AFTER HARM

MEDICAL ERROR AND THE ETHICS OF FORGIVENESS

BERLINGER
After Harm
RECENT AND RELATED TITLES IN BIOETICS


Mark P. Aulisio, Robert M. Arnold, and Stuart J. Youngner, eds. *Ethics Consultation: From Theory to Practice*

Audrey R. Chapman and Mark S. Frankel, eds. *Designing Our Descendants: The Promises and Perils of Genetic Modifications*

Ezekiel J. Emanuel, Robert A. Crouch, John D. Arras, Jonathan D. Moreno, and Christine Grady, eds. *Ethical and Regulatory Aspects of Clinical Research: Readings and Commentary*

Grant R. Gillett. *Bioethics in the Clinic: Hippocratic Reflections*


Carol Levine and Thomas H. Murray, eds. *The Cultures of Caregiving: Conflict and Common Ground among Families, Health Professionals, and Policy Makers*

Thomas May. *Bioethics in a Liberal Society: The Political Framework of Bioethics Decision Making*

Thomas H. Murray, consulting editor in bioethics
After Harm
Medical Error and the Ethics of Forgiveness

Nancy Berlinger
Deputy Director and Associate for Religious Studies
The Hastings Center
Garrison, New York
To
Andrew Berlinger;
Virginia Ashby Sharpe,
and
Julia Boltin
This page intentionally left blank
Preface ix
Acknowledgments xvii

1. Narrative Ethics 1
2. Physicians’ Narratives 11
3. Patients’ and Families’ Narratives 28
4. Disclosure 40
5. Apology 51
6. Repentance 63
7. Forgiveness 81
8. Ethical Action 92

Appendix 115
Notes 121
References 139
Index 151
In the years since the release of To Err Is Human—the Institute of Medicine’s report on the problem of medical error in the United States—made front-page news across the nation in November 1999, it has become almost de rigueur for scholars, health care professionals, and journalists to begin their books and articles by invoking the report with its startling statistics on the extent and the cost of the problem. This book is no exception, but my reason for doing so is arguably different from the ritual invocation of the report as shorthand for the “problem of medical error.” Rather, I am interested in the implications of the report’s title for how physicians, health care administrators, injured patients, and the families of injured patients think, speak, and act in the aftermath of harmful medical mistakes. Clearly, the phrase “to err is human” is intended as a reminder that attempting to eliminate medical error is futile as long as human beings are involved in delivering health care, because making mistakes is part of being human. But it may also remind us of something important about the aftermath of error; notably, the complete aphorism to which the title alludes is “to err is human; to forgive, divine.”

When I first heard the title of the IOM report, I naively assumed that the report was going to say something about the nature of forgiveness after medical error—forgiveness being a time-honored, if imperfect and often misunderstood, way of dealing with the aftermath of intentional and unintentional harm between persons and between societies. Finding nothing in the report about this dimension of medical error, and finding nothing in the burgeoning theoretical and empirical literature on forgiveness that addressed the aftermath of unintended harm in the context of health care, I started thinking, talking, and writing about what “forgiveness” might mean in this context. The result is this book.

Forgiveness is a word that signifies “religion” to many people, particularly but not exclusively those who are familiar with Jewish and Christian teachings, practices, and expectations with respect to what ought to happen when one person harms another person. However, these religious teachings, practices, and expec-

tations have permeated secular culture in the West for so long and in so many ways that it is completely natural to talk about error, guilt, shame, confession, apology, repentance, and forgiveness without any reference to religion. Think of any recent confession of wrongdoing by a politician, business leader, or other public figure, which tends to follow this script: Mistakes were made; I am sorry for any pain my actions may have caused, I take full responsibility; I hope those affected by my mistakes will forgive me, find closure, and be healed. Think as well of the post-Watergate lesson reminding public figures that the cover-up is worse than the crime: because a lack of candor breeds suspicion in the minds of others, it is better, ethically and strategically, to tell the truth and accept the consequences than to devote oneself to dissembling, concealment, and lies.

