather than reduce problematic behaviors, an enthusiasm for professionalism and codes may, in the worst case scenario, actually increase the risk of such behavior. Marianne Paget, an author who studied medical errors, has suggested that the hallmark of professionalism - claims of knowledge, great social importance, and ethical rigor create an illusion of infallibility rather than the specter of trial, error, and uncertainty.¹⁸⁴ The illusion is powerful, and in the field of medicine, it minimizes the extent to which the process of “acquiring, interpreting, managing and reporting the disorders of human illness is error ridden and in need of qualification and elaboration at almost every turn.”¹⁸⁵ So errors occur and

medicine, as a profession, is unwilling and unable to respond to them.

Many of these inter-connected issues surfaced when the Clinton Committee sought to validate the scope of the plutonium research. And here the second and the third stories about the birth of bioethics share similarities. The physicians who were interviewed underscored the importance of context when making decisions: poor people were chosen for research *because* they “were easily intimidated, didn’t ask questions and belonged to a different social order.”¹⁸⁶ When physicians described various other research activities that involved involuntary subjects they noted that: “We were taking care of them [the poor] and thought we had a right to get some return from them.”¹⁸⁷

The power of context was further evidenced in 1993 when Vanderbilt University tried to justify its involvement in the radioactive isotope studies. The Associate Vice Chancellor noted that: “While it would not be acceptable *today* to give radioactive isotopes to pregnant women, it is also clear that this was carefully evaluated at the time. We want to be as helpful as we can, but to create the feeling that we’ve done something wrong, we don’t want to do that.”¹⁸⁸

The Power of Perception

The tales recounted in this third story are important because they show that foundations for ethical decision making are not based solely on normative, theoretical principles and approaches, or on short term crises, but also on long established socially determined, context-driven, perceptions of acceptable behavior. The plutonium studies, for example, evolved in a culture that was mesmerized by the potential of atomic studies.

That context justified a veil of secrecy so that even Secretary of Defense Charles Wilson's directive that outlined protocols for informed consent was kept classified.¹⁸⁹ The behavior of the physicians was shaped by the profession's view of the social, historical, and political values of the day. During the years when the plutonium research was being conducted, all of the key players - the Atomic Energy Commission, the Defense Department, and the National Institutes of Health knew that research should only proceed with the consent of subjects, but they chose another path.¹⁹⁰

If there was any doubt about the importance of following legitimate research protocols, the Nuremberg trials that began at the end of World War II should have instilled a sense of caution. Twenty-three physicians were placed on trial for crimes performed in the name of medical science. And yet the American physicians and scientists participating in more than 40 years of experimentation in this country saw no connection between their behavior and the Nazis. In the 1940s and 1950s, physicians routinely used patients without either their knowledge or consent.¹⁹¹ They disputed the applicability of the Nuremberg Code; it was "written for barbarians,"¹⁹² not scientists engaged in legitimate research. There was a belief that no code written for barbarians would be relevant in the United States.¹⁹³ Even in recent times, condemnation of actions has been softened. The Atomic Energy Commission called the plutonium studies a "small price to pay to keep America safe."¹⁹⁴ All of those statements reflect values that have been shaped by the social, economic, political, and religious factors of the day.

Those values, in turn, shape our perspectives of cultural legitimacy. Indeed, many of the scientists and physicians who were interviewed as part of the Clinton Committee

Oral History Project, described their activities as culturally legitimate. In those days, the ethics of research seemed like an obstacle to human progress.¹⁹⁵ Leonard Sagan, a doctor who worked for the Atomic Energy Commission in the 1940s, noted that obtaining informed consent often conflicted with a researcher's professional goals.¹⁹⁶ As he explained:

Doctors who were doing research wanted to be professors, and in order to be a professor, you had to have lots of publications, so your highest priority is to conduct research and publish it. You're the doctor. Here's a patient that you want to experiment on..... Is it going to contribute to your research if you inform the patient? What can happen if the patient says, "No, I don't want to do that." That's not in your interest. Your interest is to have that patient participate, so do you tell him or her? No. Does anybody care? No. So you don't tell them. So that's why they [ethical rules] were ignored, because there's a conflict between informed consent and the ability to conduct research and the physician is interested not in the patient's welfare, he's interested in his or her welfare. So he doesn't inform him.¹⁹⁷ (Welsome, 1999, 212)

As those statements suggest, the "professional" perspective on ethical conduct is not as unequivocal as one might expect. One might claim that Sagan's comment represented sentiments of an earlier time. And yet his comment is not so far removed from a statement offered in the final report published by the Clinton Advisory Committee on Human Radiation Experiments. The Report notes that in the great majority of cases, the experiments were conducted to advance biomedical science, to advance national interests in defense or space, or to serve both biomedical and defense purposes.¹⁹⁸ It also suggests that the government officials are blameworthy for lacking policies and procedures that protect the rights and interests of human subjects. However, it also notes that they are *less blameworthy* to the extent that there was reason to believe the research might provide a direct medical benefit to subjects, government officials, and biomedical

professionals.¹⁹⁹ The very careful wording of the Clinton Advisory Committee Report - the notion of *reason to believe* and potential benefits to government officials and biomedical professionals - underscore the close connections that continue to link our professional healthcare ethics and our social, political, and economic values. And those links are not always “ethical.”

In fact, the belief in the potential value of a “medical benefit” is so ingrained in our national consciousness that our current perceptions of “legitimate research” are not entirely different from the beliefs articulated by Boas and Peary, namely that “many things heretofore unknown have been learned.”²⁰⁰ Perhaps that seems caustic. But consider the brief reference made, in the second story, to the pharmaceutical companies that conduct drug trials in third world countries. In the year 2000, Pfizer received some media attention because it used Nigeria’s meningitis epidemic to conduct experiments on children.²⁰¹ The researchers at Pfizer believed their new, though untested drug was promising, and Wall Street analysts suggested that Pfizer might reap a billion dollars a year if it won approval by the U.S. Food and Drug Administration.

An article describing a series of questionable research activities detailed the death of a child enrolled in the Pfizer study and noted that corporate drug experiments in Africa, Asia, Eastern Europe, and Latin America are booming. Many of the experiments are poorly regulated, involve risky procedures and have little independent oversight.²⁰² One study gave premature babies in Latin America a placebo instead of a proven therapy in order to test an experimental drug.²⁰³ Such a research activity would be prohibited in the U.S., but the Food and Drug Administration has limited authority overseas.

The limited authority of the FDA certainly mitigates some of its responsibility, but what is particularly relevant, in light of Rosenberg's notion about the importance of context, is that there is little social pressure to limit such drug experiments. The companies use the drug trials to produce new products and revenue streams, "but they are also responding to regulators, Congress and lobbyists for disease victims to develop new medicines quickly. By providing huge pools of human subjects, foreign trials help speed new drugs to the marketplace - where they will be sold mainly to patients in wealthy countries."²⁰⁴

What Rosenberg calls "contextual factors," this blend of economic, social and political pressure was certainly evident when regulators, Congress and lobbyists provided the impetus to pass a federal mandate that requires hospitals to immediately inform their designated "organ procurement organization" [OPO] in all cases of death or "imminent death,"²⁰⁵ and to ask, if the OPO identifies the organs as suitable, the family for a donation. Ostensibly, the rule was placed to increase the supply of organs for those who need transplantations. Numerous problems, however, are associated with such a request. Families may have limited understanding of the protocols that must be honored if a donation is authorized. Some families may feel coerced when asked. A request may violate cultural or religious beliefs and social practices or may complicate adherence to advance directives. Finally, organ transplant centers generally provide transplantations only to those patients who have sources of reimbursement. Thus the potential benefits of transplantation are not universally available. But in ways reminiscent of Boas' comment, the concerns are carefully re-framed. An Associated Press article, published in a Seattle

newspaper, suggested that “communities that fail to donate organs - or the organ banks that serve them - are partly to blame for the long waits [for organs].”²⁰⁶ According to that article, the nations’ best organ banks “move four times as many organs from the dead to the living” and are less “hampered by ethnic minorities who are more reluctant to donate.”²⁰⁷

Thus, claims of “national interests” and “potential medical benefit” create ways to define “legitimate behavior.” This same pattern was also evidenced by a series of medical and military decisions associated with the Gulf War. One could expect that the Department of Defense, given the research problems associated with the plutonium studies and other regrettable initiatives, might be wary when suggesting questionable research protocols. But here the lesson about context returns: political concerns are more powerful than ethical protocols. When the Pentagon made the plans for the invasion of Kuwait in 1990, there was much concern about Saddam Hussein’s capacity for chemical and biological warfare. Possible agents included nerve gas, the anthrax bacteria, and the botulism toxin. The Pentagon wanted to vaccinate soldiers, as a protective strategy, but there were some problems with such an action. Neither the vaccines for anthrax and botulism toxin, nor the pills for nerve gas, had been approved for use in the military.²⁰⁸ Indeed, the botulism toxin vaccine is considered to be “investigational” by the Food and Drug Administration (FDA). The Pentagon, however, approached the new FDA Commissioner, Dr. David Kessler, and sought a waiver of the normal informed consent requirement so that the Pentagon could use “investigational” drugs.

In response to that request, the FDA created an exception and allowed the

Pentagon to “use the drugs with the Desert Storm troops without informed consent [of the soldiers].”²⁰⁹ In the years since the drugs were given, a number of problems, such as Gulf Syndrome, have become apparent. There is a “rough sense of how many took the drugs” but there was little documentation; as veterans began to experience medical problems, there were no records of who took the drugs or under what conditions.”²¹⁰

To further muddy the water, the vaccine supply that was used for botulism was 20 years old and there was some concern that it would break down into toxic products.²¹¹ In addition, the vaccine was probably not effective because it requires a series of four injections and most troops received only two.²¹² Indeed, the Army committee responsible for reviewing the use of the vaccine was unsure of its effectiveness. Some, including persons in Congress, believe the FDA’s permission to waive regulations demonstrates its intimidation by the Defense Department.²¹³ The agreement between the FDA and the Defense Department “called for all soldiers asked or ordered to take the medications to be given an information sheet about what they were taking, but that information was rarely provided.”²¹⁴ The FDA chose not to respond to the failure to comply with that directive and in fact, “failed to call the armed forces to account for this breach of the agreement, even after the war.”²¹⁵

These tales all share a central theme: patterned, sustained actions shape perceptions and social, economic, and cultural perceptions of acceptable behavior shape actions. When the Pentagon was seeking permission to use questionable drugs, the potential seriousness of the waiver of informed consent was noted, even by people in the military. A 1990 military memo noted that: “A military justification for involuntary

receipt of investigational products because of strategic, doctrine or discipline concerns resembles all too closely the logic used by Nazi doctors to rationalize using human in research that had predictably destructive outcomes.”²¹⁶

Some of the problems discussed in this third story - especially those that seem to replicate past mistakes - may seem almost inexplicable. These problems keep re-occurring, in part, because bioethics has not taken a broad, flexible, deeply contextual approach to its own origins. Failing such an examination, modern bioethics has fallen prey to the vices of institutional momentum and, as Rosenberg notes, the enterprise has found it increasingly difficult to articulate and apply a foundational ethical basis for particular social actions.”²¹⁷ Given such uncertainties, new problems develop. As Carl Elliot has noted: “The money [in bioethics] is not hard to find.”²¹⁸ The major bioethics centers in the US and in Canada enjoy strong corporate financial support. Their programs are funded by entities like du Pont, Schering-Ploughman, Smith-Kline Beecham and Sun Life. Bioethicists have seats on scientific boards, are given honoraria for drug company talks, and serve on for-profit Institutional Review Boards.²¹⁹

While it is surely understandable that a committed practitioner, such as Jonsen, might emphasize and celebrate the field’s positive virtues, it is equally clear that the structures that have been developed, the social pressures to support certain actions, the rigorous normative approaches, and the professional cadres can be viewed, in themselves, as a kind of seductive technology. Perhaps bioethics, suggests Rosenberg, has become too institutionalized; it has not only questioned authority, it has come to constitute and legitimate it. Herein Rosenberg offers his strongest criticism of a discipline that has

failed to evaluate the importance of context:

As a condition of its acceptance, bioethics has taken up residence in the belly of the medical whale; although thinking of itself as still autonomous, the bioethical enterprise has developed a complex and symbiotic relationship with this host organism. Bioethics is no longer (if it ever was) a free floating, oppositional and socially critical reform movement: it is embodied in chairs and centers, in an abundant technical literature, in institutional review boards and consent forms, in presidential commissions and research protocols.... It is not an accident that the bioethical enterprise has routinely linked bureaucracy - committees, institutional regulations and finely tuned language - with claims to moral stature.²²⁰ (Rosenberg, 2000, 38)

A Nurse Revisited

Rather than celebrate the model for bioethics that has evolved over the past 30 years, historians like Pernick and Rosenberg see the need for a larger picture, a more integrated, interdisciplinary approach that would allow us to move “outside the box”²²¹ and create an ethics of care that integrates value assumptions with contextual realities. This alternative approach would encourage a probabilistic way of thinking, one that anticipates obstacles, recognizes that the setting or place influences medical choices, and adjusts to the larger context, the social, economic, legal, and political realities of the day.²²²

An approach to bioethics that is based on contextual realities might interest the rural nurse who was described in the opening paragraph of this chapter. That nurse - and the nurse who was described in the Preface - certainly experienced morally distressing situations. Neither of those nurses knew if their problems would be considered “bioethical.” The nurses, however, did recognize the importance of values and both knew

that those values shape healthcare decisions. Both seemed to realize that values could not be separated from the “lived experiences” of community members. This third story appears to have room for the kinds of issues faced by both nurses. If the field of bioethics encouraged this more context-sensitive approach, healthcare providers might recognize the link between bioethics and the care that they provide.

The Wake of the Whale

These three stories about the genesis of the discipline certainly offer some justification for the philosopher Stephen Toulmin’s comment that medicine “saved the life of ethics,”²²³ by moving an abstract, philosophical discipline into the dynamic arena of healthcare. H. Tristram Engelhardt, one of the field’s original scholars, notes that in its formative years, “Bioethics as a secular, scholarly undertaking, appeared able to supply what had once been sought from religion as well as from the special insights of healthcare professionals: clarification of claims and ideas.” Given the need for such clarification, the conversations of the pioneering bioethicists had an “echo in some very private places - the closeted conversations between doctors and their patients about medical problems.”²²⁴ Those conversations, suggests Jonsen, re-enacted in small compass the evolving discussion of healthcare ethics.

As bioethics moved into the halls of the hospital, it mirrored the patterns that characterized the early years of the field. The forefathers who were celebrated by Jonsen, those who initiated the first bioethics conferences and centers and those who set the standards for the bioethics discourse, were the ones who provided direction as the

enterprise moved into the clinical care setting. They created an array of institutional services that brought philosophers, physicians, lawyers, and clergy into the hospital, and provided an opportunity for them to learn and practice the necessary vocabulary, grammar, and process of ethical decision making.²²⁵ They created journals and textbooks developed ethics consultation services, and created summer institutes that trained clinical ethicists. The distinctions between experimentation, research and innovative procedures in the practice of medicine became less clear.²²⁶

Jonsen suggests that the common language, literature, and methodology that emerged during the formative years of the field, facilitated the development of the institutional models. Through the efforts of two influential bioethicists, Beauchamp and Childress, the use of the principles became formalized into an approach called principlism. Medical schools and hospitals throughout the country developed bioethics curriculum based on principlism, normative ethics, and structured processes for ethical analysis.

Thousands of persons, Jonsen notes, became familiar with issues like withholding or withdrawing treatments and many hospital committees developed the skills to respond in an orderly and informed manner. He states that the most competent among the ethics committees improved their institution's library resources, sought consultation from trained bioethicists, and created networks.²²⁷ By the later 1980s, the stage was set. The field of bioethics had become more rigorously and more narrowly defined. The key players had been identified. Bioethics moved into the halls of the hospital and eventually to the bedside.

CHAPTER II

A POD OF WHALES

The rural hospital administrator was certainly familiar with the model of an ethics committee. He also knew that, for nearly 30 years, hospitals have been strongly encouraged to create such entities. He did not, however, believe that an ethics committee would be very useful in his hospital. He noted that ethics committees typically address the highly technical problems that accompany medicine, not the day to day problems that he encounters. Given that consideration, he was skeptical about the extent to which ethics committees provide useful services. “As far as I know,” he explained, “most ethics committees are dormant, floundering, or somewhere in between.” Further, he doubted whether a service like an ethics committee would be well received in his community. “I don’t think people in this community would want their personal business discussed, behind their backs, by folks who supposedly know more than anyone else,” he noted. “In our town, an ethics committee does not seem like a very good idea.”

The administrator’s skepticism about the utility of an ethics committee provides a framework for examining the emergence of formal ethics services in healthcare settings. When the enterprise of bioethics came to hospitals it took, as its quintessential form, the ethics committee. Thus the examination of institutionalized bioethics begins with a discussion of the factors that led to the development of ethics committees in hospital settings. The development of committees, in turn, leads to an analysis of their roles and

functions and a discussion of “principlism,” the primary philosophic approach that has been used to solve the moral dilemmas that complicate healthcare decision making. The chapter will then explore a growing body of criticism, within the bioethical establishment, that has been leveled against principlism and against the limitations of institutions bound by particular theoretical approaches.

The rural hospital administrator was correct when he stated that hospitals have been strongly encouraged to develop formal ethics services such as ethics committees. That encouragement, which began in the early 1980s, emerged in response to the questionable research studies noted in the preceding chapter.²²⁸ Those studies blurred the lines between research and clinical care. The patients who received the plutonium injections, the pregnant women who were given the radioactive cocktails, and the men who were enrolled in the Tuskegee studies all received their “treatments” in hospital settings and with the aid of hospital staff.

In addition, even in the early days of bioethics, philosophers, physicians, and lawyers realized that the ethics-related problems associated with patient care would increase rather than decrease. Issues that involve the retrieval and allocation of organs for transplantations, access to kidney dialysis machines, or the use of life extending therapies like ventilators were increasingly visible and controversial. New problems, associated with issues like genetics, were looming on the horizon. These problems were recognized by many of those early leaders referenced in the preceding chapter. Ruth Macklin has used the term “big ethics” to define these high profile problems that involve dramatic situations, life and death decisions, media attention, and sometimes, precedent setting

court decisions.²²⁹ Indeed a “big ethics case,” a dramatic, high profile situation is frequently cited as the impetus that spurred the development of ethics committees in hospital settings. The dilemmas associated with this landmark case developed in 1976 when 21 year-old Karen Quinlan slipped into a coma. After Quinlan had been unconscious for about a week, she was moved to a Catholic Hospital where life support facilities could be provided. Extensive brain damage was confirmed, and expert opinion held there was no reasonable possibility that she would ever emerge from her comatose condition.²³⁰ As her condition deteriorated and her body began to contract, the family asked their parish priest for guidance. He advised them that the Roman Catholic church did not require extraordinary measures to support a hopeless life. After several months of care and no evidence of improvement, the Quinlans asked the physicians to remove Karen from the respirator; without the respirator, most physicians believed that Karen would die. Though Karen’s physician initially agreed with the family’s request, he later determined that such an action would not be morally supportable. He believed that removal from the ventilator would violate the harm principle.²³¹

A Model Emerges

The case received considerable media attention as it moved through the New Jersey Superior Court and finally the New Jersey Supreme Court. When the justices of the New Jersey Supreme Court were struggling with their decision, they read an article authored by Dr. Karen Teel. In her article, Teel recommended the formation of ethics committees to support those who make difficult decisions associated with impaired

newborns. She knew ethics committees were used in a few institutions to determine which patients would have access to scarce technologies such as kidney dialysis machines. Her pediatric training led Teel to believe that advice from a committee would be preferable to leaving decisions to parents who cannot make unbiased decisions or to physicians who may also be vested in a particular outcome. Parental decisions may be unsatisfactory because even though parents are presumed to act in their children's best interest, they do not always do so.²³² Physicians may also find it equally hard to make unbiased decisions, for everything in their training propels them in the direction of prolonging life, curing diseases and achieving positive, desired outcomes.²³³

The justices were intrigued with Teel's argumentation and cited her article when they wrote their opinion. In their opinion, the justices underscored the family's right to choose the attending physicians. If the guardian, family, and attending physicians all agreed that there was no reasonable possibility that Karen would emerge from her coma and that life support should be discontinued, they could submit the case to the *hospital ethics committee*. If that "consultative body agrees that there is no reasonable possibility of Karen's ever emerging from her present comatose condition," there would be no civil or criminal liability for disconnecting the life support apparatus.²³⁴

This endorsement from the judicial system enhanced the credibility of ethics committees and suggested that such committees have an important role in the decision making process. When Jonsen discusses the Quinlan issue, he adds an interesting detail: the structure of the committee suggested by the justices was subtly different from that described by Teel. According to Jonsen, Teel's committee was interdisciplinary. An

interdisciplinary committee would involve persons like physicians, lawyers, and philosophers. The court opinion, however, indicated consultation with an ethics committee consisting of competent physicians.²³⁵

If one considers the Quinlan decision in terms of time and place, the referral to an ethics committee seems like a reasonable approach. In 1976, the Belmont Commission was in session and was receiving national attention. A committee of experts appeared to offer an innovative and effective approach for solving ethically difficult issues. Further, it seemed reasonable and even preferable to seek solutions outside the court of law. As the philosopher Ruth Macklin noted, the law is a blunt instrument, not well suited to resolving moral disputes.²³⁶

The Belmont Commission did offer an interdisciplinary model (physicians, lawyers, and philosophers), but the justices' choice of a committee consisting of physicians also seemed like a reasonable approach. In the early 1970s, "applied ethics" was a pioneering effort and, as Macklin suggests, virtually unknown within the mainstream philosophy departments.²³⁷ There was still a prevailing notion within the medical profession and among many patients that doctors know what is best for patients.²³⁸ The justices did not want to usurp the medical discretion of physicians.²³⁹

There is little doubt that the medical profession would have been generally supportive of the justices' sensitivity to the medical turf. The medical profession has a historic commitment to the notion of "medical discretion" and physicians, by virtue of their "profession" have a high level of autonomy in enforcing that world view. When physicians justify their actions, they often cite their legal and professional responsibility

for decision making, the need to rely on solid principles and rules rather than the particulars of the individual, and the need for certainty since patients will usually do what doctors suggest.²⁴⁰ This firm belief in their overarching legal and professional accountability heightens the moral standing of the physician.²⁴¹ Given this cultural milieu, the justices were understandably hesitant to interfere with the medical decisions of physicians.

Though the justices' referral of the case to an ethics committee certainly piqued interest in such structures, a number of logistical problems hindered the formation of ethics committees in most hospitals. The purpose and function of ethics committees, as outlined in the Quinlan decision, were vague.²⁴² The term "consultative body" did not indicate whether such committees should determine prognoses, make final decisions, or only give advice.²⁴³ For a number of years, ethics committees were discussed theoretically but implemented only sporadically. Indeed, when the physician Stuart Younger gave a presentation to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in 1983, he noted that only 1% of hospitals had ethics committees.

Younger, however, believed that ethics committees were an important intervention. He must have given a very persuasive presentation that day because the Commission responded by publishing a model statute that outlined the role and composition of hospital ethics committees. Further, the chief product of the commission, a report entitled *Deciding to Forego Life Sustaining Medical Treatment*, specifically encouraged healthcare institutions to "explore and evaluate various administrative

arrangements for review and consultation, such as ethics committees, particularly for decisions that have life or death consequences.”²⁴⁴

While the support offered by the President’s Commission was helpful to the budding ethics committee movement, the promulgation in 1985 of the Baby Doe Regulations, dispelled any lingering resistance. The regulation was developed by the U.S. Department of Health and Human Services in response to several difficult cases that involved use of life sustaining treatments for newborns with serious impairments. The regulation strongly encouraged that hospitals caring for newborns establish case review committees when the withholding of life sustaining treatment was being considered.²⁴⁵ The response to the Baby Does regulation was quick: by 1985, estimates suggested that 60% of U.S. hospitals had ethics committees.²⁴⁶ Two states, New Jersey and Maryland, mandated the establishment of ethics or prognosis committees.²⁴⁷ The specific influences that encouraged ethics committees to become more inclusive in terms of membership is unclear, but by the late 1980s, the bioethics literature typically described ethics committees as “interdisciplinary” structures.

Since the late 1980s, ethics committees have become well accepted and the bioethics literature now suggests that such entities exist in the vast majority of hospitals throughout the country.²⁴⁸ They are envisioned as the locus of competing responsibilities that allow attention to the questions posed by the patient rights model and the complex moral dynamics of clinical medicine.²⁴⁹ In fact, a number of regulatory entities such as the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) and the American Hospital Association, as well as federal initiatives like the Patient Self

Determination Act require hospitals to develop and provide ethics-related services.²⁵⁰

Such encouragement is based on the belief that hospital ethics committees neatly address two basic needs: the need to resolve conflicts without recourse to courts of law and the need for an authority on clinical ethics in order to clarify the moral ambiguities that complicate healthcare decision making.²⁵¹

The Growth of Ethics Committees

In 1976 when the Justices referred the Quinlan case to an ethics committee, the modern enterprise of bioethics was in its formative years. The Belmont Commission was still in session. The Bioethics Library at Georgetown had been in existence for only five years. As Jonsen noted, the collection of “641 titles, a valuable index of the available literature for scholarly research,” was quite an accomplishment.²⁵² Given Jonsen’s story about the genesis of the field, and his description of the “lofty nature of the problems”²⁵³ that confronted bioethicists, the availability of theoretical rather than practical literature is not too surprising. Bioethics was a field that thrived on “systematic analysis of concepts, examination of assumptions, and the like.”²⁵⁴ The moral philosophers who entered the bioethics field used “medicine as a testing ground to argue their doctrinal differences.”²⁵⁵ The bioethics texts discussed the “conceptual foundations of bioethics, ethical theories such as utilitarian and rights-based theories of ethics and the various moral principles and theories.”²⁵⁶ In other words, the theoretical foundation for the discipline was in place but that foundation did not clearly specify what bioethics committees should or could do.

By 1985 however, there was a growing interest in the clinical services provided by

bioethicists. Jonsen and his peers began to focus their attention on two models for services: ethics committees and ethics consultation. Interest in those two models has been sustained for over 25 years and there are now hundreds of articles and books devoted to the development of ethics committees and provision of ethics consultation. Because they have served as the dominant models for services, both ethics committees and case consultation require some discussion and analysis.

Ethics committees seem like a good starting point for the discussion. As the story told thus far suggests, there was some agreement within the Courts (Quinlan and Baby Doe) and within the medical profession (Teel and Younger) that ethics committees were a sensible intervention. As ethics committees became more prevalent, a general consensus about the role and function of ethics committees evolved. They are typically assumed to have three central roles: education, consultation, and policy development.²⁵⁷ Those roles can involve a number of diverse but interrelated functions that include: providing ethical advice and analysis, counseling, determining prognosis, peer review, quality assurance, resource allocation and rationing, risk management, and patient advocacy.²⁵⁸

Ethics committees respond to these various functions by facilitating resolution of conflict, informing institutional efforts and assisting individuals in handling current and future problems.²⁵⁹ Given the scope of these diverse expectations, much attention has been directed toward the training of committee members. To date, the most definitive discussion of training requirements has been offered by the American Society for Bioethics and Humanities (ASBH), the flagship professional organization for bioethics. That organization was created in January 1998 through the consolidation of three existing

associations in the field, the Society for Health and Human Values (SHHV), the Society for Bioethics Consultation (SBC), and the American Association of Bioethics (AAB).

In 1999, the ASBH defined the education and training standards for the field of bioethics when it published *Core Competencies for Health Care Ethics Consultation*. In a manner reminiscent of earlier efforts like the Belmont Commission, the ASBH empaneled leading bioethicists and asked them to consider the competencies essential for the individuals and the committees who provide ethics services. Twenty-one nationally respected bioethicists as well as representatives from the Joint Commission on Accreditation of Healthcare Organizations, the American Medical Association, the American Hospital Association, the Department of Veterans Affairs, the College of Chaplains, and the Association of Critical Care Nurses helped craft this report. In addition, 40 academic departments, bioethics centers, and regional networks throughout the country provided materials and input.

The report on core competencies suggests that all members of an ethics committee need to acquire certain basic competencies and at least one member of each committee requires more advanced training.²⁶⁰ Basic competencies include knowledge skills, process skills, and communication skills. The skills can be acquired through bioethics intensive courses, conferences, seminars, traditional academic courses in bioethics, ethics or moral theology, structured mentoring processes, or similar efforts.²⁶¹ More advanced skills require longer periods of education and training such as fellowship programs, clinical practicums, and advanced academic programs that emphasize ethical analysis.²⁶²

The threads that tie the ASBH report together are closely related to those that gave

form to the discipline in its early years. The mastery of “basic competencies” ensures that committee members will understand the fundamental theories of medical ethics, a cognitive skill recognized as important by early leaders such as Jonsen. Training also ensures that members have a “template” for analyzing ethical dilemmas and “making critical distinctions.”²⁶³ This emphasis on the use of “proper approaches” harkens back to the ideas of Jonsen and the other founding fathers who underscored the importance of rigor - “the necessary vocabulary, grammar and process of ethical decisionmaking.”²⁶⁴

Overall, ethics committees and the services they provide are quite highly regarded. Jonsen notes that when ethics committees are well educated, they advance bioethical discourse. Macklin offers an equally positive interpretation. When she described her initial experiences with an ethics committee, she admitted she was uneasy about the role of *ethicist*. She soon realized however that, as a philosopher, she could identify the ethical principles and help reach a satisfactory conclusion. She could formulate questions on the “meta-level of analysis” and that was a valuable service.²⁶⁵ A device like the ethics committee offered a chance to make the conversation about ethical principles more purposive and focused.

In recent years, the support for ethics committees has grown. Articles in medical, nursing, and ethics journals assert that ethics committees are beneficial.²⁶⁶ Proponents suggest that ethics committees encourage a positive ethical environment; they enhance the quality of care and caregiver well-being.²⁶⁷ Some judges have suggested that courts give deference to prior committee determination.²⁶⁸ Physicians and other healthcare personnel find committees are helpful when decisions involve withholding or

withdrawing life supports and determining the level of care for a person who is terminally ill.²⁶⁹ According to one study, the ability to discuss ethical problems involving patient care and practice, was one of three main concerns for surveyed nurses.²⁷⁰ Nurses who had some access to ethical forums also were more satisfied in their jobs.²⁷¹ In a setting where significant responsibility has historically been coupled with a subservient role, a means of discussing ethical matters appears to be an extremely beneficial feature.

The bioethics literature also suggests that ethics committees are beneficial for patients and families.²⁷² According to some commentators, when ethics committees were first created, many patients and families did not know the meaning of a “do not resuscitate” order and thus had no voice in treatment decisions.²⁷³ Many ethics committees responded by developing policies that include patients, families and staff members in ethical decisions.²⁷⁴ In short, the bioethics literature generally endorses the services offered by ethics committees. With adequate training and support, many commentators believe that ethics committees can competently fulfill their primary functions and successfully address an expanding array of issues relative to patient advocacy, protection of patient rights, staff support, clarification of values, and resource allocation.²⁷⁵

The Process of Analysis

The template generally used by ethics committees has been heavily influenced by two constructs: normative ethics and principlism. Because principlism has been referenced as the “cornerstone for many decisions,”²⁷⁶ a cursory understanding of the

methodology might be useful. Principlism is an approach associated with Beauchamp and Childress, two philosophers who were mentioned in the preceding chapter. They were key players in the formative years of the discipline and their landmark text, *Principles of Biomedical Ethics*, was published a few months after the publication of the Belmont Report. The Beauchamp and Childress method focuses on the use of four principles: beneficence, non-maleficence, justice, and autonomy. Autonomy, a concept that is based on the notion of respect for persons, is generally viewed as the predominant principle.²⁷⁷ The emphasis on autonomy is not too surprising, especially when one considers the troublesome research activities chronicled in the preceding chapter and American society's traditional emphasis on individual rights. Autonomy assumes that patients have rights of self determination and informed consent. In the years since the 1979 publication of the Beauchamp and Childress text, principle-based methodology has become the dominant approach when dealing with bioethics-related concerns in healthcare settings.²⁷⁸

According to Beauchamp and Childress, the analysis of a case begins by first identifying which of the four principles are directly involved. One then weighs and balances the competing claims. Several difficult cases in the early 1980s indicated that it could be difficult to balance the principles one against the other. As a result, Beauchamp and Childress added some Justificatory Conditions. Autonomy generally remained the heavier of the principles, but the "conditions" helped refine decision making. The "justificatory conditions" specify that the moral objective must be realistic, no morally preferable alternative action is possible to honor both duties, the solution minimizes the

infringement of duties, and one should try to minimize the effects of the infringement.

According to Beauchamp, the principles and conditions provide a framework that condenses morality to its central elements and provides a set of moral standards.²⁷⁹ In the third edition of their book, Beauchamp and Childress note that the process is not as straightforward or automatic as it may initially sound. Each case must be interpreted and analyzed, specified and connected to other norms; they note that experience and sound judgement are critical.²⁸⁰ But they believe that the process works and they suggest it is advantageous because it allows a certain distancing from the more subjective, contextual aspects of a particular situation. Further, they believe that such “distancing” helps avoid bias and self interest.²⁸¹

Principlism may seem a bit abstract but in the bioethics literature, mastery of principlism has been regarded as an important accomplishment for ethics committees. At the same time, it is not the only approach that is encouraged. Al Jonsen, for example, has written and co-authored several texts that favor the use of “casuistry.” This approach has been associated with traditional Jesuit methodology. Casuists compare a given case to a paradigm or similar case and decisions are made on the basis of those comparisons. Jonsen suggests that clinicians like casuistry because they are impatient with the more “vague speculation of principlism and prefer the concreteness and directness of casuistry.”²⁸²

Jonsen suggests that this “alternative approach” provides a way to give a concise summary of current opinions on diverse topics like refusal of care or persistent vegetative state. Indeed a text that Jonsen co-authored, *Clinical Ethics*, reads almost like a pocket

guide to solving difficult problems.²⁸³ However, though casuistry differs from principlism in its approach (arguing from a case rather than a principle), the theoretical foundations of the two approaches are similar. Both approaches embody a “substantial prior understanding” and the “deep metaphysical structure of normative ethics.”²⁸⁴ Both approaches accept common principles - beneficence, non-maleficence, justice, and autonomy.

In that respect, both casuistry and principlism are closely related to other theoretical approaches that have been suggested throughout the years. These other approaches include narrative ethics, consensus ethics, virtue theory, caring ethics, phenomenological ethics, and feminist ethics.²⁸⁵ All of these approaches have some particularities, but all share common threads. They are based on western philosophic approaches and offer expansions or variations of the same core values.

Given the preceding discussion, the creation of a well educated ethics committee is clearly a daunting task. In this respect, we have not traveled far from Jonsen’s reference to the need for a “proper theologian and a proper philosopher [who can provide] some scholarly ethics.”²⁸⁶ Access to such scholarship is perceived as essential because educational attainment creates the foundation for other activities coordinated by ethics committees. Other activities include the development, review, and evaluation of hospital policies and protocols. Policy-related activities are important because hospital policies are scrutinized as part of the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) review process.

At this point, the relationship between the standards of entities like the Joint

Commission on the Accreditation of Healthcare Organizations and the creation of ethics committees becomes more apparent. The Joint Commission's standards, for example, require hospitals to address ethical issues in providing patient care. This requirement can be met by designing a policy that describes the functioning of a multi-disciplinary ethics committee. The Joint Commission's standards require that a patient's right to treatment or services is respected and supported. This requirement can be met by involving the ethics committee in the creation of policies that detail protocols for admission, transfer, referral, and discharge. Since the Joint Commission review addresses many areas of patient care, the ethics committee may find that policy-related functions can be demanding and time-consuming. The policy function is closely tied to educational initiatives because a poorly educated committee cannot adequately develop, review, and evaluate policies.

The Leviathan's Heart

In we return to the imagery of the whale, case consultation serves as the leviathan's heart. It has often been described as the most important function assumed by ethics committees, the one that keeps the ethics committee attentive and focused. Focusing on this "heart" provides some insight, not only into this specific function, but the greater "ethical circulatory system" as well.

