Introduction

Medicine, dealing as it does with human beings when they are most vulnerable, is a combination of science, technology – and ethics. All human action has ethical implications, and this book is an exercise in making explicit the ethical implications of action by practicing physicians and other clinicians in the context of a particularly vulnerable population, the infants and children in pediatric medical practice. The book is aimed at several possible audiences, including the primary-care providers who care for children with a high mortality risk or the potential for significant debilitating morbidity, and the physicians in tertiary-care institutions, for whom the clinical scenarios described will sound very familiar. It can serve as a case collection for ethics education of ethics committee members, medical students, and residents. But it is hoped that it will be useful as well to those non-medical professionals who play a role in the ethical life of healthcare institutions, or to lay people who have reason to seek to learn more about the specialized and sometimes confusing world of high-tech care for seriously ill children and the thoughtful and well-intentioned healthcare professionals who wrestle with ethical issues in that world.

To maximize its usefulness to this variety of possible constituencies, the editors have chosen a case and commentary format, asking physicians (and in one case a nurse) to provide detailed clinical accounts of cases in their practice which presented perplexing ethical issues. We have then matched each case with a bioethicist, asking for an ethical commentary on the issue which seems most salient to the respondent, on the basis of the description given by the clinician. With each chapter the editors have included short discussions of ethical issues raised by or discussed in the case and commentary, including references for further reading in the medical and bioethics literature.

There is considerable variation in the way the cases are presented, reflecting different styles of case review. While the degree of attention to blood chemistry or particular pharmaceuticals in some cases may be bewildering to the non-clinician, it is attention to such empirical details that reveals the clinical picture to the physician;

and the ethical dimensions of a medical case are implicated by the clinical picture. Predictive clinical data provide the context in which value judgments are made about whether or not a medical intervention counts as a viable therapeutic option. Non-clinicians seeking to improve their familiarity with clinical culture will find the meticulous medical detail and attention to context of the clinical cases an illuminating change from the often schematic and spare examples typical of many introductory bioethics texts.

It is not surprising that many of the cases feature hard decisions around care at the end of life. Such cases are memorable, conflicted, and complex, and often incorporate tacit or explicit conflicts of obligation, of commitment, and of loyalty. Sometimes no good can be obtained without forgoing another good; sometimes the only choice is between equally bad options. The high emotions, the clinical unpredictability, and the heightened impact of decisions at the end of life can contribute to turning a clinical crisis into an ethical one. While this concentration on the frontiers of medical practice makes some ethical issues very salient, it remains true that the same range of issues arise in many more familiar cases drawn from primary-care practice, where the stakes may be as high and the consequences as tragic for patients and their families.

Pediatric medicine

Pediatric clinical ethics is to be distinguished from general clinical ethics for several reasons. Pediatric medicine must take account of a three-way relationship, involving physician, patient, and family (normally the parents) rather than the dyadic relation that is more typical in adult medicine. The adult patient can participate in the decision-making process. While husband or wife, mother or father may have an advisory role in determining treatment strategies, the adult patient has the final say in consenting to treatment. By contrast, in the pediatric setting the parents are usually the consenting parties. The pediatrician is thus more explicitly responsible to the parents than the oncologist or internist typically is to the family members of his or her adult patient.

Adult medicine also may deal with incapable patients – with individuals incapacitated by age, disease, or injury, as well as nominally adult patients who have for various reasons never attained capacity. For previously capable patients there is some possibility of considering what their treatment preferences might have been were they not incapacitated. Advance directives, previously expressed opinions, or remembered discussions give clues for surrogates attempting to exercise substitute judgment for now-incapable adults. The question of surrogate decision making for pediatric patients has different parameters. “Precedent autonomy” of the sort invoked by some writers in connection with treatment decisions for Alzheimer’s

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patients (Dworkin 1993) is not available for very young infants, who have had no opportunity to form patterns of preference or to indicate their wishes. The only possibility is to invoke something like "precursor autonomy": to recognize that the presently incapable child is potentially a capable future person for whom the maximum of available options should be held open.

Such considerations, except for adolescent patients, are typically "best interests" judgments, not substitute decision making. One commentator has suggested that while respect for patient autonomy is the governing value in adult medicine, in pediatric medicine the duty of beneficence takes precedence over autonomy. Thus professionals may presume to protect or promote the patient's welfare with fewer limits on their authority than in the case of adult medicine (Miller 2003: 2).

