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Introduction

A. M. Viens and Peter A. Singer

You probably faced a clinical issue today with an ethical component. Did you recognize it? Did you know how to address it? Did you have an organized framework? Did you know what to say to the patient and their family? Did you know what to do? Did you feel comfortable and confident in this aspect of your clinical practice? This book seeks to address how greater recognition of ethical issues and their resolution can improve patient care, research practices, and institutional arrangements.

What is bioethics?

Bioethics, while a modern term, is as old as medicine itself. The Code of Hammurabi and the Hippocratic Oath, for instance, include provisions concerning the importance of ethical considerations to clinical practice. In addition to its initial focus on ethical issues relevant to clinical care, bioethics concerns the moral, legal, political, and social issues raised by medicine, biomedical research, and life sciences technologies.

While bioethical considerations will remain a central aspect of medicine, it can do so at different levels. One can distinguish between three broad spheres of bioethics. The first is academic bioethics, a sphere primarily focused on how theoretical and practical aspects of medicine affect considerations such as special obligations or responsibilities of clinicians, what is valuable, good, right, etc. in the biomedical context and how one might go about providing systematic accounts of such considerations. The second is public policy and law bioethics, where concerns lies in how legal and extra-legal institutions can and should be involved in the regulation of clinical and research practices. The final sphere is clinical ethics, and its focus is directly related to how the incorporation of bioethics into clinical practice can help to improve patient care. Indeed, as a multidisciplinary field, these spheres are often interconnected, and scholars and clinicians can work across multiple spheres. This book seeks to incorporate the best of all three spheres, with primary attention paid to clinical ethics.

Audience of the book

This book has been written with practicing clinicians (e.g., physicians, surgeons, nurses, dentists, physical/occupational/respiratory therapists, etc.) and allied health professionals (e.g., social workers, bioethicists, healthcare managers/executives, etc.) in mind, but it can also be invaluable to educators teaching bioethics in medical schools, residency programs, and continuing medical education programs. Additionally, this book will also be relevant for researchers and students in non-clinical disciplines interested in bioethics (e.g., philosophy, law, religious studies, health policy, public health, health administration/management, etc.) as illustrative of how the recognition and management of ethical issues at the clinical interface relates to theoretical considerations and organizational

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structures. As such, we also expect that the book will serve as a textbook for courses in bioethics. Finally, since bioethics has moved very much to the public arena, we also anticipate that the book will be of interest to patients and the public. Its case-based approach makes it particularly accessible.

Aims of the book

Firstly, the book is meant to be *practical*. In particular, the practical aims of the book are *pedagogical* and *clinical*. The goal is to support performance (i.e., what clinicians actually do) by helping to develop awareness and skills in the analysis of normative considerations that affect clinical and research practices. All of the chapters provide guidance on applying bioethical concepts in daily practice and serve to show how the integration of such bioethical knowledge into clinical practice facilitates the ability to make well-reasoned and defensible decisions. Almost 30 years ago, Mark Siegler (1978; cf. Siegler *et al.*, 1990) emphasized that the goal of teaching bioethics is to improve the quality of patient care by identifying, analyzing, and attempting to resolve the ethical problems that arise in the practice of clinical medicine. Today, virtually all medical schools incorporate bioethics into their curricula and most regulatory authorities require the teaching of bioethics as a condition of accrediting residency programs. Clinicians desire and actively seek help with how to deal with ethical issues in clinical practice. For instance, the British Medical Association (BMA) receives several thousand enquiries about ethical issues from clinicians – indeed, in just one week, the BMA's online ethics guidance was accessed by more than 1400 visitors (BBC, 2003).