The literature suggests that once a committee has a good grasp of methodology and a keen understanding of policies and procedures, it can begin to respond to requests for consultation. This activity, often regarded as the most challenging function assumed

by an ethics committee, is designed to help patients, families, surrogates, healthcare providers, or other parties address uncertainty or conflict regarding “value laden” issues in healthcare.²⁸⁷ Ostensibly, consultation provides a way to offer expert opinions and advice about a difficult healthcare issue. As noted by the respected bioethicist George Agich, the development of this service is prompted by many factors including medicine’s own aversion to law and the recognition that certain classes of clinical decisions should occur within the doctor/patient relationship rather than under court supervision.²⁸⁸

If a “consult” is requested, several approaches could be considered, including the use of a full ethics committee, a smaller ethics team, or an individual ethics consultant. The committee, team, or consultant could be asked to consider a retrospective, concurrent, or prospective review of a case. Further, consultation can involve two related domains, clinical ethics or organizational ethics.²⁸⁹ To date, the primary emphasis has been placed on clinical ethics and issues that involve the beginning of life decisions, end of life decisions, organ donation and transplantation, genetic testing, and the spread of sexually transmitted diseases.²⁹⁰

The least problematic approach, among the options noted above, involves retrospective case review by the full ethics committee. Since a retrospective case has already been resolved, there is usually no intrusion into the patient/clinician relationship.²⁹¹ The review is perceived as a useful activity because it educates the committee about the range of ethical issues and provides an opportunity to practice methodology such as principlism. Such practice, in turn, promotes consistency in committee recommendations and that consistency is beneficial to the organization and to

patients.²⁹² As might be expected, a concurrent or prospective case review may be perceived as more controversial. The degree of controversy may be further influenced by the purpose of the review - whether it is required or optional and whether the recommendation is required or optional.²⁹³

Interestingly enough, there is no specifically proscribed methodology for conducting a case review. In general, the committee usually meets as a whole and reads or hears the case that is presented by physicians, nurses, and others involved in the situation.²⁹⁴ The organizational policies that define the ethics committee typically specify those who may be involved. In most cases, there is no independent gathering of evidence, review of medical records, or interviewing of all interested parties by the committee.²⁹⁵

A concurrent or prospective review of a particular case can involve the entire committee; more frequently, however, it involves the efforts of a small group or an individual. In recent years, the use of an individual “bioethics consultant” has become quite common. The more individualized service is perceived as desirable because individuals have greater flexibility, direct access to patient charts, the ability to communicate with key persons, as well as more visible and personal accountability.²⁹⁶

In many respects, the emergence of the individual consultant is a logical outgrowth of Jonsen’s founding story. He notes that initially bioethics committees sat outside the intensive care units and the hospital rooms. As bioethicists realized they needed to learn the “pace and pulse of medical life,” they joined physicians at the bedside and began to participate in clinical discourse.²⁹⁷ In 1978, Mark Siegler wrote an article entitled “The legacy of Osler: teaching clinical ethics at the bedside.” He suggested that

the case consultancy model offered a chance to identify, analyze, and resolve moral problems that arise with a particular patient.²⁹⁸ Those who celebrate this service suggest that case consultation, as a methodology, brought the general ethical considerations being shaped by the literature into the decision making of physicians.

The way in which the consultant identifies, analyzes, and resolves moral problems that arise with a particular patient²⁹⁹ is somewhat discretionary. In truth, there is no consensus in the bioethics literature on *exactly* what a consult is or what a consultant should do. According to the literature, the optimal *approach* to case consultation is based on both the goal of the consultation and the role of the consultant. This harkens back to notions of “competency” and “professionalism,” skills and moral authority. As Jonsen notes, in modern medicine, “competence has become more than the first virtue; it is essential, the comprehensive virtue.”³⁰⁰ Given that orientation, the intent of case consultation, obviously, is to address uncertainty³⁰¹ in a competent manner³⁰² so as to enhance patient care through the “identification, analysis and resolution of ethical issues.”³⁰³

Ostensibly the goal is met by a series of activities that include gathering information, formulating recommendations, and conducting follow-up evaluations. Most commentators appear to agree that the role of the consultant assumes some independence of judgement, and imposes a duty to review records, gather information and make assessments.³⁰⁴ Beyond those general parameters, however, paths diverge. The philosopher Terrence Ackerman believes that the case consultant should have a high degree of autonomy. He notes that “as an investigator of moral problems, the integrity of

the ethics consultant's role seems to depend upon the freedom to frame whatever analyses or recommendations regarding the subject matter investigated are warranted by sound application of the methodology of the discipline. This freedom to frame issues seems important, given that existing laws, social norms, and institutional guidelines are often deficient from a standpoint of various moral parameters."³⁰⁵

George Agich, a noted bioethicist at the Cleveland Clinic, offers a different approach. He uses the characterizations of watcher, witness, teacher, and consultant to describe the different roles or approaches that he has found most common. The roles are dependent upon the situation and the character of the consultants. The watcher is disinterested and objective, the witness maintains the quality of a stranger, the teacher offers a discipline-restrictive orientation, and the consultant offers academic expertise.³⁰⁶

Paul Reitemeier, a philosopher at the University of Nebraska Medical Center, uses still a slightly different metaphor. He sees ethicists as coaches who serve patients and clinicians "by combining careful study of healthcare services, including detailed observation, searching reflection, rigorous analysis, and detached objectivity concerning the actions of those who seek their advice."³⁰⁷

In its report on *Core Competencies for Healthcare Ethics Consultation*, the American Society for Bioethics and Humanities opted to discuss the role of the consultant in terms of three models: the authoritarian approach, the pure facilitation approach, and the ethics facilitation approach.³⁰⁸ Some concerns were expressed about the first two approaches. The authoritarian approach, similar to that referenced by Ackerman, emphasizes the consultants as the moral decision makers. While it may be effective in

some situations, it can be problematic because it places the personal moral values of the consultant over those of other parties. As a result, relevant parties may be excluded from moral decision making.³⁰⁹ The pure facilitation approach is designed to forge a consensus among involved parties. This approach can meet the needs of those most directly involved in a situation and may achieve a consensus. However, it may fail to clarify the implications of societal, legal, and institutional values.

The ethics facilitation approach was deemed by the authors of the report as the most appropriate for contemporary society. This approach involves two features: it identifies and analyzes the nature of the moral uncertainty and facilitates the building of a consensus.³¹⁰ Consensus was an important goal for those involved in the core competencies project, and the report suggests that consensus might even be viewed as a primary criterion for possible evaluation activities.

There is reason to believe that the endorsement of the ethics facilitation approach, offered by the American Society for Bioethics and Humanities, will hold some weight. When one considers the controversial nature of the healthcare system, agreement about any kind of approach is an accomplishment. Further, the core competencies report has been broadly disseminated and heartily endorsed within the field of bioethics. Edmund Pellegrino, one of the forefathers of bioethics, describes the report as timely and welcome; he suggests that it “introduces order into what has been a burgeoning but diffuse, unregulated, and largely under evaluated practice.”³¹¹ He notes that the report very adequately addresses the skills and competencies of consultants, the process for consultation, and the potential for abuse and misuse.³¹² Edmund Howe, the editor of the

Journal of Clinical Ethics, also applauds efforts toward the development of standards.

He notes that when a new field such as ethics consultation is being established, standards of practice should be promulgated as quickly as possible.³¹³

Different Voices, Different Visions

Those laudatory comments about ethics committees, ethics consultation and principlism appear to be well substantiated by those who have provided leadership to the field of bioethics. At the same time there are subtle hints, especially when one considers the very different stories that were chronicled in Chapter One, that alternative perspectives about ethics committees and ethics consultation may be written in the margins. A comment offered by the philosopher Judith Wilson Ross serves as a fitting introduction to this alternative tale about the utility of ethics committees and ethics consultation. After studying the ASBH report on core competencies for ethics consultation, she reported that she “had lost the forest for looking at the trees and lost also the mushrooms, grass blades, and beetles.”³¹⁴ In short, Ross was not fooled by the carefully scripted attempts to define the parameters of the field by identifying core competencies or endorsing the “ethics facilitation” approach.

Ross begins her critique by admitting that she is skeptical of ethics consultation. In part, that skepticism is rooted in her belief that bioethics’ underlying hostility toward the power of the physicians becomes an attempt to counter that power with an equal power - the sword of ethics.³¹⁵ She suggests that the focus on standards embodies a trace of self righteousness and a scent of unearned and destructive certainty. Further, she

suggests that the emphasis on consultation diverts attention from the real issue - the need to promote structures for supporting ethical behavior.³¹⁶ Indeed, Ross contends that there is no documentation of the need for standards and no proof that the standards offered by American Society for Bioethics and Humanities or any other entities are the “right” standards. Rather, the attention to the issue of “core competencies” suggests a hidden agenda, an attempt to standardize behavior even though there are no outcome data to support such standardization.

Ross’ suspicions and her intriguing selection of words - “a hidden agenda,” “a sword of ethics,” and “a scent of unearned and destructive certainty” - are particularly interesting when one considers the various perspectives that surround seminal events such as the Quinlan decision and the Baby Doe regulations that were cited in earlier sections of this chapter. As was previously noted, the apologists who herald the creation of ethics committees use cases, like that of Karen Quinlan, to underscore the need for a more humanistic, less litigious approach to problemsolving. They are reassured by the involvement of those who are “authorities on clinical ethics.”³¹⁷ A well educated committee seems preferable to what Macklin described as the “blunt instrument of law.”³¹⁸

But as Light and McGee suggest, the “moral intuitions” of the philosophers can be compared to an elaborate, tribal ritual of upper middle-class culture.³¹⁹ The enterprise of bioethics has been so successful, in part, because philosophers offered a legitimate, essentially conservative way to help the physician avoid the onus of the social. The traditional focus on analytic philosophy minimized the social perspective on personal and

communal moral life.³²⁰ Such a focus made it possible for bioethicists to ignore issues such as the “bureaucratic structure of hospital organizations, the capitalist expansion of the medical industrial complex, disparities of income and life chances between rich and poor and gender inequities, as if these more sociologically defined areas were without important moral dimensions or consequences for practicing physicians.”³²¹

The historian Tina Stevens seems to agree with these critics and suggest that the mainstream analysis³²² of a case like Karen Quinlan’s should be questioned. When Stevens analyzes the Quinlan case, she offers a sort of underbelly perspective. She spins a tale of seduction, a tale about how bioethics, as a discipline, actually aids and abets the authority of physicians while subtly managing society’s fears of medical technologies. As noted previously, Stevens does not reference the ideas of her fellow historian, Charles Rosenberg, but the issues she examines clearly underscore his assertion about the importance of “context” - the social, political, and economic factors of the day. Further, Stevens’ chronicle, *Bioethics in America*, is certainly consistent with Rosenberg’s description of an enterprise that has taken up residence in the belly of the medical whale.³²³

Stevens notes that the Quinlan case surfaced at a time when competing priorities - or factors of the day - were clamoring for the attention of physicians and medical researchers. There was considerable interest in the “redefinition of death,” in part because there was a desire to increase the supply of transplantable organs.³²⁴ There was unease about the use of life-sustaining technologies and the quality of the life that would be sustained through reliance on those technologies. But there was even more unease

about the discontinuation of such technologies. When Karen Quinlan collapsed, medicine was facing the “liability vexed atmosphere at the beginning of the medical malpractice crisis.”³²⁵ When viewing the story through Stevens’ eyes, the Quinlan case offers not a clear-cut justification for creating ethics committees, but an intriguing way to reinforce the unsettling connections that link the interests of physicians, technology, and the evolving field of ethics.³²⁶

There is no question that the U.S., as a nation, responded passionately to the young woman’s misfortune. The media became fixated with the almost fairy tale imagery of the young woman - “a sleeping beauty” - who was “brain dead” and artificially “kept alive” by technology.³²⁷ The media inferred that the physician’s refusal to discontinue the respirator was typical of medical professionals.³²⁸ According to this mainstream perspective, the Court turned to a reputable, deliberative body, an ethics committee. The ethics committee was able to apply a “moral balm” that eased the presenting problem to closure and charted a new and cleaner path for future problemsolving.

To state it mildly, the story, spun by the media, was less than accurate. Karen Quinlan did not have a flat electroencephalogram; she responded to external stimuli and was not brain dead. Further, the “customary medical practice” of the day did not encourage efforts to keep chronically vegetative people on respirators.³²⁹ The media interpretation of Karen’s release from the jowls of technology was erroneous. In fact, a careful analysis of the court’s language suggests that what the courts gave to the Quinlans in terms of a right to privacy, they took back when specifying the declaratory relief.³³⁰ In short, the case was less about the rights of the patient and more about the *freedom of the*

*profession of medicine from civil or criminal liability.*³³¹ In that respect, the Quinlan case does not mark “the beginning of the movement to deal compassionately with terminally ill patients. It marks the “beginning of this movement’s fatal turn - from the ambit of patients, doctors, families, clerics and communities to the sphere of the courtroom and the language and limitations of rights.”³³²

The alternative perspectives offered by scholars like Ross, Stevens and Rosenberg suggests that the discipline of bioethics, as it has matured and become *institutionalized* in healthcare system, has failed to measurably enhance patient care. It has remained committed to the limited role of establishing guidelines for the procedures and technologies that it perceives are inevitable and it has refrained from “seeking answers to and informing the public about how and why specific biomedical technologies were created.”³³³ When Stevens offered those thoughts, she was referring to the enterprise of bioethics, as a whole. But the impact of the institutionalization of bioethics services can be examined via a cluster of specific issues that involve the function, composition, approach, cultural compatibility, exclusivity, and accountability of ethics committees. Such an examination is a worthwhile endeavor because ethics committees have become the focal point for ethics-related services in many healthcare settings.

Of necessity, a discussion about the limitations of ethics committees begins with a backward glance. It is interesting to remember that when Jonsen chronicled the birth of bioethics, he described “serious, disciplined and deep philosophical reflections”³³⁴ among male academicians. He named physicians who made contributions to the field of medical ethics but there was no similar celebration of nurses and the role of nursing ethics. In the

formative days of the discipline, a certain level of exclusivity was taken for granted. Issues were discussed by “splendid scholarly panels” and conversations improved when “a proper theologian and a proper philosopher were invited to do some scholarly ethics.” Given the “lofty nature of the problems,” Jonsen noted that the public was rarely invited to participate in the evolving bioethics discussions.³³⁵

When the discipline of bioethics moved into the hospital via the ethics committee, more than a trace of that insularity remained. Ethics committees were often medical staff committees that were heavily dominated by physicians. The role of the physician, as chief decision-maker, cannot be underestimated. Indeed in a 1990 text, Jonsen noted that the Biblical Good Samaritan represents the good physician of today. He is a consummate professional, charged with distributing his time, energy, and money among those who can benefit.³³⁶ Many ethics committees are still comprised primarily of physicians, even though some studies suggest that physician dominated committees are less successful in terms of rounds, guideline development, and consultations.³³⁷

Certainly some recognize the need for more diverse voices when making patient care decisions, but ethics committees have remained fairly exclusive. Nurses are still poorly represented and the nurses who are invited to serve are usually nurse managers rather than those who provide more clinical services.³³⁸ Some studies suggest that 50% of American nurses can request an ethics consultation.³³⁹ While that statistic was offered by an author as a measure of progress, it can also be viewed as a cause for concern. Indeed a 1990 study of physicians showed that only 69% believed that nurses should serve as members of ethics committees and only 58% believed that nurses should have access [be

able to make referrals] to an ethics committee.³⁴⁰ Other studies suggest that nurses are hesitant to use ethics committees and do not view them as helpful when resolving ethical issues.³⁴¹

The depth of this traditional exclusivity was evidenced in a recent article published by the *Annals of Internal Medicine*. The authors affirmed the value of clinical ethics consultations and noted that the attempt, by the ASBH, to define the core competencies was a step in the right direction. But they decried what they termed a lack of sufficient rigor and vigorously argued that using a nurse with a Masters degree in ethics as a consultant to an ethics committee could “compromise the integrity of the field.”³⁴² Rather than including a nurse, they suggested that all ethics consultation teams should include a physician, a lawyer, and a philosopher.

The comments offered by Spike and Greenwall suggest that certain perspectives are superior to others. Physicians, for example, are presumed to have the right moral answers because they know the most about the disease process and are legally and professionally responsible for medical decisions. Sarah Shannon suggests that such perceptions of moral superiority, however, are not helpful; in fact, they create interdisciplinary conflict.³⁴³ In response to what has been termed exclusionary tactics, many in the nursing profession have called for alternatives like nursing ethics committees.³⁴⁴ They note that existing ethics committees do not consistently address the concerns of nurses and that in most hospital settings, the majority of nurses have no forum and no opportunity to participate in ethics-related discussions.³⁴⁵ Studies indicate that ethics committees are so exclusive that, in many hospitals, nurses are often unaware

that ethics committees exist.³⁴⁶ Another study suggests that the presence of an ethics committee discourages conversation among healthcare team members. Ethics-related issues, in effect, are left to the committee and ignored by most of the hospital staff.³⁴⁷

The concerns about exclusivity directly involve a number of other issues because the composition of a committee can determine its approach to its roles, functions, and decision making processes. A committee's understanding of roles, for example, can directly impact the kinds of services provided to patients and families. As indicated previously, most committees define their functions in terms of consultation, education, and policy development.³⁴⁸ From both a nursing and public policy perspective - especially when one considers the murky history of medical research in the U.S. - one would assume that an additional key role or function would involve patient advocacy and patient protection. To date, however, no agreement has been achieved on that point. Indeed, one study found that philosophers and theologians tend to provide the majority of ethics consultations but fewer than 2% of the philosophers who served as consultants assumed the role of a patient advocate.³⁴⁹

Further, data do not indicate whether committees typically focus on assessment of the moral interests of the patient or the interests of other relevant parties such as physicians or hospital administrators.³⁵⁰ In addition, no consensus has evolved as to whether patients and family members should have a right to veto a potential meeting, whether patient permission is required in order to support informed consent, whether patients and families should be allowed to attend meetings, or whether patients and families should have access to committee deliberations or reports.³⁵¹ Finally, there is no

agreement as to whether patients, or members of the public, should be allowed to serve on ethics committees. In short there is, according to Agich and Younger, a striking lack of clarity regarding what access means or should mean.³⁵²

Ironically, most families probably would not veto a meeting or attend a meeting of an ethics committee since a number of studies show that patients and family members are rarely aware of the existence of such entities.³⁵³ Groups like the President's Commission, The Hastings Center, the American Medical Association and the American Hospital Association say that patients and families should be involved, but they do not offer specific suggestions.³⁵⁴ The omission implies a difference between the ideal and the reality, the latter being that doctors dominate hospitals and the decision making process.³⁵⁵

Perhaps most troubling, even if ethics committees choose to provide more patient-centered services, the assistance they offer may not be very helpful. The disparity between the expectations of healthcare providers and concerns of patients has been well recognized.³⁵⁶ One particularly interesting study examined the perceptions of ethics committee members and the perceptions of patients. The ethics committee members believed they could help resolve conflicts among family members, patients, and physicians. They believed that families would want "support" when they felt "overwhelmed" with medical information.

Family members, however, rarely mentioned the kinds of conflict described by ethics committee members. Further they suggested that the *medical staff*, not the families, needed education. In fact, the problems experienced by families often involved

the insensitivity of healthcare team members, the lack of quality care, and similar issues. Indeed families did not feel “overwhelmed” with information; if anything, they were frustrated by the lack of information.³⁵⁷

In part, this disparity between perspectives of patients and healthcare providers is not surprising. The bioethics literature has consistently underscored the importance of “training”³⁵⁸ but has not precisely indicated who should receive training in ethics, how that training should be provided, or how it relates to the needs of patients. This point was underscored by a recent study of the ethics-related curricula used in medical schools. The study found that among medical schools, there was little agreement relative to course objectives, content, teaching methods, or student assessments.³⁵⁹

In fact, what emerged was a clear suggestion that medical training does not necessarily help physicians address morally distressing issues. Though physicians are widely presumed to have the moral authority to resolve difficult healthcare issues, only 31% of U.S. medical schools provided content in ethical reasoning and problem solving. Only 22% of programs provide coursework that addresses codes, oaths, and compliance. Other issues such as cultural diversity, care of the family, substance abuse, patient experiences of illness, use of ethics committees, and ethics consultation are even more rarely addressed.³⁶⁰

In short, something appears unsatisfactory in this “training agenda.” The medical ethics curriculum appears to be designed with the notion that physicians, by virtue of their *profession*, “will act in the best interests of patients, even without guidelines or constraints on acceptable conduct.”³⁶¹ That assumption is particularly interesting, given

that the standard ethics curriculum “has left certain areas and topics undisturbed.”³⁶²

Those who design the medical ethics curricula have evidenced “hardly any concern with physicians’ personal conduct or their financial conflicts of interest.”³⁶³

The ethics training provided to nurses may also be inadequate. Commentators in the nursing profession suggest that nurses are not prepared educationally to either recognize or deal effectively with ethical concerns.³⁶⁴ While those issues do not directly impact the functioning of an ethics committee they suggest that it might be hard to find qualified committee members among the nursing staff.

These issues are difficult to examine because there is a lack of consistent evaluation protocols that examine the effectiveness of bioethics services for either patients or healthcare providers.³⁶⁵ Indeed, even the notion of evaluation has proven to be a fairly controversial topic. Some commentators question whether evaluation of ethics committees is a legitimate question. Joseph Fletcher, one of the founding fathers of the field, argues that an evaluation that aims to measure the worth of a program by determining its effects or outcomes is not an appropriate approach for ethics committees.³⁶⁶ Others have argued that a criterion like cost effectiveness is inappropriate since concern should rest with the “quality” of the deliberations, not the cost.³⁶⁷ Increasingly, however, some commentators have discredited such assertions and note that public policy makers cannot continue to mandate entities like ethics committees without examining them more critically.³⁶⁸

Concerns about ethics committees are linked to even more fundamental concerns about reliance on the moral validity of the “Western, *principle-driven*, biomedical

model.”³⁶⁹ As was apparent in Jonsen’s version of the founding tale, bioethics has historically tried to structure a “single, coherent area of moral and conceptual investigation.”³⁷⁰ That is a challenging endeavor, especially when one considers philosopher Ruth Macklin’s reference to the long standing debate between the competing theoretical approaches of Kantians and utilitarians.³⁷¹ A moral judgement offered by a consultant may be based on a commitment to one or the other theoretical perspective.³⁷² James Childress, for example, has noted that “a straightforward consequentialist approach to research involving human subjects, particularly one based on utilitarian calculation and unfettered by deontological constraints, might justify research that is deceptive or coercive as a way to produce significant benefits for a large number of people.”³⁷³ Those who served on the Belmont Commission tried to bridge that philosophic chasm by identifying three “universal” principles - beneficence, freedom, and justice.³⁷⁴

In recent years, however, bioethics has been redefined; the religious morality and bioethics of the west has been supplanted with an orientation that is post-Christian.³⁷⁵ In this evolving milieu, it is far harder to identify universal principles. Issues that involve autonomy, acceptance of treatment, or patient involvement in the care plan may have cultural and moral dimensions that preclude the kind of “unified approach” that bioethicists often seek.³⁷⁶ For example, many American Indian cultures emphasize the well-being of the group as opposed to the well-being of the individual. More valued is the ability to listen than the choice to speak.³⁷⁷ In such a culture, autonomy and self determination are not primary values.

In addition, different cultures may have very different notions of disease and the

cause of illness. This issue was explored very well by Anne Fadiman in her book, *The Spirit Catches You and You Fall Down*. To understand the Lee family's interpretation of their daughter's illness, one had to "think a less like an American and a little more like a Hmong."³⁷⁸ The family's hesitancy to fully comply with western approaches for seizure control was certainly complicated by the family's belief that their child's soul had fled her body when the child's sleep was interrupted by the slamming of a door.³⁷⁹ On the one hand, the family knew that infantile epilepsy was a serious disease; on the other hand, epilepsy was viewed as a disease of some distinction. Hmong epileptics often become shamans; they can perceive things that others can't see and can travel in the realm of the unseen.³⁸⁰

Dealing with diverse cultural beliefs, notes Fadiman, requires changes in perspective. But bioethicists, according to the philosopher H. Tristram Engelhardt, have a hard time "taking moral pluralism seriously and adjusting their approach and methodology accordingly."³⁸¹ Indeed some commentators vigorously assert that any suggestion that we should move entirely outside our ethical framework in favor of a patient's culture is mistaken.³⁸² Given this lack of introspection, western bioethics fails to see the problems that arise from "the unflinching believe in the universality of scientific truths or moral principles."³⁸³

This resistance to change has resulted in a vision for bioethics that has become increasingly less satisfactory for both patients and healthcare providers alike. The academic, philosophic, and cultural exclusivity that has been a predominant feature of the field can give the impression that there is a "uniformity of thought" among members of

an ethics committee. Engelhardt, however, suggests that such uniformity is a fallacy and that such a canonical moral vision does not exist. If it did, bioethicists would be the moral “high priests of our culture.”³⁸⁴ Even the secular bioethicists, he argues, are sectarian advocates of “particular moral visions” and these particular visions often, if not usually, come without warning.³⁸⁵

This “lack of warning” can present problems for patients. Patients are not typically aware of the theoretic orientation espoused by a consultant or an ethics committee. They may not be told that different philosophic beliefs could render very different, but equally “ethical” recommendations. Rather, as was noted by Engelhardt, quite the opposite can occur: the emphasis on rigor and methodology can leave the impression that bioethics is a science and that patients and healthcare providers can trust the moral distinctions made by bioethicists. But, suggests Engelhardt, given that a unified, canonical, moral vision does not exist, bioethicists cannot “unambiguously disclose a unique, content rich, moral vision to guide society.”³⁸⁶

Three philosophers, Fletcher, Hoffman, and Veatch, offer some comments that are relevant to Engelhardt’s contention. Admittedly, the comments were not made specifically in reference to Engelhardt’s quote, but they certainly reinforce the notion that bioethicists may be influenced by their personal philosophic orientations. Veatch notes that “it is becoming increasingly clear that different ethical positions will lead to different conclusions about what is morally appropriate in these circumstances. Someone committed to an ethic emphasizing liberty may well come to a different conclusion than someone committed to maximizing patient welfare or someone committed to the priority

of equality in allocating resources.”³⁸⁷ Fletcher and Hoffman readily admit there are some exceptions, but their experiences have suggested that most members of ethics committees engage in little serious study of clinical ethics, and in practice each member tends to “maintain his or her own *personal* concept of ethics.”³⁸⁸ One’s personal concept of ethics, regardless of its source, can have a profound impact on decisions.

This point is underscored, perhaps unintentionally, by Ruth Macklin in her book *Mortal Choices*. There she described a case in which a pediatric resident questioned the wisdom of placing a baby with a terminal illness on a respirator, knowing it may be impossible to successfully wean the child from the respirator. The resident noted that healthcare providers would only be involved with the case for a limited period of time while the “poor parents have to bear the brunt of the agony of seeing their baby suffer and get worse and worse, all while hooked up to some machine.”³⁸⁹ He noted that it might be better for the parents and the healthcare providers to resist placement on a ventilator, even if it meant the child would die sooner.

Macklin appeared to be fairly shocked by that suggestion; she said that to withhold treatment from the child because of the perceived benefit to the parent was a violation of Kant’s principles and the resident had his “ethical priorities backwards by paying too much attention to the family’s well-being at the expense of the child’s.”³⁹⁰ Given Macklin’s reliance on “Kant’s famous categorical imperative”³⁹¹ one can understand her perspective. At the same time, an ethicist who ascribes to a different theoretical foundation might have offered the hospital staff and the family a very different perspective.

Engelhardt's description of "particular moral visions that come without warning"³⁹² is also evidenced in the textual discussions of case studies. The studies, published in various bioethics journals provide a way to consider the extent to which competing moral theories shape decisions. When the *Journal of Clinical Ethics* publishes a case study, it usually outlines the key features of the case, explains the ethical analysis, presents specific recommendations, and summarizes the outcomes. The reader knows which moral choice the author deems as most appropriate. When analyzing the use of placebo controlled drug trials in developing nations, the article summarized the need for the research and referenced the utilitarian argument used to justify the research. The utilitarian argument placed a heavy emphasis on common good.

The proponents of the utilitarian argument believed that the proposed drug trials adhered to principles of autonomy, beneficence, and justice. The author of the article, however, disputed that perspective and believed that contextual issues in the third world countries inhibited adherence to the principles of autonomy, beneficence, and justice. He concluded that the researchers had an ethical responsibility to uphold the integrity of national and international guidelines and that the placebo controlled studies should be suspended.³⁹³ He then noted that the National Institute of Health suspended the studies.

The *Hastings Center Report* uses a much different approach for case analysis. It outlines the key features of the case and, without making any judgement calls, presents two or more commentaries that offer markedly different ways of resolving the situation. In one case, a child with breathing problems was brought to the hospital. A serious congenital heart defect was diagnosed and cardiologists recommended surgery. The

parents, members of an Amish community, believed such intervention was beyond the will of God and would not consent to the surgery.

One commentator suggested that the wishes of the family should be respected. She did not believe that relevant law, in this case, required referral to the state child protective agency.³⁹⁴ The other commentator believed that the parents were making a mistake in refusing surgery and the cardiologist had a responsibility to protect that baby from the parent's mistake. The second commentator believed that if assistance from an ethics committee was not available, the case should be referred to the court.³⁹⁵ Thus the optimal decision was not clear, and the repercussions for the healthcare providers, patient, and family could be dependent upon the orientation of the consultants.

Given such considerations, some commentators have started to question the theoretic foundation upon which bioethics has been built. They suggest that the reliance on traditional western, moral philosophy has created an orientation that is "abstract and removed from the nuances of clinical life."³⁹⁶ Approaches that are abstract and removed from the reality of life can be hazardous because they create a disconnect between bioethics and what really matters to people.³⁹⁷ As was noted in Chapter One, the philosopher Robert Solomon finds this "disconnect" sufficiently problematic as to call into question the primacy of philosophy as the home for bioethics.

To some extent, this disdain for what Solomon calls "appeal to the emotions" was evidenced when Ruth Macklin described the case of the infant and the ventilator. She rather scathingly noted that "the indignant resident thought that ethical problems should be resolved by feelings rather than by principles."³⁹⁸ Perhaps all of the

participants in that debate needed to ponder their perspectives because illness, says Solomon, is very much about action, passion, emotion, and even heated arguments. When emotions are lost, so too are the seeds for action.³⁹⁹

Solomon's assertion offers an intriguing link to Rosenberg's notion of context. Both Solomon and Rosenberg speak of a "dis-connect" in the healthcare system. Rosenberg characterizes the disconnect as a failure to respond to the human implications of technical and institutional innovation.⁴⁰⁰ For patients like the author Paul West, this disconnect is experienced in very personal terms. In his pathography, West noted that his physicians were academically brilliant, but emotionally distant and unsatisfying. They may have been able to articulate a theoretically sound moral vision and may have offered the "right" protocols for the care that he needed, but they did not understand his experiences of his illness and so did not understand him, his life, or his values. To them, he was just an overweight, frightened, confused, and often difficult patient. In the face of those partial and negative characterizations, West was lonely and afraid, "unable to tell his doctors what it felt like to see oneself as a cut worm."⁴⁰¹

West's perception of himself with the Kafka-like imagery of a cut worm seems core to the problem that both Solomon and Rosenberg reference, a problem of perspective. Jonsen noted that the field of ethics was enhanced when a proper philosopher and a proper theologian joined the discussion. Now it is time, suggests Solomon, to liberate bioethics from such rigid confines.

Interestingly enough, those concerns about "confines" have led directly to concerns about principlism, an approach that has been widely used by ethics committees

throughout the country. With language similar to Solomon's, the critics of principlism suggest this approach is impractical and theoretically flawed, the principles too abstract and removed from daily practice to be of help.⁴⁰² Principlism "reduces ethical practice to correct technique and promotes an overly mechanical (and therefore insensitive) compartment to ethical problems."⁴⁰³ The sociologist John Evans is particularly intrigued with this reduction of practice to correct technique and suggests the importance of understanding why principlism has become so prominent and how the discourse of ethics has been changed because of that prominence.⁴⁰⁴

The social determinants of principlism, according to Evans, emerged in 1494 when the first text book for double entry bookkeeping was written.⁴⁰⁵ Double entry bookkeeping, he claims, supported the distillation of information that allowed for calculability, efficiency, and predictability in human action. The new methodology provided a way to discard information extraneous to decision making and a measurement that made information more precise.

This story about double entry bookkeeping may seem distant from bioethics, but Evans contends that it is intimately linked. American society values reduction and predictability, and so it is no surprise that principlism emerged as a primary tool for bioethicists. Principlism allows information to be whittled down to a more manageable level and that process allows for simpler decisions.⁴⁰⁶ It allows a process of agreement in the midst of competing theoretic approaches. Beauchamp and Childress, the architects of principlism, do not dispute that assertion. In fact, they find principlism advantageous *because* it condenses morality to its central elements and allows a certain distancing from

contextual features.

Before the advent of principlism, bioethics was a “mixture of religion, whimsy, exhortation, legal precedents, various traditions, philosophies of life, miscellaneous moral rules and epithets.”⁴⁰⁷ Thus, an ethical decision was not calculable or predictable. “But principlism takes the complexities of actually lived moral life and translates this information into four scales by discarding information that resists translation.”⁴⁰⁸ Although Beauchamp is a professed “rule utilitarian” and Childress a professed “rule deontologist,” their metric of principles creates a decision acceptable to both in spite of the longstanding differences of opinion between deontologists and utilitarians.⁴⁰⁹ Principlism, in short, offers the lure of calculability and predictability,⁴¹⁰ a “common coin of moral discourse.”⁴¹¹

An approach that minimizes profound philosophical differences and allows for systematic decision making may appear advantageous. Evans, however, is concerned about all the information that is discarded. We are left, he suggests, with the limitations that characterize a recent report, the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Sciences. This is the report that is generally referenced as *Splicing Life*. As the Commissioners struggled with issues of human genetic engineering, they “accepted the scale of risks and benefits and found various methods of discounting, putting off for later discussion, or debunking claims that could not be translated to it.”⁴¹²

Evans is not alone in his criticism of principlism. Engelhardt notes that when persons of different theoretical perspectives have been able to co-author books that use

common principles to solve moral problems, there is an inference that a substantive, common, moral, canonical understanding is available. Such an inference, however, is only a reflection of the common, ideological standpoint from which the authors began. He suggests that real ideological or moral differences would not be so easily distilled.

European bioethicists like Jones and Kessel have also entered the fray. They suggest that bioethics, in the form of principlism is “endeavoring to become a global enterprise by claiming neutrality.”⁴¹³ However, the discipline of bioethics - and principlism in particular - has refused to acknowledge the limitations of its own world view and hence lacks an understanding of its “applicability and appropriateness in diverse social and cultural contexts.”⁴¹⁴ They suggest that the global transplantation of this “culturally neutral” approach is “illustrative of the imperialistic and hegemonic nature of Western bioethics in accord with unequal global power relations.”⁴¹⁵

The rural hospital administrator, quoted in the opening paragraph of this chapter, noted that an ethics committee did not seem like a very useful intervention in his community; he also had doubts about the efficacy of case consultation. When compared to the rural administrator, the philosopher Judith Wilson Ross certainly has a great deal more experience with formalized ethics resources, but she is also skeptical of the benefits of case consultation. She went so far as to complain that a review of the ASBH core competencies left her feeling that she “lost the forest for looking at the trees and lost also the mushrooms, grass blades, and beetles.”⁴¹⁶

A cogent response to the concerns noted by the rural hospital administrator and Ross is somewhat difficult to formulate. As the discipline has moved from the academic

chambers to the clinical hallways, the quiet and at times dissident voices from the margins have been muffled by the chorus of approval. The literature suggests that ethics committees exist in all hospitals, perform useful and similar functions, and employ standard philosophic approaches. Most commentators assume that bioethics services are helpful, enhance patient care, offer some protection against litigation, and create forums for interdisciplinary discussions. The development of standards like the core competencies appears to offer assurance of quality.