Yet there is more to forgiveness than the clichés trotted out in the aftermath of scandal. It is valid and useful to approach the problem of medical error—in particular, the problem of medical harm—from the perspective of how individuals living in this society have long been taught, whether by religion, by other cultural influences, or by their parents, to think about what ought to happen when one person unintentionally harms another person. Most medical harm does not result from the negligence of “bad” doctors. Most physicians feel genuine remorse, even anguish, when they realize that their well-intentioned actions have injured or killed a patient who was under their care, even though they may be in profound conflict about what ought to happen next. They must weigh their obligations toward such patients and their families against their fears about the consequences of fulfilling these obligations.

This book looks at medical harm from “error” to “forgiveness,” with stops along the way at “disclosure,” “apology,” and “repentance,” words that describe the sequence of practices and expectations that may culminate in forgiveness—a voluntary response by the person who has been harmed, in recognition of the sincere words and tangible actions of the responsible person or parties. I am not proposing an ethic of forgiveness in which the harmed person is responsible for bringing about resolution simply by forgiving the person whose actions resulted in harm. Such an ethic would be counterproductive to goals of patient safety as well as neglectful of the concrete needs and responsibilities brought about by harmful mistakes. Rather, I ask—and attempt to answer—the following question: What are the words and actions of individuals and what are the policies and practices of institutions that, if completed in the aftermath of medical harm, may offer injured patients and their families the possibility of forgiving those responsible for the harm?
This book constitutes a religious studies perspective on the aftermath of medical harm in two respects. First, it draws on interdisciplinary work on error, truth telling, apology, repentance, and forgiveness by scholars, both inside and outside the formal discipline of religious studies, who are attentive to the religious roots or dimensions of these themes and to their secular counterparts or expressions. Second, it draws on a particular area of religious studies, Christian social ethics, and the work of a particular Christian theologian, Dietrich Bonhoeffer (1906–1945), whose writings on ethics address many of the questions that are germane to issues of error and forgiveness: What does it mean to tell the truth? Who suffers as the result of harm, and what are our concrete responsibilities toward each of those who suffer? What is the nature of the relationship between a patient and a physician, and between that patient and a health care institution, after that patient has been unintentionally harmed by this physician, in this institution? What is forgiveness, and how can we avoid the temptation of presuming we will be forgiven for our mistakes rather than acting in such a manner as to make it possible for those whom we have harmed to forgive us?

My use of Bonhoeffer’s work reflects my own academic background and the ideas that have informed my thinking about the ethics of forgiveness after medical harm, ideas that are readily accessible to readers who may not have a background in religious studies or any knowledge of Christian social ethics. I make no special claims for the intrinsic merit of this or any other religious or theological perspective applied to the problem of medical harm over against secular philosophical perspectives. For example, Bonhoeffer’s theory of the “view from below,” discussed at the end of chapter 1 and mentioned throughout the book, is not too far from John Rawls’s “veil of ignorance,” from “standpoint” theories described by Sandra Harding and other feminist philosophers of science, from Michel Foucault’s theory of “disqualified knowledges,” or from Emmanuel Levinas’s ethics of the “Other.” Any of these theories has the potential to stimulate fresh and productive thinking about how to improve the care of persons affected by medical mistakes; how to listen for and include different voices and different stories in efforts to resolve individual cases of harm and to make medical education and health care systems more responsive to the needs of injured patients and their families; and how to recognize the Other—the harmed patient, the grieving family, the physician who made the mistake—not as an adversary but in terms of one’s responsibilities toward the Other. However, given that attentiveness to religion-derived concepts and practices associated with error and forgiveness may assist in understanding and responding to the needs of persons affected by medi-
cal mistakes, it is possible that Bonhoeffer may, by virtue of his vocabulary and commitments, be an especially useful theorist to draw on in addressing this problem, even for readers who do not have any background in religious ethics.

