Bioethics and Women
This page intentionally left blank
In loving memory of my mother and my sister
and for all of our daughters
This page intentionally left blank
My thanks are due first to Anne Drapkin Lyerly, who might have been my coauthor if other obligations hadn’t intervened in the task. Annie was, in a sense, my inspiration for writing the book. Later on, Lisa Harris, another obstetrician-gynecologist, reviewed a great deal of the manuscript, and provided me with extremely helpful suggestions.

Thanks too to various members of the faculty in the Department of Obstetrics and Gynecology and the MacLean Center for Clinical Medical Ethics at the University of Chicago, which has been my academic home since 1990. These include but are not limited to Sarah Adams, Daniel Brauner, David Cohen, Ismail Mahmoud, Ernst Lengyel, William Meadow, Maura Quinlan, Jaideep Singh, and Diane Yamada. The willingness of these clinicians to review material, discuss cases, and answer my questions has surely made the book more clinically credible than it would otherwise be. Kenneth Iserson, from the University of Arizona College of Medicine, has also been helpful in this regard. Other members of my department who performed tasks for which they had better expertise than I include Steve Gadzinski, Gail Isenberg, and Beatrice Merigold.

I am grateful to members of the Center for Biomedical Ethics at Stanford University, with whom I spent most of the academic year 2001–2002 working on the book and enjoying my interactions with them. During this time, I also benefited by detailed and thoughtful suggestions from anonymous reviewers at Oxford University Press.

Because I spent the first part of my academic career in a philosophy department, the content of Bioethics and Women has undoubtedly been influenced by
philosophers whose work I read, especially those who have dared to focus on issues of particular relevance to women. I have long counted Alison Jaggar, Rosemarie Tong, Joan Callahan, and Laura Purdy in this group. In addition to Laura, Jennifer Parks, Nancy Snow, and Sara Goehring have been generous enough to review parts of the manuscript and give me helpful feedback.

Jeffrey House was my first contact at Oxford, and as with previous books, he handled the project wisely and efficiently, particularly when I worried about losing a coauthor and being unable to meet Oxford’s deadline. Peter Ohlin, who picked up the baton from Jeff, has proved a worthy successor, ably assisted by Lara Zoble. Cynthia Garver did an excellent job of copyediting, and Linda Donnelly, the production editor, facilitated the project not only through her helpful suggestions but also through ease of contact. Two people offered relevant photos or sketches for the book’s jacket: Annette Mendola, whom I hope someday to thank in person, and Germaine Wieman, a longtime friend, whom I will thank in person sometime soon.

Last but definitely not least, I want to thank Tony, my life partner and best friend, who has not only contributed to the book through his loving support of me, our children, and my work, but also by helping me to avoid mistakes in his area of expertise, developmental biology and genetics.
At its conception, this book was intended for practitioners who provide health care for women. The goal was to offer a helpful guide to them on the numerous ethical issues that arise in treatment of women across the life span. Issues relevant to this goal include many that are unrelated to reproduction. With regard to those that are related, however, my aim was to write the book in a way that showed respect for the different convictions of those involved, whether women or men, practitioners or patients, about the moral status of the human embryo or fetus. I wanted to track how these convictions may also have implications for nonreproductive decisions, particularly those made at the end of life. And because the book would be devoted to women’s health care, I hoped to facilitate recognition of women’s own standpoints as central to ethical decisions by and about us.

Since the book was intended for clinicians, I invited a young obstetrician/gynecologist to join me in the project. Her expertise, experience, and youth were complementary to the input I could provide. Together we felt able to write a book on bioethical issues that had not yet been available to clinicians who care for women: one authored by women themselves at different ends of their own life spans. To be useful to practitioners, we wanted the book to accentuate the clinical as well as ethical complexity of cases rather than the theoretical arguments and analyses that academic bioethicists bring to their work.

Fortunately or unfortunately, as often happens in the lives of those who nurture others’ lives, family-building events prevented my intended coauthor from finishing the project. At that point, my editor and publisher advised me to go ahead on my own, which I have done.
Going ahead on my own meant broadening the targeted audience to include students and teachers of bioethics. To be useful to this wider readership, I have expanded the theoretical chapters (part I) and reduced the amount of clinical complexity or specialized language in the chapters devoted to practical topics (part II). I have also added a chapter addressing the plausibility and desirability of an ideal of justice in health care and gender justice in women’s health care.