And there, perhaps, lies the rub. We do not know if those assumptions are true. Certainly those assumptions about the development and provision of ethics services may fail to calculate the extent to which rural healthcare settings mirror the conditions in urban and academic healthcare settings. Indeed, rural communities may not mirror urban conditions at all. Alvin Moss, the director of the Center for Health Ethics and Law at West Virginia University, notes that the core competencies detailed in the report of the American Society for Bioethics and Humanities, pose formidable challenges for healthcare institutions in rural and frontier settings.⁴¹⁷ Moss notes that most hospitals in West Virginia are part of a formal ethics committee network and still, most ethics committee members rated their competencies as below what were described in the report as basic skills and knowledge. Rural healthcare settings face three major barriers: a lack of ethical expertise on site, a lack of resources to pay for the education of consultants, and a lack of time for personnel to acquire the knowledge and skills that are expected.⁴¹⁸ In addition, Moss notes, research has not verified whether ethics committees and ethics consultation are appropriate in rural areas.

Given those issues, the rural administrator, cited in the opening paragraph, may be excused for looking askance at the bioethical leviathan. Rural hospitals cannot afford the ethicists and consults so admired by the field, and those approaches may seem quite removed from what rural healthcare providers might call “ethics.” The challenge then, is to compare the theoretic with the practical and examine the extent to which bioethics services exist in rural environments and whether those services respond to actual needs. The physician/philosopher Robert Potter, calls such an examination “hardball bioethics,” a sharp shift from fluffy rhetoric toward the firm reality of accountability.⁴¹⁹

Moving the examination of bioethics to rural areas takes us to a place where “natural” bioethics still reigns. Behind the hard questions that rural healthcare providers ask of institutional bioethics, lie not only a series of healthcare dilemmas that are shaded by economic, social, political, and geographic factors, but an ethical context with which to deal with these issues. What can we learn from the ethical dilemmas and the native solutions that emerge in rural areas? The ensuing three chapters will document research into bioethics needs and behaviors in rural areas. The contrast that rural areas offer to the urban bioethical leviathan yields many insights into modern bioethics broadly conceived, and opens the way to discussions of reform.

CHAPTER III

EXPLORING THE ENVIRONMENT

The stories and examples threaded through the previous chapters offer different ways to envision the modern enterprise of bioethics. The varying perspectives, however, also conjure a web of theories and practices that may have little relevance in rural settings. That point is illustrated by a rural ethics committee that has been struggling in its attempt to provide services to rural healthcare providers. The ethics committee was created nearly 10 years ago. Formal activities have been limited, but some progress was reported; in recent months, the committee has discussed problems associated with two different patients. As the committee chair noted: “Those discussions are the closest we have ever come to anything like consultation.” Throughout the past 10 years, the committee has consistently tried to follow the textbook guidelines, but found more questions than answers. “We don’t do research and don’t see ourselves as policy makers,” explained the chair of the committee. “The committee members have all read articles about ethics committees. But how do we stack up? What do you hear about other rural ethics committees?” The nurses who served on the ethics committee were particularly intrigued by those two questions. As the discussion continued, committee members identified a number of issues that increased the stress levels for healthcare providers and perhaps compromised patient care. Some of the issues involved failed processes such as working with the physician who “always ignores advance directives,”

or encountering the nurse who does not understand the care plan but seeks no clarification from other members of the healthcare team.

As the committee members continued their discussion, they realized that a number of pervasive problems had never been formally discussed by the group. As one nurse noted: "I've never considered the fear of calling a doctor to ask about an order as an ethical issue." Yet the failure to consider such issues could and certainly had compromised patient care. The committee chair struggled with the implications of his new awareness. "I think we're doomed to failure if we stay on the same track and just continue to meet as a committee," he noted. "Do you hear these stories at other rural hospitals and do you see many committees that function like ours? What should we do differently?"

Given the issues discussed in the preceding chapters, the fact that the rural practitioners have found few answers in the standard bioethics texts is not surprising. The field of bioethics has emphasized the importance of linguistic strictures and discouraged use of empirical analysis.⁴²⁰ The landmark cases that defined the field in its early years occurred in tertiary care centers. The research studies that support the need for bioethics services have generally been conducted in urban areas. Those who teach bioethics generally live and work in urban areas. The scholars who write about ethical issues and those who serve on the review boards that publicize ethics-related books and journals usually have an urban orientation. Indeed, the editorial panel for the *Journal of Clinical Ethics* is comprised of 35 people, not one of whom appears linked to a rural institution.

The short answer to the question about rural ethics committees is that little has been known about the ethics-related services that exist in rural areas, the issues that emerge in rural settings, or how those issues are resolved. The authors of a 1999 article published in the *Hastings Center Report* applauded the publication of four “new studies” on the topic of rural bioethics. The term “new” was slightly misleading. The studies conducted in 1992 and 1996 were the most recent; the other two studies were more than 15 years old.⁴²¹ All four studies were limited in scope. The 1996 study involved telephone interviews with seven nurse practitioners in northern California and Colorado.⁴²² The 1992 study examined strategies used by physicians in Kansas to protect confidentiality.⁴²³

Other rural studies have been conducted in past years, but they are few in number and limited in scope. In general, the articles have addressed one of three topics: standards of practice for physicians in rural areas,⁴²⁴ how to create ethics committees in rural hospitals,⁴²⁵ or geographic and economic realities that complicate the provision of rural healthcare.⁴²⁶ None of those topics provides the kind of detail that helps rural healthcare providers recognize and resolve the problems they face.

Although commentators have suggested that ethics committees exist in most, if not all hospitals, there is reason to believe that such entities do not exist in most rural hospitals. As indicated in the previous chapter, urban and suburban ethics committees place a heavy reliance on expertise, training, and standardization.⁴²⁷ They require members who are knowledgeable about ethical issues, spend time developing expertise, and cultivate an ability to apply ethical theory.⁴²⁸ An adequate budget, increased numbers

of meetings, and a chairperson with specific training in bioethics positively influence the success of hospital ethics committees.⁴²⁹ In rural healthcare settings, budgets are tightly restricted and persons with graduate degrees in clinical or theological ethics are rarely available. In addition, the time constraints that characterize rural healthcare allow few opportunities to develop the specialized expertise associated with ethics consultation.

Yet the issues noted by the rural healthcare providers in the opening paragraph, their questions about quality care and appropriate conduct, deserve attention. Financial support provided by the Rockefeller/ Culpeper Foundation and the Greenwall Foundation has made possible a closer look at the ethics of rural care. The research illuminates a number of problems that complicate the transplantation of the urban approach to bioethics services into rural environments.

The Research

Four central research questions provided the structure for the studies.

1. Context: What kinds of bioethics-related issues emerge in rural communities and rural healthcare settings?
2. Practices of Healthcare Providers: How do healthcare providers resolve the ethics-related problems that develop in rural settings?
3. Perception of Need: Do healthcare providers believe additional ethics-related resources are needed and if so, what resources would they use?
4. Local Values: Are there cultural or contextual issues that shape the ethics of health care in rural communities?

When those four questions were initially proposed, the difficulty of answering them was only dimly recognized. Ethics committees were widely presumed to be helpful and appropriate; their utility in rural areas had never been questioned. A project that identified the existing committees, encouraged the development of new ones, and perhaps even linked rural ethics committees together seemed like a good idea. The process of documenting the existence of services, however, led to ever more questions and an ever more complicated research agenda. Thus over a four year period, nine individual research studies were designed and completed.

The discussion of this research agenda and the identification of key findings present some complications. The kind of research that was conducted is social science research. As such, it must meet the standards of that discipline. To some extent, the standards require a language and an approach not unlike that of early bioethicists who called for the “right grammar, language and processes” in order to cogently discuss the issues.

The need for a rigorous and respectable research design became apparent even as the initial grants to support this effort were being prepared. Some reviewers scoffed at the need for “rural considerations” in terms of either the issues that develop in rural areas or the models most appropriate for services. Some suggested that rural communities could simply adopt a “communitarian” ethic as the foundation for decision making and could use the expertise within the growing field of ethics in order to structure their rural ethics committees. Other reviewers suggested that the proposed research was “too particular” - that findings from an “outlying state” like Montana would have little

relevance in the greater world of medicine and science.

To mitigate their concerns, the review panels continually required evidence of “good science.” They questioned the samples, the instrumentation, and the statistical procedures used for data analysis. Without such proof of “reliability,” they believed that findings would be suspect. Thus considerable attention was given to the design of each study, and the discussion of this research consequently will be wrapped in the language appropriate to “qualitative and quantitative [social science] methodology.” The attempts to respond to the concerns of the academicians appear to have been successful. The Culpeper and Greenwall Foundations are highly regarded in the world of bioethicists. And they have funded this research. Additionally, articles discussing the findings from this research have been published in six professional journals - all of which are widely respected in the field.

The attempt to respond to this call for rigor however, also poses a danger. The transition to a jargon and a scientific ritual as thick as those used by modern bioethicists could make this account of some fascinating discoveries an ironic disruption of an otherwise lucid exercise in cultural history. To minimize that disruption, common English will be used whenever possible and the validation of the various instruments of inquiry and of their results will be told as a story of ever widening, ever deepening knowledge of an environment largely overlooked by bioethicists.

With those caveats in mind, the walk through the research studies will begin. The research discussed in this chapter used “qualitative and quantitative methodologies,” including surveys, key informant interviews, and focus groups in order to obtain “key

findings.” Concerns for reliability and validity were addressed by triangulation,⁴³⁰ a process that increases scope, depth, and consistency.⁴³¹ Thus, the research process involved asking ever more questions of ever more people in order to systematically examine a strange new environment. A list of the instruments of inquiry follows. The dates attached to each study will indicate the time that was given to this exploration of rural America.

1. A survey of hospital administrators in six western states, Montana, South Dakota, North Dakota, Alaska, eastern Washington, and northern Minnesota (1997)
2. A survey of nurses who work in those same six states (1997-98)
3. A survey of nurses who are members of a national constituency, the Rural Nurse Organization (1997-98)
4. Key informant interviews with directors of nursing in 21 rural hospitals in the six state area (1998-99)
5. A survey of rural physicians in Montana, Wyoming, and North Dakota (1999-2000)
6. 33 key informant interviews with healthcare providers, patients, family members, and community leaders in Montana, New Mexico, West Virginia, Tennessee, Vermont, and New Hampshire (1999-2000)
7. 18 focus groups in those same areas and with the same constituencies as listed in the above study (2000)
8. A survey of 1,700 rural healthcare providers in Montana, New Mexico, West Virginia, and Tennessee (2000-01)
9. A survey of 1,600 physicians in Vermont, New Hampshire, and Maine (2000-01).

The quantitative studies were designed to investigate the broad scope of concerns related to rural bioethics. Such studies would document the ethics-related issues that develop, the availability of ethics-related services, the perceived need for services, the use of problem-solving strategies, and similar issues. The qualitative studies were designed to provide a deeper and richer understanding of those issues, specifically information about what ethics-related services are important, how they should be constructed, and the

impact that the availability of services has on patients, families, and healthcare providers.

Since the nine studies were conducted in “rural” settings, the relevance of the research findings to urban communities is difficult to determine. Admittedly, the definition of the term “rural” is a matter of some debate. The literature in sociology over urban and rural distinctions is extensive and often contentious. There are at least four generally accepted definitions of the term. The U.S. Census Bureau typically uses that term to describe communities with populations of 2,500 or fewer. Proximity to metropolitan areas and population densities of less than six people per square miles (frontier) are often used as additional descriptors. The term “rural” has also been used, in more general terms, to describe communities of reduced social density, communities where residents know one another well.

The studies discussed in this chapter generally involved persons who live in communities with reduced social densities. In terms of healthcare, the communities share some common features. The local hospital is generally small; long term care and acute care are often provided in the same facility and with the same staff. Primary care is the major emphasis and patients frequently have to travel considerable distances to obtain speciality care. The economic health of the community is closely tied to the economic viability of the hospital. The rates of poverty and disability are higher than those experienced in urban communities. Finally, there are few professional training programs in close proximity to these communities.

While those characterizations make it difficult to assess the degree to which findings are widely applicable in areas of greater social density, the ongoing requests for

information that have been received by the author suggest that many of the findings may be relevant. More studies are certainly needed, but future research may indicate that persons who live in urban neighborhoods, or who are members of special ethnic or cultural groups, may experience some of the same issues and challenges referenced by rural residents.

Each study is discussed individually. The studies are then discussed as a whole and specific findings are linked to each of the four research questions. A series of graphs has also been developed so as to provide a visual representation of key findings. These graphs are included, as a group, in Appendix A so that the reader, if uninterested in the logistics of research design, might obtain a more succinct overview of key findings.

Study of Hospital Administrators

The first study involved hospital administrators. At the time this research was initiated, the bioethics literature, governmental agencies, and national hospital organizations were reiterating the need to establish competent, well trained ethics committees in all healthcare settings. However, there were no published data specific to the prevalence of ethics committees or any other formal ethics-related structures in rural settings. Little was known about the ethical issues that developed in rural areas, the processes used for decision making or the perceived need for “ethics” services.

Given the lack of published data, the survey of hospital administrators⁴³² was designed to accomplish four tasks: (1) document the status of bioethics committees or other bioethics mechanisms in a multi-state rural demonstration area; (2) investigate the

functions of existing bioethics committees; (3) investigate the perceived need for bioethics committees or other ethics-related services in hospitals that do not currently have such entities, and (4) identify bioethics resources that respond to identified needs. Such baseline information was required in order to build a foundation for developing bioethics services in rural areas. Many of the findings that emerged from this first research effort were unexpected - at least to urban bioethicists. Thus the findings from this first study led to the development of new instruments and new studies and so supported the cumulative process of discovery.

The six state area that was selected for this study is served by 216 acute care hospitals. Freestanding psychiatric and rehabilitation hospitals were excluded from the sample because they are not representative of typical rural structures. A six state area was used in order to respond to concerns about the extent to which findings may be more rural-specific as opposed to state specific. Administrators of the 216 acute care hospitals received a letter describing the research, a copy of the survey, and a request to provide information detailing the hospital's approach to bioethics services. In order to meet concerns about valid instrumentation, the survey was based upon a model developed and used by Glenn McGee, Ph.D., University of Pennsylvania Center for Bioethics.

All respondents were asked to answer questions regarding the hospital size, occupancy rates, number of employees, presence of an ethics committee, needs for bioethics services, roles and membership (or potential roles and membership) of ethics committees, benefits and obstacles of such committees, technical assistance, and training needs. For hospitals without bioethics committees, a two page, 16 item survey was

provided. A series of 28 items expanded the survey completed by hospitals with bioethics committees. Those items included questions about the structure, procedures, function, activities, and effectiveness of the committees, as well as their training and consultation practices. Since every survey included the name of the hospital and a primary contact, hospital personnel could be contacted in order to obtain additional information or clarification. Since some of the information that emerged was quite unexpected, approximately 12 percent of the respondents were re-contacted to verify information provided in the survey.

Sample Description, Analysis, and Interpretation

One hundred and seventeen surveys (54.16% of the sample) were analyzed. Sixty seven percent (67.2%) of the respondents were hospital administrators. Thirteen percent (13.4%) of the respondents were directors of nursing and 9.2 percent of the respondents were members of ethics committees. The data suggest many issues are of concern to all hospitals in this area rather than to specific states. Indeed, the comparison of Montana, North Dakota, and South Dakota showed no significant differences in the distributions relative to the presence or absence of bioethics committees, the presence or absence of JCAHO accreditation, or the identification of roles and issues.

Data indicate 58.8 percent of the hospitals do not have bioethics committees or any formal mechanism to resolve ethics-related dilemmas. Logistic regression analysis suggests a predictive relationship between the size of the hospital, the presence of an ethics committee, and accreditation by the Joint Commission for the Accreditation of

Healthcare Organizations (JCAHO). Small hospitals were less likely to have bioethics committees ($R=0.304$, $p<.01$) and less likely to hold JCAHO accreditation ($R=0.365$, $p<.01$). Fifty percent (50.4%) of all surveyed hospitals had neither bioethics committees nor JCAHO accreditation. Among hospitals with fewer than 25 beds 90.6 percent lacked accreditation and 85.2 percent lacked ethics committees. Overall, 63.9 percent of hospitals participating in the survey do not have JCAHO accreditation.

The lack of accreditation was an important finding because JCAHO accreditation is considered a standard quality benchmark for hospitals. Among hospitals with fewer than 25 beds, 90.6 percent lack accreditation and 85.2 percent lack ethics committees. Nearly 45 percent of the hospitals in this area report fewer than 25 beds and nearly 70 percent report fewer than 50 beds. Even hospitals that reported JCAHO accreditation reported very limited bioethics-related activities. That finding was of interest because JCAHO standards require a formal mechanism for ethics services. When these findings were published, they received a considerable amount of attention - largely because the bioethics literature has presumed the universality of both accreditation and ethics committees.

Although survey respondents from hospital without ethics committees thought that ethics committees might increase dialogue among healthcare providers and patients, the data from hospitals with ethics committees suggest that expectation was not realized. In fact, the “existence” of ethics committees in 41 percent of the hospitals may be a bit mis-leading. Ongoing communication between the existing ethics committees and other hospital staff was rarely evidenced. Formal activities or functions were rarely reported;

some committees “existed,” but had not met for several years. When education activities were conducted, they rarely extended beyond the parameters of the committee and rarely involved activities other than reading journal articles. The survey contained a list of five standard hospital policies. The policies involved issues like determination of death, withdrawing of medical care and development of protocols for organ donation. Fewer than 30% of the existing committees had any involvement in any activities related to policy development, review, or evaluation. Only 10 percent of the ethics committees met on a regular basis. The terms “regular” was defined by some as quarterly or semi-annually. None of the respondents indicated that case consultation services were available.

Although bioethics committees are widely viewed - at least by those in the field of ethics - as “helpful,” the respondents to the hospital survey expressed uniformity in their skepticism about the usefulness of ethics committees. They suggested that ethics committees are time-consuming, expensive and difficult to sustain. In most rural communities, medical staffs are small, the differences in education levels among staff are considerable, on-call schedules are demanding, and requests to serve on more than one hospital committee are numerous. These factors make it difficult to schedule committee meetings and difficult to create an education agenda that meets expectations such as those promulgated by the ASBH. Further, the rural respondents generally believed that a committee with a membership of physicians, administrators, nurses, social workers, clergy, and community members could complicate problemsolving. Finally, there was also a belief that the unequal relationships within such a committee (physician versus

nurse, physician versus family) might intimidate other health care providers and family members. The vast majority of hospital administrators were also skeptical of case consultation and inter-institutional ethics committees. Inter-institutional ethics committees presented a specter of one airing one's problems in public. Case consultation was perceived as a cultural taboo. In fact, case consultation was not cited by any of the respondents as a benefit - or a potential benefit - on even one survey.

The respondents suggest that ethical problems in rural settings typically involve: patient autonomy, patient competency, patient-clinician relations, and end of life care. Although 30 percent of the population in some areas lacks health insurance, issues related to cost allocation or rationing are virtually never addressed by existing committees. Patients or families are rarely informed of any bioethics services that might be available. Patient advocacy services are particularly limited. In fact, patient advocacy services are provided even less frequently than research activities.

In their comments, respondents indicated that the issues that emerge in rural healthcare setting are complicated by familiarity - a factor that seems to pervade all relationships in rural communities. In communities where there are no strangers, the life of one friend may be balanced against the healthcare of other friends.⁴³³ Respondents expressed a strong interest in community education services as well as an awareness of the need for such services. More than 75 percent of the respondents indicated a desire to receive ethics-related resources and to participate in an ethics research project.

In many respects, the response to this survey exceeded original expectations. Not only did the rural administrators respond to a fairly detailed instrument, they participated

in subsequent phone calls. In addition, 30 administrators also agreed that their hospitals could be used as research sites in order to help field test bioethics resources. Responding to the survey appeared to offer the rural administrators an opportunity to explain why the approaches so heavily endorsed in the literature - like the use of an ethics committee - do not meet rural needs. The enrollment in the research project appeared to allow them to see if appropriate models for rural services could be identified.⁴³⁴

Studies of Nurses

When the information from the hospital survey was analyzed, a new series of questions emerged. The hospital administrators said they encountered problems with autonomy and competency. Those terms were listed on the survey because they are heavily used by bioethicists in order to categorize problems. The data from the hospital administrators, however, did not indicate specifically what kinds of autonomy or competency-related problems develop in rural settings or why rural healthcare providers experience those issues as problematic. Further, the administrators wanted resources, but did not want ethics committees or case consultation - the kinds of resources that are most prevalent.

In order to obtain more information about issues and needs, three studies were designed specifically for rural nurses. The studies included surveys of two groups, nurses who work in rural hospitals in a 6-state area and nurses who are members of the national group, the Rural Nurse Organization (RNO). The research design was expanded to include the involvement of the RNO because that cohort would allow for a comparison

between a regional and national rural sample. The third study involved key informant interviews with the directors of nurses in 21 rural hospitals. Thus it was the first of the qualitative endeavors and provided a framework to help interpret the survey findings. As a group, these studies⁴³⁵ were designed to identify: (1) the ethical issues encountered by rural nurses; (2) the frequency with which such issues occur; (3) the extent to which nurses respond to the issues; and (4) the resources or training topics rural nurses consider useful.

Sample Description, Analysis, and Interpretation

A 14 page survey was developed, pilot tested, and mailed to a sample of nurses from randomly selected rural hospitals with fewer than 75 beds in the six-state area. These criteria were used because data from the hospital survey indicated that 70 percent of the hospitals in this area have fewer than 50 beds. In total, 21 directors of nursing in rural hospitals were asked to distribute the survey instrument among nurses employed at the hospital. In addition, surveys were provided to the national RNO office. The national office then mailed the surveys to nurses who worked in rural areas other than the six state area already included in the research design. This methodology allowed for comparison of responses between the two groups.

Two hundred and four surveys were analyzed by using standard statistical methods and procedures for evaluation. A reliable response rate is difficult to calculate because the surveys were distributed by a nursing administrator in each rural hospital and the national RNO office. Each survey had a stamped, pre-addressed envelope so surveys

could be returned confidentially. At the time the survey was conducted, the State Board of Nursing was not willing to provide the names of nurses. By the time the survey of healthcare providers in Montana, New Mexico, West Virginia, and Tennessee was conducted, the state boards, however, were willing to release state lists.

The survey served as a descriptive and predictive assessment tool. The instrument was designed to map demographics, note professional involvement, assess need for ethics resources, as well as identify the ethical issues faced by rural nurses. To this end, it requested descriptive information about the nurses' education, years of experience, areas of responsibility, access to resources and technical assistance, and consultation practices when encountering problems. Finally, the survey contained a list of 36 ethical problems; the problems were related to issues like autonomy, competency, patient-clinician relationships and end of life care, problems that surfaced in the survey of hospital administrators. The nurses were asked to indicate the frequency of encountering such problems and the likelihood of acting upon them. To aid in the interpretation of data, follow-up interviews were conducted with 21 directors of nursing at participating rural hospitals.

Data showed no significant differences in the distributions relative to any measures between the two samples used for the survey, so the results that are reported reflect the combined samples. The two samples included 77 nurses from the Rural Nurse Organization and 127 nurses from the 21 rural hospitals in the six state region. Ninety percent of the nurses who participated in this survey were female. Sixty seven percent (67.2%) of the nurses were aged 40 years or older; 53.9 percent had more than 15 years of

experience. Thirty percent (30.4%) of the nurses had received a baccalaureate degree; 7.4 percent reported graduate level training in nursing. More than 55 percent of the respondents described themselves as a “staff nurse.”

Most of the nurses work slightly less than full time; the average was 35.5 hours/week. However, a sizable percentage of the nurses work more than 40 hours per week. The time commitment appears indicative of work patterns in rural areas. Patient census is variable and part-time work schedules are common. However, if emergencies develop or if patient census is high, nurses may need to work overtime. A substantial number of nurses (51.5%) typically work in three or more departments on a *daily* basis. The departments most frequently cited included: medical/surgical, emergency room, long term care, and birthing. In many hospitals, nurses regularly rotate between patients who are receiving long term and acute care. As one nurse explained: “There’s only a janitor’s closet separating the two wings.”

Nurses responded to the list of 36 ethical problems by indicating the frequency with which they encountered the problem within the past year, and whether they acted on the problem. Frequency was indicated via a five-point scale, ranging from never to very frequently. Some problems occurred frequently but were not typically acted on; other problems occurred infrequently but when encountered, a majority of nurses indicated that they acted on them. For instance, nurses frequently encounter patients who request more aggressive treatment options than the nurse would want, but 51 percent of the nurses indicate they are unlikely to act when encountering that issue. On the other hand although the problem is infrequently encountered, 62 percent of nurses are likely to act

when encountering abusive behavior on the part of patients or family. The problem that occurred most frequently involved a lack of clear orders for patients. Seventy nine percent (79%) of the nurses indicate they take action if the patient has confusing orders, but decreasing percentages of the nurses were willing to act on any of the other thirty five issues. The data suggest that organizational constraints, the nurses' role in the power structure, the nurse-patient relationship, cultural concerns, and other factors may inhibit action.

More than 72 percent of the nurses believe ethical issues are approached differently in rural areas than they are in urban areas. The survey provided space to explain any perceived differences. The primary response centered around issues of familiarity, an issue that has both personal and professional consequences. As one nurse explained: "Rural hospitals know clients. Familiarity and confidentiality problems arise often." Another wrote: "we can't send an old woman home when she has an untreated bladder infection, as they can and do in a larger hospital. How can we face her daughter, her son, her grandchildren." Added another: "You know the patient from childhood." Familiarity also has professional consequences. Nurses cited, as one of the four most frequent problems, the need to work with incompetent colleagues. They were, however, hesitant to act on this issue. They noted that the incompetent colleague may be a friend, relative, someone with whom a relationship must be maintained.

The survey instrument listed 18 potential ethics resources and asked the nurses to indicate how often they consulted these resources. The listing consisted of resources such as consulting another nurse, consulting a physician, referring to the ANA code for nurses,

consulting clergy, or using resources like a patient's bill of rights. A slight majority of the nurses, 52.8 percent, indicated they often consult with each other. Fewer nurses, 40.5 percent often consult with their nursing leadership, and only 31.5% often consult with physicians. Interestingly, only seven percent of the nurses said they often or even occasionally consult with clergy. Two of three nurses (67%) never or rarely refer to the ANA code for nurses. Almost half of the nurses (48%) indicate they often or frequently rely on their own personal values. As one nurse explained: "Personal judgement is used more due to the lack of resources." These last figures are particularly interesting when viewed in light of the position statement by the American Nurses Association that says that the ANA code for Nurses is "nonnegotiable and that each nurse has an obligation to uphold and adhere to the code of ethics."⁴³⁶

Fifty percent (50.5%) of the nurses reported the presence of journals or magazines in their hospital. This finding was somewhat encouraging, though the nurses who responded to the survey did not specify if the journals or books were ethics-related. When the directors of nursing were contacted and asked to identify the journals that were available in their hospital, they typically cited one of two publications, *RN* or *Nurse*. Neither periodical is specifically designed to address ethics-related issues. Further, the directors of nursing who were interviewed report they have no access to bioethics journals. Audiovisual materials about bioethics were typically unavailable, and only a minority of the respondents thought it would be helpful to receive ethics information through video conferencing or tele-medicine. Less than half of the nurses who participated in the survey had access to hospital-based continuing education programs,

informal ethics-related discussions, or ethics consultation services. More enhanced services such as staff development programs and ethics grand rounds were particularly limited. Most survey respondents reported little or no exposure to formal education about bioethics during their academic training.

Nurses were asked to indicate their interest in receiving additional training in seven topic areas: professional responsibility, patient rights, privacy and confidentiality, truth telling, reproductive ethics, distributive justice, and research ethics. Most nurses, 88.2%, asked for information about professional responsibilities. This topic area included: emergency treatment duties, provision of continuity of care, rights and duties of professionals and patients, and understanding one's limitations and biases. Most respondents (80.4%) also wanted information on patient rights, including autonomy and informed consent, medical and legal dimensions of decisional capacity, process to follow if treatment is refused, and the appropriate use of ethics committees or consultants. Nearly 70 percent wanted training related to privacy and confidentiality, and 68.1 percent asked for information regarding truth-telling, which encompassed situations when it might be morally justified to withhold or delay information. During one of the interviews, a director of nursing in a rural hospital provided insight into this issue when she described the distress she experienced when a physician's order included a mandate to withhold information from a patient suffering from terminal cancer. She honored the physician's order and did not respond honestly to the patient's queries. As she described the situation, the ethically appropriate course of action was not as clear.

Among the seven topics listed in the survey, the area of least interest, less

desirable even than research ethics, involved reproductive ethics. Topics relative to reproductive ethics included issues such as the legal and ethical issues of reproductive decision-making. The nurses did not provide reasons for the lack of interest in this topic. However, one director of nursing described the discomfort that occurred in a small conservative community when a new physician began ordering a routine amniocentesis for pregnant women who were more than 35 years of age. Community members wondered if this meant that “certain children are no longer wanted.” This and other stories suggest that the issue of reproductive ethics can be highly polarized in rural communities.

During structured key informant interviews with the 21 directors of nursing, respondents indicated the lack of resources inhibits the resolution of problems. Typifying this, one nurse said: “we have no protocols for ethical issues.” Added another: “you try to act on issues with varying degrees of success.” In expressing a need for information one nurse said: “We’re starting from scratch, anything you have [to offer], we are interested.” The directors of nursing suggested that nurses have a hard time knowing how to resolve ethical issues.

During the interviews, most of the directors of nursing questioned both their own and their nurses’ abilities to recognize ethical issues. The directors of nursing experienced difficulty articulating either the ethical issues they encounter or those encountered by patients or families. This finding was also evidenced when directors of nursing were asked to suggest ethics resources that might prove helpful. “I’ve had so little exposure to the topic” said one nurse manager, “that I’m hesitant to make any

suggestions.” Another nurse added, “I’ve attempted to take action on ethics issues, but nurses don’t understand their rights or what they should do.”

However, close to 70 percent of nurses responding to the survey expressed an interest in participating in a research project that would provide bioethics resources. They would be willing to allocate, on average, nearly nine hours/month for this purpose. Nearly all of the directors of nursing suggested that a formal ethics committee would not work in their setting; however, they thought such a committee would theoretically provide “backing,” a place where issues could be handled in a more formalized manner. This survey is identified as NurseS when key findings are discussed as part of the comprehensive findings from all research activities.

Study of Rural Physicians

The survey of nurses expanded the knowledge base with respect to bioethics in rural areas. The results provided a framework for thinking about issues like autonomy, competency, and patient clinician relationships as well as issues like the willingness to take action on most ethics-related issues. In a sense, however, the findings also opened a series of new questions. We did not know if physicians encountered similar issues and we did not know how rural physicians solved their ethics-related problems. Thus the survey of rural physicians⁴³⁷ was designed to identify: (1) the ethical issues encountered by rural physicians; (2) the frequency with which such issues occur; (3) access to ethics-related resources; and (4) processes used to resolve issues and related concerns.

Sample Description, Analysis, and Interpretation

A two-page survey was mailed to a sample of 600 randomly selected physicians in Montana, Wyoming, and North Dakota. The names were obtained from alphabetical membership lists generated by state medical associations. In Montana and North Dakota, the sample excluded cities with populations larger than 35,000 according to the US Census Bureau estimates of July 1, 1998. The excluded cities were Billings, Great Falls, and Missoula in Montana and Grand Forks and Bismarck in North Dakota. The elimination of those cities also excluded physicians who practice in tertiary medical centers. This resulted in a sample consisting of physicians, most of whom reside in towns of fewer than 10,000 persons. In Wyoming the overall number of physicians is very low and in order to achieve an adequate sample, there were no exclusions, so the cutoff for population size was 55,000 or smaller. Except for state residency, responses were not tracked so as to honor the privacy and confidentiality of sensitive information. Since anonymity was promised, physicians who did not respond to the initial mailing could not be re-contacted.

The sample corresponded to approximately one third of the physicians who met the criteria. This number was determined in order to ensure an adequate number of respondents given the projected rate of return. Physicians are historically reluctant to participate in survey activities. The survey instrument was an abbreviated version of a survey previously used for surveying nurses and hospital administrators. The survey requested data on age, gender, specialty, years in the profession, and in the community. It also included a list of 16 ethics-related problems used in the surveys of hospital

administrators and nurses. Physicians were asked to indicate the frequency with which they encountered each problem via a four-point Likert-like scale. For reporting purposes, the four categories were dichotomized into: *frequently* (categories 3 = sometimes, 4 = often) and *less frequently* (categories 1 = never and 2 = rarely). The survey asked physicians to indicate how they resolved ethics-related problems, whether they had ever referred problems to an ethics committee, received ethics education, or perceived urban/rural differences in the kinds of ethical issues encountered.

Descriptive statistics for all variables were derived for the entire sample. Pearson correlations or Chi square, when appropriate, were calculated between key variables and were evaluated for significance. Since the differences of distribution of responses among the states were non-significant on most variables, the sample was analyzed as a whole. A total of 118 physicians responded to the survey, giving an adjusted response rate of 19.67 percent. Thirty seven percent of the physicians were from North Dakota, 32 percent from Montana and 31 percent from Wyoming.

Most of the responding physicians were males between the ages of 36-55. The majority had practiced for more than 15 years, and almost half had practiced medicine in their *present community* for more than 15 years. The average physician reported working approximately 55 hours/week. Of the respondents, 33.1 percent were family practitioners, 17.8 percent were internists, and smaller percentages were distributed among other disciplines. Exposure to formal ethics-related course-work during their medical education was related to age. Overall, the majority of physicians had completed ethics course-work, but the percentage varied from 94.1 percent among the newer

physicians (1-5 years in practice) to only 37.7 percent of the older cohort (more than 15 years in practice).

Only 28.8 percent of physicians reported the availability of any ethics-related resources. Most of the physicians (74.6%) had never referred a case to an ethics committee. Only 31 physicians (26.3%) had ever served on an ethics committee at any time during their medical careers or medical training. The most common problem encountered involved communication with patients. While this -- in itself -- is not generally perceived as an “ethical” issue, difficulties with communication can certainly lead to ethical concerns such as the ability to obtain informed consent or the patients’ failure to understand diagnosis and treatment. Certain issues, including confidentiality, cost containment, patients’ failure to understand diagnosis and treatment, and patients who fail to follow recommendations for treatment were more common for the newer physicians, 1-5 years in practice, than those with more experience, in practice more than 15 years.

Concerns about confidentiality were reported more frequently by the female (89.5%) than male (58.3%) physicians. Similarly, concerns about confidentiality were cited more commonly by family practitioners (71.1%) than by other groups (61.1%). In spite of the problems noted, 111 (94.1%) of the physicians believed they can keep their patients’ interests an utmost priority.

In order to resolve ethics-related issues, survey respondents relied on personal values and experience; they utilized informal resources - and in particular, personal resources - much more than formal ones. There was a heavy reliance on personal values.

Representative comments included phrases such as: faith in God, the Ten Commandments, my own judgement, quiet personal reflection, discussion with a spouse, pray, what my conscience tells me to do, the right thing, the best I can. Informal resources available to the respondents included peers and colleagues (22.0%) or other hospital personnel (15.3%). Other hospital personnel included nurses, social service department, legal services, or the hospital CEO. Only 8.6 percent of the respondents cited use of clergy.

Overall, 60.9 percent of the physicians reported having an interest in receiving ethics-related resources, while 87.5 percent of the those who had practiced 1-5 years indicated interest in receiving ethics resources. The comments of the respondents suggest their academic training in ethics may not have prepared them for the ethical issues that emerged in rural settings. This survey is identified as “PhysicianS” when key findings are discussed as part of the comprehensive findings from all research activities.