All physicians seek to satisfy the best interests of the patient. When that patient is a minor, a helpless and vulnerable child, the importance of protecting those interests is particularly pressing. At the same time, the pediatric physician, more than many of his or her peers, must consider the situation, the interests, and the preferences of the family as part of the agenda. The child's interests cannot be viewed in isolation from the family, for it is the family that typically forms the major enduring and sustaining context for the child. The possibility of a conflict between the child's best interest and the family's best interest adds a dimension when ethical issues arise in the care of children. In cases where there is a clear conflict, such as parental abuse, negligence, or requests by parents for non-beneficial treatment, the professional duty to the child takes precedence, despite practical difficulties that arise in obtaining alternatives to the parents as advocates for the child. Pediatric medicine is an exercise in psychosocial, as well as technical medical, expertise.

Medical ethics, clinical ethics, bioethics

Healthcare organizations and the professionals employed or contracted with them have generally relied on professional or clinical ethics to provide guidance for difficult decisions. Physicians, nurses, and hospital administrators all operate under professional codes which are "Hippocratic" – that is, they acknowledge the primacy of the welfare of the patient as the governing value of their functions. The same is true of other health professionals. Professional ethics is fundamental to the dyadic relationship of the patient and the responsible physician, and enjoins honesty, confidentiality, attention to technical competence and good character, and advance of medical knowledge. Medical ethics is an important part of the education and professional socialization of medical professionals.

Clinical ethics, a patient-centered application of biomedical ethics, has developed for dispute resolution and mediation in clinical settings. A relative newcomer to the medical context, clinical ethics is premised on the assumption that people with a variety of professional (or personal) perspectives and roles may have an equal moral stake in the care of a particular patient, and need to have their voices heard in making treatment decisions in conflicted or ethically complex cases. This development has several roots. It is partially a result of a growing consumer activism that has extended into many areas, having as one result attention to patients' (and families') rights. It is responsive as well to shifts in healthcare delivery. Health care in the last few decades in the United States has increasingly been delivered through a team model in complex institutions. When numerous clinicians and hospital personnel are directly involved in patient care, cases can arise where inadequate communication, conflicts between caregivers, or differences between family members about appropriate treatments can create impediments to or interruptions in the implementation of plans of care for individual patients. It has thus become a condition of accreditation for US hospitals of more than 200 beds to establish an "ethics process," typically an ethics committee, to advise in the adjudication of such disputes. Discussions of these individual clinical cases may involve informed-consent issues, life-and-death decision making, pain and suffering, and the uses of power in clinical settings, as well as such issues as communication, disclosure, and truth telling. Clinical ethics focuses on making differing perspectives explicit and, where possible and appropriate, working toward agreement on the proper priority of shared values. It is typically a multidisciplinary practice, involving physicians and nurses, but also clinicians from allied health professions, social workers, chaplains, sometimes lawyers with health-related specialties, and individuals from such academic disciplines as philosophy, religion, or the social sciences who have familiarized themselves with clinical medical practice. People who identify themselves as clinical ethicists are involved in education, institutional policy deliberations, and ethics consultation in healthcare organizations, contributing to hospital ethics committees and engaging in discussion with clinical practitioners about ethical issues which arise in practice settings. Clinical ethics has been described as "a bridge between the clinical world of health care practice and the theoretical disciplines of bioethics and medical humanities in the academic world" (Fletcher *et al.* 1997: 7). Many of the chapters make reference to the presence and involvement of ethics committees in the cases discussed.

Bioethics as a social movement and academic practice has developed rapidly since the early 1970s. It is to some extent misleading to suggest that bioethics is a discipline. It is more properly described as a multidisciplinary research and practice, involving individuals with many different academic and professional backgrounds. Some sociologists, anthropologists, and historians, some philosophers, nurses, and theologians, some biologists, lawyers, and many physicians, draw upon and contribute to the burgeoning literature of bioethics. Nor is it solely theoretical. One scholar, contrasting bioethics with clinical ethics, characterizes bioethics as "greatly concerned with public policy issues" (Siegler 1979: 915), and in the USA as in many other countries one of the most visible forums for bioethical deliberation is in state- and federal-level bioethics commissions. The European Union and the United Nations have similar committees working on the international level.