While reorienting the book to a broader range of readers, I did not attempt either of two tasks that could be well accomplished by others, or perhaps addressed in my next book: examination of each topic, issue, and case with as full academic rigor as it deserves, and development of a well-reasoned argument from well-supported premises to a definitive conclusion or position on each of the ethical questions raised. Doing this adequately would require an entire book or at least a full article for every topic and issue identified. Because the book offers rich fodder for these analyses, I look forward to reading and learning from others who provide them. In the meantime, the material presented here can be fruitfully used to provoke ongoing, thoughtful discussion not only by students and scholars of bioethics but also by practitioners and the public at large. Fueling and focusing such discussions on women’s health care is long overdue.
# CONTENTS

Introduction 3

**PART I: A BIOETHICS FOR WOMEN**

1. An Egalitarian Overview 9
   
   - Diverse approaches to bioethics 10
   - Verities, variables, and maxims 15
   - Conceptions of justice 18
   - Standpoint theory and its implications for just caring 24
   - Privileging women’s standpoint in our health care 26

2. Distinguishing Features of Women’s Health Care 30
   
   - Some sex and gender differences 31
   - Models of the practitioner-patient relationship 35
   - Possible modifications of principlist and casuistic methods 37
   - Who is the patient? 40
   - Patients and “dependent moral status” 44
   - Guidelines and regulations 47
3. Different Starting Points, Standpoints, End Points  50
   Key terms  51
   Meaning and significance of moral status  54
   Moral relevance of the gestational tie and other relationships  56
   Personhood and potential for personhood  58
   Thresholds of development and moral status  62
   Intermediate positions about moral status  66

PART II: TOPICS, ISSUES, AND CASES

4. Preconception and Prenatal Decisions  73
   Preconception counseling  74
   Preimplantation genetic diagnosis  78
   Prenatal testing  81
   Misattributed paternity and carrier testing  85
   Sex selection  88

5. Medically Assisted Reproduction  92
   Criteria for patient selection  93
   Gamete “donation” and “surrogacy”  97
   Disposition of in vitro embryos  101
   Multiple gestations  104

6. Noncompliance during Pregnancy  109
   Refusal of hospitalization  110
   Dietary noncompliance  114
   Refusal of cesarean section  117

7. Decisions at Parturition and Birth  123
   Mode of delivery  124
   Cesarean sections for nonmedical reasons  126
   Decisions for impaired or very premature newborns  130
   Sex assignment at birth  134

8. Treatment of Minors  140
   Teenage pregnancy and motherhood  141
   Confidentiality issues  145
   Ritual female genital surgery  149
   Eating disorders  153
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. Preventing Pregnancy and Birth</td>
<td>158</td>
</tr>
<tr>
<td>Contraception and sterilization</td>
<td>159</td>
</tr>
<tr>
<td>Abortion</td>
<td>163</td>
</tr>
<tr>
<td>10. Violence and Discrimination toward Women and Children</td>
<td>172</td>
</tr>
<tr>
<td>Child abuse and neglect</td>
<td>173</td>
</tr>
<tr>
<td>Elderly abuse and neglect</td>
<td>176</td>
</tr>
<tr>
<td>Violence against women</td>
<td>179</td>
</tr>
<tr>
<td>Gender discrimination and sexual harassment</td>
<td>182</td>
</tr>
<tr>
<td>11. Nonreproductive Health Issues</td>
<td>186</td>
</tr>
<tr>
<td>HIV testing and AIDS</td>
<td>187</td>
</tr>
<tr>
<td>Breast and gynecological cancers</td>
<td>190</td>
</tr>
<tr>
<td>Menopause and hormone replacement therapy</td>
<td>194</td>
</tr>
<tr>
<td>12. Care of the Elderly and End-of-Life Care</td>
<td>198</td>
</tr>
<tr>
<td>Health-related issues</td>
<td>199</td>
</tr>
<tr>
<td>Caregiver issues</td>
<td>203</td>
</tr>
<tr>
<td>End-of-life decisions</td>
<td>207</td>
</tr>
<tr>
<td>13. Research Issues</td>
<td>214</td>
</tr>
<tr>
<td>Women as research subjects</td>
<td>215</td>
</tr>
<tr>
<td>Maternal-fetal surgery</td>
<td>220</td>
</tr>
<tr>
<td>Cloning and stem cell research</td>
<td>223</td>
</tr>
<tr>
<td>PART III: AN EGALITARIAN IDEAL</td>
<td></td>
</tr>
<tr>
<td>14. Virtue and Gender Justice in Health Care</td>
<td>233</td>
</tr>
<tr>
<td>Recapping the perspective</td>
<td>233</td>
</tr>
<tr>
<td>Obligations, virtues, and ideals</td>
<td>235</td>
</tr>
<tr>
<td>Individual decision-making and an egalitarian ideal</td>
<td>237</td>
</tr>
<tr>
<td>Virtue in women’s health care</td>
<td>238</td>
</tr>
</tbody>
</table>