Secondly, the book is meant to be *versatile*. Each chapter provides a focused and detailed examination of bioethical issues, which can be read sequentially, used as a reference when particular problems arise, and used as a set text in group teaching or open learning environments. While some readers will want to read all of the chapters, the book is structured in thematic sections that provide an easy and accessible way of concentrating on how ethical issues surrounding a particular topic are connected. Professional performance with respect to bioethical matters depends on many factors, including the clinician's values, beliefs, knowledge of ethical and legal constructs, ability to recognize and analyze ethical problems, and interpersonal and communications skills. Although this book cannot address every aspect of bioethics in medical practice, the contributors hope that it will provide a helpful starting point for clinicians, and its versatility will also serve to complement educational and training initiatives. In many cases, the relevant chapter will be all a busy clinician needs to read for help in dealing with an ethical issue faced in patient care.

Thirdly, the book is meant to be *comprehensive*. The book is comprehensive in terms of the *breadth and substance* of the over 60 chapters that are organized under 10 key sections presenting the most vital topics and clinically relevant areas in bioethics: (I) Information problems, (II) End of life-care, (III) Pregnant women and children, (IV) Genetics and biotechnology, (V) Research ethics, (VI) Health systems and institutions, (VII) Using clinical ethics to make an impact on healthcare, (VIII) Global health bioethics, (IX) Religious and cultural perspectives in bioethics, and (X) Specialty bioethics. The book is also comprehensive in terms of its *interdisciplinarity*. Chapter contributors have trained and practiced in a wide spectrum of clinical specialities and academic disciplines (e.g., medicine, surgery, pharmacy, physical medicine, law, philosophy, theology). This interdisciplinary approach will help to ensure that concepts are described faithfully with respect to their empirical context in medicine and with an understanding of their theoretic roots in ethics and law. Finally, it is comprehensive in terms of its *internationalism*; in virtue of both having expert contributors from a number of different countries (e.g., Australia, Canada, China, Israel, Oman, South Africa, Syria, UK, and USA) and ensuring that the material is internationally applicable. Clinicians become involved in healthcare choices as facilitators of the patient's decision-making process. As such,

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they need an awareness of the cultural and religious background that may influence their view of the patient's situation, as well as familiarity with religious and culturally based values different from their own. Although understanding and accommodating the unique cultural and religious views of patients – especially in relation to the ethical aspects of practice – is a critical determinant of quality of care, guidance for clinicians on how to do so is not easy to locate in the medical literature.

Structure of the book

Each chapter begins with one or more clinical cases highlighting the issue under discussion and ends with suggested approaches to these cases. The cases reflect the authors' experience and are not intended to refer to any particular patient. We have included clincial cases as a way of presenting ethical dilemmas within a specific, plausible context and providing a means of contextualizing the relevant ethical issues in terms of how they related to clinical practice (also cf. Kimball, 1995; Davis, 1999). These cases illustrate that bioethics is not an esoteric pursuit removed from the exigencies of everyday practice; rather, bioethics is in the background of every encounter between clinicians, researchers, administrators, patients, and their families. All clinicians understand why the chapters begin and end with cases – cases are how we learn medicine. As the great Canadian physician Sir William Osler (1906) said: ''. . . the student begins with the patient, continues with the patient, and ends his studies with the patient, using books and lectures as tools, as means to an end.''

Each chapter aims to answer three basic questions about the bioethical issue at hand. Firstly, *what is it?* – i.e., how the concept/issue so defined is to be understood in the context to be discussed and why it has relevance to clinical practice. Secondly, *why is it important?* – i.e., how the concept/issue has clinical relevance from the perspectives of ethics, law, policy, and empirical studies. Thirdly, *how should it be approached in practice?* – i.e., how the concept/issue under consideration is applied and/or can be used in clinical practice to improve patient care. The chapter concludes by discussing the resolution of the case(s) introduced at the beginning of the chapter.

The book is based on the very popular 28-part series, *Bioethics for Clinicians*, published in the *Canadian Medical Association Journal* between 1996 and 2002 and edited by Peter A. Singer. These frequently downloaded articles have been used by clinicians throughout the world and have been translated into several languages. This collection, however, provides a far more comprehensive and up-to-date resource, but with the same spirit of improving clinical practice. Therefore, our goal in writing this book is to provide clinicians with the knowledge and tools they need to provide better care to patients and research subjects.