The taxonomy of medical error is vast, colorful, and at times confusing. There are slips, lapses, harmless hits, and near misses; errors of omission and of commission; operator errors, system errors, accidents, complications, and bad outcomes. There are even more elaborate ways to describe and to disguise error: as an “inevitable occasional untoward event,” for example. This book does not pretend to offer definitions of medical error that will satisfy all readers and apply to all clinical circumstances; in any case, essential readings on this subject already exist. Rather, my primary focus is on the experience of medical error (or, in a few cases, suspected error) that results in injury or other harm to a patient, or to that patient’s family. Although this book makes use of a variety of terms, in most cases, I am writing about medical mistakes, those errors defined as “errors of conscious thought” and “misapplied expertise” rather than those defined in terms of poorly designed systems or momentary, unconscious lapses in routines. Mistakes are made by individuals, even if these individuals are working within systems. And they are experienced by individuals: by the individuals who make them, and by the individuals who may be harmed by them. It may, therefore, be helpful to think of this book as an effort to enlarge the accurate but often defensive statement “mistakes happen” to acknowledge the experience of the patient and family to whom harm “happens” as the result of mistakes. The other dimension of medical mistakes that this book addresses, in chapters 3 and 5, in particular, is the harm done to the physician-patient relationship, and to real patients and real physicians, when mistakes are made in the aftermath of an actual or a suspected error, compounding the initial trauma.

Too often, discourse on the problem of medical harm is reduced to a shorthand of “individuals” versus “systems,” rather than being discussed in terms of individuals in systems, whether that system is a solo practice, a group practice, a community hospital, an academic medical center, or a medical school. This book focuses on the experience of individual clinicians, patients, and family members in the aftermath of medical harm, but it assumes a systems context for these experiences and argues for systems approaches to improving care after medical harm, in particular, with respect to supporting concrete practices such as disclosure, apology, and fair compensation.

Throughout this book, the “clinician” is almost always a physician. To date, most literature and research on the aftermath of harmful mistakes focuses on
physicians, who have a professional obligation to disclose mistakes and are accountable for the care of their patients; thus, disclosure is frequently discussed in the literature within the context of the physician-patient relationship, not the provider-patient relationship. Although other clinicians—nurses, technicians—may make or be involved in mistakes that injure patients, these clinicians are in a different place in the system’s hierarchy and stand in a different relationship to patients. A mistake made by a nurse or a technician would most likely be disclosed by the treating physician or by a hospital administrator. Moreover, nurses and other clinicians, as well as risk managers, clinical ethicists, chaplains, hospital attorneys, and other health care professionals who may be involved in the resolution of medical mistakes, have their own professional cultures, which must be taken into account when proposing changes in the ways individuals within systems respond to needs resulting from medical mistakes. Such are my excuses for limiting the focus of this book to the culture of medicine and its subcultures, with the hope that other health care professionals may find something of use in these pages and that other scholars will take up the challenge of exploring these issues, especially with reference to the culture of nursing.

This book is organized into three parts. Chapters 1 through 3 examine how medical harm is experienced, remembered, and written about by physicians who have made harmful mistakes and by patients and families who have been affected by such mistakes, and propose ways to use these personal narratives in medical education and other settings. These chapters also launch the narrative arc of this book—from error to forgiveness—by offering accounts of what the immediate aftermath of medical error (or suspected error) looks like from the perspectives of the persons most directly affected. We are able to grasp something of the emotional chaos of the immediate aftermath of harmful mistakes when we read a physician’s own account of disclosing a fatal error to the patient’s family even as the physician could barely comprehend what had just happened; or a surgeon’s account of making a mistake while racing against the clock to save a drunk driver’s life; or a spouse’s account of hearing her husband’s surgeon assure her that while her husband’s death was “unpleasant” for her, it was “shattering” for the surgeon himself; or another spouse’s awareness, captured in a deposition transcript, that his wife’s death meant he was suddenly the single father of a nine-month-old. We also recognize that the words and actions offered to the patient and family at this time, and thereafter, matter intensely, that there really are right and wrong, appropriate and inappropriate, compassionate and callous, things to say and do. When I discuss these personal narratives with medical students and residents, the
story of the surgeon whose idea of comforting a widow was to tell her that he felt worse than she did always gets a strong, almost visceral, reaction. Even if these students and early-career physicians have already learned to be defensive around the issue of medical error and its disclosure (“mistakes happen,” “it’s all about how you define ‘error’”), they recognize that what this surgeon said was inexcusable. They don’t want to become this kind of physician, and perhaps, having read, discussed, and remembered this story, they won’t become him when they do, inevitably, make a mistake that harms a patient.