Qualitative Studies

After completing the surveys of hospital administrators, nurses, and physicians, the need for more qualitative research became apparent. When the key informant interviews were conducted among the 21 directors of nursing in the rural hospitals, a great deal was learned about the culture of rural care. The nurses provided a context for evaluating the research findings and helped identify and explain some of the issues that emerged. Additional qualitative studies could arguably provide a context for understanding a number of issues that had emerged in all of the studies. The healthcare

providers, for example, encountered problems with patient competency, autonomy, and patient clinician relationships. The extent to which non-healthcare providers would agree with those findings was unknown. Respondents to the surveys uniformly indicated a desire for resources but those resources were not well defined.

Thus two qualitative studies were designed to provide deeper and more descriptive information about ethics-related issues that develop in rural areas. The studies obtained information from a diverse group that included healthcare providers, patients, family members, and community leaders who live in rural communities. The use of key informant interviews and focus groups was especially appropriate since the research focused on the importance of context, setting, and the subjects' frame of references.

In keeping with sound qualitative methods, the research questions were formulated not as hypothesis, but rather as broad-ranging inquiries that help identify and describe the cultural and organizational processes that facilitate or hinder the recognition and resolution of ethics-related services in rural healthcare settings. The instruments for both the key informant interviews and focus groups were developed as a collaborative research activity among members of the Greenwall Rural Bioethics consortium. The instruments were field tested in Tennessee before their use in the research studies.

Sample Description, Analysis, and Interpretation

Key informants are selected for participation in a study because they have certain characteristics that are important to the research effort: informants are willing to talk,

have greater experience in the setting, and are especially insightful relative to what goes on in those settings.⁴³⁸ The healthcare providers, patients, family members, and community leaders who were selected for this study met those criteria. With the aid of collaborators in a research consortium supported by the Greenwall Foundation, 54 interviews were conducted in small, rural communities in Montana, New Mexico, West Virginia, Tennessee, Vermont, and New Hampshire.

All interviews were recorded and transcribed. The data were then coded and analyzed using standard qualitative methodologies. The qualitative data provided the contextual basis for interpreting the findings of the surveys research. In general, respondents described their expectations of healthcare as core to their values, their beliefs about what is right or worthwhile. These beliefs about “rightness” involved decisions relative to issues such as: end of life care, management of chronic illnesses, patient/clinician relationships, or use of technology.

When describing their values, three dominant themes were referenced as factors that consistently shape healthcare decision making. Those themes involve expectations relevant to: 1) patient-clinician relationships; (2) access to competent care; and (3) rural culture and values. Access to competent care included both the competency of available healthcare providers as well as geographic or economic access to healthcare services.

Healthcare providers, community leaders, and patients uniformly reported that they were unprepared for the ethics-related issues that emerge and the decisions that are required. A key finding related to the recognition and adherence to the “community rules” that outline appropriate conduct within the community. There was no item on the

key informant instrument that asked about rules, but in every interview, the respondents referenced the topic of “rules” as a way to explain perceptions of acceptable behavior in their community. The data clearly indicate that failure to honor community rules risked one’s acceptance as a member of the community.

Respondents said they had access to few if any formal processes that support discussion or resolution of ethics-related concerns. They generally affirmed the need for resources, though rarely could they specify what kind of resources might be helpful. They wanted resources that would be accessible, not too “academic,” and interactive. The participants generally agreed that the lack of ethics-related resources discouraged important conversations and thus had an adverse effect on patient care. Healthcare providers acknowledged that they are hesitant to initiate discussions that are organizationally or culturally sensitive. Further, they questioned their ability to discuss issues that have ethical implications. All participants noted that culture and norms have an important role in how medical care is perceived and delivered, whether treatment recommendations are accepted, and whether the quality of care is appropriate. The cultural expectations that emerged suggest that urban models for bioethics services are not easily transplanted onto rural environments. All participants expressed strong interest in useful resources and materials and believed that hospitals should expand their public education services to increase opportunities for dialogue between the hospital and the community it serves.

Sample Description, Analysis, and Interpretation

Eighteen focus groups were conducted in the same geographical area and with the same constituencies as noted in the previous study. The themes that emerged in the key informant interviews were used to design the focus group instrument. The groups ranged in size from six to fifteen participants.

The group discussions were taped, transcribed, and analyzed using Atlas.ti software. The data from the focus groups strengthened the findings from both surveys and key informant interviews, and helped to create a theoretical foundation for bioethics services in rural communities. When describing their values, the focus group participants consistently referenced the three dominant themes identified by the key informants. They described in detail their expectations for patient/clinician relationships, competent care, and cultural sensitivity. Issues related to culture were referenced three times more often than any other topic.

The data from this effort provided an interesting frame of reference for a number of findings that emerged from the other studies. For instance, in the physician survey, the newest physicians (1-5 years in practice) more frequently experienced problems with confidentiality, cost containment, patients' failure to understand diagnosis and treatment, and patients who fail to follow recommendations for treatment. In the focus groups, those specific issues were discussed in detail. Participants were aware of the difficulties experienced by the new physicians. They attributed those difficulties to unfamiliarity with rural environments and failure to understand the extent to which cultural expectations shape responses to treatment.

To be sure, some of the issues that emerge in rural areas may not significantly differ from those that emerge in urban areas. A lack of money to pay for prescription drugs would be such an issue. There were issues, however, that appear to be very distinct. Those issues typically involved concerns associated with: geographic and economic factors - such as lack of insurance, vulnerability of family homesteads, and the need to travel great distances - that complicate access to healthcare, expectations for relationships between providers and patients, and demonstrations of respect for culture and norms. To ignore or minimize those three primary concerns compromises patient care.

Focus group participants also affirmed the need for access to bioethics-related resources. They believed such resources should be relevant, interactive, not overly academic, and context sensitive. They wanted materials that would model a good decision-making process. At the same time, since they had very limited experience with such resources, they were hesitant to make any suggestions for delivery or content.

Study of Healthcare Providers in Montana, New Mexico, West Virginia, and Tennessee

The research studies discussed thus far provided important information about the ethics of care in rural communities. The data from the focus groups and interviews underscored the importance of relationships and culture. It provided a frame of reference for understanding findings like the nurses' hesitancy to take action when encountering ethical issues. The data suggested that organizational issues such as lines of

responsibility, reporting of medical errors, and responsibility for patient care decision making were also important factors when resolving ethical issues.

Thus a regional survey of physicians and nurses who work in rural communities was designed to validate the data obtained from the other seven research studies and to specifically: (1) identify the most frequent and most problematic ethical issues encountered by rural healthcare providers; (2) determine the extent to which healthcare providers respond to ethical issues; (3) assess the relevancy of prior training in ethics; (4) examine the links between cultural values and decision making; and (5) identify the resources or services that would be most helpful.

Sample Description, Analysis, and Interpretation

A total of 1,750 surveys were sent to randomly selected physicians and nurses who work in rural counties in Montana, New Mexico, West Virginia, and Tennessee. In order to obtain responses from rural healthcare providers, any *county* that had a city larger than 50,000 was excluded from the sample. The names of nurses were obtained from lists maintained by the respective state Boards of Nursing. The names of the physicians were obtained from lists maintained by the State Medical Boards. In order to obtain sufficient responses for analysis, physicians were over-sampled; as a result, no attempt was made to reflect the actual proportions of the populations of nurses and physicians. Thus, 875 surveys were sent to nurses and 875 sent to physicians.

A two page, 43 item survey was developed and mailed to the names of those randomly selected from the lists. The survey contained demographic information such as

age, occupation, gender, length of time in practice, and length of time in the community. The survey also contained a listing of 20 ethics-related issues that emerged in previous studies and seemed to be of importance to rural healthcare providers. Respondents were asked to indicate the frequency with which each issue occurred and whether the issue was problematic. Other items in the survey pertained to issues such as: reporting of medical errors, trust and confidence in the local hospital, availability of ethics services, completion of prior training, process for solving issues, and importance of culture.

The data were coded and entered into a data base and analyzed with standard statistical methods using SPSSX. Overall, the adjusted response rate was 25 percent of the sample. The gender distribution of the respondents was fairly even, 42.7 percent males and 56.2 percent females. The distribution among the professions was similar, 46.6 percent were nurses and 53.4 percent were physicians. Overall, this was a stable group in terms of long-term involvement in their communities and in their professions. Most of the respondents, 70.7 percent, reported that they lived in the community in which they worked. Interestingly, 41.5 percent had been members of their community for more than 15 years. Similarly, 46.8 percent had worked in their present occupation more than 15 years. As the percentages indicate, the age of the respondents was relatively evenly distributed across age groups: <35 - 13.7%; 36-45 - 30.8%; 46-55 - 30.8%; 56+ - 23.7%. More physicians, 81.2 percent as compared to nurses, 67.9 percent, lived and worked in same town.

The three most frequently encountered issues included: (1) patients cannot follow medical recommendations because of cost; (2) patients fail to understand treatment; (3)

patients fail to understand medical diagnosis. However, the three issues that were most frequently marked as *problematic* probably provide a good indication of the specific challenges that complicate rural care. Those issues include: (1) patients cannot follow medical recommendations because of cost; (2) transportation is a problem for patients who need health care, and (3) patients fail to understand treatment.

Interestingly enough, the least frequently encountered issues included: (1) denying care because of a patient's inability to pay; and (2) believing a patient's confidentiality is violated. Data suggest that rural healthcare providers do not actively deny care but patients are then unable to follow treatment recommendations because of cost. The findings related to confidentiality are also interesting. The bioethics literature has historically suggested that confidentiality-related issues are problematic in rural communities but the healthcare providers who responded to this survey do not seem to agree. The data from interviews and focus groups enrich our understanding of this issue and suggest that rural healthcare providers develop strategies for how to handle confidentiality. As a result, protection of confidentiality is not viewed as a particularly problematic issue.

Among both nurses and physicians, the issues *least* frequently marked as problematic involved dual relationships with the patients. Indeed, the vast majority of rural healthcare providers, nearly 75 percent, reported that they have personal and professional relationships with their patients and only 11 percent of the respondents indicated that dual relationships were "problematic." More than one third of the respondents reported that they encounter patients with whom they have "dual

relationships” on a weekly basis or more often. Dual relationships are generally discouraged by professional standards, but in rural communities they are unavoidable and further, they appear to be expected and valued. In this respect, the findings from this survey are congruent with the data that emerged in the other studies.

Some differences emerged when analyzing the nurses’ and physicians’ assessment of whether issues were problematic. Seventy seven percent (77) of nurses, for example, identified failure to understand diagnosis and treatment as a problem whereas only 60.6 percent of physicians described that issue as a problem. Some differences in responses were particularly relevant to the quality of care. Respondents were asked: if patients are informed about medical errors, whether reporting errors increases or decreases trust in the hospital, if lines of responsibility were clear, who has responsibility for patient care decisions, and whether the respondent would want family members treated at “their” hospital. There were significant differences between the responses of nurses and physicians to four of these five issues. Three of four physicians (76%) believe that patients are always informed of medical errors whereas only 2 of 4 nurses, 49.7 percent believe that such notification occurs. There were differences in perceptions regarding clear lines of responsibility - 80 percent of the physicians thought lines of responsibility were clear; the corresponding figure for nurses was 59 percent.

Confidence in the treatment offered by the local hospital was also related to professions. When asked to indicate whether the respondent would want family members treated at the hospital, 64 percent of the physicians said yes, whereas only 46% of the nurses said yes. Five percent of physicians said they would *never* want a family member

treated at the local hospital, 10 percent of the nurses gave that response.

Thirty percent of the physicians indicated that responsibility for patient care decisions belonged to the physician, patient, and family; 26 percent of nurses indicated that responsibility belonged to the physician, patient, family, and hospital staff. Aside from those two figures, there was no agreement about the assignment of responsibility for patient care decisions. Indeed, approximately 15 percent of physicians and nurses said responsibility for decisions belonged entirely to patients. The assignment of responsibility for decisions is an interesting problem, given that the most common problems, encountered by rural practitioners, involved the patients' inability to understand diagnosis and treatment.

Respondents evidenced more agreement relative to the consequences of reporting medical errors. Only 48 percent of all respondents believe that reporting errors increases trust in the institution; therefore, there might be a hesitancy to report errors to patients or others. The different perceptions regarding issues as important as the patient's lack of understanding of treatment, the clarity of orders for patients, responsibility for decision making, reporting of errors, and trust in the healthcare institution require more study. Disagreements in those areas could compromise the quality of care and might increase the likelihood of errors. Indeed, nurses who believed that lines of responsibility were unclear also believed that patients were not usually informed of medical mistakes, and that they would not like family members treated at their hospital.

The respondents were asked about training in ethics, using ethics services, and responding to ethics-related issues. In terms of training, sizable percentages of the

respondents had never received *any* formal course work or training in ethics. More than half of the respondents, 52 percent of both physicians and nurses who had worked more than 15 years in their respective fields, had never received any course work. Interestingly, 32 percent of respondents who had worked between 6-15 years reported they had received no course work. Similarly, 31 percent of those who worked for less than a year report they had no course work. When the sample of physicians as a whole was analyzed, more than half of the physicians had received no course work in ethics. Less than 40 percent of the respondents believed that their course work in ethics had prepared them to work in rural areas.

In terms of access to bioethics services, 61.9 percent reported that they have access to ethics committees (68% of the respondents from New Mexico, 62% of those from West Virginia and 58% of those from Montana). Physicians were slightly more likely to have access - 63.7 percent of physicians, as opposed to nurses - 59.5 percent. However, most healthcare providers have had no formal experiences with ethics committees. Overall, most of the respondents (83%) have never served on an ethics committee. Service was related to the profession: 92.6 percent of all nurses in the sample have *never* served on an ethics committee and 75.7 percent of all physicians in the sample have never served on an ethics committee at any time during their career. In addition, relatively few respondents, fewer than 30 percent had ever referred a case to an ethics committee *at any time* during their training or careers.

The lack of training and the lack of experiences with formal entities like ethics committees may have influenced the responses that were given to ethical problems.

Respondents were given two scenarios and asked to indicate what actions should be taken. The first scenario stated that “the patient, who you know is too ill to return home, has been scheduled for discharge from the hospital. The patient is concerned and asks you if it is safe to go home. What would you do?” A series of options was provided. Choices included: no action, discuss with family, discuss with physician, discuss with other members of health team, reassure the patient, request a consult, and consult with supervisor. Respondents were asked to indicate all actions they would pursue. Eighty three different combinations for action were offered. In short, there was no consistency in terms of how to approach or resolve problems. Sixty five percent of all respondents included, as an option, referral of the case to social services. Only 45 percent indicated they would share their concern with the patient and only 39.2 percent would bring the issue to a supervisor.

However, the response to those issues differed between nurses and physicians. Of those who would share their concerns with patients, 61.7 percent were physicians. Of those who would refer to a supervisor, 77.5 percent were nurses. Referral to social services was almost equal. Physicians were also more likely to indicate the category “other;” 62 percent chose “other” as one of their options. Generally, nurses were most likely to refer to social services, then a supervisor and then discuss with a colleague. Physicians are most likely to refer to social services agencies, share concerns with patient, and contact insurance.

The second scenario stated that “a patient you trust and have referred to a colleague tells you she was very unhappy with the care she received. What would you

do?” Respondents were asked to select their choices from a list of options that included: no action, express regrets, contact the healthcare provider, stop referring to the healthcare provider and other. Most of the respondents, both physicians and nurses, indicated that they would express regrets to the patient. Indeed, more than thirty percent would only express regrets to the patient. Most of the physicians, 63 percent also said they would also contact their colleague. But fewer than 23 percent of the physicians would stop making referrals to that colleague. Considering the difficulties associated with a lack of speciality care in rural areas, other options, such as use of a different specialist, might not be possible.

Culture-related issues have been receiving more attention in the bioethics literature and the data suggest that cultural issues are quite important in rural areas. The vast majority of the respondents, 90.9 percent indicated that more than half the time, cultural values shape practice decisions. There were no statistical differences in occupation (nurse or physician) or state - in other words, broad agreement prevailed about the importance of culture. These data also correspond with the qualitative data that emerged from the focus groups and interviews. When analyzed with the software Atlas-ti, issues related to culture were discussed three times more often than any other issues. Similar to data that emerged in the previously mentioned studies of the nurses and physicians, 61% of the respondents believed that there were rural/urban differences in terms of how ethical issues are resolved.

While there was considerable uniformity in responses among the three states, significant differences emerged when analyzing the issues that were identified by the

respondents as “problematic.” Four issues require more research. These issues may be related to greater levels of managed care penetration in West Virginia and New Mexico as compared to Montana, or they may reflect perceptions in the field that the length of time allocated for patient visits has decreased in recent years. For example, a larger percentage of respondents from West Virginia, 75 percent, said the lack of time to meet patient needs was problematic. That figure contrasts with 65.9 percent in New Mexico and 53.8 percent in Montana. Likewise, more healthcare providers in New Mexico, 68.4 percent, and West Virginia 61.1 percent indicated that arranging referrals for patients was problematic as compared to 41.6 percent of the respondents from Montana. In addition, more respondents from New Mexico, 51.4 percent, and West Virginia, 47.3 percent, found it “problematic” that referrals could only be made to providers in a given network. In Montana, which has a low HMO penetration, this was a problem for only 27.6 percent of the respondents. Respondents from West Virginia and New Mexico also reported that a lack of time for patient advocacy was problematic, 75 percent and 65.9 percent respectively. Significantly fewer, 53.8 percent, Montana healthcare providers rated this issue as problematic. This survey is identified as WestS Physicians or WestS Nurses when key findings are discussed as part of the comprehensive findings from all research activities.

Study of Rural Physicians in New Hampshire, Vermont, and Maine

The final study involved a survey of rural physicians who live on the East coast. This survey was conducted for two reasons. The data could indicate the extent to which

East coast healthcare providers concurred with their peers who participated in the Montana, New Mexico, West Virginia, and Tennessee study, as well as the Montana, Wyoming, and North Dakota survey of physicians. The survey was inserted in a monthly newsletter that is mailed to members of the Dartmouth Primary Care Cooperative Project. The data obtained from the Eastern survey were analyzed separately because the sample was not comparable to that used in the other states.

Sample Description, Analysis and Interpretation

As noted, the sample was limited in scope to members of the Dartmouth Primary Care Cooperative Project. The membership list of 1,600 persons consists primarily of physicians who live in Maine, New Hampshire, and Vermont.

This effort used the same instrument, collection, and data analysis procedures, described for the survey of healthcare providers in Montana, New Mexico, West Virginia, and Tennessee. The overall, adjusted response rate was 16.6 percent. The distribution among the states was as follows: Maine - 21.3 percent; New Hampshire - 36.4 percent; Vermont - 42.3 percent. The gender distribution was unequal; 70.8 percent of the respondents were male and 28.1 percent were female. The majority of respondents, 92.6 percent were physicians; 5.7 percent were nurse practitioners and 1.2 percent were physician assistants. The respondents to this survey were also slightly older than in the other survey, 67.1 percent, were more than 45 years old.

The issues that were most frequently encountered and most problematic were similar to those indicated in the other survey but the order (frequency and whether the

issue was problematic) was different. The three most *frequently encountered* issues were ranked as follows: (1) lack of time to meet patients' needs; (2) patients can't follow medical recommendations because of cost; and (3) patients fail to understand treatment. Perceptions related to a lack of time to meet patients' needs is an interesting problem, especially when one considers the overall changes in the healthcare system, the increased presence of managed care in eastern communities, and the expectations in rural communities for personalized care. The East coast physicians clearly experienced fewer problems that involved transportation-related considerations.

The *most problematic* issues were (1) patients can not follow medical recommendations because of cost; (2) lack of time to meet patients' needs; and (3) patients fail to understand treatment. Interestingly, the majority of respondents (56.6%) *did not* think that ethical issues faced by healthcare providers were different in rural areas.

Similar to findings that emerged in the other survey, the least problematic issue was having a personal or business relationship with a patient. Indeed, the vast majority of rural healthcare providers, nearly 81.9 percent, reported that they frequently have personal and professional relationships with their patients, and only 12.2 percent of the respondents indicated that dual relationships were "problematic." Similar to the findings in the other survey, 31.3 percent of the respondents reported that they encounter patients with whom they have dual relationships on a weekly basis or more often. Also similar to the other study, 72.2 percent of the respondents indicated that having to deny care because of a patient's inability to pay was "not a problem." The physicians appear to be willing to honor an appointment; the problem develops when the patient cannot afford to

follow recommendations for treatment. Fifty six percent (56.5%) of the respondents said protection of confidentiality was not a problem. Eighty nine percent of respondents indicated that half the time or more often, cultural values and community rules or values shape practice decisions.

In terms of training, 54.3 percent reported that they have never received any formal training in ethics. Only 27.8 percent indicated that the ethics-related training they received prepared them for rural practice. This group, when compared to the healthcare providers in Montana, New Mexico, and Appalachia, has greater access to ethics services. The vast majority, 85.8 percent, do have access to an ethics committee. The availability, however, has not translated into use. More than two out of three of the respondents, 68.0 percent, have never served on an Ethics Committee and most, 53.2 percent, have *never* referred a case to an ethics committee at any time during their career.

As in the other survey, the lack of training and the lack of experiences with formal entities like ethics committees may relate to the responses given to ethical problems. Respondents were given the same two scenarios indicated in the previous survey. The first scenario involved the patient who was too ill to be discharged. Similar to the other study, there was no consistency in responses. The most frequent category selected was to make a referral to social services. Indeed, 75.1 percent of the respondents chose that option. The second most frequent response (56.9%) was to share concerns with the patient. The most frequent combination was to share concern with the patient, to make a referral to social services and to contact insurance to seek extension of hospitalization. However, that 3-part combination was indicated by only 8.7 percent of the respondents.

Only 12.6 percent of the respondents would refer such a case to an ethics committee.

The second scenario involved the patient who was very unhappy with the care she received. Most (75.1%) of the physicians indicated that they would express regrets to the patient. Most (60.9%) also said they would contact their colleague. Only 1.2 percent said they would take no action. But fewer than 21 percent of the physicians would stop making referrals to that colleague. Considering the difficulties associated with a lack of speciality care in rural areas, other options, such as use of a different specialist, might not be possible.

When the respondents were asked to identify who has primary responsibility for patient care decisions, the most commonly marked combination was that responsibility belongs to the patient, family and physician. However, that combination was selected by only 30.2 percent of the respondents. Interestingly, in the other survey, 30 percent of the respondents made that same selection.

Sixty four percent (64.4%) of the respondents believe that patients are always informed about medical errors. However, 34.4 percent indicate that patients are sometimes or rarely informed, so this issue remains troublesome. Still, most (69.2%) of the respondents believe that informing patients of medical errors increases trust in the hospital. This group appeared to have slightly more confidence in their hospitals. Seventy three percent, (73.4%) would want a family members treated at their local hospital. The vast majority of respondents (80.3%) believed that lines of responsibility were clear. However, this survey was offered only to physicians. This survey is identified as “EastS Physicians,” when comprehensive findings are discussed.

Comprehensive Findings

As noted previously, little was known about the status of bioethics services in rural communities when this research agenda was initiated. Each study expanded the understanding of previous findings and as such, provided a richer and more comprehensive response to the research questions. In general, information was obtained from a fairly knowledgeable cohort; many of the physicians, nurses, administrators, patients and family members who participated in research activities had worked in their profession and/or lived in the same communities for more than fifteen years. However, the involvement of younger cohorts, physician and nurses with fewer than five years of experience, provided a way to evaluate issues encountered by a less experienced cohort. Since anonymity of responses was ensured in all of the surveys except that of the hospital administrators, it is difficult to ascertain what populations might have been missed. The demographic data, however, appears to reflect what is generally known about rural healthcare providers in terms of age, gender, speciality training, and length of time in practice.

As an additional qualifier, the response rates to some of the studies were not as high as might be desired. To an extent, low response rates to surveys that involve healthcare providers have been well documented. Some commentators have indicated that hospital administrators are actually encouraged not to participate in surveys. However, the number of studies, the inclusion of diverse constituencies, the geographic expanse that was covered, the use of both qualitative and quantitative methodology, and the congruency of responses to similar measures in the different studies suggest that the

key findings accurately represent rural perspectives.

Key findings relative to each research question are summarized below. Since the research agenda was quite complex, a series of 12 figures has also been provided to help explain the relationships between the studies and key research findings. The illustrations are provided in the Appendix.

Research Question 1: What Bioethics Issues Develop In Rural Healthcare Settings?

There was considerable uniformity among physicians, nurses and hospital administrators in their identification and assessment of the ethics-related problems that emerge in rural areas. The problems that are most frequently encountered by rural healthcare providers involve patients who cannot afford to follow medical recommendations because of cost, patients who fail to understand diagnosis and treatment, and patients who lack important resources such as transportation to healthcare services. These same three issues were consistently referenced by the majority of those who participated in the focus groups and interviews. The data suggest that healthcare providers in rural communities encounter these issues with similar frequencies and seem to share similar views as to whether these issues are problematic.⁴³⁹

These issues are perceived as “ethical” and intimately involve the healthcare providers’ ability to “do good” and to “avoid causing harm.” Healthcare providers appeared to recognize their responsibilities to help patients understand diagnosis and treatment. Thus they were concerned when, as was indicated by some respondents, there was a lack of time to meet patient needs.

The first two figures provided on pages 238-39 provide a visual display of the extent to which the problem of “patients who cannot follow medical recommendations because of cost” is encountered and is viewed as problematic. For most healthcare providers, this problem is encountered on a weekly basis or even more frequently. The data from the PhysicianS survey is not included in the Figure 2 because the survey instrument asked about the frequency of encountering that problem, but did not ask if that issue was also “problematic.”

However, the comments offered by rural physicians who responded to the PhysicianS survey suggest that the issue of inability to follow recommendations because of cost is perceived as problematic. The following response, offered by a physician, is representative of common sentiment: “What is beneficence? Are you really doing “good” when you prescribe something but know the patient cannot possibly follow your recommendations because of the cost involved? Do you just look the other way?”

Data suggest that three issues that are most frequently encountered by rural healthcare providers are not typically addressed by ethics committees. As indicated in Figure 3 on page 240, nearly 75 percent of the hospital administrators said that problems associated with the cost of care and distribution of scarce goods and services were rarely or never discussed in ethics committees. Further, nearly 69 percent said cost containment issues were rarely or never discussed by ethics committees. Issues related to patient competency were also rarely addressed. Thus the perception of rural healthcare providers that ethics committees do not address issues that are problematic has some basis in fact.

The ability to resolve those three problems - patients who cannot afford to follow

medical recommendations because of cost, patients who fail to understand diagnosis and treatment, and patients who lack important resources such as transportation to healthcare - appears hampered by a number of other issues. The additional issues, while not specifically identified in the bioethics literature as “ethical problems,” appear to complicate the provision of quality rural healthcare. The additional problems include orders for patients that are often non-existent or unclear, unclear lines of responsibility for patient care decision-making, differences in perception about the locus of responsibility for patient care decisions, and differences in perception about the reporting of medical errors. As indicated in Figure 4, nearly three of four respondents to the NurseS survey encountered orders for patients that are unclear or confusing; in WestS survey, two of five nurses indicated that in their hospital, decision-making about patient care is characterized by unclear lines of responsibility. Those problems are connected to other issues such as the willingness to have family members treated at the hospital or the reporting of medical errors. Indeed, most of the nurses who reported unclear lines of responsibility, also indicated that patients were not informed of medical errors, and that they would not want family members treated at their hospital.

The respondents to the WestS survey and the EastS Physician survey, evidenced little agreement relative to who has primary responsibility for patient care decisions or how the ethics-related scenarios should be resolved. The vast majority of physicians, nearly 85 percent, did not believe that responsibility for patient care decision-making should be shared with other hospital staff such as nurses. These kinds of system-wide problems may certainly inhibit the nurses’ willingness to take action when ethics-related

problems develop. As previously indicated, the respondents to the NurseS survey were hesitant to take action on most ethics-related issues. Representative comments from respondents provide insight into their hesitancy to take action. As one rural nurse explained: “I worked here for nearly 9 months before I had any idea what to do when problems develop.” Another nurse noted that the extremely demanding schedules leave “no time to consult a handbook and I’m too afraid to question the physician.” Another noted that “physicians are not available at night so there is no ready resource.” Interestingly, the lack of time to think about ethics-related issues when on duty was one of the most common problems reported by those who responded to the NurseS survey.

Certain issues have been suggested, in the literature, as particularly troublesome in rural areas. Those issues include difficulties in maintaining confidentiality⁴⁴⁰ and a greater resistance to use of technology.⁴⁴¹ Confidentiality-related issues have been repeatedly cited as a pervasive rural problem, but, as indicated in Figure 5, most rural healthcare providers believe that violations of patient confidentiality occur infrequently. Further, most rural healthcare providers said that violation of patient confidentiality is *not* a problematic issue.

The responses from those who say the problem is *never* or rarely encountered in rural healthcare settings suggest that rural perceptions about “confidentiality” and what “ought not be divulged” may not fit the textbook guidelines. Several additional findings lend credence to that assumption. Nearly 80 percent of the respondents to the NurseS survey believed that ethical issues are resolved differently in rural communities, and almost half of the nurses took no action when confidentiality-related issues were

encountered. The potential certainly seems to exist for sharing a great deal of information. More than 80 percent of the respondents to the East and West surveys have dual relationships with patients, and for nearly 88 percent of the respondents those relationships are not viewed as problematic.

The data from the WestS and EastS Physician surveys provide additional information about this relationship between relationships, culture, and “confidentiality”. More than 77 percent (77.4%) of the physicians over 56 years of age who responded to the WestS survey and 71.8% of those who responded to the EastS survey said patient confidentiality was not a problematic issue. However, the younger physicians who responded to those surveys *and* to the PhysicianS survey, more frequently rated confidentiality as a problematic issue. Among those who responded to the PhysicianS survey, the physicians with fewer than 5 years of experience in their rural communities experienced the most difficulty when encountering confidentiality-related issues. The findings from that survey reflect their greater level of concern with confidentiality-related issues.

To further understand these issues, the topics of confidentiality and dual relationships were discussed in detail by those who participated in focus groups and interviews. The vast majority of those who participated believed that protecting confidentiality was not a serious problem. Participants suggested that the younger physicians were more likely to report problems with confidentiality because they have less understanding of the rural community’s norms, rules and expectations. The rural healthcare providers and community members noted that there are “few secrets” in rural

communities. Health care providers have multiple relationships with community members, police scanners are widely used by community members, and persons develop the skills to expect and to cope with the lack of secrecy. Interestingly, the data from the survey of hospital administrators indicate that only 20 percent of the committees often discuss confidentiality related issues.

The degree to which resistance to technology impacts medical decision making in rural areas is difficult to assess. The information obtained from the qualitative studies, as well as several findings related to the economics of care, suggest that “resistance” to technology or even failure to follow specific medical recommendations may be based largely on economic and geographic factors.

These findings associated with this first research question provide useful information about the environment in which bioethics-related problems develop. Most nurses who participated in the NurseS survey did not take action when encountering most of the 36 ethics-related issues. Most of those nurses worked in three or more departments on a daily basis. Fewer than one third of the nurses had received baccalaureate level training. One of the problems they encountered most frequently involved “having to work with incompetent colleagues.” The vast majority of respondents had no access to ethics related resources and no time to think about ethics-related issues when they were working.

In the WestS survey, the nurses, when compared to physicians, were less likely to believe that medical errors were reported to patients and more likely to believe that lines of responsibility were unclear. They also differed from physicians in their perceptions

about the locus of responsibility for patient care decisions. Further, they were less likely to want family members treated at their hospitals. These issues deserve serious consideration. They appear to shape patient care practices and require more research.

Research Question 2: How Are Bioethics Problems Resolved?

Rural healthcare providers generally use informal resources to resolve ethics-related problems. As indicated in Figure 6, most rural healthcare providers have never served on an ethics committee and, as indicated by Figure 7, have never - even when committees are available - referred a case to an ethics committee. The data from NurseS survey indicate that the vast majority of rural nurses lack access to an ethics committee or any other formal ethics resources. In the PhysicianS survey, only 29 percent of the respondents reported access to ethics related resources.

Even informal resources, however, are used sparingly. In the NurseS survey, only 52.8 percent of the respondents indicated that they often consult with peers. Even fewer nurses, 31.5 percent, often consult with physicians, only 23.8 percent cite other health professionals, and only 7 percent consult clergy. In the PhysicianS survey, 22 percent of the respondents consulted peers and colleagues. Similar to the data from the nursing survey, only 15.3 percent consulted other hospital personnel, including nurses, social service department, legal services or the hospital administrator and only 7.6 percent cited frequent use of clergy.

Ethics committees were rarely cited as a resource, even when such entities were available in their hospitals. Although this issue requires more research, existing ethics

committees may not address issues that healthcare providers define as most problematic. As noted previously, ethics committees infrequently discuss issues related to cost containment, cost allocation, or patient competency. Indeed, issues associated with the distribution of goods and services were discussed frequently by only 6 percent of existing ethics committees. Further, only one third of the existing committees have any role in policy development, review, and evaluation. However, the data from key informant interviews and focus groups suggest that policy-related issues such as differences in perceptions about the meaning of a DNR order, differences in perception about lines of responsibility, and differences in perceptions about how to resolve ethics-related issues are quite problematic for rural healthcare providers and patients.

Research Question 3: Perception of Need

The subjects who participated in the qualitative studies found it hard to define the word “ethics” and were uncertain if the issues they faced were “ethical.” That finding may be related to the fact that most rural healthcare providers, as indicated by Figure 8, have not received any formal training in ethics. Among all of the respondents, the physicians with fewer than 5 years in practice were more likely to have received some ethics coursework; responses from that cohort may account for the exposure to ethics education noted by those who responded to the PhysicianS survey.

When given an opportunity to engage in discussions, the participants in the interviews and focus groups recognized problematic issues, appreciated the opportunity to talk, and, as indicated by Figure 9, uniformly wanted to receive ethics-related resources.

The healthcare providers, patients, and family members suggest that the lack of education and training in ethics and the lack of ethics-related resources hinder informed decision making, inhibit the willingness of healthcare providers to respond to ethical concerns, complicate the overall management of healthcare problems, increase the risk of secondary conditions, and diminish the quality of care in rural areas.

The attempt to identify “useful” resources is somewhat problematic. Since most rural healthcare providers have such limited access to any ethics-related resources, are uncertain if their issues are “ethical,” and have never used resources like ethics committees, they find it hard to describe the most desirable options. The most detailed information about resources was obtained from the NurseS survey and is depicted in Figures 10 and 11.

The field-testing of resources that is currently underway in rural hospitals may provide more information about the most suitable resources. The lack of interest in resources like journals, books, conferences, and audiovisual materials might suggest that such traditional approaches do not meet perceived needs. The articles in journals or the presentations at conferences, for example, do not typically involve rural situations and do not usually offer practical steps for problemsolving. Options such as continuing education programs, on line resources, and staff development programs should probably be explored in more detail.

In the qualitative studies, the participants specifically requested interactive activities that facilitate discussions among all key players and among all staff levels. During the focus groups, participants often realized that they had never talked with one

another about ethics-related issues and never explored their different perceptions about values. That finding may explain why certain activities such as ethics rounds, staff development programs, and continuing education programs are desired. Those options are perceived as “interactive,” inclusive, and responsive to issues that develop “at the bedside.”

Research Question 4: Local Values

The “context” of care appears to be an important issue in rural communities. Cultural values and community rules and expectation shape healthcare decisions. The qualitative studies provided a wealth of information about rural values and the ways in which values shape healthcare decisions. A heavy emphasis is placed on trust and the fact that trust evolves from the nature and quality of social interactions.

The community values and rules will be discussed in some detail in the following chapters. Most of the persons who participated in research activities believed that rural healthcare providers face different issues when compared to their urban counterparts. They cited contextual factors such as the importance of relationships, cost of care, few opportunities to cost-shift, and conformity to local culture and values. However, as indicated by Figure 12, two cohorts did not perceive differences. That area would benefit from more investigation and perhaps indicate that some of the rural findings are relevant to urban medical practices.

