



CHAPTER 1

# Introduction

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## DISCLAIMER

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### **Handbook for Rural Health Care Ethics: A Practical Guide for Professionals**

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## Introduction

William A. Nelson

### from *SMALL TOWN*'

Got nothing against a big town...  
But my bed is in a small town  
Oh, and that's good enough for me

—*John Cougar Mellencamp*

Today approximately 60 million people—one-fifth of the United States' overall population—live in rural communities, which are distributed over more than three-quarters of our country's land mass.<sup>2</sup> Many rural residents have significant disabilities related to illness and injuries, and they may encounter tremendous obstacles when seeking needed health care. Rural Americans have limited access to clinicians, health facilities, and specialized services, and their care is hampered by geographical and climatic barriers, as well as heightened social, cultural, and economic challenges. The burden of illness for rural populations is considerable, placing great demands on a resource-poor clinical care system. Consequently, rural people are increasingly recognized as an underserved special population. Attaining an appropriate standard of care for rural people, moreover, has emerged as a major concern in the national discussion of health disparities.

With the growing understanding of rural health care has come an emerging awareness of the special ethical considerations inherent to clinical practice in closely-knit, tightly interdependent small community settings. It is difficult, for example, for a provider to protect the privacy of rural patients when the care of such patients occurs in clinics where neighbors, friends, and relatives may work. Similarly, it is difficult to establish a professional clinician-patient relationship when the patient is the doctor's former grade school teacher, or a member of the nurse's local parish. Ethical aspects of care are especially relevant and sensitive when the patient's health problem is stigmatizing, as is the case with mental illnesses, drug-abuse disorders, and infectious diseases. Because of these distinct pressures in the community context, the solutions that practitioners develop to resolve complex ethics dilemmas arising in rural areas may differ from solutions derived in urban areas. Providing health care to a family member, friend, business associate or neighbor may become necessary in a rural setting, whereas urban contexts—with the greater availability of diverse health care clinicians, facilities, and resources in the immediate area—may permit greater role separation between clinician and patient, and clearer personal and professional boundaries.

Despite the unique character of rural ethics issues, there are limited comprehensive written materials that specifically focus on assisting

rural clinicians and facility administrators who are confronted with complex ethics dilemmas. Rural clinicians have expressed concerns about professional codes of ethics and ethical standards of practice that are not tailored to the dilemmas that exist in small communities. These formal documents often appear most applicable to the resource-enriched, less interdependent urban communities. Furthermore, rural clinicians have less access to local ethics committees and consultants, and fewer opportunities for ethics education. For these reasons, clinicians who are entrusted with providing competent and ethically sound clinical care in rural settings have identified a need for the development of resource documents that can offer guiding principles.

Surrounding all these ethical challenges are the basic characteristics of the rural environment. In fact, that's what rural health care ethics is about—it's about the context, the wonderful and complex rural settings that surround and foster many of the ethics conflicts. Rural health care ethics is the application of an ethics framework and ethical standards to the unique rural environment. What is unique to rural ethics is not so much the basic ethical domains, such as ethics conflicts about end-of-life decision-making or questions regarding privacy and confidentiality. Ethics challenges regarding those domains can occur in any setting, and are not unique to rural practice. What is unique is how the rural context's characteristics and features can shape and weave their way into the dimensions and dynamic surrounding the ethical uncertainty or question as well as the response to the challenge. This *Handbook* focuses on how that rural context is interwoven into the presentation of such ethics conflicts, and how the health care professional responds to the conflicts.

In 2006, a group of multidisciplinary health care professionals, including physicians, nurses, health care ethicists, and hospital administrators, gathered at a Dartmouth College retreat center in the woods of New Hampshire to share and explore a common interest in the ethics of rural health care. The participants were selected on the basis of their scholarship, teaching, and research in the field of rural ethics. Over several days, the professionals discussed many topics, such as the nature and scope of the field; ethics issues that rural clinicians and administrators experience, in contrast to their urban counterparts; the limited resources and training that are currently devoted to rural

ethics; and the challenges in applying traditional ethics standards and professional guidelines to rural issues and ethics programs in small rural facilities.

The group did not agree on all aspects of rural ethics issues, but did agree that what makes rural health care unique is the context—the rural environment and culture that is woven into the fabric of the ethics issues that they all encounter. The participants acknowledged that the essence of rural health care ethics is the contextual environment that shapes and influences ethical challenges. As Dr. Tom Townsend notes in Chapter 7 of this *Handbook*, “The intimacy of rural life is a key factor to many aspects of rural health care ethics discussions. An ethical relationship with strangers is different from the ethics of close-knit relationships. The ethics issues within the patient-provider relationship change when strangers, rather than friends, neighbors, or acquaintances, are involved. This distinction is key to many of the differences between urban and rural health care ethics.”