When participating in policy or clinical discussions, participants with theological commitments may take those into consideration, just as lawyers may consider first the legal constraints or precedent cases. Philosophers who have turned their attention to bioethical issues, on either the policy or clinical levels, often have a temptingly rich body of philosophical ethical theorizing at their disposal. Those who prove most useful in those contexts, whatever their background, are able to draw from their areas of expertise elements which, when introduced into discussion, are able to broaden the range of issues under consideration, present perspectives that enlighten participants, and provide good reasons for one or another policy or course of action. In a pluralistic society the reasons that seem determinative for one participant or another, be they legal or theological, consequentialist or cultural, may be less persuasive to other affected parties. The purpose of a book on ethics and medical practice is not to provide definitive "right answers" that can silence dialogue, but to remind us that it is good reasons that provide both justification and motivation for action, and to encourage, and to illustrate, the search for reasons for treatment decisions.

Ethical approaches to clinical issues

There is a wide range of variation in the commentaries as well as in the cases, since the respondents come from different theoretical backgrounds and have a wide range of interests, reflecting the wide range of concerns in the changing field of bioethics. The commentators tend to be collaborators rather than critics, often tacitly entering into dialogue with the perplexities of the clinicians, or contributing their perspective with the freedom that can come from being an observer, rather than a participant. Philosophers predominate among the respondents, but clinical and legal training have also informed various commentaries.

Opening a dialogue between medicine and bioethics requires choosing a common vocabulary in which the issues can be discussed, and as the various respondents interact with the descriptions of the cases provided by the physicians, different commentators choose different vocabularies. One might think of the different uses of ethical vocabulary as "styles" of reasoning – principlism, casuistry, narrative. The common discourse of legal obligations features in some of the commentaries. Other commentators, and some of the physicians as well, utilize the vocabulary of the bioethics principles introduced in the first bioethics commission report in 1982 – beneficence and non-maleficence, autonomy and justice – to illuminate aspects of the cases which seem particularly deserving of ethical attention

(President's Commission 1982). The "methods" debate in bioethics is reflected in the different styles of commentary, with some commentators utilizing, others criticizing, application of ethical principles to specific clinical cases. Though each response is quite specific, the editors hope that the cumulative effect will broaden readers' appreciation of the range of ethical concerns clinical cases raise, and the variety of approaches available to deal with those concerns.

Ethical deliberation arises when agents ask "what should I do?" In some unproblematic situations the answer may be "whatever I can." In other situations agents may have cause to wonder whether something within their power is nevertheless a less preferable option, or find themselves wrestling with the consequences of doing their best. It is such cases that fill the following pages. In problematic situations, decision makers find themselves asking: What are the risks and benefits of each alternative? What are the rights of the individuals involved? How are the benefits and burdens of each possible course of action distributed (Foreman and Ladd 1991: 2–3)?

There is one consistent feature of the vocabulary, and of the concerns, of actors and commentators in the cases discussed: a recognition of the extent to which medical intervention, especially, if not uniquely, in pediatrics, is also an intervention into the varied, complex, and intimate arena of family relationships. The presumption, usually justified, is that parents have their children's best interests at heart, and are exercising affection and knowledge, as well as authority, over their children's lives. Anything that impacts the most vulnerable member affects the entire family, and this recognition permeates the book.

The complexity of the relation of children to their families in the light of third-party interventions, especially, although not only, medical interventions, has been the subject of considerable recent discussion. Contemporary liberal society has been characterized by a great emphasis on privacy and individual rights. Various critics, including feminists, communitarians, and disability-rights advocates, have complained that the liberal ideal insufficiently values intimate relations and devalues lives that include as central components various kinds of dependencies and interrelations. Several recent books have attempted to deal in detail with the relation of parental rights and family privacy to the general social and the specific medical obligations to protect the welfare of children, seeking to find a balance between acknowledgment of the importance of the family to the growing child, and the recognition that as a person-in-process the child may have some needs and interests other than those provided by the family (Nelson and Nelson 1995, Ross 1998, Miller 2003).