Bioethical methodologies and our approach

There are a number of different bioethical methodologies that have been advanced for the incorporation of bioethics into clinical practice. Broadly speaking, there are four such approaches (Agich, 2005).

The first is practical or applied ethics, or even an applied philosophy of medicine. This approach addresses ethical issues that arise in practice through the application of aspects of particular ethical theories, or specific notions/concepts (e.g., double effect, treatment versus enhancement distinction, etc.), to concrete clinical or research cases. The focus is not on providing a decision procedure for how to solve ethical issues but to provide theoretical framework concerning, for instance, what considerations would make an action good or a policy right. For more on this approach, see Caplan (1983), Beauchamp (1984), and Young (1986).

The second is principlism. This approach seeks to provide ethical guidance in clinical practice through a specified number of moral principles. By applying general principles to ethical problems, it

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is argued that such principles do a better job of obtaining the right answer concerning what one morally ought to do compared to trying to reason through what to do in each instance. The most famous versions of bioethical principlism are articulated by Beauchamp and Childress (2001), with the principles of autonomy, beneficence, non-malfeasance, and justice, or, for instance, some catholic healthcare institutions, which adopt a theologically based form of principlism. While principlism has been notably criticized for being too blunt an instrument in trying to apply a few ethical principles to all problems in all circumstances, and thus being too insensitive to the complexities and tensions inherent in morality, some forms of this approach are more multifaceted and responsive to the intricacies of moral considerations related to medicine. For more on this approach, see Clouser and Gert (1990), Daniels (1996), Richardson (2000), and Beauchamp and Childress (2001).

The third is casuistry. This case-based approach addresses ethical problems by guiding clinicians through specific issues via paradigm cases that have come up in clinical education or practice – something analogous to the use of case-based reasoning in the process of differential diagnosis. As opposed to theory-laden or top-down approaches, which apply general frameworks or concepts to particular issues when they arise, casuistry provides a bottom-up approach where clinicians use case-based reasoning to identify the morally relevant features of a situation and relate it to the specific circumstances of a previous case and its resolution. Given the prominent use of cases in clinical practice (e.g., case reports in journals, case conferences and rounds, etc.), clinicians may find this approach an appealing way to deal with ethical problems (for some of the reasons we have highlighted in the previous section). However, as a standalone bioethical methodology, the approach has been criticized for not providing a clear method for working through ethical issues. For more on this approach, see Jonsen (1991), Kopelman (1994), and Jonsen and Toulmin (1998).

The fourth is combination of techniques for identifying and resolving ethical conflicts, disagreements, and related problems. This approach treats the ethical issues that arise in clinical practice as those similar to inter-personal issues alleviated through techniques such as conflict resolution, mediation, negotiation, and arbitration. This approach has been criticized by some on the basis that, in treating ethical issues as just another set of considerations that can cause disagreement, it fails to adequately address the source of moral conflict or why we have good reasons to act one way as opposed to another in favor of securing consensus amongst participants. Admittedly, compromise plays an important role in clinical practice; however, achieving agreement for its own sake fails to appreciate sufficiently what is distinctive about moral considerations and how greater attention to resolving ethical issues can improve clinical practice. For more on this approach, see West and Gibson (1992), Dubler and Marcus (1994), and Reynolds (1994).

We believe none of these methodologies gets everything right. Since the aim of the book is not to argue for which methodology, or combinations of methodologies, is correct, we recommend that clinicians will most benefit from borrowing the best of each methodology in an effort to better recognize and resolve ethical issues in practice. Each chapter in this book contains elements of all these approaches. The chapters start and end with clinical cases, and this most resembles casuistry. In the section on why a particular topic is important, the ethics subsection will often emphasize principles and often expands this into a practical ethics approach. However, we recognize that the sources of knowledge and frameworks required by clinicians are not limited to ethics, so the chapters also review and apply relevant legal and policy frameworks to the topic. Moreover, empirical research also helps to illuminate how clinicians can effectively approach a clinical ethics problem, so we include a section on empirical studies too. The section on how a clinician should approach a particular problem in practice emphasizes the techniques and tools a clinician can use to resolve the particular ethical challenge. Therefore, the methodology in this book can be described as a ''mixed methodology'' that is focused on the goal of optimally supporting clinicians in identifying and attempting to resolve ethical problems they face in actual clinical practice.