CHAPTER IV

THE LEVIATHAN MEETS THE TROUT

The minister acknowledged that the past six months “have been pretty frustrating.” When he moved to the rural community, he was excited about his relocation and anxious to provide some chaplaincy services to the rural hospital. He also believed he could make an important contribution to the hospital ethics committee. As part of his ministerial training, he had completed an ethics internship at a prestigious, university medical center. He could discuss the normative foundations of ethics and demonstrate the application of principlism. “But I’m getting a cold shoulder,” he noted. “I was trained to analyze the issue, determine an ethical course of action and justify the decision. Last week during a meeting of the ethics committee, I offered a very reasonable argument for a clear course of action. To explain my reasoning, I showed them how they could categorize the issues into four quadrants. No one said much; they just looked at me and then the whole conversation came to a halt when one of the committee members said: “Well, you could be right but then again, it all depends, you know, on whether you’re upstream or downstream.”

The committee member who offered that insight was trying to explain the importance of “reading the water” and knowing what that “reading” means in terms of one’s position in the water. When the water is high and fast, for example, upstream travel can be difficult if not impossible. That imagery of the water offers an important lesson about bioethics. The enterprise of bioethics in urban areas has been described as a leviathan in the ocean; in rural areas it can be envisioned as a trout in a stream. These

two beasts of the water - the leviathan and the trout - share a few common features, but the differences are deep and striking. So too, with bioethics. Much of what the urban, academic leviathan values - a normative foundation, deep philosophical reflection, academic expertise, experienced consultants - is viewed with skepticism by the wily trout. And perhaps that difference in perspective should not seem too surprising. Few would suggest that the world of the leviathan can be replicated in even the most blue ribbon of trout streams.

The combined data from the nine rural studies provide a way to contrast the urban leviathan with its rural cousin. The most obvious differences are readily apparent. The literature suggests that ethics committees are required in all US hospitals;⁴⁴² in reality, such structures are not legally required and have not been created in most rural hospitals. The literature suggests that most urban healthcare providers have access to an array of ethics-related resources, most rural providers, however, do not. Even the perceptions of “critical issues” are quite different. The urban enterprise has focused considerable attention on issues like the core competencies for ethics consultation, physician assisted suicide, genetics, and end of life care.

In rural areas, interest in those issues appears minimal. Physician assisted suicide was not identified as a serious issue in *any* of the nine research studies. Indeed in one study, 97 percent of the respondents identified physician assisted suicide as an issue that was *never* discussed in rural areas. Likewise, respondents suggested that end of life care was not usually a problem in rural areas, in part, because the process of dying was described by key informants as “more natural in rural areas.”

Rural healthcare providers are more likely to encounter more mundane issues such as unclear or confusing orders for patients, patients who cannot afford needed treatments or patients who fail to understand treatment protocols. These issues are perceived as problematic. Unclear orders can lead to medical errors and a patient's lack of understanding raises issues related to competency and autonomy. In addition, healthcare providers and patients are deeply concerned about inter-personal relationships among healthcare providers and patients, patients' expectations for care, and adherence to community norms and values.

Admittedly, these issues may not seem "ethical" when using a traditional, philosophical definition. But, as Nussbaum has noted, the traditional philosophical definitions of bioethics have relegated whole tracts of the subject to the outer darkness.⁴⁴³ Without doubt, suggest Light and McGee, one's knowledge about an action and features such as organizational dynamics shape the moral deliberations and the process by which decisions are made.⁴⁴⁴ They involve who does what to whom under what circumstances and as such directly involve issues such as free will and harm to self and others.⁴⁴⁵

The rural healthcare providers who participated in this research appear to agree with such assertions. They suggest that in rural areas, contextual issues such as the nature of a relationship determine what it means to do good and to avoid harm. Finally, rural healthcare providers were not supportive of urban approaches such as case consultation or ethics committees; neither service was generally regarded as a beneficial in rural areas.

Those differences among urban and rural healthcare providers regarding the proper definition of "bioethical" issues may help explain why rural healthcare providers

were hesitant to initiate discussions of ethics-related issues with patients and co-workers and why they found it “hard to know what to say” when asked about “ethical” issues during the interviews and focus groups. In nearly every interview and focus group, participants questioned if their problems would be considered “ethical.” The vast majority of those who participated in the rural studies said they had never talked about ethics in a formal way. They often suggested that “ethics” was the kind of topic that was discussed in University classrooms and perhaps at urban medical centers. Some thought that persons needed “special training” in order to talk about ethics. Some suggested that they did not encounter “ethical” problems when making healthcare decisions, but encountered personal issues or issues related to cultural diversity, or differences in values.

The subject of “ethics” appeared so unfamiliar that those who participated in the interview and focus groups often talked for an hour or so before saying something like: “well, I don’t know if *you* would consider this *ethics*, but....” When given the time to talk about the kinds of issues they encountered in their hospitals, however, they talked about deep and troubling moral concerns. They described the difficulty of knowing what is good, and what is fair. They described their confusion and pain when important values were compromised.

The respondents to the surveys did not have an opportunity to talk about “ethics” in a manner similar to those who participated in interviews and focus groups, but they did have an opportunity to identify ethics-related issues, indicate decision making processes and rate their use or interest in resources like ethics committees, case consultation, conferences, grand rounds, journal articles, and seminars. When they identified issues,

they often related them to cultural and ethnic factors. Interestingly enough, 90 percent of the respondents to the surveys of nurses and physicians in Montana, New Mexico, West Virginia, Tennessee, New Hampshire, Vermont, and Maine believed that culture frequently shaped healthcare decisions. The cultural factors shaped not only the kinds of issues that develop, but the willingness of healthcare providers to respond to them.

In general, there was little interest in any of the ethics-related resources that are typically suggested in the literature. The majority of respondents from hospitals without ethics committees did not believe that an ethics committee would work in their setting. They also questioned the usefulness of case consultation, journal articles, conferences, and academic course work. Most healthcare providers had heard about approaches like principlism, but questioned the use of such a rigidly defined methodology in communities where healthcare decisions are based on a tapestry of contextual issues that may or may not meet the conditions established by ethicists such as Beauchamp and Childress.

When asked to describe the characteristics that make healthcare ethics different in rural areas, respondents typically cited the inter-connected nature of rural life. Those who participated in the interviews and focus groups told stories about a world where “people are tight” and “everybody is a little bit of kin.” A patient who represented common sentiment explained: “people love the fact that everybody knows them well enough to ask how their grandmother is.”

The participants also noted, however, that the high level of “connectedness” and expectations relative to mutuality heighten both perceptions of responsibility for high quality care *and* feelings of guilt when problems developed. The respondents to the

surveys, the majority of whom also believed that both healthcare and “ethics” are different in rural areas, characterize those differences by phrases such as: “not fitting the textbook guidelines,” or having “a different understanding of confidentiality.” or “everyone is related,” or “not being able to turn people away,” or “the close and connected nature of life.” In short, the cultural framework used in rural communities is different than the framework described in the typical bioethics text. As a result, decisions in rural communities are not always based on what has been described as the “temporally bounded, individualistic, and mechanistic perspectives that prevail in Western culture” and western bioethics.⁴⁴⁶

This sense of familiarity and “connectedness” was certainly evidenced when visiting rural hospitals. In the hospital lobbies the hospital staff talked to patients, asked about other family members, and discussed mutual participation in upcoming community events. Patients talked with one another and compared and contrasted their treatment regimens. The hospital walls were frequently lined with pictures drawn by local elementary school children or other community members.

The rural residents often used historical references to describe the interpersonal connections that exist among healthcare providers and patients. They described community efforts to build, furnish, and support the local hospital. They described physicians and other healthcare providers who were native to the area and had “close relationships” and long-time friendships with community members. “The docs hunted with us and fished with us,” explained a community member. They described physicians who responded to emergency situations and offered assistance, even when the medical

problems did not strictly fall within their area of speciality. The following comment was typical: “I could always trust Dr. Pete; I always *knew* I could trust what he said or did.” These historical connections were valued by community members and healthcare providers. Further, those connections create a legacy and a framework for expectations. As one nurse explained: “They [historical connections to community] mean that we have a responsibility to be near and dear to the heart of this community.”

Respondents did not generally believe that such “personalized” care would be provided in urban healthcare settings and they often cited personal experiences to prove that point. For example, an informant who was referred to an urban surgeon for a biopsy said that when she asked him what was wrong, he crisply answered: “I am a surgeon. I cut on the dotted line. I don’t diagnose and I don’t treat. The biopsy report will be sent to your doctor.” Those who heard the comment agreed that in a rural area, a doctor “couldn’t get away with acting like that.” Informants claimed that such a physician would be “called on the carpet.” A patient who was referred to a neurologist for nerve studies noted that the physician refused to listen to her when she tried to explain the problems she experienced when trying to move her arm. “He didn’t understand *where* the problem was and he didn’t think my experiences had any value at all,” she said. Another patient who had a problem with neuropathy said that she was told by an urban specialist to take *prozac* for her “panic attacks.”

Sometimes stories, such as those recounted above, were also used to explain why urban consultants were often perceived as neither desirable nor helpful. “They think they can buff us up and make us think just like they do,” explained one hospital administrator.

He noted that the “urban docs come up here and try to talk people into surgeries and other things they don’t need and don’t want.” A particularly interesting example of this cultural mis-match involved a nationally respected bioethicist who came to a rural area and presented a guest lecture on physician-assisted suicide. Attendance at the lecture was sparse. A nurse who did attend suggested that “people have been muttering about that talk for days.” The staff at the urban medical center who arranged for the presentation were trying to offer the rural residents an opportunity to discuss an issue that was receiving national attention. The organizers did not realize, however, that members of the rural community were not comfortable addressing, in a public way, an issue they perceived as very private.

Those comments about urban healthcare experiences have been offered because the skepticism of “city ways” was a pervasive theme that emerged in all of the studies. Particular concern was expressed about urban healthcare providers who decide to move to rural communities. Those who became immersed in community life appeared to be well accepted and well appreciated. Those who chose a less engaged approach were typically given a variety of names - outsiders, city slickers, boomers, strangers, hired guns, and short-timers.

The topic of “outsiders” was discussed in detail by those who participated in the focus groups and interviews. Informants noted that in rural areas, “outsiders” are easily recognized by their dress, their ideas, their patterns of speech, even the way they walk. As a result - regardless of their profession, their skills, or levels of education - they are not entirely trusted. In one community, this was evidenced by the fact that rural resident

and healthcare providers expressed less confidence in the skills of a highly competent physician who recently moved to their community and more confidence in the skills of the long-time physician who was known to have a severe alcohol problems. The long time physician was not “all that bad.” The residents noted that acceptance of one’s skills is a process that “takes awhile.” The outsider has to demonstrate that he or she values the community and wants to be part of community life. The outsider has to create some connections. This suspicion of “outsiders” was evidenced by a resident of a rural community who, during a key informant interview noted: “You have to wonder what’s a doctor from Philadelphia doing in a place like this. Is he hiding out from someone?”

The key informant’s concern about “Dr. Philadelphia”⁴⁴⁷ was not unique to that single community. Indeed, so many similar stories and phrases about “outsiders” and the need to understand local values emerged during the key informant interviews, that a brief “Dr. Philadelphia scenario” was designed and incorporated into the focus group instrument. When the Dr. Philadelphia scenario was offered to the focus group participants, they generally laughed. The vast majority claimed that the scenario was very representative of perceptions in their communities and many *insisted* that the vignette was based *entirely* on events that occurred in their respective towns. The focus group participants typically offered variations and expansions that further explained their perceptions and concerns about Dr. Philadelphia-like healthcare providers. Since the interviews and focus groups were conducted in diverse rural communities in a six state area, the issues associated with “Dr. Philadelphia-like” individuals merit discussion.

An expanded Dr. Philadelphia case study and a Dr. Philadelphia script as told

from five different perspectives were developed in order to present and discuss some key research findings. The case study was shared with rural healthcare providers who either attended presentations about the rural bioethics project or field-tested bioethics resources. The rural healthcare providers reported that they like the case study/story approach. They suggested that it provided “a safe way” to recognize and discuss a number of the research findings, especially since the findings seemed to match their experiences. Since the Dr. Philadelphia character described in the story was based on a composite, rural residents and healthcare providers suggested that they did not feel “exposed” to any particular blame when they heard or read the story. Rather, the contextual framework allowed them to recognize key ethical issues, help them discover the “words” to discuss such concerns, and help them envision how these concerns could be addressed..

The Dr. Philadelphia case study/story is provided because it offers a contextual framework with which to consider the implications of key findings. Obviously, the whole problem of bioethics in rural areas is bigger than simply a dilemma that involves an outsider who moves to a rural community. But the story provides a way to initiate a discussion by presenting a number of troubling issues experienced by Dr. Philadelphia and members of his new community. Some of these issues involve different perceptions of quality care and concerns associated with organizational ethics. In many respects, the issues that develop in the story represent the notion, offered by McGee and Light, that bioethics involves who does what to whom and under what circumstances.

It is important to note that the story about Dr. Philadelphia is only one of a series that have been developed in order to accommodate a range of ethically problematic issues

that emerge in rural communities. Other scripts have been developed to deal with issues such as mortal superiority, organ donation and allocation of healthcare resources. As has been the protocol used throughout this paper, the names used in the Dr. Philadelphia story are pseudonyms. Further, the quotes and example used in the story have been gathered from a 12 state area, and so any connection to particular individuals should not be inferred.

Admittedly, the Dr. Philadelphia story does not follow the format typically used in medical school texts and in bioethics journals. In addition, attention is not focused on the resolution of a specific moral problem or dilemma. Rather, attention is focused on exposing the context of care, the social, political, and economic factors that shape perceptions of appropriate behavior in a rural community. In order to clarify the kind of approach that may be most helpful, the story is told in a fashion requested by those who participated in our studies. The tale is accessible, non academic, inter-disciplinary, and heavily imbued with context. And that may be why the Dr. Philadelphia story has been so well received - bioethics in rural areas is a little bit different and requires different forms and different approaches.

A Whale Edges to Shore

Dr. Philadelphia would be surprised to learn that anyone, in his community, suspected that he was “hiding out from someone.” He gladly participated in a key informant interview and was anxious to discuss his experiences of rural life. He moved to his new community four years ago, intrigued, he says, the moment he heard that the

rural community needed a new physician. For the most part, he is pleased with his relocation. He believes that the skills he developed during a 20 year career in an urban setting well prepared him for the diverse problems he encounters in his new community. He provides a level of care that patients could previously obtain only by traveling - sometimes by air ambulance - to a larger city. "You don't hear the 'flight for life' helicopter as often these days" Dr. Philadelphia noted with pride. The re-location has also offered some personal benefits. Dr. Philadelphia has purchased a few acres, bought some horses, built a home, and escaped the chaos of big city life. Overall, he thinks the exchange has been beneficial for everyone involved. He enjoys his new life as a rural physician, and the community's access to healthcare has been significantly improved.

Admittedly, there have been a few small "glitches." Dr. Philadelphia noted that on a social level, he shares few common interests with the local residents. He does not really have "friendships" with community members. His friends are people he has known for years; he travels to visit them or they visit him at his country home. As a rule, he does not personally participate in community activities. To an extent, that lack of involvement is not surprising. Dual relationships, he noted, are discouraged by professional codes. However, he has generally offered financial support to community causes and certainly provided pro bono care when such care was indicated.

Dr. Philadelphia suggested that communication styles are a "little different" in rural areas and he thought that communication - and a better understanding of the services he offers - could be improved with opportunities for staff and community training. That need for "training" was reiterated several times during the interview and Dr. Philadelphia

described the kinds of training that have been helpful in urban hospitals. He also contrasted those initiatives with the lack of training opportunities in rural areas. He noted that most of the nurses at the rural hospital have not received baccalaureate level training. He suspected that few if any of the other healthcare providers had ever received any training in ethics. He thought that many people in these rural areas - even nurses - do not really understand how much the system of healthcare has changed in recent years, or what kinds of services should be provided. He noted that patients often fail to understand treatment regimens. Nurses tend to ask questions and make demands that are not really “appropriate” or “necessary.”

To explain his perceptions, he cited a recent situation that involved one of his patients who underwent orthopedic surgery. Dr. Philadelphia made certain the patient’s blood pressure medications were adjusted for the surgery, but an orthopedist performed the surgery. Dr. Philadelphia knew that the nurses were angry when he did not visit the patient after the surgery and they were upset when they asked him about some pain medication and he refused to be involved. Dr. Philadelphia believed their anger was misplaced. “The nurses kept trying to ask *me* questions” he explained, “but the surgeon was responsible for the patient’s care. Their questions were not appropriate.” Similarly, he described as “entirely inappropriate” the time the nurses called him to the emergency room because a woman was in the final stages of labor. He had not delivered a baby, he explained, since he was in medical school. “I am no more equipped to deliver a baby,” he noted, “than a man on the street.” When Dr. Philadelphia was asked if there were any particular rules or standards for living in his new community, he looked puzzled.

“Humans,” he suggested, “are basically the same everywhere.”

Many of Dr. Philadelphia’s perceptions, however, were not shared by members of his new community. Very different stories emerged during interviews and focus groups that involved patients, family members, community leaders, and healthcare personnel. When asked to describe healthcare in their community, his name was frequently mentioned. There was little doubt that Dr. Philadelphia was widely viewed as a city slicker, an “outsider.” Further, his approach to healthcare was not well received. As one community member noted: “we call him the Heartless Horseman.”

In part, his designation as an “outsider” was viewed as “his own fault.” An outsider, as a community leader explained, “stands out in a small community and you are considered an outsider until you make yourself *familiar* to other people and that doesn’t depend *only* on your professional service or your work.” Dr. Philadelphia, suggested the informants, had not made himself “familiar.” A nurse noted: “We always have to call him *Doctor* Philadelphia, as if that title was just about the most important thing in the world.” Explained a family member: “He was my husband’s doctor. We *never* saw him. If I knew what he looked like, I’d wrestle him to the floor.”

At times, there was grudging respect for his expertise - “folks say he is supposed to be well trained” - but there was a definite hesitancy to use his services. Community residents explained the hesitancy by noting that the *quality* of the relationships among healthcare providers, patients, and community members was as important as the professional skills. “You have to be able to trust your doctor,” explained one participant and “in this environment, it takes a long time to trust and no time at all to lose that trust.”

Dr. Philadelphia, suggested the informants, *really* needed some training.

Clearly one of the most troublesome issues involved a reality that was completely overlooked by Dr. Philadelphia. Contrary to what the doctor believed, there was wide agreement, among those who participated in the interviews and focus groups, that there *are* rules for living in rural communities. Indeed, the topic of “rules” was consistently referenced as a way to explain both expectations of and personal experiences with healthcare. “We have a certain set of rules” explained a nurse, “and everyone needs to know what those certain rules are.” Another nurse noted: “Dr. Philadelphia doesn’t know the rules and I doubt he’ll ever get it.” One administrator cautiously stated that Dr. Philadelphia was trying to learn the rules, and that he had “made some adjustments.” A patient, however, was less tolerant of his adjustments: “You never hear the “flight for life” helicopter anymore; he wants to keep us in this hospital. He’s trying to kill us.” Interestingly enough, even successful outcomes, when associated with Dr. Philadelphia were viewed with suspicion. When one community member noted that a friend had actually recovered and seemed pretty satisfied with the care that had been provided, another retorted: “Well, they don’t kill everybody.”

“I’ll be honest,” explained Ruth Jones,⁴⁴⁸ a 52 year-old nurse who has worked in the community hospital for 15 years. “He’s like a fish out of water.” Ruth noted that for many years she was proud of the hospital and the services it provided. As she spoke, she skillfully outlined the framework for healthcare in her community. She noted the hospital’s historic relationship with the community. She explained that community members helped build the hospital, they “pounded the nails, laid the flooring, and painted

the walls. “I don’t know if this is what you mean when you talk about ethics,” she explained, “but over the years, people have been cared for as if they were family members.” Ruth noted that the care was so good that the hospital was a magnet, and people from the adjacent communities would gladly “make a trip over here” when they needed healthcare. Her assessment was not too surprising since people in the surrounding communities have known one another for generations and rely on each other for advice and suggestions.

There have been changes, though, in the last few years and some of those changes were directly attributed to Doctor Philadelphia. Ruth referenced a situation that still troubled her a great deal. She was on duty five years ago - “before Dr. Philadelphia’s time” - when a local rancher, 59-year old Carl Peterson arrived at the hospital. He was experiencing severe back and shoulder pain. A well known and well respected physician, one who has since retired, examined Mr. Peterson and diagnosed a heart attack.

The hospital staff stabilized Mr. Peterson and monitored him very carefully throughout his stay. “Dr. Kelly stayed with us most of that first night, and Mr. Peterson received really good care” explained Ruth. She noted that “you could trust Dr. Kelly; he was there if you needed him. There was no confusion; he always made sure we knew exactly what to do.” Fortunately, the heart attack was not severe and after several days of hospitalization, Mr. Peterson was discharged and reported feeling quite well. Throughout his stay, Ruth provided much of his care. When Mr. Peterson left the hospital he was on medication and planned to start an exercise program and make some changes in his eating habits.

Ruth knew the Peterson family, prior to the hospitalization, because her sister was a close friend of the Peterson's eldest daughter. She felt very comfortable explaining to Mr. Peterson and his wife the reasons for various tests, and what their results meant. She also explained what to expect during the recovery period and was very responsive to their fears and anxieties. She provided both the information and confidence needed for Mrs. Peterson to care for her husband after he was discharged. At home Mr. Peterson recovered relatively quickly. With Ruth's encouragement, his wife's care and his own persistence with a good diet and exercise program, he was soon able to perform many of his old duties on the ranch. Life was almost back to normal.

However, a few weeks ago Mr. Peterson suffered a second heart attack, one that seemed more serious. He was treated in the hospital emergency room and then was transferred to one of the clinical care rooms. Mrs. Peterson was nervous about the severity of the heart attack and asked Ruth and the other the nurses if Mr. Peterson should be airlifted to the larger hospital in the city. Ruth Jones was not certain how to respond. She knew that Dr. Philadelphia told the Petersons that it would be best to continue treatment at the local hospital; he said a trip on the helicopter "was not indicated" at the time. "That's easy for him to say" explained Ruth bitterly. "He calls the shots, writes the orders and then goes home. We are here, in the hospital, on our own and wondering if we're doing the right thing." Ruth also noted that the Peterson family did not really understand what was happening or the course of treatment that Dr. Philadelphia was suggesting. The family was standing in the hall when Dr. Philadelphia was talking to them. "I don't think they felt like they had any choices," she noted.

Ruth, the other nurses and the Peterson family experienced a very stressful evening. Ruth was worried about Mr. Peterson's condition, and Mrs. Peterson kept asking questions. Several times during the evening, Mrs. Peterson asked Ruth to call the doctor and see what else should be done. Mrs. Peterson's frequent requests to call Dr. Philadelphia increased Ruth's stress level. "Dr. Philadelphia doesn't like to be called after he's left the hospital," explained Ruth. "If Dr. Kelly was still here, I'd call him in a minute; he wouldn't get upset, he wanted us to check in when we were not sure what we should do. But Dr. Philadelphia gets irritated. So, I had this problem that night. What was I supposed to tell Mrs. Peterson? I reassured the family, I said things were going as expected, but I didn't really know if things were going to be all right or not."

Later that evening, Mr. Peterson suffered a cardiac arrest. In spite of everyone's best efforts Mr. Peterson died. Ruth remains very upset about the episode. She, the other nurses as well as Mrs. Peterson wonder if Mr. Peterson should have been air lifted to a regional center. Mrs. Peterson recently called Ruth and said that she has "heard" some things about Dr. Philadelphia and had a number of questions for Ruth. "I can't avoid her; I see her all the time" said Ruth. At the same time, Ruth is not sure how much information she should give to Mrs. Peterson. Ruth believes that if one of the other local physicians had been caring for Mr. Peterson, the helicopter would have been called or at least there would have been a long conversation with the family. "They wouldn't have been so sure that what they were doing was right" she explained. And maybe Mr. Peterson would still be alive.

Ruth suspects that a case like Mr. Peterson's might not be viewed as a "huge deal"

in an urban hospital but it is a “big, huge deal” in her community. She noted that “people from all over the valley used to come to our hospital” for their healthcare. Now folks are less certain about the “quality” of the care they will receive. If they can’t trust Dr. Philadelphia, perhaps they can’t trust the hospital. As a result, some people in the community - and in the adjacent communities - are saying they should go to the rural hospital in the adjacent county.

When people feel that way, it can create serious problems for the whole community. Ruth explains that “if there are fewer patients, our hours get cut.” As if to underscore her concerns, Ruth said that people in the community are “talking” and when she went to the grocery store, someone said to her: “Well, I hear they’re killing people over there now.”

When Dr. Wiseman, another local physician was interviewed, he talked about “judgement calls” and noted that “one tries to make the right decision but these things aren’t cast in stone.” He also noted that Dr. Philadelphia was a “good clinician.” Dr. Wiseman had made referrals to Dr. Philadelphia in the past, and believed he would continue to do so. He explained that Dr. Philadelphia has a level of expertise that was otherwise unavailable in the rural community.

Dr. Wiseman was not at the hospital the night that Mr. Peterson died. He suspected, given the severity of the heart damage, that Mr. Peterson would not have survived the plane trip to a regional center. He believed that Dr. Philadelphia would have authorized the air ambulance if that option had been appropriate. “But I am kind of an arm chair anthropologist” he said and as a result, suggested that the conversation whirling

around the community was not really about a “medical problem.”

Dr. Wiseman has lived in the community for a long time and believes that the Peterson situation involves the way people “feel about each other.” Relationships, he noted, are very important in rural areas. He also suspects that the family did not really understand either the diagnosis or the implications of any treatment. To explain his point, Dr. Wiseman described one of his patients, a man who also had some heart problems. Several months ago, Dr. Wiseman recommended a full evaluation at a regional center because he thought that a procedure like an angioplasty or even a “bypass” might be needed. The patient rejected his advice. The patient understood the reason for Dr. Wiseman’s recommendation, but did not want to travel to a city hospital and did not want to incur the costs associated with the recommended treatment. The patient noted that a costly procedure could jeopardize the financial security of the family ranch and it would be better to leave an intact ranch to his sons, even if it meant the loss of his life.

“These kinds of issues are not really about having access to technology and they are not really about whether one lives or dies,” Dr. Wiseman suggested. “We all know we are going to die. These issues are about the culture and the relationships that you have with one another.” Dr. Wiseman said that if he had been providing care to Mr. Peterson, he would have spent more time with the Peterson family. That would have occurred naturally because he often thinks of his patients as “my friends.” He noted that “we all know we are in this together.” If, in the coming months, his rancher-patient dies of heart failure, people will believe that he and the rancher “talked things over,” that he had been available when he was needed, and that things worked out “pretty much as expected.”

A Community's Perspective

“It’s been hard these past few months,” explained Mrs. Peterson. “And from what I hear from lots of folks in this community, we’re not the first who have had problems.” She admitted to being overwhelmed by everything that happened the day her husband became ill. “When I found Carl,” she noted, “he was hanging on to the fence and said he couldn’t breathe. After we got to the hospital, I *thought* Dr. Philadelphia said that Carl couldn’t ranch anymore.” She noted: “We were standing in the hall and he kept talking about all this stuff.” She remembered that, at one point, Dr. Philadelphia talked about “options” and, among other things, asked if the family had health insurance.

Mrs. Peterson now wonders, however, if the family’s lack of insurance was the reason the air ambulance wasn’t used. She thinks that “the doctor said he wouldn’t use the air ambulance if he was in my shoes,” but she is not sure what he meant by that statement. Mrs. Peterson is not certain that her husband’s life could have been saved - even if another physician had been involved. But she is quite certain that she no longer trusts the care offered by Dr. Philadelphia. “I just wouldn’t go to him again. I think he just saw this old man lying in a bed and figured that he wasn’t worth the trouble.”

Mrs. Peterson reported that she sees Ruth Jones nearly “everywhere since everyone in the community has connections to people at the hospital.” In the past few weeks, she has asked Ruth about Carl’s hospitalization and the decisions that were made that night. Mrs. Peterson noted that she has also talked to “lots of folks,” including some other nurses, the hospital’s kitchen staff, and a local pharmacist. “I don’t want to get the nurses in trouble,” she stated, “because I think they were trying their best.” But she

suspects that the nurses are “a little afraid of Dr. Philadelphia. They kept saying that he doesn’t like to be called at night.” She also explained that Dr. Philadelphia is “not someone who you see around town.” She has heard that he even home schools his children.

All of these issues have been discussed “around town” for the past few months. Ruth noted that people are also beginning to wonder about the hospital administrator. He is also relatively new to the community and, Ruth suspects, is “more interested in paying the bills and keeping Dr. Philadelphia happy. I’m not sure that what happens to us makes much difference.”

At the outset, one might question the extent to which the story about Dr. Philadelphia, his peers and his community has any relevance beyond the boundaries of a particular rural locality. One might also question the relationship between the issues, offered by rural residents, and the enterprise of bioethics. Admittedly, the concerns articulated in the story do not specifically fall within the traditional scope of bioethics, especially as the enterprise was outlined in the first two chapters. Further the issues that emerged in this story, and in similar stories recounted by rural residents from diverse rural communities throughout the country, are not issues typically addressed by bioethicists or entities like bioethics committees. Indeed, bioethicists have rarely considered the social, cultural and historical influences on their ethical thinking.⁴⁴⁹ Likewise, bioethicists have been criticized for not considering the consequences of their outlook for policy makers and for society.⁴⁵⁰

But if one uses Rosenberg’s notion of context or the Light and McGee “who does

what to whom” model, Dr. Philadelphia’s approach to medicine has ethical implications that operate at personal, clinical, and organizational levels. His approach to healthcare impacts the health of his patients, the credibility of the hospital, and the health of the broad, social community. Indeed Dr. Philadelphia’s conduct was used as a reference point when discussing ethics-related issues as diverse as: trust and confidence in the healthcare providers, access to quality healthcare, fair and equitable treatment, honest reporting of medical errors, respect for confidentiality, confidence in the local hospital, dual relationships, and understanding and acceptance of community culture. Rural healthcare providers, patients, family members, and community leaders believe these practical considerations form the context for the ethics of care in rural areas. They also believe that when these contextual factors are overlooked, ethically problematic situations develop and the quality of healthcare is abridged.

A number of the contextual factors that emerged in the rural research studies were evidenced in the Dr. Philadelphia story. Those factors suggest that the story does not only involve issues associated with “outsiders.” For example, the Peterson family viewed the nurse as their advocate; they had a personal relationship with her, trusted her, and hoped she could offer guidance. Ruth, the nurse, was a longtime member of the community and valued her relationship with the Peterson family. At the same time, she was hesitant to take any particular action other than to offer reassurance. She was caught between competing interests - her relationship with the Peterson family, her continued employment at the local hospital, and the unclear lines of responsibility that characterized patient care decisions. As a result, she felt paralyzed and did not pursue any alternative

course of action. Dr. Wiseman trusted Dr. Philadelphia's clinical judgement. He had made referrals to Dr. Philadelphia and would probably continue to do so since access to speciality care is limited in rural areas. Dr. Wiseman suspected that in the Peterson case, cultural norms were violated. However, he did not talk to the nurses about the episode and had never discussed the topic of rural ethics with Dr. Philadelphia. Mrs. Peterson was confused about what happened the night Carl died. She did not understand the diagnosis or treatment; she basically thought her husband would be unable to continue to ranch.

A definition of bioethics fluid enough to include the diversity of issues that were identified by rural residents is not a novel concept. As was noted in the first chapter, the historian Charles Rosenberg suggests that medicine is intimately tied to values and interests, to perceptions of right and wrong, and appropriate standards of practice.⁴⁵¹ DeVries and Subedi have suggested that the use of more sociological perspective would allow all involved in an ethically problematic situation to "get the whole picture."⁴⁵² They suggest that the "acontextual" bias of the field has hampered the ability of bioethicists to identify what really matters. In rural areas the appropriate standards of medical practice appear to clearly involve a partnership that integrates community rules, values, and expectations. Textbook protocols have little place here.

Those rules shape expectations for interpersonal relationships and for overall healthcare. When key elements of the "partnership" are not honored, the quality of healthcare can be seriously compromised. Healthcare providers may leave the community. Patients may reject the services of local physicians or hospitals. Indeed,

patients may travel considerable distances to seek healthcare in other communities, rather than accept what is perceived as inferior care. Hospitals may face financial consequences such as the loss of potential patients and the defeat of local tax levies designed to provide financial support to community hospitals. Hospital staff, like nurses, aides, custodians, and cooks, may lose jobs. Everyone knows about this web of connections and responds accordingly.

The connections between the concerns of the rural residents and the enterprise of bioethics can only be understood when they are examined as part of a broad social context. For example, in one focus group, participants described a Dr. Philadelphia-like physician, relatively new to the community, who did not go to the emergency room when called because the patient's problem would require treatment at a tertiary center and was outside of the physician's "area of expertise." When the physician learned that his failure to respond to a request from the emergency room was a major topic of community discourse, he was quite irritated. He believed that the nurses had discussed the issue with community residents and breached protocols for "confidentiality." Others who described the situation, including some nurses, did not believe that confidentiality was abridged. They suggested that when you live in rural communities, you need to know who you can trust. Since the physician refused to come to the emergency room, community members believed that he did not really care about their well-being. They suggested that a reliance on such a physician could jeopardize one's health.

Furthermore, most suggested that the physician's belief that his actions would be kept "confidential" was naive and uninformed. "This is Scannerville," explained a

hospital administrator, “everyone has a police scanner and everything that happens in the hospital will be discussed on Main Street.”

In this example, the physician was operating within a framework that presumed anonymity. But the hospital staff, community leaders, patients and families who described the situation presumed a high level of familiarity and had a different vision of what “ought not be divulged.”⁴⁵³ They accepted the fact that, given the interconnected nature of rural lives, there would be few secrets in their community. They also knew, as one community leader explained, that “even if you’re not always the closest friends, you have to rely on others for assistance and support.” More important than protection of confidentiality was the need to nurture overlapping relationships, know who you can trust, and offer support to those members of the community who might need care. The litmus test seemed to involve not whether the information would be divulged, but for what purposes and whether the actions of the key players were fair, appropriate, and in the best interests of the community.

The determination of fair and appropriate can require a careful balancing act among competing priorities. In one community, a new hospital administrator realized that the local newspaper was publishing the names of those admitted to the hospital. He immediately forbade the release of such information and informed his staff, the local ministers, and the newspaper that publication of such information was a breach of confidentiality. In fact, the publication of such information would not only be considered as an “ethical lapse,” but would also constitute a serious breach of the new privacy rule mandated by the Department of Health and Human Services. The rule, formally known as

the Health Insurance Portability and Accountability Act severely limits the extent to which hospitals can share information about patients. The new administrator's action, however, was not viewed as appropriate or well-informed by most of those involved. His staff regarded the new rule as an action by an uninformed outsider, a city slicker. "He's just a hired gun" noted one informant.

The community, with the support of many seasoned healthcare providers, neatly circumvented the new policy. A team of elderly women "cruised" the halls every morning. They checked to see who was hospitalized, gathered at the local coffee shop and started the phone tree. How else could community members know who needed casseroles, a ride to the hospital, or other support?

There were times, however, when divulging information was definitely perceived as unfair. For example in several communities, a number of rural residents were shocked to learn that hospitals could release information about a patient, without the permission of the patient or family, to Organ Procurement Organizations. That action *did* seem like a serious breach of confidentiality because it involved sharing information with people outside the community - people who had "no right to know." Some believed that such notification could create tensions within the community since many rural families have had little or no access to even basic levels of healthcare. Some characterized the release of information and the request organ donations from those who have so little as "unfair," and a guarantee that "those who receive the most support from the system can receive even more." That characterization seemed especially pertinent when healthcare providers knew that certain individuals or members of their families, given their financial

circumstances, would not be placed on waiting lists if they needed transplantations. The most vivid comment was offered by a hospital administrator who noted: “They have taken the coal, the timber, the oil and the very land. They have polluted our rivers and our skies. And when there is almost nothing left, they want the body, the last thing that might have value.”

Concerns about “playing fair” and “mutuality” also surfaced when research participants discussed “dual relationships.” As the data from the rural studies indicate, both personal and professional relationships are expected. Indeed, the vast majority of rural healthcare providers reported that they routinely have dual relationships with patients. Dual relationships were not perceived as problematic, rather they were part of the mutuality that is expected in rural communities. As one healthcare provider noted: “This is our neighbor, this is the store owner, we can’t walk into a grocery store and expect them to not know who we are.”