The retreat involved long discussions about what makes the rural environment unique in the United States—despite regional differences between the Northwest, Appalachia, the Southwest, New England and other rural communities, there are many common health-related characteristics that influence and create ethics challenges, including those listed in Box 1.1.

## **THE NATURE OF RURAL HEALTH CARE**

During the retreat, in an exercise to explore the various cultural characteristics that shape rural health care ethics, participants read and discussed the book, *A Fortunate Man*—a moving description of a rural physician. John Berger’s book delivers a poignant portrait of an English country doctor caring for people in a remote community. Berger wrote that, “Landscapes can be deceptive. Sometimes a landscape seems to be less a setting for the life of its inhabitants than a curtain behind which struggles, achievements and accidents take place. For those who are behind the curtain, landmarks are no longer only geographic but also biographical and personal.”<sup>3</sup> The doctor portrayed in this book finds a great commitment and passion for his work in the remote community, and builds strong bonds with the rural townspeople whom

**BOX 1.1****COMMON HEALTH-RELATED RURAL CHARACTERISTICS**

- Small populations and long distances from urban-based tertiary medical centers
- Overlapping personal and professional relationships between health care providers and community members
- Rural isolation which may exacerbate care providers' stress
- Limited availability of health care services, specialists and providers
- Small hospitals, many with fewer than 25 beds
- Residents with close-knit, shared connections and experiences
- Residents' strong sense of self-reliance and independent thinking
- Shared values, interdependence and culture
- Challenging economic and employment situation(s)
- Poor health status compared to non-rural populations
- Hazardous work environment(s)
- Limited rural ethics resources, i.e., a lack of rural ethics literature, rural ethicists, rural ethics training, and rural ethics committees in the area

he supports. These positive attributes of the life of a country doctor help the protagonist transcend any professional isolation, challenges, and stressful workload as the only provider in town with no backup—he “is” the hospital.<sup>4</sup> Berger’s writing helped to remind the retreat participants that despite the many challenges of living and working in rural communities, there is great meaning and satisfaction in being a rural health care professional.

In addition, one evening, partly for entertainment, the participants watched the film *Doc Hollywood*—the tale of an urban physician’s experiences in rural America. In *Doc Hollywood*, Michael J. Fox plays the role of a young, aspiring plastic surgeon, who takes off on an adventure, driving cross-country from Washington, D.C. and heading to a high-paying new job in Beverly Hills. The doctor encounters adventure more quickly than expected when he crashes his Porsche in

a tiny, remote rural community, destroying some property and ending his dreams of completing his trip uneventfully. The small town's judge sentences Fox's character to 30 days working as the town's country doctor, while the town's regular doctor goes on vacation. The rest of the comedy portrays a predictable, yet funny and believable tale of how the doctor and residents grow to know and appreciate each other.<sup>5</sup>

On a more serious note, the film reflects how the rural setting affects the professional's ability to deliver health care. Fox's character learns to cope with, and even comes to appreciate, the challenges and rewards of being a typical country doctor, which include professional isolation, the stress of managing a clinic single-handedly, and unexpected situations. He develops meaningful relationships with the townspeople, and becomes committed to working in this very remote, previously unknown community. Thus *Doc Hollywood* shows a glimpse of the world of the rural health care provider that is not often seen or understood by anyone, even doctors, living in urban areas.<sup>4</sup>

It has been suggested that the discipline of bioethics has evolved historically into a field with many wide-ranging areas of focus. The *Encyclopedia of Bioethics* noted four particular overlapping areas of inquiry: theoretical ethics, clinical ethics, regulatory and policy ethics, and cultural health care ethics.<sup>6</sup> Theoretical health care ethics focuses on the underlying foundations of moral reasoning that are applied to various health care topics. Clinical ethics refers to specific questions or uncertainty in individual patient care. Regulatory and policy health care ethics is the organizational and legal focus of health care-related ethics questions. Cultural health care ethics is an effort to systematically relate health care ethics to the cultural, ethnic, religious, and social context in which ethics conflicts arise. In health care ethics, one of those cultural subgroups of inquiry is the rural setting with its unique characteristics.

In both *A Fortunate Man* and *Doc Hollywood*, we are taken behind the curtain to a unique setting, the "Small Town" as John Mellencamp sings, unknown and rarely understood by many who live in metropolitan and urban settings. These works, along with the personal experiences of the gathered retreat participants, contributed to a contextual understanding of rural health care ethics. That same rural context



affects the approaches that health care professionals use in their response to the ethics issues. It is this rural context that is the basis for rural health care ethics.