Coda: a personal reflection

One of us (PAS) has been working in the field of bioethics for almost 30 years, a pathway initiated in the following way. I finally decided to make a career of bioethics when many years ago as an intern I was caring for a young woman with disseminated cancer. She also happened to have a low phosphorus level in her blood. I realized that I could rattle off 20 causes of low phosphorus, but when it came to whether or not we were going to resuscitate this young woman when her heart stopped, we wrote that order in pencil on the nurses' notes and rubbed it out afterwards. I thought at the time that, even if the scientific problem of low phosphorus and the bioethical issue of end of life care were equally important, the rigor with which we approached the bioethical issue was disproportionately low. In caring for many patients, I also realized that there is no ''one size fits all'' framework for approaching clinical problems. Clinicians have a heuristic for approaching abdominal pain and another for approaching chest pain. That is why we do not offer a single set of principles, or a decision-making rubric, to address all clinical problems. Context matters in medicine. These clinical insights and experiences have shaped a framework to approaching bioethics problems that over the years has evolved into this book.

The approach herein has also been shaped by working with my colleagues Mark Siegler and Edmund Pellegrino on a review of bioethics every 10 years. The writings of Mark and Ed are the best of class and have stood the test of time in relation to emphasizing a clinically based approach to bioethics, and how bioethics is at the moral center of the clinician's work. As Mark used to emphasize, the bull looks different from the stands than it does from the bullring. Another close colleague and mentor, the late Alvan R. Feinstein, emphasized this very same theme in another field – clinical epidemiology – although he was also deeply interested in the ''softer'' side of medicine and humanistic care. For Mark, and Ed, and Alvan, the clinical experience is everything, and they are right. This insight is infused throughout this book.

In closing, every clinician knows why bioethics is important. What is often missing is how best to approach bioethics problems in a practical way. Although a textbook can only take us so far, and dialogue, role modeling, experience, attitude, and character take us the rest of the way, we have tried herein to provide an effective textbook platform for improvements in patient care related to bioethics. If, in the course of caring for patients, you consult one of these chapters, and your care and the patient's experience is improved as a result, we have reached our true objective in writing this book.

REFERENCES

Agich, G.J. (2005). What kind of doing is clinical ethics? *Theor Med* **26**: 7–24.

Beauchamp, T.L. (1984). On eliminating the distinction between applied ethics and ethical theory. *Monist* **67**: 514–31.

Beauchamp, T.L. and Childress, J.F. (2001). *The Principles of Biomedical Ethics*, 5th edn, Oxford: Oxford University Press.

BBC (2003). Doctors make medical ethics plea. *BBC News* 2 December (http://news.bbc.co.uk/1/hi/health/3253786.stm) accessed 1 November 2006.

Caplan, A.L. (1983). Can applied ethics be effective in healthcare and should it strive to be? *Ethics* **93**: 311–19.

Clouser, K.D. and Gert, B. (1990). A critique of principlism. *J Med Philos* **15**: 219–36.

Daniels, N. (1996). *Justice and Justification: Reflective Equilibrium in Theory and Practice*. Cambridge: Cambridge University Press.

Davis, M. (1999). Case method. In *Ethics and the University*. London: Routledge, pp. 143–74.

Dubler, N. N. and Marcus, L. J. (1994). *Mediating Bioethics Disputes: A Practical Guide*. New York: United Hospital Fund of New York.

Jonsen, A. R. (1991). Casuistry as methodology in clinical ethics. *Theor Med* **12**: 295–307.