Patients talked about trusting healthcare providers *because* “they know us and we know them.” A community leader and businessman described his dual relationship with the hospital: “We have a business relationship and we tend to have opportunities for social relationships. Our kids go to school together and to church programs and that sort.” A healthcare provider explained that many of his patients addressed him by his first name because “they knew me that way when I was a child.” Another healthcare provider noted: “I try to think of them not only as *professional* relationships but as *personal* and friendly.” The expectation for these kinds of relationships was an issue that Dr. Philadelphia did not understand.

As the Dr. Philadelphia story suggests, when healthcare providers resisted dual relationships, community members perceived that behavior as a lack of mutuality and a disregard for community rules. The extent to which these notions of “playing fair” and “mutuality” are part of a larger social contract was evidenced in two different communities when healthcare providers and community members noted that the “new physicians” home-school their children. The rural residents perceived that action as a rejection of the community and its culture. As one informant explained: “if they don’t trust our schools, do they trust us?”

An issue like home schooling involves more than simply a lack of “trust.” In these resource-strapped communities, the decision to home school displayed a lack of mutuality because the state funding, received by the local school district, is dependent upon school enrollment. A decision to home school means fewer dollars would be granted to the local school. As an informant explained: “if they don’t give back to the community, they are just leeches, taking our money.” In another community, the hospital administrator said that when he moved to the community, he had planned to “home-school” his daughter; he quickly realized, however, that such an action would not be well received. The other members of the focus group laughed when he offered the comment, but they readily agreed with his assessment. When he indicated that his daughter was starting preschool that week, there was a nod of approval. “My daughter went to that pre-school,” said one person;” another offered: “I helped start that school.”

Many research participants realized, however, that changes in the healthcare system have started to erode this sense of connectedness and mutuality. The participants

in the interviews and focus groups frequently described the “old docs” who have retired. They noted that the “new physicians” more carefully delineate their commitments to the community. In ways similar to Dr. Philadelphia, some new physicians are less socially involved. As one research participant noted: “the changing of the guard has brought people from the outside who may not be as connected and who may not really care about us.”

The lack of caring was sometimes paired with the belief that the new physicians may anticipate a limited rather than a lifetime commitment to the rural community. “By their age and their attitude,” noted a community leader, “you suspect they won’t be here for long. And sure enough, they pick up and go.” In another community, the focus group participant suggested that “Dr. Dan, by being here the longest of any of the current doctors now has a level of respect and acceptance. The rest are just fly by night.” Adding dimension to this issue, one healthcare provider echoed a comment similar to the one heard in Dr. Philadelphia’s community: “rural communities are a little suspicious of anybody who would come - is there something wrong that you can’t make it in the big city?”

How best to accommodate the desire for “connectedness” in a system that is rapidly changing presents some challenges. Dr. Philadelphia does not believe that the concerns of the rural residents are “ethical” in nature. They are cultural artifacts and Dr. Philadelphia believes that rural residents need to make some adjustments. During his interview, he noted that the system of healthcare has changed and if rural communities want physicians who can provide competent, high quality services, physicians have to be

accepted on their terms. He said: “I need to understand their lives. But if I am not interested in their community activities, I should not be expected to participate.”

Dr. Wiseman, a physician who seems well accepted by his rural community, offered a different perspective. He believes that the rural concerns are “ethical” in nature. Further, he noted that “if people choose to go into a culture that is very different from their own, then the burden is on them to change to meet the culture, rather than changing the culture to meet their expectations.” He also noted that when someone is hospitalized, a gesture as small as “a five minute poke your head in the door” could make a big difference. “They just need to know you are one of us,” he suggested. Dr. Wiseman’s contention was reinforced by a patient who applauded the efforts of a new physician in his community: “Dr. Smith tried to talk like us. I will never forget when he started to say howdy because somebody said howdy to him.”

While the differences in perspective are justifiable, Dr. Philadelphia’s personal beliefs might compromise his ability to provide quality care. A lack of personal interaction appears to decrease the community’s trust and confidence in his services. A decrease in trust is a clinical concern since data indicate rural residents are hesitant to accept the recommendations of healthcare practitioners unless they are trusted. Indeed, the most scathing comments were reserved for healthcare providers who did not believe that the healthcare covenant was based on relationships.

The linkage between “ethics” and “relationships” was so strong that those who participated in interviews and focus groups offered statements about relationships and community rules three times as often as *any* other topic - even topics as important and

problematic as access to healthcare or cost of healthcare. Implicit in these statements was the need to recognize, understand, and respect the culture of a community. As one focus group informant firmly explained to the interviewer: “that’s what I’m talking about, that’s what I’m trying to explain - the rules for living here!”

The Rural Context

Even when rural healthcare providers know the rules and have solid relationships with their communities, attempts to provide quality care and adhere to ethical standards can prove elusive. Rural hospitals are not Gardens of Eden. At times, research participants worried about the quality of care that one receives in rural settings. “Sometimes,” as one informant indicated, “you wonder if the care you get in a rural hospital is as good, as up-to-date as what you would receive in a urban hospital.” And indeed, research participants described errors or problems that had occurred in rural areas. Some of the examples involved serious issues like mistaken diagnosis, errors during surgery, and improper medications. One nurse, for example, noted that the need to rely on peers for advice can be problematic. She described a procedure that definitely required a sterile environment. Her supervisor, however, did not think that a sterile environment was needed. The situation was “resolved” when another nurse, one with limited formal training, was asked to comment; she stated that a sterile environment was not needed.

A number of “problematic” issues that were identified in the studies - cost of care, misunderstandings about diagnosis and treatment, unclear orders for patients,

unclear lines of authority, diffuse responsibility for decision making, limited opportunities for training, and a hesitancy to report medical errors - are certainly not conducive to the development of a high quality, error-free work environment. At the same time, one can understand why such problems occur. Given the lack of resources, the demanding schedules, the diverse assignments, the dual relationships, unclear lines of authority and the overall changes in the healthcare system, the fact that rural healthcare providers frequently defined their jobs as “difficult” and “morally distressful” is not surprising.

In such an environment, perceptions about proper conduct can differ drastically. Throughout his interview, Dr. Philadelphia repeatedly affirmed the desire to provide good care. He thought that good care was related to his specific expertise and adherence to proper clinical protocols. He believed that the community did not understand the parameters of good care. In fact, Dr. Philadelphia noted that the “revered old docs did not necessarily provide good care from a medical perspective.” He suggested that the community members needed to “change their ideas” about what constitutes “good care” if they wanted to retain competent providers like him.

Other local healthcare providers, especially ones who were trusted by the community, were willing to let Dr. Philadelphia grapple with the issues by himself to see if he could “figure out” what he should do. This willingness to let him “dangle” and perhaps “hang himself” was not unique to Dr. Philadelphia’s community. Both healthcare providers and community members blamed Dr. Philadelphia for a number of problems; they did not recognize, however, the ethical implications of their own

behavior. For example, research participants generally viewed what they termed “quality care” through the lens of cultural competency. A competent person would be able to “figure out” what it takes. Thus, they made few attempts to inform Dr. Philadelphia of the rules. If Dr. Philadelphia “could not figure out what it takes,” then he “should go back to where he came from.”

The process of “figuring out what it takes” requires that healthcare providers learn how to balance four specific but interrelated ethical challenges. The first challenge, as is apparent from earlier quotes, involves the notion of relationships. In rural communities, people are connected to one another and expect that those connections will be honored. As one nurse explained: “People expect to be cared for like family; you can’t turn them away.” At the same time, there is a competing challenge. Healthcare may have to be rationed because in rural hospitals profit margins are narrow and the levels of reimbursement for healthcare services are often inadequate. Rationing, in turn, means that healthcare may not be provided to those with whom one has multiple connections. At the very least, healthcare providers know that recommendations will not be followed because of financial factors.

The interconnection between relationships and economics was well evidenced by the various stories told by rural healthcare providers. Some talked of “sending patients home” when they knew that the patients were too ill to care for themselves. But they did not know what they could do to change that situation. They noted that the costs associated with healthcare could mean the loss of land, the loss of other valuables, even the potential loss of the family homestead. One provider noted the importance of

understanding “how much poverty there is and the inequity of resources and the need to carefully determine what people do and do not get.” Others described “more who can’t get it [healthcare] than can.” These issues were ranked as “very problematic” for healthcare providers. They worried about the consequences associated with rationing of care because when healthcare is limited or denied, that rejection can be experienced not only by the patient, but by the family, the church group, the service club, the community. All those constituencies have long memories. Given those complications, healthcare providers were not sure what to do. Confusion about the best course of action was underscored by the 83 different scenarios, indicated by healthcare providers who responded to a vignette about a patient’s safety following premature hospital discharge. Healthcare providers seem to respond to these cost-related dilemmas by affirming the importance of the relationship and doing what is possible - such as scheduling an appointment - while recognizing the fact that the patient may not be able to follow the treatment recommendations.

The third challenge is quality related: in rural areas, healthcare providers are not always able to provide the “quality care” that is expected by people who describe themselves as “close, personal and interconnected.” In part, the inability to provide quality care is related to the economic issues such as those noted above. In addition to the economic restrictions, the directors of nurses noted other problems such as the inability to hire experienced rural nurses and the reduced levels of education among those who provide direct care. In most rural hospitals, there is a heavy reliance on aides and nurses with fewer than four years of academic training. Indeed, fewer than one third of

the nurses who responded to the surveys had baccalaureate degrees. When the lack of training is complicated by logistics such as working in three departments on a daily basis, the quality of care is reduced. The nurses who responded to one study seemed to recognize these issues; only 46 percent of the respondents wanted family members treated at their hospitals and those who believed that lines of responsibility were unclear were even less likely to want family members to receive treatment at the local hospitals.

The challenges associated with patient/clinician relationships, economics, and quality of care can lead to the fourth problem, loss of access or limited access to healthcare. If patients believe that relationships are not honored or if they do not trust the quality of care that is provided, they may be hesitant to use the services of a local hospital. If the patient census drops, the hospital faces financial consequences and perhaps even closure. During key informant interviews and focus groups, the participants spoke of “the guilt” that can accompany a decision to seek care outside the community. They recognized that if a rural hospital is forced to close, a countywide area may lose access to health care. Since the hospital is usually the major employer in the rural community, the community can suffer a “cascading effect on population, school enrollment, and local business.”⁴⁵⁴ Noted one hospital administrator: “we not only provide healthcare. We provide livelihood and a sense of commerce and business for this whole county. If we weren’t here, half of the businesses would not be in this community.”

These interrelated problems can place healthcare providers in a difficult predicament. If one only considers the emphasis placed on relationships and

“connectedness,” it is hard to understand why most of the nurses who responded to the surveys were hesitant to “take action” when encountering ethical problems. These nurses know the importance of relationships. Most have lived in their communities for more than 15 years; they know their patients. Their lives intersect in churches, schools, 4-H clubs, and little league teams; they may be related to one another.

The nurses, however, are faced with competing priorities and know that they have to be careful. Actions such as questioning the hospital’s resource or allocation policies or questioning a doctor’s orders could create organizational conflict. If tensions exacerbate or if the hospital’s financial problems increase, the nurses have few options for alternative employment. In the Dr. Philadelphia story, Ruth Jones experienced a number of issues that emerged in the research findings. She was connected to community members and felt protective of those relationships. Ruth knew Mrs. Peterson quite well. She was not certain that care decisions had been appropriate but did not know how much information she should share with the Peterson family. Ruth was unsure of some of the doctor’s orders and to an extent, confused about the lines of responsibility, and her role on the patient care team. She tried to reassure Mrs. Peterson rather than share concerns or seek action. Ruth’s experiences were not unusual. As one nurse explained during a key informant interview: “You have to think about it [taking action] if you want to be here until you retire.”

Perhaps those four interrelated ethical challenges make the cultivation of relationships so essential in rural areas. The realities of rural life - the resource scarcities, the potential for adverse outcomes, the inability to guarantee high quality

services, and the need to rely on one another for assistance in many circumstances - all shape the context of care. They require a level of involvement and a commitment to relationships that might not be as rigorously enforced in a more urban situation.

The influence of these contextual features - and the search for a fair resolution - was underscored by an example offered by an administrator in one community. The case involved a premature baby who was born to a young family with long and deep connections to the community. The physician who was providing care had multiple connections to the family. The infant was thriving but the physician believed that risk factors associated with prematurity indicated that a shot of gamma globulin should be provided. Such a shot costs approximately \$1000. The family had no health insurance and no way to pay for the medication. The hospital pharmacist was concerned when asked to order the shot. He was a close friend of the physician and also knew the family. He knew that the baby should be given the shot. He also knew the hospital could not afford to provide the medication if there was no reimbursement. The hospital pharmacist and the physician met with the hospital administrator. The administrator noted that since the situation was not “emergent” the hospital was not obligated to provide the service.

All of the key parties realized, however, that such a legalistic determination would not “sit well” with the community. The decision to deny the medication could also reflect poorly on the hospital administrator. He felt quite well accepted by the community but noted that he had lived there for only five years and so was considered a “newcomer” and was not yet entirely trusted. After some “wrangling,” a plan of action was initiated. The hospital administrator contacted a pharmaceutical representative who worked with the

parent company; eventually the rural hospital managed to get the needed medication donated to the infant. Those who described the situation noted that it took a lot of time and effort but all parties involved were well pleased.

That story about a successful intervention in a rural community offers an important lesson for Dr. Philadelphia. In part he was resented, not for his lack of expertise, but for his perceived lack of caring. Community members and patients were not certain of his commitment to community-wide connections. As the more seasoned Dr. Wiseman realized, the story about Mr. Peterson was less about medicine and more about culture.

Indeed, Dr. Wiseman was probably correct when he said he would not be blamed if his patient died. Local people had confidence in what they termed his “common sense.” Likewise, the data from the studies indicate that when relationships were honored, people were tolerant, even when personal goals could not be met. A number of representative comments illustrated that point. Said one physician: “I realized that if I was *genuine* that I would be forgiven whatever mistakes I made.” A patient who defended his physician said: “he didn’t know a lot, but nobody knew a lot back then from what I’ve discovered.” Another patient noted that if physicians care about their patients, rural people “support them [doctors] and go back to them and will never just write them off just because they made a mistake. Because they are human beings.” A testament to this level of acceptance was offered by the patient who acknowledged that his doctor was an alcoholic but said “that doesn’t make him all bad.”

However, as the story about Dr. Philadelphia illustrates, the reverse was also true.

When relationships with patients were not honored, the levels of scorn, skepticism, and hostility were clearly apparent. A number of comments from surveys and interviews were instructive: “he never learned who we were;” “he should go back to where he came from;” “he was growing a practice at the expense of good decisions for his patients;” “he didn’t last very long;” “I’ve seen how he treats his horses;” “I told my doctor don’t you ever refer *anyone* to that guy again;” “my patience with him is as short as a mutt’s hind leg.”

CHAPTER V
WALKING ON WATER

“Sometimes I feel like this hospital is having an identity crisis,” explained the rural physician. We are not exactly sure who we are or what we should do. Over the past ten years, the town and the hospital have both grown. We have some new physicians and we can offer some of the cutting-edge technologies. But all in all, we are still this little facility in this little valley; and we are surrounded by other little towns. In terms of culture, we have these old values and connections, these old ways of doing things. We value relationships. We try to take care of our own. We like practical, common sense solutions.”

“I don’t know if the problems we face are ethical dilemmas. I have never taken an ethics course. But I know that the problems we encounter cause a lot of distress. Are you doing good if you give the patient a prescription, but know he could never afford to get it filled? Sometimes I wonder what it means to “do good.” We saved a kid with a severe head injury, but he has never regained consciousness. The medical bills are so huge that the family has nearly lost the ranch. We all feel guilty when we see his parents because we know what has happened. Did we do good for that family or did we cause them great harm?

These kinds of issues get all mixed together. Now the government says that when someone is dying, we have to ask family members to donate organs. I understand why the government wants to help those who are waiting for an organ transplant. But more than 30% of the families in our community are uninsured. If their family members

needed organs, they would not be placed on waiting lists for organs. The whole system is pretty overwhelming. We keep trying to do what is right, but we cannot walk on water.”

To some extent, the problems referenced by the rural physician clearly evidence philosopher George Agich’s belief that problems develop in healthcare settings, “not because rights are violated or morally repugnant decisions are made, but because of genuine existential confusion and frustration.”⁴⁵⁵ Problems develop because of poor communication, misunderstanding, and suspicion; they grow from personal incompatibilities and the angst associated with technology.⁴⁵⁶ These kinds of problems - regardless of whether they occur in rural or urban environments - create considerable stress. In fact, national trends indicate the stress associated with the provision of healthcare is increasing and that healthcare providers spend more time trying to resolve the stressful episodes that emerge.⁴⁵⁷

The field of bioethics has responded to these diverse, ethics-related challenges by developing an academic speciality, a cadre of well educated, media-savvy moral experts, national conferences, books, journals, internet sites, and institutional ethics services like ethics committees and case consultation in hospitals across the United States. As noted by DeVries and Subedi, there is a plethora of seminars that offer training in bioethics and bioethics courses are a regular part of the curriculum at universities, colleges and medical schools.⁴⁵⁸ Ostensibly, this wealth of resources ensures that sufficient attention will be given to the moral dilemmas that accompany the provision of healthcare, and that healthcare providers, patients, and families will know how to respond when problems develop. In fact, as one commentator noted when reviewing an article on this rural

bioethics research: “Given all of the resources on the internet, it seems impossible to believe that rural healthcare providers lack access.”

Most rural healthcare settings, however, do not fit the national profile. Indeed, most rural hospitals have neither formal resources like ethics committees, nor the “proper theologians and proper philosophers” who are dedicated to, in Jonsen’s words, “thinking, writing and teaching about a subject like bioethics.” Given the field’s traditional emphasis on disciplined reflection, proper language, rigorous methodology, and appropriate academic training, the legitimacy of the expertise available in rural areas may be discounted. As was noted previously, two commentators, Spike and Greenlaw, have suggested that the use of a nurse with a Masters degree in ethics as a consultant to an ethics committee could “compromise the integrity of the field.”⁴⁵⁹

Even if the expertise of rural providers was not questioned, the identification of their problems as “ethical” may be. Some commentators insist that the issues identified by the research participants - resource limitations, moral distress, a compromised work environment, familiarity, a lack of understanding about treatment and diagnosis - are not ethical problems and should not be classified as ethical problems.⁴⁶⁰ They suggest that such problems should be classified as psychological, anthropological, or sociological in nature.⁴⁶¹ Indeed, that very point has been made by the review panels that have considered grants relative to this rural bioethics research. The critics have often emphasized the need for “more careful distinctions” between issues that are “ethical” and those that are “morally distressing.”

These formal distinctions about the “realm of ethics” have created some specific

problems. They have produced, as claimed by Rosenberg and Stevens, a focus on “narrowly defined” and technological concerns. Thus issues like cloning, organ transplantation, or core competencies are vigorously debated in the bioethics literature and analyzed at high profile conferences. Those distinctions have also influenced the way that dilemmas are analyzed. The case studies published in journals and books often cite normative foundations and base decisions on a doctrine of rights⁴⁶² or one of responsibilities.⁴⁶³ Indeed, the bias against a more contextual approach is so great that Fox and Devries assert that even the commentators who authored chapters in the text *Bioethics and Society* “wear the same blinders” as the more traditional bioethicists.⁴⁶⁴ They try to discuss more issues from a contextual perspective, but lack sociological reflections on their own work.⁴⁶⁵

Finally, the formal distinctions about the “realm” of ethics have also influenced the way services are visualized. Ethics committees and case consultation - interventions that typically require advanced training - are typically offered as the appropriate models for service. Few have questioned the relevancy of this overall vision in rural areas. In fact, some grant reviewers have bluntly stated that tele-medicine could solve rural problems related to access and when, in the next ten years all healthcare providers have received academic training in ethics, issues related to expertise will also be resolved. Certainly, noted one reviewer, the newly trained physicians who move to rural communities will want and will demand services like ethics committees.

Instead of resolving the problems that develop in rural areas, those approaches heightened the “dis-connect” between academic theories and rural problems. Rural

healthcare providers have a different angle of vision. They are not interested in formal argumentation and see little relationship between that kind of academic discourse and the appropriate clinical pathways or “best practices” for ethical conduct in rural hospitals. Thus, as was noted by a typical research participant: “From what I can tell, bioethics seems pretty irrelevant; there is no budget line item for it in our hospital.”

This discrepancy between academic discourse and rural practice was clearly articulated by a rural healthcare provider who contacted the rural bioethics project with a request for assistance. He noted that his hospital had created an ethics committee. The committee, however, was not functioning very well. He explained that “the committee members often miss meetings; sometimes only a couple members will show up.” Meetings, he said, were rarely productive. Some folks thought that training would help, and so two people went to a bioethics summer institute. Now the committee, he noted, is “doing worse than ever. Committee members try to understand and differentiate between what is an actual ‘ethical’ issue and what is emotional care-taking.” The struggle to meet the formal definition of an “ethical issue” leaves the committee members discouraged and frustrated. The problems that are most distressing for patients and for healthcare providers do not get discussed or resolved, the overall hospital environment does not change, and there is “absolutely no incentive for physicians or other hospital staff to contact the ethics committee.” He closed the letter by asking: “What should we do?”

The comments of the rural healthcare provider evidenced a number of common rural problems. Rural residents are less likely to encounter the “narrow” or technological concerns that are vigorously debated by academic bioethicists. They are more likely to

encounter an array of *broadly* defined issues that have clinical, organizational, and personal ramifications. The rural problems will, in all likelihood, involve failed processes, lack of resources, mistakes, unclear communication, and intentional oversight.

Examples of these broadly defined events include:

- ▶ the scheduled dose of a morphine derivative, prescribed for pain, was administered by 3 different nurses; the patient suffered an overdose and emergency treatment was required.
- ▶ an orthopedic surgeon performs surgery at a rural hospital one day each week. When a patient tried to stand after hip replacement, the hip fractured. The physical therapist and other hospital staff did not realize that the patient's pain was related to another fracture. The fracture was not diagnosed until the surgeon returned a week later; by that time, other serious complications had developed. During the interim, the patient was not seen by another physician because there was no orthopedist on staff.
- ▶ a nurse was uncertain how to carry out the physician's orders but noted that she did not contact the physician and clarify instructions because he "doesn't like to be called." She was afraid that the physician, if called, would complain about her lack of skills.
- ▶ A nurse suspected that a patient, authorized for discharge, had acquired a bladder infection during the hospitalization. She did not inform the patient nor did she talk to the physician about the potential infection because the hospital would be required to provide additional, un-reimbursed care if the

infection was “hospital- acquired.” The need to provide such care could compromise the financial solvency of the rural hospital. She believed that the administration “did not want her” to register her concerns.

These kinds of practical, bedside issues are rarely discussed in formal bioethics books, journals, conferences, or even in ethics committees. Assuredly some of the problems that develop may not meet the technical, academic definition of “bioethics” as it is defined by Jonsen and other scholars. These problems, however, compromise the quality of care and may increase the risk of error and adverse events.

The Pequod II

When one considers that list of problems, the usefulness of approaches that involve delineating bioethical issues in terms of narrow and specific categories, or arguing positions based on a doctrine of rights⁴⁶⁶ or one of responsibilities⁴⁶⁷ become suspect. Such approaches do not help rural healthcare providers solve the dilemmas they encounter. The rural problems are cultural and ethical, but they are also historical, psychological, and sociological. Some of the problems have economic consequences and most are part of the fabric of everyday life. They involve the practical considerations of where and how families wait for care, how patients and families are given bad news and asked to make decisions, the way cultural diversity and staff relationships are handled.

When rural healthcare providers talked about the moral values associated with healthcare, they rarely referenced singular principles like justice, autonomy, beneficence, and non-maleficence. They did not cite the ideas of Immanuel Kant or John Stuart Mill.

Certainly the lack of any reference does not mean that those principles and individuals are irrelevant. It does suggest, however, that rural residents use a different framework to describe their moral values.

For example, most of the research participants would probably vigorously contest Spike and Greenlaw's assertion that the wisdom of the bioethics consultant is more important than the character.⁴⁶⁸ Rural residents suggest that wisdom and character are inextricably linked. A good doctor is one who knows his craft and has the personal attributes that allow him to serve the people. When talking about the qualifications for bioethics consultations, Spike and Greenlaw associate wisdom with specific professions - doctors, lawyers, and philosophers. The rural residents were suspicious of the "wisdom" and the moral superiority that accompany a given profession's claims of knowledge, great social importance, and ethical rigor. Wisdom flows more from character than from a profession. Healing exists in proportion to the relationship. Again and again, rural residents affirmed the notion that the wisdom of a healthcare provider - and the ability to trust that provider - is evidenced by one's character.

Similarly, a principle like justice is certainly important. But justice involves compassion and kindness, mercy, and a love of humanity. Embedded in justice is the notion that people are not turned away from the hospital or the doctor's office when they need care, that those who may be able to help quickly respond when a problem develops, that postoperative complications will be recognized, and that mistakes will be honestly acknowledged. Justice is translated into action when community members, regardless of their professions, join together and "build the hospital, paint the walls and lay the carpet"

so that those who need help will receive it.

In a similar vein, rural residents value concepts that the field of bioethics links to autonomy. But those concepts do not involve a Patient's Bill of Rights, The Patient Self Determination Act, or the Required Request for Organ Donation - the latter which ostensibly ensures that every potential donor will have an "opportunity" to donate. Autonomy involves the extent to which a family understands what the healthcare provider is saying so that an informed decision can be made. It involves the extent to which an environment may be experienced as coercive. Concepts like an informed decision and freedom of choice for an individual can only be understood in the context of a family and a community. Thus autonomy involves the recognition and acceptance of the values of others, rather than - as was evidenced by Dr. Philadelphia - rigid adherence to one's own.

Admittedly, the rural residents were not certain how one would define the words "ethics" or "culture," but they spoke articulately about their way of life, about the importance of connections, and a willingness to "care for our own." Most of the research participants believed that ethics was different in rural areas. Those differences, however, were not easily described in academic terms - they were threaded into the fabric of their lives. As one person explained, "if you have to ask how we're different, you missed the boat."

This perception of "differences that are hard to describe" creates an interesting problem. When the rural bioethics studies were initiated, some of the collaborators in the Greenwall consortium hoped to create a theoretical framework for "rural bioethics." They questioned the "tightly defined framework"⁴⁶⁹ that the enterprise of bioethics has

traditionally offered. They agreed with the critics who claim that a tightly defined framework is inherently limited and thus may be neither applicable nor appropriate in diverse social and cultural contexts.⁴⁷⁰

The search for a theoretical framework for rural bioethics, however, may be inappropriate for two reasons. Some of the issues that surfaced in the rural studies may also be experienced in urban and inner-city environments. Indeed, a number of bioethicists like Jonsen and Siegler have broadly suggested that clinical ethics should consider - among other things - the preferences, values, and goals of the physician and patient.⁴⁷¹ How such “consideration “ is effected, however, is an issue that should be evaluated by urban as well as rural residents. Secondly, rigid theoretic approaches are rarely amenable to diverse cultural realities - and rural communities can be quite culturally diverse. Thus a more helpful response may be one that reduces the gap between theory and practice, that focuses less on theory and more on processes that affirm the abilities of diverse groups to willingly engage in conversations about their morally challenging issues.

Charting a Different Course

This more practical vision for rural bioethics cannot be realized by simply offering more technology like tele-medicine, or ensuring that every healthcare provider receives academic training in bioethics. Rather, it requires a greater awareness of broadly defined, bioethics-related issues, acceptance of personal responsibility for actions and choices, and a willingness to take action. Such an agenda is steep, though not insurmountable.

Efforts to increase the awareness of ethics-related issues are a logical first step. Most rural healthcare providers have received little or no training in bioethics and initially found it hard to identify or discuss ethical issues. Many of those who had received training did not judge it to be relevant to their rural practices. Nurses, for example, said that they needed training to help them recognize ethics-related dilemmas and “words” to help them talk about the issues they encounter with patients and with other members of the healthcare team.

The need to respond to this request for “words” and opportunities for dialogue cannot be overemphasized. Healthcare providers and patients believe that the failure to respond to “ethical issues” they defined as problematic - relationships, personal values, cost containment - compromises healthcare decision making in rural communities. Given the pace of change within the healthcare system, the range of problematic issues they encounter will probably increase rather than decrease. For example, rural residents stressed the need for healthcare providers who share their cultural expectations. However, if rural residents do not learn how to create mutually supportive relationships with new physicians like Dr. Philadelphia, they may not find physicians who will work in their communities.

In order to increase the awareness of ethical issues, a number of resources have been field-tested in 30 rural hospitals throughout the past 30 months. When developing resources, every attempt was made to meet the criteria established by the rural residents. They wanted resources that are: linked to their practical concerns, intellectually accessible to persons with diverse educational experiences, non academic, and interactive. They

want resources that offer options for taking action.

The request for those kinds of resources makes sense, given the findings associated with cooperative learning strategies. Some theorists suggest that people learn 10 percent of what they read as opposed to 70 percent of what they talk over with others. Learning is further enhanced when materials are used in some way and shared with others. When materials are used in daily life, retention increases to 80 percent.⁴⁷²

In general, the resources that have been developed and provided to rural healthcare settings have been well received. Rural healthcare providers have given high ratings to case studies that are based on real clinical situations that develop in rural settings. They have responded favorably to the interactive critical thinking tools that accompany the case studies and support discussion of decisions, strategies, and action steps. Healthcare providers have also endorsed a bookmark, an ethics map, a chart form, and fact sheets that involve topics like medical errors, patient rights, professional duties, and other ethics-related issues.

They have been very enthusiastic about the usefulness of case studies that have been turned into scripts for the readers theater. One nurse noted that a number of people from rural communities in her state met to discuss an upcoming bioethics conference. As part of the planning session for the conference, they decided to read the Dr. Philadelphia script. Moments later, the hospital administrator joined the meeting. He had never been very supportive of what he termed the nurses' "ethical concerns." After the script was read, the participants began to discuss the various issues. The administrator joined the discussion and announced, with enthusiasm, that "at last I can see what you are talking

about.” He then wanted to make sure that the script would be used at the upcoming ethics conference.

Some of these resources have been provided through the internet, and that approach appears to be an effective model for dissemination. Using the internet promotes the participation of rural healthcare providers who live in distant communities, far from interstate highways and learning institutions, and across several time zones. The difficulty of providing ethics-related services in such a diverse area was captured by the nurse who endorsed the use of web-based resources and noted: “With the distances we encounter in the rural areas and the shortage of personnel, it is difficult for them [nurses] to travel to workshops and seminars, pay for the cost involved, or allow staff to be away from their work site. An on-line resource in rural bioethics solves many of those problems.”

Given such interest, the array of resources available through the internet should be expanded. A platform like Blackboard could be used to offer healthcare providers resources such as case studies, chat rooms, multi-media presentations, video streaming, and a virtual library. Options that include chat rooms and list-serves could offer some novel ways to strengthen relationships and promote an understanding of rural culture. Links could be developed to inform rural healthcare providers about other potential resources such as the comprehensive accreditation manual developed by the Joint Commission of Accreditation of Healthcare Organizations. Though most rural hospital do not have JCAHO accreditation, that text has some useful information. Physicians and allied healthcare providers who are unfamiliar with rural environments could dialogue

with established peers who enjoy successful rural practices. On-line mentoring relationships could be nurtured during residency and in nursing programs and could continue into the early years of practice. Such a strategy could help the newer physicians and nurses find a way to negotiate the boundaries between personal, organizational, and community needs and expectations.

If this internet approach is going to be viable, however, two issues need to be resolved. The first issue is financial - the development and maintenance of such a web site requires some financial resources. Rural hospitals have limited resources and many have never budgeted funds for “ethics.” The second issue involves orientation. Those who develop the resources and coordinate activities and suggestions cannot use what has been perceived as the typical academic approach. If the web based resources are perceived as overly academic, impractical, or irrelevant, they will not be used.

Serious consideration should also be given to the development of ethics-related resources that are useful for patients and community members. That constituency needs opportunities to dialogue with healthcare providers in order to define and accept a hierarchy of shared values. The old vision of ethics as “too lofty for public discourse” is no longer appropriate. Community education could be pursued through resources available on the internet or through “real time” interactive activities like readers theater. This approach, briefly referenced in an earlier paragraph, was developed by the East Carolina School of Medicine. It is non-threatening and accessible to audiences with varying degrees of academic training.

The “readers” for this activity use a script that has been adapted from a short

story about a medical issue. Each reading lasts approximately 30 minutes. The readings are followed by discussion among the “actors” and audience members. This model has been popular in rural communities; it is inexpensive, inclusive, and encourages dialogue and reflection about issues that are important to people who live in rural areas. In fact, when a script based on Dr. Philadelphia was presented to two groups - residents of a small town and Native American students from several reservations, both groups were certain the story chronicled activities that occurred in their community. In fact, the students were certain that the story was about reservation healthcare.

If a readers theater is presented as a joint hospital/community activity, it could help someone like Dr. Philadelphia learn the rules for living in a rural town; it could also help the other healthcare providers and the community members clarify and re-evaluate their expectations and ethical responsibilities in light of the changing healthcare environment. As was evidenced by the case study presented in the previous chapter, patients did not trust Dr. Philadelphia, but did not know how to resolve that issue. Dr. Philadelphia believed he was providing competent services and did not understand the reasons for the growing tension within the community. Members of the community made limited efforts to help Dr. Philadelphia. Interestingly enough, when the story was presented to the different groups, most participants agreed that without some specific “intervention,” no one would inform Dr. Philadelphia of the rules.

If unresolved, the inability to find shared values - regardless of the specifics of a problem - will become increasingly problematic. This will occur, in part, because the “new medicine” has dramatically changed the way that healthcare is provided. The

restrictions posed by corporate medicine and the evolving roles of primary healthcare providers - like that of the gatekeeper - require physicians and other healthcare providers to build relationships with patients in which power can be shared over time.⁴⁷³ According to the bioethicist Haavi Morreim, this sharing of power requires patients to assume substantially greater responsibility for decision making.⁴⁷⁴ To expect anything less of the patient, Morreim notes, is to regard the patient as something less than a moral agent.⁴⁷⁵

Identifying Approaches

When one considers the lack of ethics-related resources in rural communities, the interventions discussed thus far are an important, practical, and affordable “first step.” At the same time, an increased awareness of bioethics-related issues may not foster either the acceptance of personal responsibility for actions and choices or the willingness to act. After all, the profession of medicine has endorsed principles such as beneficence and non-maleficence for years, and yet the profession has not seriously considered the specific practices that should be encouraged so as to reduce the medical errors and mistakes that compromise patient care.⁴⁷⁶

Medicine cannot be cited as the only culprit. This search for a process that will create an ethical environment reflects a long standing tension within the discipline of ethics. As noted earlier in this work, the tradition of analytic philosophy has emphasized the need for conceptual as opposed to empirical analysis.⁴⁷⁷ In fact, there is a scepticism of people who “only want answers.” Thus issues like the efficacy of case consultation, the implications of “bioethical wisdom” on public policy, and the protocols for teaching

ethics to hospital staff have not been empirically examined to any great extent.

Even the commentators who call for a more expanded vision for bioethics provide very few specifics. The books, journals, and internet resources that are currently available have not offered much practical guidance. Commentators have offered conceptual ideas. Pernick notes the need to think outside the box. Rosenberg, Light, McGee and others call for a more contextual approach and the inclusion of economic, political, cultural, and historical factors. None of these commentators, however offer any specifics as to how this new vision can be accomplished. DeVries and Fox seem well aware of this deficit and note that even the bioethicists who call for sociological introspection fail to cast a sociological eye on their own work.⁴⁷⁸ Thus the discussions about ethical problems remain a priori, rather than empirical. Even in the SeVries and Subedi text, a work formed exclusively around the need for a more sociological approach to bioethics, no specific details or empirical studies of possible approaches are cited.