Chapters 4 through 7 explore each of the sequential steps in the relational process that may culminate in forgiveness after medical harm. The subject of chapter 4 is “disclosure,” the very first ethical action that can be undertaken in the aftermath of known or suspected harm, the practice of consistently telling the truth to injured patients and their families. This topic is explored with reference to Bonhoeffer’s writings on the morality and meaning of truth telling, one of which he wrote in an effort to understand and defend his own practice of not telling the truth in a highly unusual situation. Such a text, and its historical circumstances, may shed light on some of the ways that physicians may justify their own reluctance to disclose mistakes and on their mistrust of efforts to improve disclosure policies and practices within health care institutions.

In discussing “apology,” the subject of chapter 5, I draw on the work of legal scholars who have explored the meaning and function of apology in U.S. law and in efforts at conflict resolution. These scholars are sensitive to religious or other traditional definitions of apology and to how these definitions may be at odds with legalistic apology formulas that, while adhering to the letter of the law, may be unsatisfying when they are offered to real human beings.

Chapter 6 explores the nature of “repentance” after harm by examining the always contentious issue of whether, and how, injured patients and their families ought to be compensated for health care needs or lost income resulting from medical mistakes. In examining three different models that aim to deliver fair compensation without litigation, and that integrate compensation into the disclosure of the medical mistake itself, I argue against suggestions that the “magic” of apology ought to be sufficient compensation for patients and families who have suffered tangible hardships resulting from medical injuries and propose that tort reform advocates acknowledge the legitimate needs of injured patients by supporting efforts to deliver fair compensation.

To discuss “forgiveness” in chapter 7, I work from Bonhoeffer’s famous condemnation of “cheap grace,” forgiveness extended or expected without any ac-
knowledgment of responsibility for another person’s suffering or any concrete efforts to alleviate this suffering. In exploring the nature of forgiveness after medical harm, and in arguing for an understanding of forgiveness as the ability to achieve detachment from an incident of harm, I also draw on recent and classic studies of forgiveness, including a study of the professional forgiveness ritual of the Mortality and Morbidity Conference (M&M), whose antecedents in ancient Jewish and Christian forgiveness rituals are obvious, if usually unacknowledged.

The book’s concluding section can be approached either as a theory of the ethics of forgiveness after medical harm, or simply as an annotated list of recommendations, practices, observations, and reflections that physicians, medical educators, ethicists, health care administrators, and others may use in thinking about the problem of medical harm and how to improve the care of patients, families, and clinicians affected by this problem. This section is organized in terms of the traditional practices of “confession,” inclusive of disclosure, apology, and other methods, both appropriate and inappropriate, of communicating in the aftermath of harm; “repentance,” which focuses on actions undertaken to relieve suffering in the aftermath of harm; and “forgiveness,” which proposes ways in which individuals and institutions may promote the conditions that may allow injured patients and their families—and clinicians themselves—to detach and move on from incidents of medical harm.
This page intentionally left blank
Acknowledgments

This book was inspired by the extraordinary intellectual community that is The Hastings Center, a community of which I am honored to be part, and where I learned to apply my longstanding interest in the religious and cultural dimensions of error and forgiveness to the problem of medical harm. In 2000, the Center launched an interdisciplinary research project entitled “Promoting Patient Safety: An Ethical Basis for Policy Deliberation,” which sought to examine the ethical dimensions of the issues that policymakers were beginning to take up in the aftermath of the 1999 Institute of Medicine report on the extent of medical error in the United States. I am deeply grateful to the creator of this project, Virginia Ashby Sharpe, who introduced me to the field of patient safety, and to Raymond Andrews and Lynne Garner of the Patrick and Catherine Weldon Donaghue Medical Research Foundation, who made possible this project and the initial research that led to the writing of this book. I am also profoundly grateful to all of my colleagues at The Hastings Center; in particular, to Thomas Murray, Daniel Callahan, Gregory Kaebnick, and Erik Parens, for their guidance and encouragement, and to Chris McKee and his library staff.