Jonsen, A. R. and Toulmin, S. (1998). *The Abuse of Casuistry: A History of Moral Reasoning*. Berkeley, CA: University of California Press.

Kimball, B. A. (1995). *The Emergence of Case Method Teaching, 1872–1990s: A Search for Legitimate Pedagogy*. Bloomington, IN: The Poynter Center for the Study of Ethics and American Institutions at Indiana University.

Kopelman, L. M. (1994). Case method and casuistry: the problem of bias. *Theor Med* **15**: 21–37.

Osler, W. (1906). The hospital as a college. In *Aequanimitas, With Other Addresses to Medical Students, Nurses and Practitioners of Medicine*. Philadelphia, PA: P. Blakiston, pp. 327–42.

Reynolds, D. F. (1994). Consultectonics: ethics committee case consultation as mediation. *Bioethics Forum* 10, **4**: 54–60.

Richardson, H. S. (2000). Specifying, balancing and interpreting bioethical principles. *J Med Philos* **25**: 285–307.

Siegler, M. (1978). A legacy of Osler: teaching clinical ethics at the bedside. *JAMA* **239**: 951–6.

Siegler, M., Pellegrino, E. D., and Singer, P. A. (1990). Clinical medical ethics. *J Clin Ethics* **1**: 5–9.

West, M. B. and Gibson, J. M. (1992). Facilitating medical ethics case review: what ethics committees can learn from mediation and facilitation techniques. *Camb Q Healthc Ethics* **1**: 63–74.

Young, J. O. (1986). The immortality of applied ethics. *The Int J App Ethics* **3**: 37–43.

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SECTION I

Information problems

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Introduction

Anne Slowther

Clinicians have many different roles in the provision of healthcare, including individual patient care, public health delivery, health services management, and policy development. Each of these roles involves complex decisions and interactions that require ethical reflection. However, for the majority of clinicians, those who provide day-to-day care in hospitals, clinics, and patients' homes, it is the relationship with individual patients that forms the professional and ethical core of their work. It is this relationship that initially attracted attention from ethicists as the field of clinical ethics developed, and which has been the main focus of regulatory guidance from professional organizations. This section focuses on three key concepts that define this relationship, namely consent, confidentiality, and truth telling.

A common thread that runs through these three aspects of the patient–clinician relationship is the importance and use of information. Patients provide information to their clinicians about their symptoms, their concerns, and their expectations of what the clinician can do to help them. Clinicians take this information, and then seek further information to develop a differential diagnosis of the patient's problem, select appropriate investigations, and identify possible treatments or management plans. Clinicians provide information to their patients about diagnoses, investigations, treatment options, progress, and outcomes. The therapeutic relationship is thus founded on sharing of information. The way in which information is used by both patient and clinician within this relationship is explored in the following chapters.

The first four chapters in this section describe in detail the concept of consent, which forms the cornerstone of clinical practice. Chapter 2 provides an overview of consent, relating it to the underlying ethical principle of respect for autonomy and pointing out that consent is not simply about acceptance of a suggested treatment but about choice between a range of options, including the option of refusing treatment. The three elements of a valid consent, capacity, information, and voluntariness, are each addressed in the subsequent chapters. Chalmers in Ch. 3 describes the ethical and legal importance of capacity as the key to determining the clinician's approach to treatment decisions. Determination of capacity is not always straightforward and this chapter leads the reader through some of the difficulties and idiosyncrasies in this process. Strategies for optimizing capacity in the clinical setting are suggested and two approaches to formal assessment are described. A key component of these assessments includes the provision of relevant information to ascertain whether the patient is able to understand and evaluate the information necessary to make a treatment decision. The importance of disclosure and the legal requirements governing its provision are discussed by d'Agincourt-Canning and Johnston in Ch. 4. They document the change in standards relating to the degree of information required that has taken place in since the 1980s, reflecting an increasing emphasis on individual patient autonomy within both the healthcare and legal systems. However, access to relevant and comprehensive information is not sufficient for a

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patient to make an autonomous decision about his or her healthcare. Freedom to make a specific choice is also required. The concept of voluntariness and what this means in the context of a patient's relationship with both an individual clinician and the wider healthcare system is considered by Dykeman and Dewhirst in Ch. 5.