That lack of specificity increases the chasm that separates theory and practice; as such, it heightens the dis-connect between the field and practicing healthcare providers. The rural healthcare providers have said that the materials, provided through this research initiative, helped them recognize “ethics-related “ problems. Many, however, still claimed that they had “no idea what to do” when problems actually developed. Since they didn’t know what to do, there was a hesitancy to take action. Most did not discuss ethics-related issues with peers or with patients.

Therein lies the challenge. In order to encourage both acceptance of personal responsibility for identifying ethics-related issues and a willingness to take action, rural

healthcare providers need to believe that they can not only *recognize* the failed processes that occur in rural settings, but they can *overcome* the organizational and cultural barriers that inhibit discussion of those processes. They need to believe that they can create a workplace environment that actively encourages the recognition, disclosure, and resolution of ethics-related issues. When those three objectives - recognizing, overcoming and creating - are in the forefront, ethics is no longer a “theoretical” or unimportant consideration. Ethics becomes linked with practical behaviors that help resolve insistent problems.

Those three objectives are not strictly “philosophical” or “medical” in nature. As noted by the psychologist David Woods, many of the dilemmas and problems that accompany the provision of healthcare are problems of psychology. Systems need to be designed with human factors in mind.⁴⁷⁹ People need to cultivate skills that help them embrace change in a purposive manner. Of course DeVries and Subedi suggest that those same general problems and dilemmas underscore the need for sociological approaches; Rosenberg would cite the historical perspective that should be considered..

While the commentators argue about the vision for a conceptual focus, we are left with an empirical problem - what works? Figuring out a practical way to cultivate the needed skills - without relying on quasi-urban approaches like a cadre of “rural facilitators” - is a daunting task. Much to the philosopher’s dismay, the methodology for such an initiative may need to rely more heavily on insights from psychology, sociology, history and other disciplines than from that of philosophy. A movement toward a truly interdisciplinary approach requires quite a paradigm shift for most bioethicists since

fields like psychology and sociology, to date, have played a very peripheral role in the development of the bioethics enterprise. Neither field, for example, is typically referenced as a helpful resource when analyzing bioethics-related problems.

Rather, as was noted by the philosopher Robert Solomon, the field of bioethics has traditionally stipulated that one is to avoid emotions and concentrate more rigorously on the time-honored methods of philosophic argumentation.⁴⁸⁰

Thus the potential resistance, within the field of philosophy, to more practical approaches may be vigorously contested. Some indication of the depth of the evolving debate was noted in the DeVries and Subedi text. The authors reference a discussion involving the withdrawing of medical care for financial reasons. In this discussion, a noted philosopher vigorously refuted the legitimacy of all of the information provided by the sociologist who was discussing healthcare problems experienced by the poor; the philosopher triumphantly noting that the sociologist's technical definition of "withdrawing care" was inaccurate.⁴⁸¹ The philosopher, suggests DeVries, was philosophically correct and sociologically wrong.⁴⁸²

As the philosopher's comment silenced the sociologist, so too, the time-honored methods of philosophic argumentation - while praised by the discipline - have discouraged discussion and resolution of ethics-related issues in rural healthcare settings. In all of the rural studies, healthcare providers suggested that they hesitant to talk with one another and with patients about "ethical" concerns. Issues that have a serious impact on patient and family decision making - like differences in the interpretation of a "do not resuscitate" order or restricting the use of pain control medications during labor and

delivery - had never been explored by members of a given healthcare team. When formal institutional services like ethics committees were available, physicians and nurses did not use them. In some cases, respondents reported that ethics committees existed in their hospitals, but they did not have access to them. Case consultation was uniformly perceived as unhelpful by the majority of respondents.

Those issues suggest the need for a different approach to bioethics services, one that loosens bioethics from its current philosophical moorings while resisting the urge to create a rigid theory, a new jargon, or a new set of experts. Without a doubt, the “fix” for rural bioethics is not going to be accomplished with a single solution. The modern enterprise of bioethics has reached its present state over a 50 year period. A period of trial and error in rural areas should be expected and encouraged.

Since I have been quite critical of the current philosophical approach to bioethics, I am hesitant to formally offer any suggestions for an alternative approach. Any alternatives that are suggested may prove as flawed as the current model. At the same time, the research studies conducted over a four year period indicate that rural healthcare providers are sincere in their requests for practical resources. They have voluntarily participated in the research and spent months field testing resources. Requests for resources are received on a weekly basis. For example, the director of nursing from one of the more “urban” hospitals in the research area recently requested more bookmarks and wondered if the moral distress scale, provided on the bookmark, could be used as a “clinical indicator.” She also noted that two committees were currently “sharing” the bookmarks and, because the bookmarks helped them find a common language, wanted to

offer a bookmark to each committee member and to the hospital social workers. The requests for resources are not limited to the US. A number of requests have been received from hospitals in Canada, Australia, and England. Because rural healthcare providers have asked for specific suggestions, that suggestion that they simply use interventions like focus groups to clarify different perspectives and find their own solutions seems unfair. A blueprint with a little more detail seems to be needed.

Given those considerations, a number of approaches might be considered. I will offer, as an example, an approach to resource development that uses the *insights* of systems theory, strategic therapy, and other modes of change well documented in the psychological literature. I am not specifically endorsing a “system theory” approach. Rather, I am merely suggesting that option as an example of an approach that might be helpful because system theory incorporates factors that rural residents perceive as important: (a) cooperation as opposed to superiority, (b) the quality of relationships between and among individuals, and (c) the need to achieve cultural compatibility or the “right fit.”

Those three factors - cooperation, quality of relationships, and right fit - appear to be essential ingredients if one is going to create pathways that link problems to solutions. Further, an approach like that of systems theory seems to meet the “context” test - it is flexible and adaptable to a variety of settings. It can be structured to focus on tasks that are within the community’s repertoire and experience⁴⁸³ and maximize the strengths of those directly involved in a given situation.

Understandably, some within the enterprise of bioethics might question the value

of such an approach. The use of insights from systems theory seems a far cry from the formal, theoretical, philosophic foundations that initially shaped the field of bioethics. Similarly other fields, like that of nursing might express resistance. For example, the reviewers of a recent grant criticized the proposal for not providing a clear enough distinction between the precise ethics education given to nurses as opposed to the ethics education provided to other cohorts. The reviewers missed the entire point about the importance of common language and common experiences. They had more confidence in “academic rigor” that linked moral superiority with a particular kind of training.

Instead of using time-honored approaches like ethics committees, consultants, core competencies, or formal academic programs, the emphasis is placed on specific sequences of people and events within a specific context. As the psychologist Steve de Shazer explains, strategic or solution based therapy is based on the “theoretical assumption that behavior, which occurs as a part of ongoing interactional recursive events, can only be understood in context.”⁴⁸⁴ Thus I am not suggesting an approach that is merely “psychological.” As was evidenced by the Dr. Philadelphia story, the problems that developed seem to maintain themselves because of the *context* in which they occur.⁴⁸⁵ That context, as Rosenberg and others so firmly assert, involves cultural, historical, economic and political factors.

Reading the Water

A number of examples could be used to illustrate how some “contextual” insights, from an approach like “systems theory,” could be used to help resolve some of the

problems that develop in rural areas. Those that emerged in the Dr. Philadelphia case exemplified a number of research findings and so that situation will be used as an example. Granted, Dr. Philadelphia did not envision his behavior as a cause for concern and may not want to make any changes in his behavior. This seems like a reasonable assumption. He came to a beautiful rural area to experience unique recreational and lifestyle opportunities and to provide what he believes are appropriate services for his patients. He encountered problems because he did not understand the contextual issues that shaped expectations for healthcare in his new community. For example, he saw little need to make interpersonal connections with community members. That perception was based on his personal experiences and, to an extent, protocols within his profession. In fact, Dr. Philadelphia seems to agree with a commentator like Portmann who likens the “caring partnership” that begins in health, lasts through recovery and endures until death as a Hollywood wedding script.⁴⁸⁶

The nurses and other members of the community responded to Dr. Philadelphia’s actions with a sort of passive resistance. They criticized his behavior, limited their interactions with him and, to an extent, fanned the fires of community discontent. If the nurses who are working with Dr. Philadelphia continue to complain and criticize him, more productive relationships between Dr. Philadelphia and the community are unlikely. In fact, increased discord is likely and it could create a new problem - it could drive a wedge between the nurses and the hospital administration because the hospital needs a physician with Dr. Philadelphia’s skills. Patients offered numerous complaints about the quality of care, but if those patients do not take any specific steps to change the nature of

their interactions with Dr. Philadelphia, the same old systemic dance will continue. Thus this dance has the following kinds of repetitive features:

1. Nurses and patients: “What’s wrong with Dr. Philadelphia? He is not connected to our community and he doesn’t seem to care about us.”
2. “I don’t know what’s wrong with the people in this community,” moans Dr. Philadelphia. “Their expectations are too high and they are trying to control my life.”
3. Nurses and patients: “Dr. Philadelphia doesn’t listen to us. It does no good to talk to him or ask him to explain his orders.”
4. “The inhabitants of this town are strange,” sighs Dr. Philadelphia. “The fishing is good, but I could never make friends with any of these people.”
5. Nurses and patients: “Doctor Philadelphia ignores advance directives. You know you’ll have problems if he’s involved.”
6. Dr. Philadelphia: “These people don’t know the meaning of a DNR order; they don’t know what that order means in the overall context of an advance directive.”
7. Community members: “You can’t trust the local hospital. We have to travel elsewhere to get care.”

A process could be designed to help change those patterns. In order to envision a framework for thinking about the different perspectives, deShazer has used the imagery of a visitor, the complainer, and the customer.⁴⁸⁷ That imagery is certainly not “foreign” to rural healthcare providers or other rural residents. They encounter all three types of

people and to an extent, have perceptions about those types of people. Dr. deShazer describes the visitor as a person who likes to talk about life, but has no interest in personal changes of any kind. In the story that was presented, Dr. Philadelphia would probably fit the designation of a visitor. He sees no need to make personal changes. The complainer is upset and is clearly able to voice his/her concerns about a situation, but is not yet ready to take specific steps towards change. Some of the patients and other healthcare providers in Dr. Philadelphia's community meet this designation. The customer is a person who is clearly "ready to buy," and willing to take steps to make things better. In the Dr. Philadelphia story, no clearly identified customers had yet surfaced.

Thus it is important, at the outset, for those involved in the situation - regardless of the specific problem to be resolved - to identify themselves and their roles in the situation as well as the changes they would be willing to make. In the example provided in this narrative, the situation could be changed if people change their behavior and their interactions with Dr. Philadelphia. Since Dr. Philadelphia, at least initially, has only a limited understanding of the problems, the burden for such change initially falls on the nurses, other healthcare providers, and patients who are have relationships with Dr. Philadelphia.

A Whale, Re-visited

At the outset, those involved in a difficult situation have to be willing to look for situations that present exceptions to the negative interactions they usually experience.

When the healthcare providers and community members talked about Dr. Philadelphia, for example, some mentioned small things that were going well. One person noted that Dr. Philadelphia was “making some adaptations.” Clearly, there are some nurses and patients who have better experiences when interacting with Dr. Philadelphia. If so, these situations should be identified with the clear intention of identifying and doing more of what “works.” By focusing on successes, the rural residents might be able to identify a range of different behaviors that could create connections and enhance relationships. These behaviors or strategies may be quite different from those identified in the standard bioethics texts. In rural areas, the strategies might involve the use of humor, or invitations to ride horses, go hunting, or participate in haying. Instead of avoiding Dr. Philadelphia, persons would be encouraged to actively engage with him and use those opportunities to acquaint him with the local rules and norms. An emphasis would be placed on awareness of past patterns and a willingness to change the old dance.

Secondly, in order to strengthen this notion of doing something different, the rural residents could be asked to envision what their hospital would look like if the situation with Dr. Philadelphia was much improved. This exercise could be used as a way to link their suggestions with the practical concerns they face, such as where and how people get care, how patients and families are given bad news and asked to make decisions, and relationships among staff members. Each person involved in the situation could contemplate the changes he or she would make and what they would do to create a context in which the changes they envision could be sustained. How would people treat each other? What would they notice? What would change?

When used as part of an approach for creating an ethical environment, this exercise is a way to envision “ethics” as the indicator of the health and richness of a place. Healthcare providers could be encouraged to identify their concerns and then watch to see how they could take action in ways that change the environment. To sustain the changes derived from this new environment, techniques like assertive communication could also be considered. In effect, the residents would look for new ways of talking about issues. This approach could be generalized so as to resolve not only a Dr. Philadelphia-like problem, but other practical considerations as well, the bedside dilemmas typically described by the rural healthcare providers and community members.

This kind of model is doable in an environment where people know and are connected with one another. If the nurses decide to look at the situation differently, or if key members of the community experience the situation differently, the greater community hears about it. Indeed, when the Dr. Philadelphia story was discussed with different groups, the members noted the central role played by the nurses and believed that someone like a director of nursing could - with some institutional support - be a very influential force for change.

In terms of dissemination, rural healthcare residents could be asked to identify successful strategies, and these could be incorporated into the readers theater scripts, case studies, and other resources distributed through the internet. Thus responsibility for change is given to those who have concerns, as opposed to relying on external expertise. Since the approaches could be tailored to respond to any given situation, each rural community is able to individualize its own intervention/change process, based upon local

values like cooperation, quality and right fit.

Upon first reading, the approach that has been suggested might not seem like a very powerful intervention. However, in a number of interesting ways, this approach appears to resonate with key findings from the various research activities and it has been well received in rural communities. When asked to identify ethics-related issues, the persons who participated in the interviews and focus groups initially faced some difficulties. When given the opportunity to discuss their experiences, they began to recognize ethically problematic issues that create ongoing stress. They identified a range of problems that had personal, clinical, and organizational components. As they examined their responses to the problems, they initially found it hard to identify how things could be “different” or what resources might be helpful.

However, when the research subjects were re-contacted several weeks after the initial interviews or focus groups, most subjects said the discussions were helpful and many identified the steps they were taking to change problematic situations. For example, during an interview a nurse explained that she felt very guilty when dealing with families who had experienced traumatic and unexpected deaths. She regretted “how much money it had cost the family” and the fact that “things didn’t go as well as expected.” During the interview, she said she “dreaded” seeing certain families and was afraid they blamed her for bad outcomes. After participating in the interview, however, she approached several families and talked about the care that was provided. She also started attending the funerals of patients who had died. Those relatively simple actions, she explained, significantly reduced her moral distress. Another nurse explained that a

physician had given an order to withhold information about a terminal diagnosis from a patient. After talking about the situation in the interview, the nurse realized that she could not, in good conscience, continue to lie to the patient. Some time after the interview, she met with the physician and assertively told him that she could not continue to deceive the patient if the patient asked a direct question about her disease and that they needed to find a different way to deal with the problem.

Three different interdisciplinary groups of healthcare providers realized, after participating in focus group meetings, that they had very different ideas about the meaning of a “do not resuscitate” order. Those differences had created emotionally distressing situations for all concerned, and yet none of the participants, in any of the groups, had explored their differences in perception with one another. Once they recognized these differences, healthcare providers wanted to take steps to resolve them.

Behavioral changes also occurred as a result of survey activities. A director of nursing called and explained that her hospital would like to use the 36 issues, listed on the nurse survey instrument, as a template for an in-service training program. The hospital had never offered an in-service training program to nurses, but after completing the survey, the nurses began to recognize and talk about the ethical issues they encountered on a daily basis. They wanted some resources and thought that an in-service program would be helpful. Similarly, hospital personnel indicated that the distribution of “ethics” bookmarks spurred a number of conversations. The directors of nursing suggested that the distribution of the bookmarks to hospital employees made “it safe to talk about ethics.”

To obtain more information about the approaches that might be helpful, healthcare providers in 30 rural hospitals were sent a revised story about Dr. Philadelphia. The revised story offered some simple, but specific interventions. The rural healthcare providers rated the story as “helpful” and have asked for similar case studies. They said the revised story helped them talk about issues they encounter and envision some specific things that they could do to resolve them. As noted previously, the story has also been developed as a script for readers theater. For the theater form, the story is told by a narrator and different characters. In the theater form, it offers a way to present research findings and interventions to healthcare providers as well as community groups.

The revised (though slightly abbreviated) story is provided. The interventions that are suggested are not complex. Without doubt, rural healthcare providers will probably identify a range of approaches that would be more helpful than those included in the current text. What seems important is that the story, though simplistic, provides a way to identify problems and envision solutions.

The Metamorphosis

The people of Two Rivers were relieved to hear that Dr. Philadelphia was moving to their community. They had been advertising for a new physician for several months. Their longtime physician, Dr. Wiseman, was reducing his hours and hoped to retire within a year. Community members were thankful that a replacement could be found. At the same time, many in the community realized that getting used to someone like Dr. Philadelphia could be a little difficult. Dr. Wiseman was a hard act to follow. He was

well loved; he had served the community for nearly 30 years, had good relationships with the nurses, knew his patients, and understood their expectations. Community members viewed Sam as both a physician as well as a dear and trusted friend.

Further, the community members knew, from first hand experience, that locating a new physician did not guarantee a long term commitment to their community. In the past few years, two other physicians had moved to their community, but had not remained. Other communities in the area had reported similar experiences. In some cases, the new physicians left the rural communities within a year or two. In other cases, the physicians stayed but patients were not satisfied with the quality of care and so traveled to other communities to receive healthcare services. The loss of local patients created a number of financial complications for the local hospitals.

This time the hospital wanted to take a more proactive stand, so the hospital administration created a Transition Committee. The Committee was comprised of Dr. Wiseman, the Director of Nursing, the hospital administrator, and several community members. When Dr. Philadelphia arrived in the community, he met with the Transition Committee. They discussed their expectations for healthcare services and identified areas where some complications might develop. Their concerns involved three different areas. The hospital administration was concerned about access to care and Dr. Philadelphia's willingness to provide on-call support to the emergency room. They talked about the range of problems associated with emergency room coverage and how those problems could be resolved. The nurses were concerned about how Dr. Philadelphia would honor the culture of care. How would he handle advance directives, especially when the

directive involved something like a “do not resuscitate” order. They also wanted to know how he would respond to their requests when they needed more information about a patient order or were concerned about the health status of a patient. The community members talked about the importance of relationships. They described their ongoing involvement with various hospital activities, their personal and professional relationships with other local healthcare providers, and the overall importance of mutuality and connectedness.

During the first committee meeting, everyone had a chance to discuss what they could do to facilitate Dr. Philadelphia’s move to the community. Dr. Wiseman agreed to serve as Dr. Philadelphia’s local guide. Dr. Wiseman noted that when he began his practice, it took him some time to get acquainted with the community and learn the local “rules.” He explained that the local rules were important and knowing the rules could save Dr. Philadelphia “a lot of grief.” The committee implemented a number of other proactive strategies. Committee members described how the town functioned and what kinds of problems typically developed. They talked about the importance of trust, the need to nurture relationships, and the unspoken rules for living in their community. Dr. Philadelphia frankly acknowledged that Two Rivers was a very different world. For one thing, he had never lived in a community where so many people had police scanners. Dr. Philadelphia agreed to meet with different members of the hospital staff on a monthly basis so they could learn about his procedures and expectations and he could learn more about their culture and their expectations.

The committee established clear guidelines for resolving potential problems.

When minor problems developed, those involved would directly contact Dr. Philadelphia. If more complicated issues developed, they could be referred to the Transition Committee. For at least a six month period of time, the committee agreed to meet on a monthly basis in order to keep lines of communication clear and resolve any recurrent problems.

In the meantime, Dr. Wiseman accompanied Dr. Philadelphia and his family to several community events. Since Dr. Philadelphia was interested in horseback riding, Dr. Wiseman encouraged him to join the local back country horsemen group. Through this activity, Dr. Philadelphia met some local ranchers as well as fishing and hunting guides. He learned that the “dual relationships” generally discouraged in the professional literature, were very much expected in rural communities. As one local resident explained to Dr. Philadelphia: “it takes a long time to trust and no time at all to lose that trust.”

Overall, the efforts of the committee were quite successful. When nurses had problems and questions, they knew that they had the authority to contact Dr. Philadelphia. Occasionally people would talk to Dr. Wiseman and he would take problems either directly to Dr. Philadelphia or to the committee for a group discussion. The Transition Committee realized that the Director of Nursing had a key role in making Dr. Philadelphia’s move to the community successful, and so the committee actively supported her efforts to serve as a positive role model. When the director of nursing observed that patients or nurses were having some problems with Dr. Philadelphia, she intervened and provided assistance. Nurses and patients were encouraged to use communication strategies that had proven to be successful when used by others. The

nurses were taught to identify issues, re-frame their concerns in a positive manner, and specify the alternatives that they thought were preferable.

The director of nursing also noted that *all parties* needed to reevaluate their expectations rather than simply expecting that Dr. Philadelphia would do all the adjusting and accommodating. She often used humor to model a different way of communication. If Dr. Philadelphia was abrupt when giving an order she would say something like: “Hey, Phil, you’re miles away from the turnpike. You moved to Mayberry.” When Dr. Philadelphia neglected to stop by a hospital room and visit a patient she called him and said: “Phil, I thought you’d want to know that you’re breaking one of our golden rules. Mr. Brown expects to see you. And, of course, he’s not the only one who is waiting for you to step into the hospital room - the whole Kiwanis Club, the ladies auxiliary, and the Little League team are waiting too.”

Things seemed to go fine until the day that Carl Peterson was brought into the hospital with his second heart attack. Dr. Philadelphia recommended that Mr. Peterson remain in the local hospital rather than being airlifted to the regional center. After writing orders for Mr. Peterson’s care, Dr. Philadelphia went home. The Peterson family was upset and asked Ruth, the Director of Nursing, if the right decision was being made. Ruth said she would immediately call Dr. Philadelphia. She called him and explained that “this is one of those cases where it is going to matter a great deal what we all do. This family needs to know that you really care and we don’t want them to feel abandoned. I understand that there may not be much that we can do, but we can spend a little more time with them.” She encouraged him to call Dr. Wiseman, discuss the case and

determine how best to allay the family's concerns. Dr. Philadelphia grumbled a little about small town politics but he called Dr. Wiseman and explained that he did not believe that Mr. Peterson would survive a helicopter ride to a tertiary care center. Dr. Philadelphia then returned to the hospital and met with the family. He told the family about his conversation with Dr. Wiseman, and they discussed all of the options that could be considered. After some discussion, all parties agreed that Mr. Peterson would continue to receive care in the rural hospital. Mr. Peterson died that evening, but everyone felt that they had done all that they could and there were no hard feelings among any of the participants. Dr. Philadelphia and the nurses attended Mr. Peterson's funeral, offered their condolences, and provided as much assistance to the grieving family as possible.

As Dr. Phil became more familiar with the community, the stereotype of the "outsider" faded and the people of the community engaged in real communication in the most positive manner possible. Of course there were problems, but the approach designed by the Transition Committee seemed to work well most of the time. In fact, when another new physician was scheduled to move to town, Dr. Phil offered to serve as a guide. He noted that without Sam Wiseman's advice, a great many mistakes could have been made.

This new Dr. Philadelphia story did not require difficult, heroic, or sophisticated actions by any of the participants. The characters in the story simply placed a priority on relationships, a willingness to talk, and a willingness to assume responsibility for one's actions. They were willing to lay aside power differences. In many respects, the

characters took the academic topics identified in the bioethics literature - patient/clinician relationships, autonomy, competency, beneficence, and justice - and placed them in the context of rural care. The context allowed them to envision a range of interventions. For example, the research data indicate that many nurses believe lines of responsibility are unclear. As a result, they are hesitant to take action when encountering ethical issues and are more likely to reassure patients than seek interventions. In this story, the nurse had organizational support for responding to the family's concerns and contacting Dr. Philadelphia.

Care in Context

In a sense, the revised story presented in this chapter restates a theme that has appeared in all of the vignettes presented in this work. Context matters, and in rural areas, the context of care matters a great deal. Charles Rosenberg recognized the importance of context when he stated that medicine is situationally negotiated and inevitably political, and that politics is cultural.⁴⁸⁸ The context of care gives shape and form to the moral dilemmas that develop. Context mattered when Mr. Peterson was dying of heart failure and it mattered in the story about a birth and a nurse who wondered if she should honor the dictates of the husband or the requests of the wife. The context of care was a concern to the hospital administrator who questioned the utility and cultural compatibility of an ethics committee. Context was an issue for the rural nurse who knew that the problems she encountered were distressing, but did not know if they would be considered "ethical" in nature. Context matters, and because it matters so much, the

ethics of care must be responsive to the context of care - the social, political, cultural, and economic values that imbue a situation.

This dissertation is a first step, an attempt to initiate a conversation about bioethics in rural areas. To date, that topic has received very little attention. I have responded to this information deficit by focusing on the problems that most commonly emerge and how they can be resolved. As such, I did not address a number of other issues that complicate the ethics of care in rural areas, such as the monetarization of medicine and shortages of rural healthcare providers. Similarly, I did not discuss the impact of evolving issues like genetics or the problems associated with technologies. But I believe that if a framework for the discussion of ethics-related issues is created, those other problems can be approached. Without a framework, such problems will become increasingly difficult to address.

Without doubt, more research about the intersection of ethics and healthcare decision making in rural areas is greatly needed. I am particularly interested in the relationship between the use of resources and more participatory decision making. Future studies could be designed to investigate the variety of ways in which the insights from psychology, history, and sociology could be blended into the practical, ethics-related resources that are offered to rural communities.

Considerable energies could also be devoted to the intersection of rural and urban bioethics. Since these studies were conducted in rural areas, the extent to which the findings might be applicable in more urban areas is open to debate. A number of issues, however suggest that the findings could be relevant. For example, changes in the

healthcare system have focused attention on the patient/clinician relationship.⁴⁸⁹

Commentators suggest that what people think about their healthcare, and the extent to which they trust their healthcare providers have clinical implications.⁴⁹⁰ Indeed, a physician who is not trusted may not be able to serve his patients.⁴⁹¹

Similarly, studies have suggested that healthcare is enhanced when patients believe that symptoms are controllable and they are cared for, heard, understood.⁴⁹² Commentators like Portmann may liken the supportive physician/patient relationship to a Hollywood script, but nursing studies suggest that the quality of care provided by nurses increases when they know the patient and the family.⁴⁹³ Thus it may be reasonable to assume that the key findings that emerged so forcibly in the rural studies - issues like relationships and culture - would also emerge in urban ones.

In the meantime, the message from the stories of healthcare providers, patients, and community members is clear. If bioethics is going to be perceived as important and relevant in rural areas, a more holistic approach, one that accommodates diverse cultures, obligations, and opportunities is needed. Thus, bioethics needs a foundation that is firmly rooted in dialogue. Many of the ethics-related issues that emerged in these rural studies were resolvable - but people had never recognized or talked them with one another. Bioethics was a topic for experts as opposed to those who stand at the bedside. Perhaps this series of rural studies has indicated the value of a “not for experts only” approach. A practical, inclusive, context-based orientation might move the enterprise of bioethics from the peripheral position of “something we don’t have time for in rural areas” to the forefront so that bioethics stands as the centerpiece of healthcare in rural areas.

REFERENCES

Appendix

Endnotes

Figure 1. Frequency of issue: Patients cannot follow medical recommendations because of cost

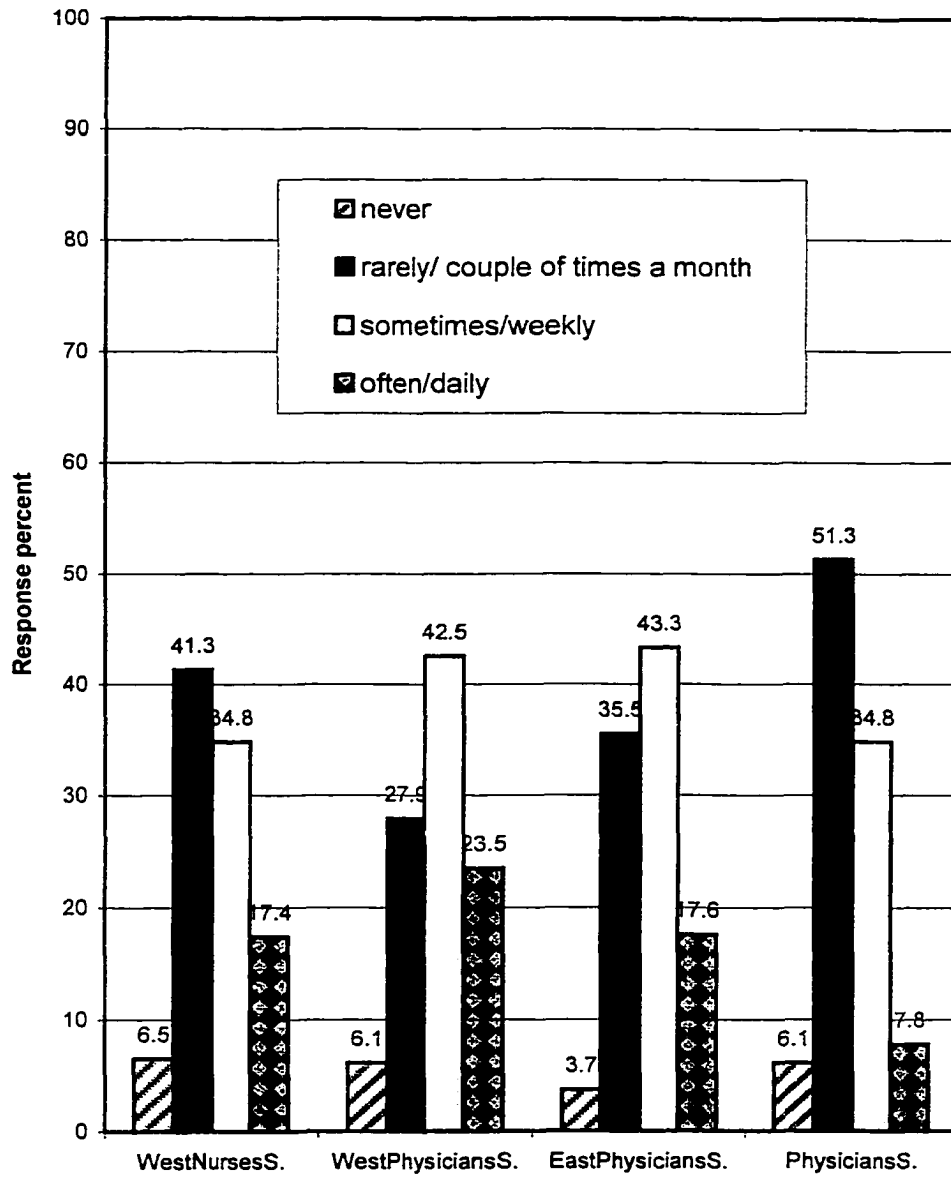


Figure 2. Rating the issue "patients cannot follow medical recommendations because of cost"

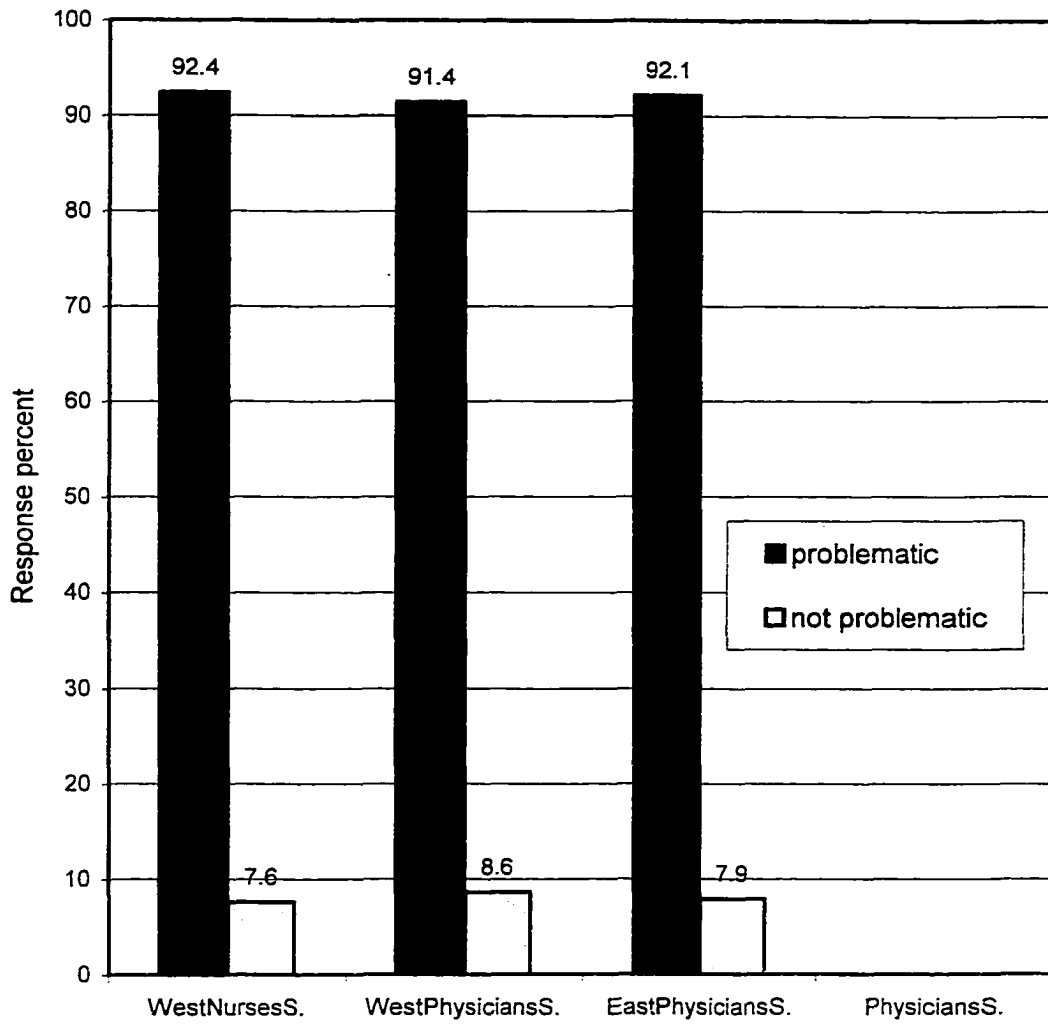


Figure 3. How frequently does the Ethics Committee discuss concerns about distributing scarce goods or services? (HospitalSurvey)