## **EVOLVING RURAL ETHICS AGENDA**

There was consensus among the participants in the 2006 retreat that rural ethics has experienced a limited focus as a component of the broad discipline of health care ethics or bioethics. The participants discussed and identified a proposed rural ethics agenda to expand the needed focus on rural health care ethics. This rural ethics agenda, reprinted below, was later published in an article<sup>7</sup> from which the text in Box 1.2 is a direct quote.

### **BOX 1.2**

#### **RURAL HEALTH CARE ETHICS AGENDA**

- “Develop a clear understanding of what constitutes the scope of rural health care ethics.
- Increase awareness and understanding of rural health care ethics issues, including the contextual nature of the ethical issues and how the issues are different from non-rural settings.
- Increase awareness and understanding of rural health care ethics decision-making, including how living and working in rural communities affects the response to ethical issues.
- In collaboration with rural health care professionals, draft guidelines for addressing common ethical conflicts.
- Explore, assess, and propose models for “doing ethics” in small rural health facilities.
- Develop training curricula and other educational resources for and with rural clinicians, administrators and policy-makers.
- Provide an ethics perspective, supported by empirical data, to administrators and policy makers who are charged with allocating health care resources.
- Foster a dialogue with the general health care ethics community regarding the unique contextual nature of rural ethical issues.”<sup>7</sup>

The small group of professionals at the retreat, self-named as the Coalition for Rural Health Care Ethics, continued to communicate following the retreat. The retreat experience fostered many ongoing collaborative activities among the Coalition members—who, like most rural health care professionals, tend to work in isolation from other rural colleagues. As an example of the collaboration, Coalition members planned and implemented several presentations for the National Rural Health Association’s annual meeting, the American Society of Bioethics and Humanities’ annual meeting, and regional gatherings of state offices of rural health. Members also worked together on various publications and grant efforts.

### **HANDBOOK FOR RURAL HEALTH CARE ETHICS: A PRACTICAL GUIDE FOR PROFESSIONALS**

As a direct outgrowth of the 2006 rural health care ethics retreat, a grant proposal was written, with its goal to plan, develop, and disseminate a handbook. The grant application to the National Institutes of Health (NIH) National Library of Medicine was approved, and the project was launched. Additional rural-focused ethicists, clinicians, and administrators were recruited to join in the effort to write the *Handbook*. So discussions that began in the woods of New Hampshire have continued to evolve in expanding the understanding of rural health care ethics and its agenda.

*The Handbook for Rural Health Care Ethics: A Practical Guide for Professionals* was conceived and written to help fill the gap in the limited ethics resources focused on rural health care. The *Handbook* is intended to help multidisciplinary rural professionals respond effectively to the complex ethics conflicts they may face each day. It addresses challenges that arise in rural settings on such issues as obtaining informed consent, establishing patient-provider relationships, adhering to treatment, boundary issues, appropriate protection of confidentiality, resolving conflicts between the interests of individual patients and the good of the overall community, distributing scarce resources equitably, and experiencing pressure to provide care in areas that are beyond the provider’s usual scope of clinical competence.

The *Handbook* has been written by and for health care professionals who are living and working in rural communities. The authors are an outstanding group of physicians, nurses, administrators, and ethicists noted for their scholarship, research, and teaching in the area of rural health care ethics. The *Handbook* is divided into three main sections:

### **Section I: Rural Health Care Ethics Overview**

This section focuses on the nature and scope of rural health care ethics. Section I includes a discussion of the ethics issues encountered in the professional life of health care clinicians and an exploration of “doing” ethics in rural settings.

### **Section II: Common Ethics Issues in Rural Communities**

Section II contains a wide range of familiar ethics issues, including both clinical and organizational issues that occur in the context of rural communities and hospitals. Each chapter begins with brief case presentations, then delivers an overview of the relevant ethics issues, and finally provides a discussion and response to the each of the cases. Because ethics issues tend to recur, each chapter will offer suggestions for anticipating such ethics conflicts, encouraging the reader to apply the suggested strategies to decrease the likelihood that such conflicts will recur, or to make them easier to cope with if they do recur.

### **Section III: Rural Ethics Resources**

The final section offers several chapters of practical information and approaches to expand the rural health care professional’s ability to manage ethics challenges.

To foster easy access to the *Handbook*, it is offered as a Web-based resource. The content can be accessed by downloading individual chapters, or by downloading the entire *Handbook*. To that end, we are providing each chapter separately in a portable document file (PDF) format, as well as the entire *Handbook* in PDF format.

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