There is no doubt that the changing conditions of healthcare delivery in the United States, including the growth of managed care and the increasing emphasis on cost-containment and efficiency, is having an impact upon clinical medicine and

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clinical ethics. Often a subtext in our cases, questions of cost and third-party control of clinical decision making are explicitly raised by the last two contributions to this volume. As the impact of these changes is increasingly felt in clinical practice, there will be more need for explicitly addressing them, through institutional focus on ethics, through political processes, and through regulation and legislation (Spencer *et al.* 2000). Professional organizations, groups of concerned citizens, formal and informal ethics and policy processes, local, state, and federal governments, are increasingly focusing on the ethical and cultural, as well as fiscal, impact of clinical decision making. It is hoped that this volume can advance the integration of ethical and medical decision making in these changing times.

Structure of the book

The book is divided into four parts. Part I, "Therapeutic misalliances," includes three cases where for various reasons the root presupposition of medical care, a relationship of trust and collaboration between physician and patient or surrogate, is disrupted. The three cases call to our attention the extent to which alteration in the conditions of trust and communication within which medical care is expected to be delivered cascades into complications in both clinical and ethical decision making.

Part II, "Medical futility," addresses treatment decisions in circumstances where a variety of factors must be taken into consideration, but none of the options can provide the most hoped-for outcome. The interpenetration of facts and values complicates these cases where medical science alone cannot resolve all questions.

Part III, "Life by any means," presents three cases where only very complex, invasive, and high-risk interventions can postpone the death of pediatric patients, and in the case discussions and commentaries it becomes increasingly clear how much clinical decision making is influenced by the wider context – not only the institutional context, but the wider social environment, including the economic, technological, and cultural environment.

Part IV, "Institutional impediments to ethical action," focuses on the institutional context, calling attention to ways in which institutional arrangements – attention to continuity of care, or to mechanisms for appropriate consultation – can help or hinder ethically excellent medical care. The final contribution explicitly addresses the effects on traditional medical practice of contemporary alterations in the way healthcare delivery is financed.

References for the chapters are cited in the text, with complete references at the end of the book. Readings associated with each "Topical discussion" follow that section.

Part I

Therapeutic misalliances

The ideal relationship between physician and patient, or in the pediatric setting, between physician, patient, and parent, is a therapeutic alliance. In this alliance, both parties have a common understanding of the goals of treatment and the means by which to achieve them. The physician's perspective is that of the medical expert who best understands the appropriate means. The parent's perspective is that of an autonomous agent concerned with the well-being of his or her baby as this bears on the interests of the entire family.

The therapeutic alliance, once established, allows the physician to concentrate on meeting an adequate standard of care appropriate to the particular case without the need to justify his or her actions. In addition, it promotes parental trust and confidence in the physician. These important results are not possible when there is a lack of agreement between physician and parent concerning the ends and means of clinical care. Call this lack a therapeutic misalliance.

The three clinical cases that are discussed and commented upon in this section are examples of therapeutic misalliances. The first involves a mother's insistence upon the use of alternative medicine in the treatment of her seriously ill child. The second concerns confusions as to the goals of treatment and a concomitant breakdown in communication between the caregivers and the family. The third is about a mother's deceptive practices and miscommunications concerning her son's illness.

In Chapter 1, Chester Randle recounts the case of Melody, whose term baby girl, Ericka, had been seriously ill but was recovering. Melody believed that Ericka's immune system was weak and wanted her spiritual advisor to attend the child. Jonathan visited the child and prescribed an herbal tea that Ericka was to ingest and have applied to her chest. The attending physician believed he had an ethical and legal obligation to assure that all treatment of the child while she was under his care was safe and effective. After a meeting with the spiritual advisor it was agreed that the tea could be applied to Ericka's chest, but was not to be ingested.

In his commentary, theologian Richard Miller points out that Randle's belief, that allowing unconventional practices is morally permissible when these appear to be

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harmless, is inapplicable in this case because he did not have sufficient information to determine whether the tea was in fact harmless. Miller also suggests that Ericka's physicians did not address Melody's beliefs adequately as they pertained to the appropriate care of her child. Miller expands on the first issue by an analysis of the use of unconventional treatment, its therapeutic status and its admissibility, if non-therapeutic. His discussion of the second issue focuses on the lack of information about Melody's beliefs and practices and their possibly harmful effect on her past and future care of Erika.