Notes 241

Index 267
Bioethics and Women
This page intentionally left blank
Work in bioethics requires both theoretical and empirical considerations relevant to each topic, issue, and case examined. This is true regardless of whether the work is done in classrooms or in clinical encounters. The format of this book, therefore, joins both types of considerations. Part I (chapters 1–3) provides an overview of theoretical considerations relevant to women’s health care and Part II (chapters 4–13) adds empirical considerations to these while addressing bioethical questions that arise throughout the life span. Part III (chapter 14) offers theoretical considerations that complement those covered in the body of the book.

Chapter 1 sketches the egalitarian perspective I have brought to my work in bioethics for many years and explains how this is different from, as well as similar to, alternative approaches. After introducing the relevant ethical principles, I argue that justice is the central principle from which questions involving disparate impact on people must be addressed, with gender justice as the necessary subset of justice from which issues in women’s health care should be scrutinized. Drawing on classical pragmatism and feminist standpoint theory, I explain how the input of minorities and women is crucial to overcoming the fallibility of decisions and policies formulated by those who hold positions of dominance or power over those who are less dominant or less powerful.

Chapter 2 identifies unique features of women’s health care, examines various models of the practitioner-patient relationship, and critiques mainstream approaches to bioethics for their overall inattentiveness to relevant differences between men and women. Where there is such attentiveness, I suggest that it is sometimes misguided, as in the tendency to view each pregnant woman as two separate patients.
in which there is widespread disagreement on various moral questions, individuals must make their own moral decisions without having adequate guidance from laws or policies that are applicable to everyone. Foremost among areas of disagreement is the question of requirements for moral status or personhood. Many people have developed cogent arguments for different answers to this question; I do not regard any of these as definitively proved or refuted. When some ethical quandaries involving women are addressed, however, an answer to the question of moral status is unavoidable, at least implicitly, and different answers have different ethical implications for the decisions of individuals. In chapter 3, therefore, I consider a range of positions about moral status, from the minimal criterion of genetic humanness that occurs in the zygote to the maximal criterion of moral agency that occurs years after birth. Through this discussion, I hope to facilitate examination of topics covered in Part II in a manner that respects the moral integrity of individuals who disagree about this pivotal issue.

Chapters 4–13 cover a wide range of topics involving women’s health care across the life span. Obviously, not all of these relate to reproduction, and some topics involve health risks raised by social circumstances such as caregiving responsibilities and domestic violence. Each chapter is subdivided into issues encompassed by the topic addressed, and each of these is introduced by cases that illustrate ethically relevant variables. Empirical and theoretical considerations about the issues and cases are then discussed. The theoretical considerations include conceptual clarifications and discussion of the principles and perspective delineated in Part I. The empirical considerations include clinical variables such as diagnoses, prognoses, and treatment alternatives as well as psychosocial variables such as the patient’s age and competence, costs of treatment, societal or cultural influences, and relationships with others. All of the cases are based on the experiences of women and clinicians who care for them. A few have been reported in the media. Where the cases have not been reported elsewhere, particulars have been altered to protect the confidentiality of the individuals and institutions involved.

No matter how thoroughly and carefully one examines, elaborates, and analyzes conceptual and ethical questions raised by specific cases, the nuances of actual, ongoing cases cannot be wholly captured through narration or discussion of them by those who are not directly involved. The actual cases in which patients, family members, and practitioners are required to make ethical decisions always entail more variables than descriptions of them can identify and analyses can address. Moreover, the ethical questions raised and the variables associated with them often change as a case progresses. Those who personally or professionally participate in a case have different standpoints as well as rights and responsibilities regarding the questions raised.

Because it is impossible to identify and examine all of the potentially relevant variables, or consider all of the standpoints relevant to each case or issue, I do not attempt to delineate all of the questions raised or provide definitive answers to all of those addressed. My goal is simply to facilitate ethical decision-making on issues in women’s health care through fuller and more critical consideration of the ethical complexity that arises in particular cases. Policies and legislation about