The ethical requirement to provide patients with information is not restricted to situations where consent to treatment is necessary. Patients have a right to know what is wrong with them, and keeping such information from them demonstrates a lack of respect, as well as potentially causing them harm. But bad news can cause distress and some patients may not want to hear it. So can it ever be ethically justified to withhold information from a patient, or even to lie to them? Chapter 6 explores the nature of truth telling in the patient–clinician relationship and its correlation with respect for persons and maintenance of trust. The authors emphasize the importance of communication skills in sharing information with patients. It is not only *what* information is provided but *how* it is provided that is crucial to good clinical practice. In the final chapter in this section, Ch. 7, we move from concerns about sharing information with patients to the issue of sharing information about patients with others. Slowther and Kleinman discuss the concept of confidentiality in the increasingly complex field of healthcare, acknowledging new and diverse challenges including the increased use of electronic information systems and the impact of genetic technology.

The chapters in this section summarize specific aspects of information sharing within the patient–clinician relationship, providing an overview of the legal and ethical principles involved. The ethical concepts of respect for persons, individual autonomy, and trust, considered here in the context of individual clinical care, are threads that run through all aspects of information sharing in healthcare. Consequently, the discussions in this section will be of wider relevance to clinicians as they reflect on the ethical issues that they face in their professional practice.

2

Consent

John R. Williams

Mrs. A is an 85-year-old woman living at home with her husband, who has moderately severe Alzheimer disease and for whom she provides daily care. She has an 8.5 cm abdominal aortic aneurysm. Three months ago she consulted a vascular surgeon, who recommended surgical repair of her aneurysm. However, another physician told Mrs. A that she "would never survive the operation." Mrs. A decided to "take her chances" and refused surgery, primarily because of her wish to provide uninterrupted care for her husband; however, she agreed to discuss the decision further with the surgeon at a future visit. Before such a visit can take place, however, Mrs. A is taken to the emergency department after collapsing at home with abdominal pain. Physical examination reveals a systolic blood pressure of 50 mmHg and a tender pulsatile abdominal mass. Mrs. A is moaning and barely conscious. The surgeon diagnoses a ruptured aortic aneurysm and believes that Mrs. A will die without emergency surgery.

Mr. B is a 25-year-old man affected by extensive muscular atrophy resulting from Guillain–Barré syndrome. For two years he has been dependent on a ventilator and his prognosis indicates no chance of recovery. One day he announces that he wants the ventilator support withdrawn and that he be allowed to die because he considers his life intolerable. Those caring for him disagree with his decision and the reasons for it because he is not terminally ill and because others with his condition have meaningful and fulfilling lives. Their arguments do not convince Mr. B and he demands that the ventilator be withdrawn.

What is consent?

Consent can be defined as the ''autonomous authorization of a medical intervention . . . by individual patients'' (Beauchamp and Faden, 2004, p. 1279). There is a widespread consensus in both ethics and law that patients have the right to make decisions about their medical care and to be given all available information relevant to such decisions. Obtaining consent is not a discrete event; rather, it is a process that should occur throughout the relationship between clinician and patient (Arnold and Lidz, 2004). Although the term ''consent'' implies acceptance of a suggested treatment, the concept of consent applies also to choice among alternative treatments and to refusal of treatment.

Consent has three components: disclosure, capacity, and voluntariness. Disclosure refers to the communication of relevant information by the clinician and its comprehension by the patient. Capacity refers to the patient's ability to understand the information and to appreciate those consequences of his or her decision that might reasonably be foreseen. Voluntariness refers to the patient's right to come to a decision freely, without force, coercion, or manipulation.

Consent may be explicit or implied. Explicit consent can be given orally or in writing. Consent is implied when the patient indicates a willingness to

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