Miller introduces a distinction between "transactional" and "transformational" approaches in the parent–physician relationship. The latter can reduce the likelihood of future illness and provide a means by which health-related habits are improved. He also notes that Melody's desire to use unconventional treatment for her baby reveals a significant difference between adult and pediatric medicine. Melody's autonomy permits her to use any treatment she wishes on herself. But autonomy plays no role in deciding on the treatment of her child, who does not have a liberty interest. This calls for a more expansive perspective in pediatric treatment than in adult treatment.

In Chapter 2, Ronald Cohen and Eugene Kim describe a fifteen-year-old unmarried mother who delivered a 23-week-gestation baby (Baby M) whom the neonatologists thought was not viable. This was explained to the mother and grandmother, who then consented to a plan of comfort care without mechanical ventilation. After she had survived for six hours, Baby M was re-examined, and with the concurrence of the family it was decided to intubate the baby and provide ventilation. She was transferred to a neonatal intensive care unit where she received complex treatment for nine months. Although conferences were held during that time in which the mother and grandmother were told of the infant's grave prognosis and high-risk status, they rejected these judgments. They had been told the baby was going to die and she was obviously alive. In addition, conflicting advice about appropriate treatment strategies was provided by a bioethics committee which was consulted; some members thought there should have been immediate and aggressive intervention at birth, and others thought no intervention should have occurred.

Respondent Simon Whitney, a physician who is also a lawyer, suggests that aggressive care of Baby M was inappropriate at any time. The fact that she survived, while good news, did not justify the treatment that kept her alive. In his commentary he discusses the issues of viability and legal doctrines that influence care decisions as they related to this case. He calls attention to the strained relations between the caregivers and the family, and notes that despite their protestations to the contrary the physicians made all the major decisions. Thus it was not the family that was inconsistent in their judgments, as suggested in the case history, but the physicians, who initially decided to do nothing but then decided to do everything.

He concludes by recommending a procedure that calls for two-way listening that would accurately and fully inform both the caregivers and the family of the material facts.

In Chapter 3, Manuel Garcia-Careaga and John Kerner introduce an 8-year-old boy who came to a pediatric gastroenterology clinic with reports of recurrent fevers, joint symptoms, chronic diarrhea, and abdominal pain. Over the course of a year the clinical picture included many visits to the GI clinic, fevers, and numerous hospitalizations. The physicians began to suspect that the mother, for complex psychological reasons, was inducing illnesses in her child. Self-induced illnesses as a means of getting attention are termed "Munchausen syndrome," and when as in this case the illnesses are in a second party, it becomes Munchausen syndrome by proxy (MSBP). The consequences of inducing illnesses in a child can be damaging, both psychologically and physically, and can lead to death.

But concrete proof of MSBP is difficult to obtain. When it is discovered, the moral obligation to protect the child from harm creates a heavy burden of responsibility on the caretakers, including the need to protect the child and help the offending parent, securing protective services and organizing adequate patient care. Overt efforts to uncover hard evidence of what one suspects can have the effect of frightening off the mother so that contact is lost with a child who is at risk. To avoid this calls for covert activities – video monitoring, searching the belongings of parents without their knowledge, as well as continuing lab tests to see if they give any clue to what is going on with the mother's interventions. The case report describes the consternation of the physicians as they began to eliminate all other causes of the child's symptoms, their growing suspicion, and finally a clear diagnosis.

The commentary by philosopher Frances Kamm consists of two parts. First she discusses the components of MSBP, conceptual issues with the use of the term "syndrome," child abuse, and the doctor's aims. Then she rigorously explores some of the ethical issues involved in the methods used to diagnose this unusual and counterintuitive pathology. She suggests that the major concern of the doctors is what is morally permissible for them to do in order to identify the child's illness. She questions whether secret monitoring can properly be described as a diagnostic tool, since it is done without the permission of the monitored individual and is not done to garner evidence for the purpose of criminal prosecution. She presents a series of possible arguments justifying secret monitoring, but finds that all of them have problems. Resolving them leads to revisions of the original arguments.

In her final analysis she notes that there are two kinds of procedures for determining whether a parent is responsible for a child's illness – those that prevent her from acting, and those that catch her in a wrongful act. She presents four procedures that fall under those two categories, and suggests an order of preferability.