Special thanks are due to Elizabeth Seth and Alissa Lyon, my research assistants; to Ann Mellor, my administrative assistant; to Juniper Lesnik, for tracking down legal references; to Julia Boltin, for sorting out countless citations; to Abby Tannenbaum, for proofreading the manuscript; and to Bette-Jane Crigger, for preparing the index. Nancie Erhard taught me how to write a book proposal, and Joseph Sharples taught me how to write a book.

Mary Anderlik, Carol Bayley, Kris Bryant, Tod Chambers, Virginia Ashby Sharpe, and Dean Weber read portions of the manuscript; Paul Batalden and Jeffrey Rice read the entire manuscript and wrote the reader’s guide; Larry Rasmussen, my thesis advisor at Union Theological Seminary, commented on early drafts of the Bonhoeffer material. All of these readers — and every peer reviewer and audience member who ever challenged me to clarify and strengthen my arguments — made my work better. Any mistakes are my own.
The Traveling Fellowship of Union Theological Seminary provided essential funding for research support. Wendy Harris, my editor at the Johns Hopkins University Press, guided this project and this first-time author. I have been deeply fortunate to work with her and her able colleagues, including Nancy Wachter, Linda Forlifer, and Sarah Shepke.

Among the dozens of scholars, patient-safety advocates, and health care professionals it has been my great good fortune to work with on the “Promoting Patient Safety” project and to talk with in the course of researching and writing this book, special thanks are due to Jean Berlin, Charles Bosk, Eric Cassell, Rita Charon, Jonathan Cohen, Donna Conroy, Lyla Correoso, Edward Dauer, Paul Derrickson, Albert Dreisbach, Joseph Fins, Arthur Frank, Sandra Gilbert, Roxanne Goeltz, George Handzo, Curtis Hart, Martha Jacobs, Simon Lee, Carol Liebman, Sandy Spencer, Lee Taft, Leslie Taylor, Dean Weber, and especially Carol Bayley and Albert Wu. All have shaped my thinking and have given me fresh insight into the clinical, legal, social, personal, and spiritual dimensions of error and forgiveness. The listserv of the National Patient Safety Foundation has been another important resource, and I am grateful to its participants and to its moderator, Holly Burt. I would indeed be remiss if I did not thank the Scerbo and Berlinger families for tolerating my habit of introducing medical error into conversations at every family gathering over several years.

Versions or portions of several chapters have previously appeared in the following publications: Hastings Center Report; Studies in Christian Ethics; Journal of Medical Ethics; Literature and Medicine; Journal of Healthcare Risk Management (© 2004 American Society for Healthcare Risk Management; reprinted with permission), and Journal of Pastoral Care & Counseling. An early version of chapter 7 also appears in the edited volume of essays from the “Promoting Patient Safety” project, Accountability: Patient Safety and Policy Reform, edited by V. A. Sharpe (Washington, D.C.: Georgetown University Press, 2004). Permission to use this previously published material is gratefully acknowledged. Versions or portions of several chapters were presented at scholarly and professional gatherings at The Hastings Center, the American Academy of Religion, Narrative: An International Conference, the College of Physicians and Surgeons at Columbia University, the David E. Rogers Health Policy Colloquium at New York Weill-Cornell Medical Center, the Department of Orthopaedic Surgery at New York Medical College, and the Center for Health Care Ethics at St. Louis University.
Like others who have had traumatic experiences, persons affected by medical mistakes may write and publish their own accounts of these experiences. These stories are rich resources for physicians and other health care professionals, for ethicists and patient-safety advocates seeking to improve the way institutions address the problem of medical harm, for survivors of medical harm, for scholars of health care narratives, and for anyone else seeking to understand what happens after a medical mistake injures or kills a patient. What are the medical, financial, emotional, spiritual, interpersonal, legal, professional, and communal ramifications of being harmed by a physician’s mistake or of unintentionally harming a patient? How is the same incident perceived and interpreted by each of the persons affected by it? What do patients and families want, need, or expect from physicians after harm? What do physicians want, need, or expect from patients and families after harm? Who is afraid of whom, and why? The answers to these questions can be found in the stories patients, families, and clinicians tell about the mistakes that have touched and, in many cases, permanently altered their lives.

A prominent feature of personal narratives about medical mistakes is the