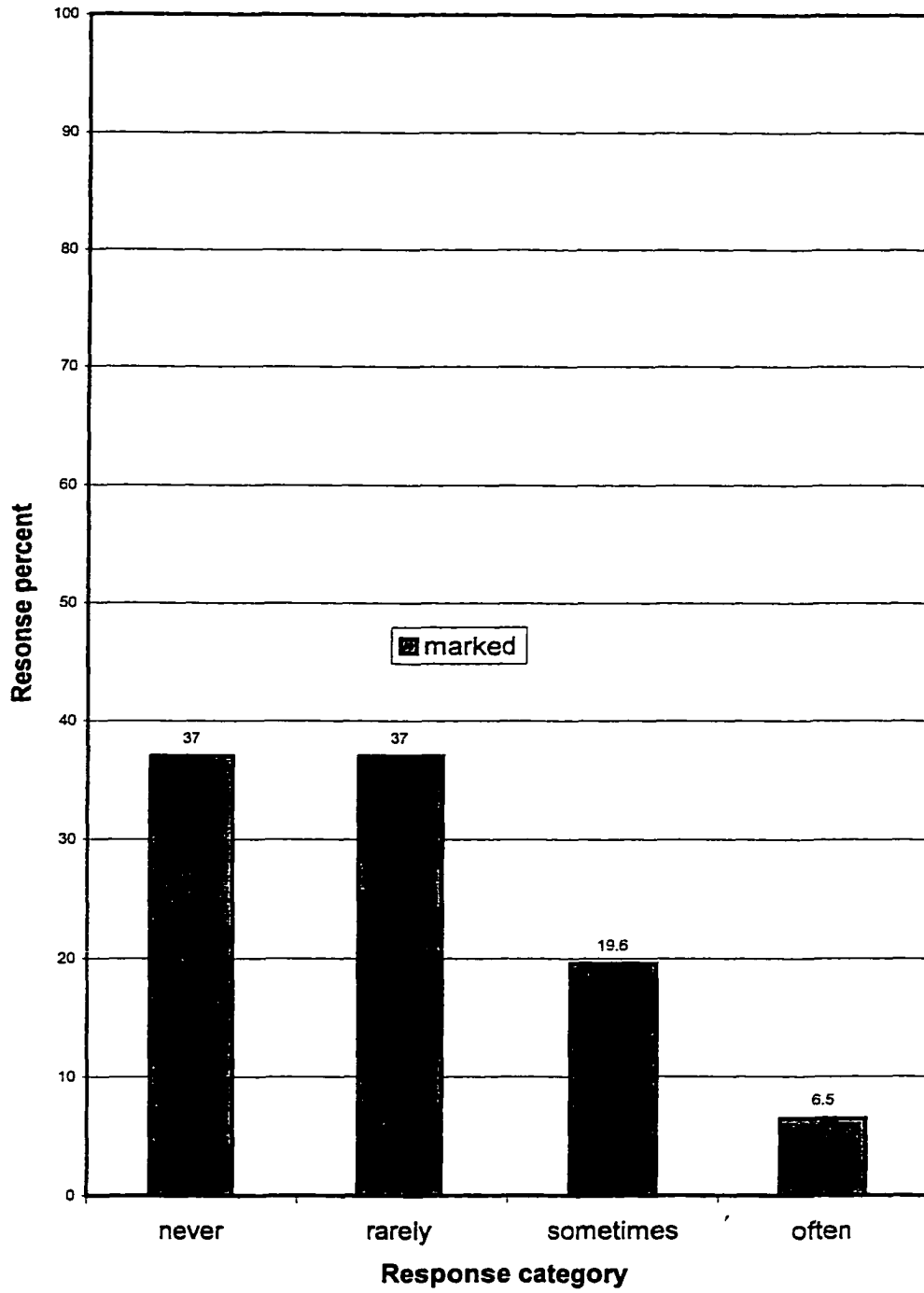


Figure 4. Critical Issues from Nurses Surveys

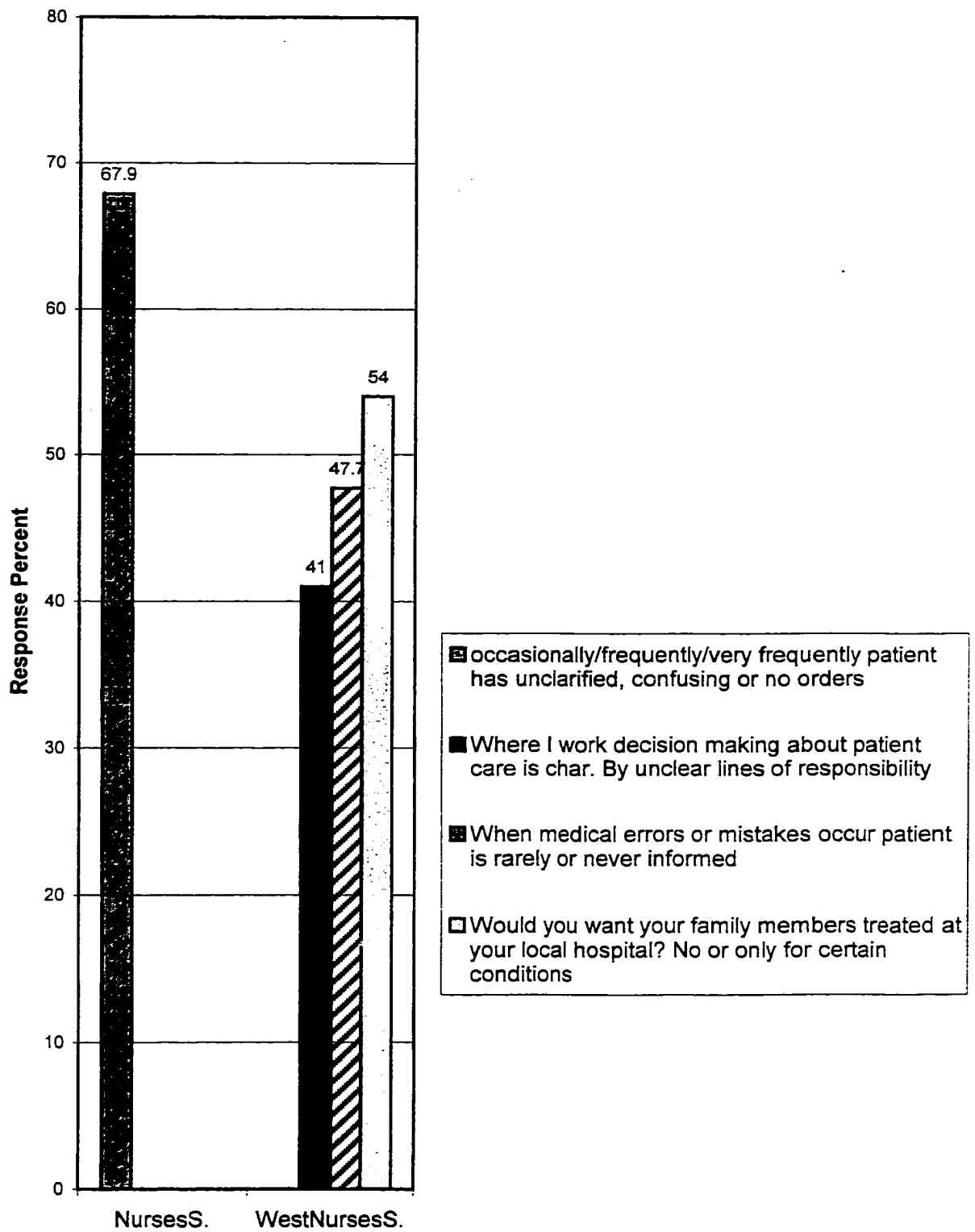


Figure 5. Patient Confidentiality is Violated

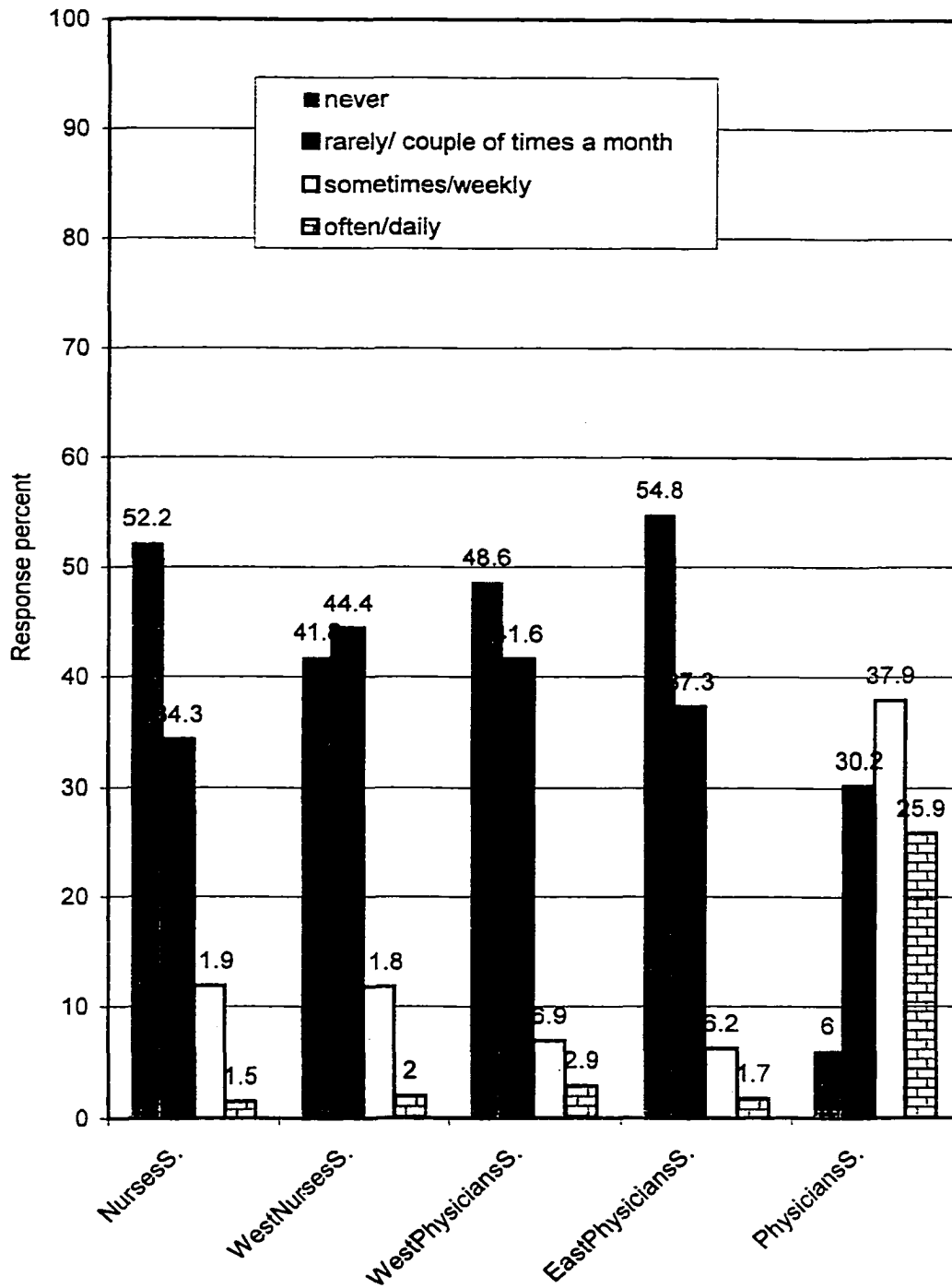


Figure 6. Have you ever served on an ethics committee?

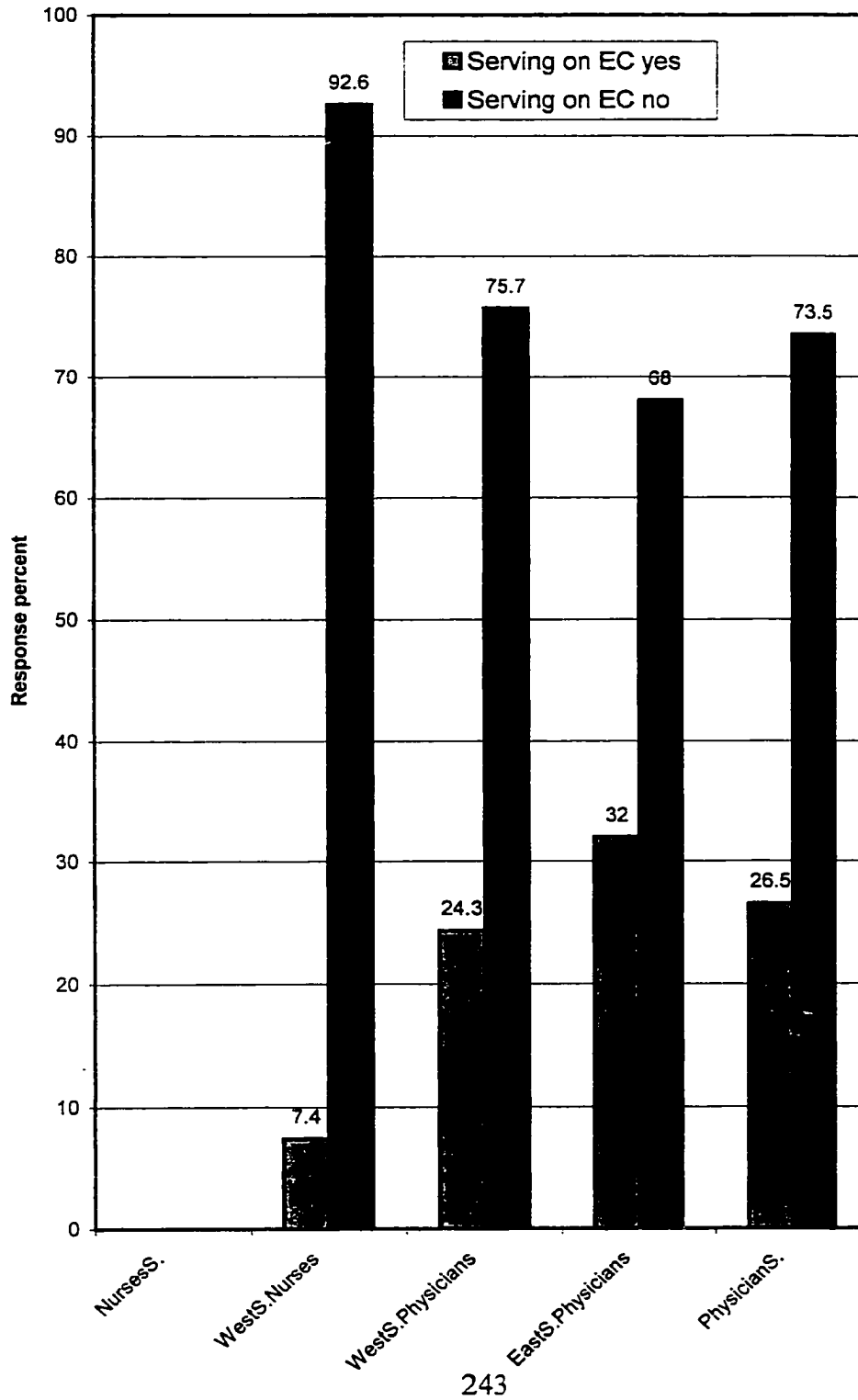


Figure 7. Have you ever referred a case to an Ethics Committee

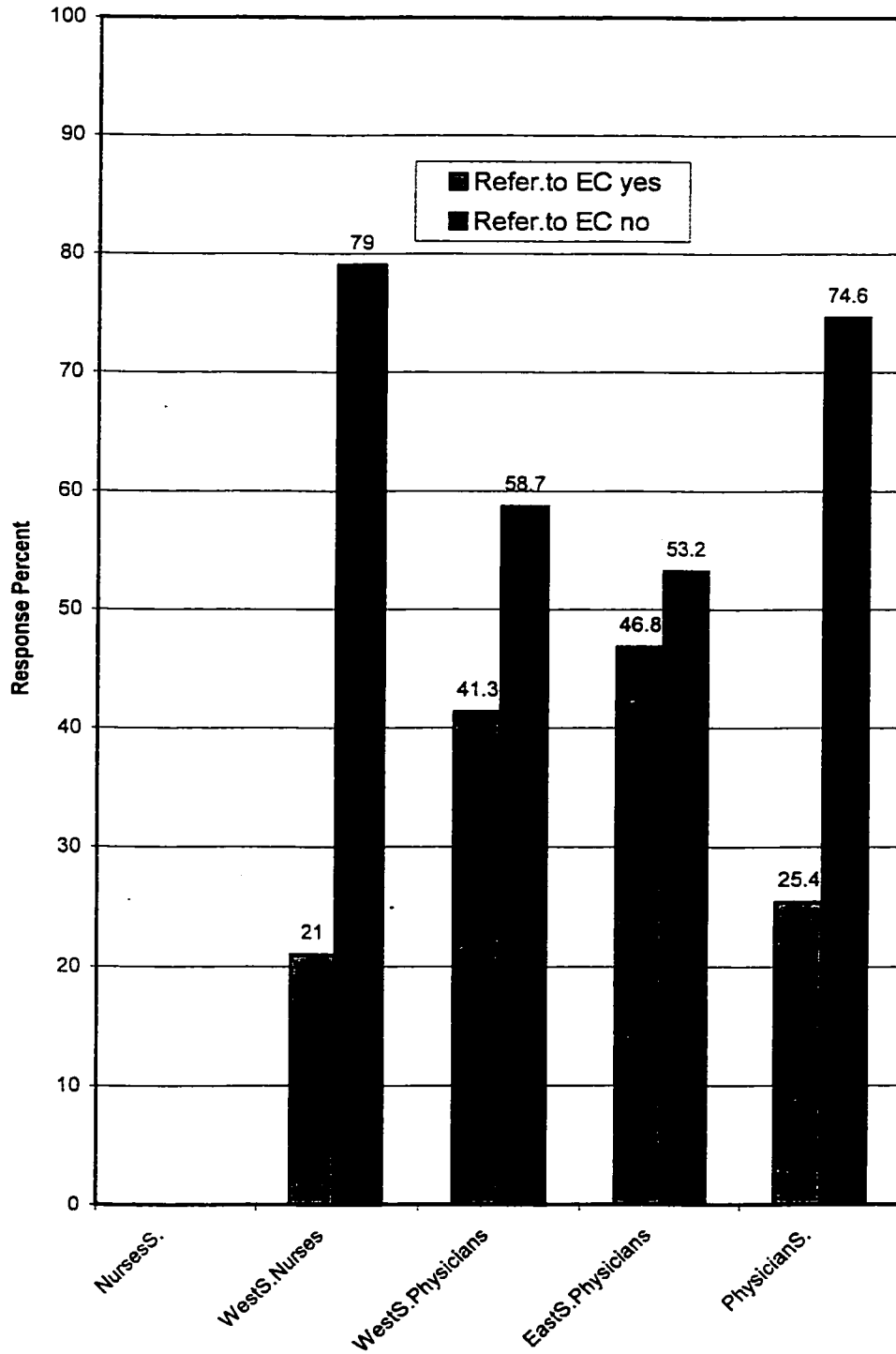


Figure 8. Was ethics part of your education/ Did it prepare you for practice in a rural setting?

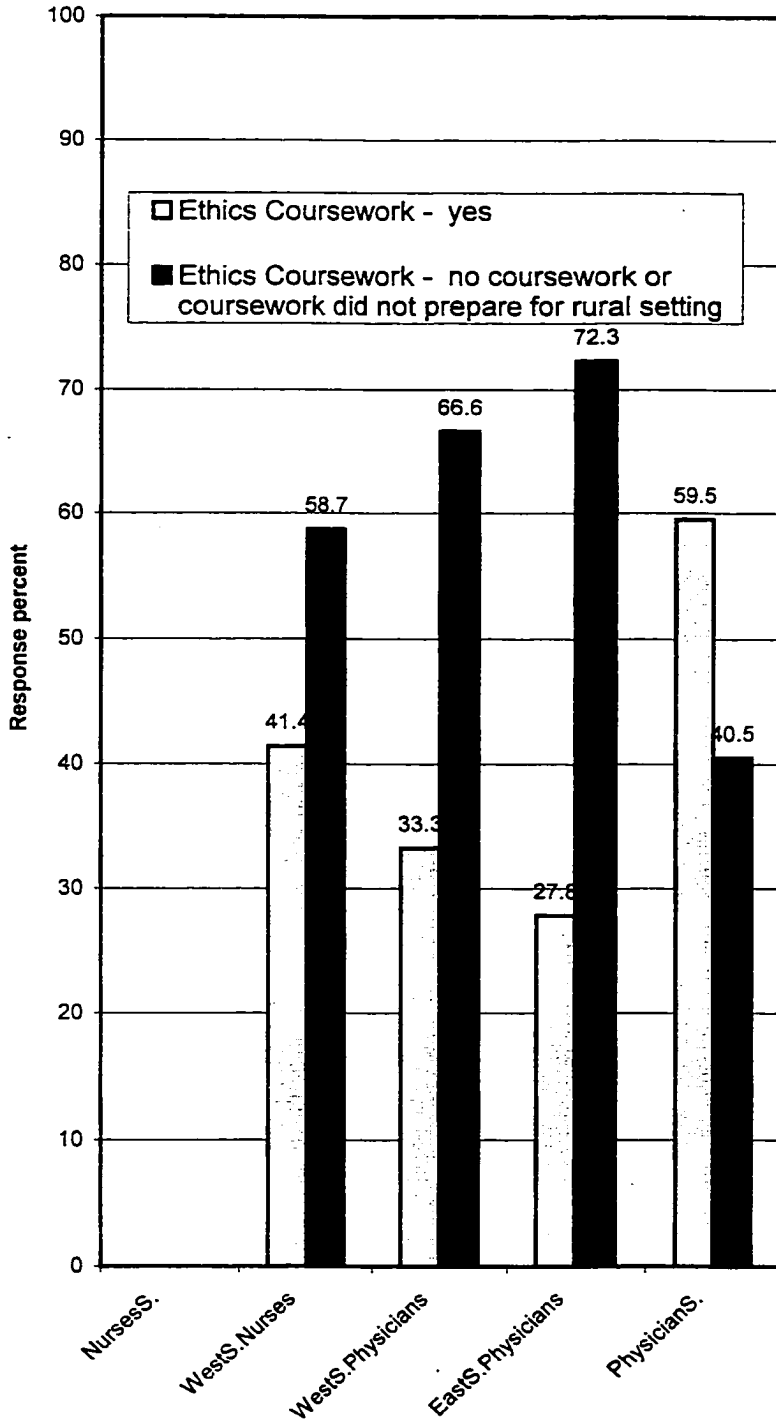


Figure 9. Interest in receiving ethics-related resources

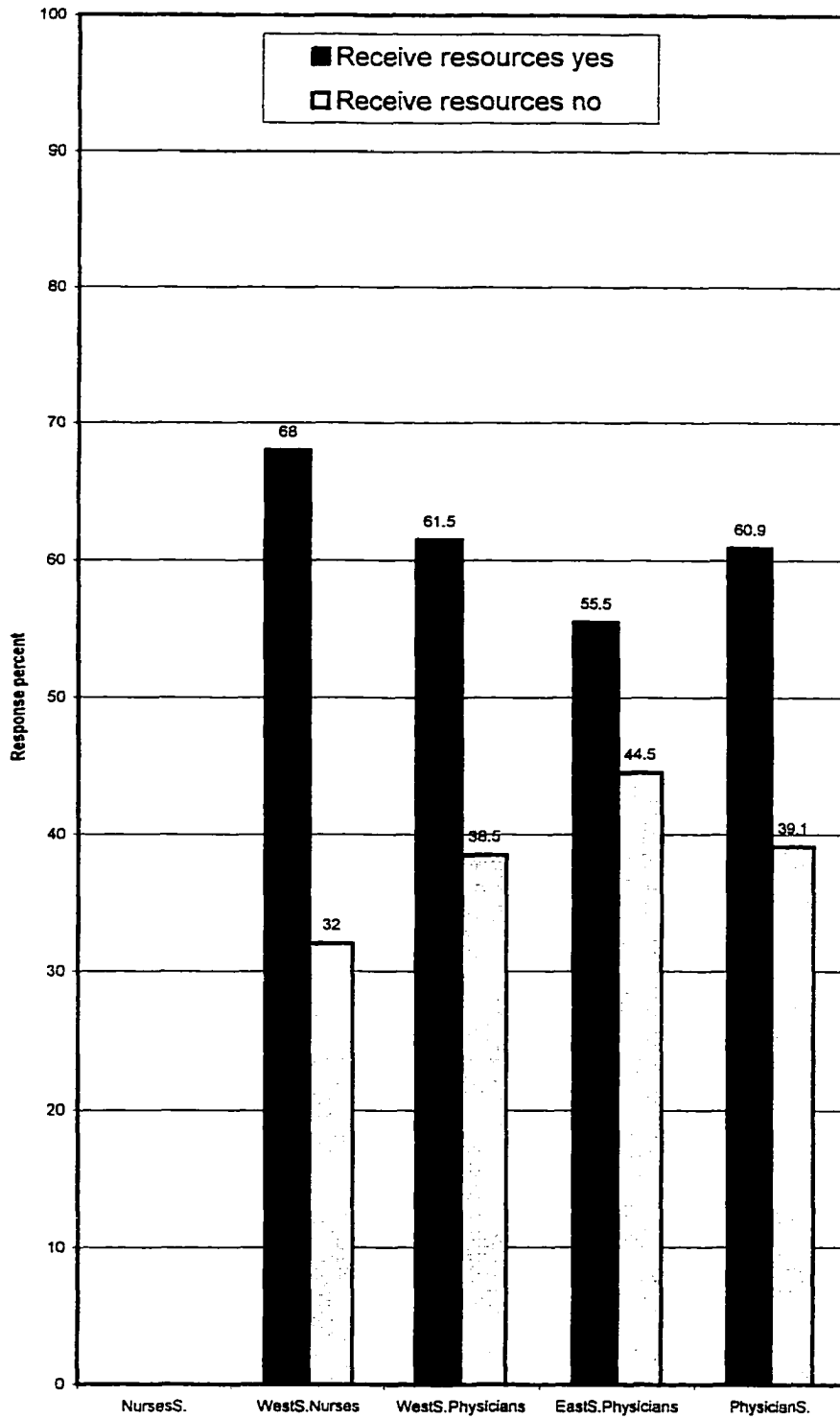


Figure 10. Health care ethics activities at the hospital (Nurses Survey)

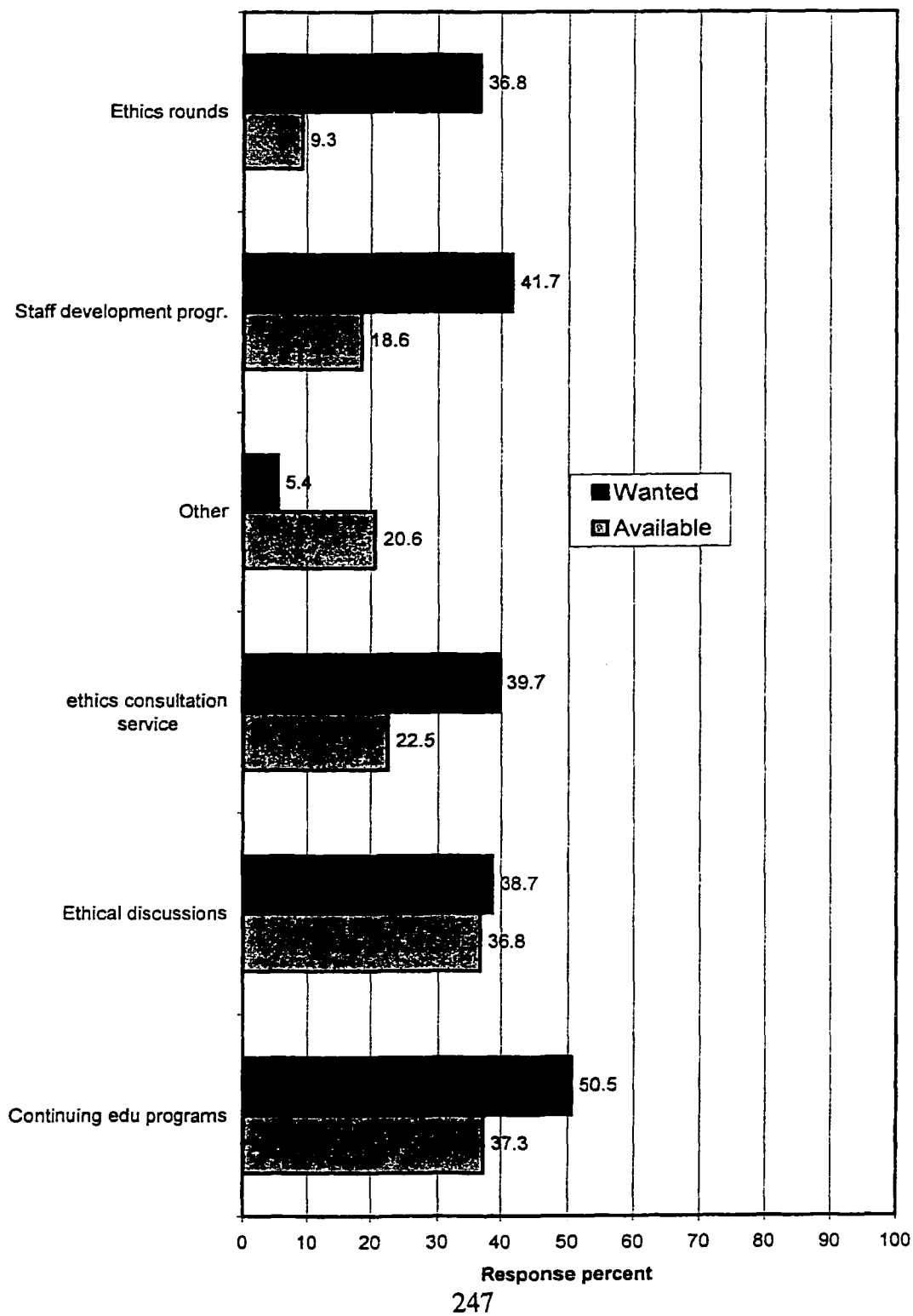


Figure 11. Ethics Resources at the hospital (Nurses Survey)

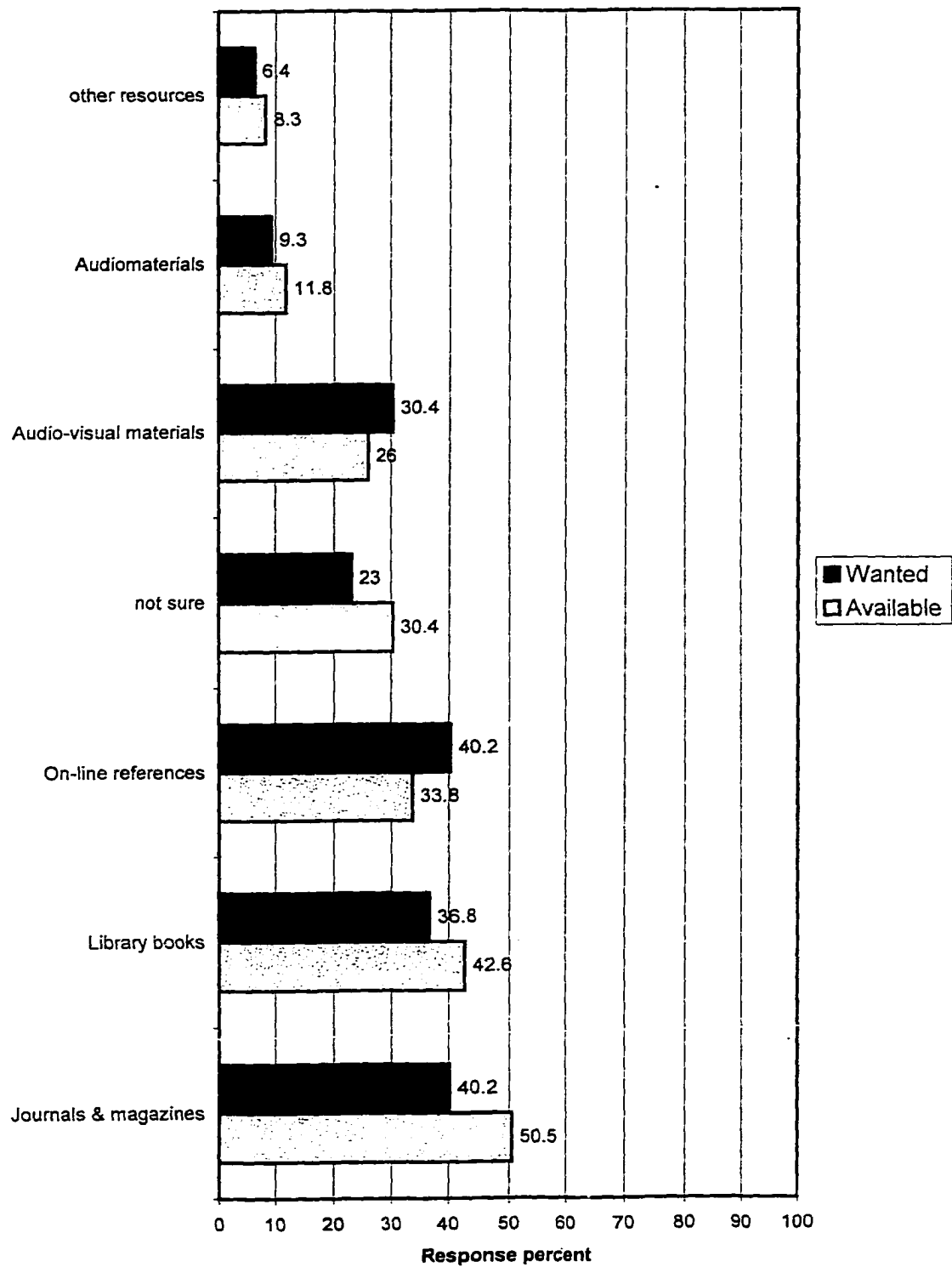
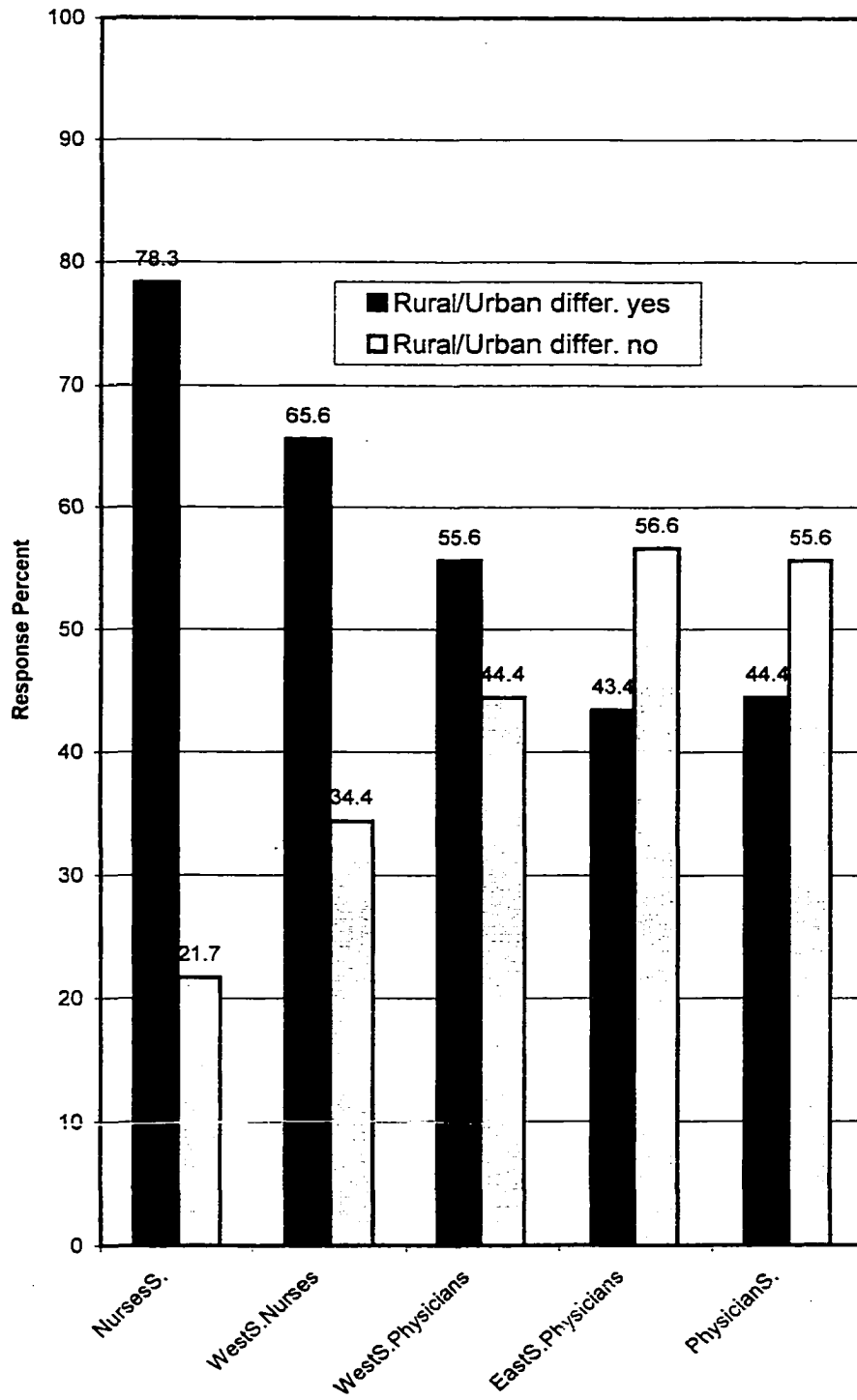


Figure 12. Rural-Urban differences in ethical issues



NOTES

1. The names used in all case studies and all examples are fictional and are not meant to represent actual persons.

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