THE SOCIAL MEDICINE READER

VOLUME

1

3RD EDITION

Ethics and Cultures of Biomedicine

JONATHAN OBERLANDER / MARA BUCHBINDER / LARRY R. CHURCHILL
SUE E. ESTROFF / NANCY M. P. KING / BARRY F. SAUNDERS
RONALD P. STRAUSS / REBECCA L. WALKER • EDITORS

THE SOCIAL MEDICINE READER

Volume 1, Third Edition

BUY

THE SOCIAL MEDICINE READER

VOLUME

1

THIRD EDITION

Ethics and Cultures of Biomedicine

Jonathan Oberlander, Mara Buchbinder, Larry R. Churchill,
Sue E. Estroff, Nancy M. P. King, Barry F. Saunders,
Ronald P. Strauss, and Rebecca L. Walker, eds.

DUKE UNIVERSITY PRESS · DURHAM AND LONDON · 2019

DUKE
UNIVERSITY
PRESS

© 2019 Duke University Press
All rights reserved
Printed in the United States of America
on acid-free paper ∞
Designed by Matthew Tauch
Typeset in Minion Pro by Westchester
Publishing Services

Library of Congress Cataloging-in-Publication Data
Names: Oberlander, Jonathan, editor.
Title: The social medicine reader / Jonathan
Oberlander, Mara Buchbinder, Larry R. Churchill,
Sue E. Estroff, Nancy M. P. King, Barry F. Saunders,
Ronald P. Strauss, Rebecca L. Walker, editors.
Description: Third edition. | Durham : Duke
University Press, 2019– | Includes bibliographical
references and index.
Identifiers: LCCN 2018044276 (print)
LCCN 2019000395 (ebook)
ISBN 9781478004356 (ebook)
ISBN 9781478001737
ISBN 9781478001737 (v. 1 ; hardcover ; alk. paper)
ISBN 9781478002819 (v. 1 ; pbk. ; alk. paper)
Subjects: LCSH: Social medicine.
Classification: LCC RA418 (ebook) | LCC RA418 .S6424
2019 (print) | DDC 362.1—dc23
LC record available at https://lccn.loc.gov/2018044276

DUKE
UNIVERSITY
PRESS

Contents

PART I. Experiences of Illness and Clinician-Patient Relationships

DUKE
UNIVERSITY
PRESS

PART II. Professionalism and the Culture of Medicine

DUKE
UNIVERSITY
PRESS

PART III. Health Care Ethics and the Clinician's Role

PART IV. Death, Dying, and Lives at the Margins

DUKE
UNIVERSITY
PRESS

PART V. Allocation and Justice

DUKE
UNIVERSITY
PRESS

Preface to the Third Edition

The eight editors of this third edition of the *Social Medicine Reader* include six current and two former members of the Department of Social Medicine in the University of North Carolina (UNC) at Chapel Hill School of Medicine. Founded in 1977, the Department of Social Medicine, which includes scholars in medicine, the social sciences, the humanities, and public health, is committed to the promotion and provision of multidisciplinary education, leadership, service, research, and scholarship at the intersection of medicine and society. This includes a focus on the social conditions and characteristics of patients and populations; the social dimensions of illness; the ethical and social contexts of medical care, institutions, and professions; and resource allocation and health care policy.

This two-volume reader reflects the syllabus of a year-long, required interdisciplinary course that has been taught to first-year medical students at UNC since 1978. The goal of the course since its inception has been to demonstrate that medicine and medical practice have a profound influence on—and are influenced by—social, cultural, political, and economic matters. Teaching this perspective requires integrating medical and nonmedical materials and viewpoints. Therefore, this reader incorporates pieces from many fields within medicine, the social sciences, and humanities, representing the most engaging, provocative, and informative materials and issues we have traversed with our students.

Medicine's impact on society is multidimensional. Medicine shapes how we think about the most fundamental, enduring human experiences—conception, birth, maturation, sickness, suffering, healing, aging, and death—as well as the metaphors we use to express our deepest concerns. Medical practices and social responses to them have helped to redefine the meanings of age, race, and gender.

Social forces likewise have a powerful influence on medicine. Medical knowledge and practice, like all knowledge and practice, are shaped by political, cultural, and economic forces. This includes modern science's pursuit of knowledge through ostensibly neutral, objective observation and experimentation. Physicians' ideas about disease—in fact their very definitions of

DUKE
UNIVERSITY
PRESS

disease—depend on the roles that science and scientists play in particular cultures, as well as on the various cultures of laboratory and clinical science. Despite the power of the biomedical model of disease and the increasing specificity of molecular and genetic knowledge, social factors have always influenced the occurrence and course of most diseases. And once disease has occurred, the power of medicine to alter its course is constrained by the larger social, economic, and political contexts.

While the origin of these volumes lies in teaching medical students, we believe the selections they include will resonate with a broader readership from allied health fields, the medical humanities, bioethics, arts and sciences, and the interested public. The many voices represented in these readings include individual narratives of illness experience, commentaries by physicians, debate about complex medical cases and practices, and conceptually and empirically based scholarly writings. These are readings with the literary and scholarly power to convey the complicated relationships between medicine, health, and society. They do not resolve the most vexing contemporary issues, but they do illuminate their nuances and complexities, inviting discussion and debate.

Repeatedly, the readings throughout these two volumes make clear that much of what we encounter in science, in society, and in everyday and extraordinary lives is indeterminate, ambiguous, complex, and contradictory. And because of this inherent ambiguity, the interwoven selections highlight conflicts about power and authority, autonomy and choice, and security and risk. By critically analyzing these and many other related issues, we can open up possibilities, change what may seem inevitable, and practice professional training and caregiving with an increased capacity for reflection and self-examination. The goal is to ignite and fuel the inner voices of social and moral analysis among health care professionals, and among us all.

Any scholarly anthology is open to challenges about what has been included and what has been left out. This collection is no exception. The study of medicine and society is dynamic, with large and ever-expanding bodies of literature from which to draw. We have omitted some readings widely considered to be “classics” and have included some readings that are exciting and new—that we believe have an indelible impact. We have chosen to include material with literary and scholarly merit and that has worked well in the classroom, provoking discussion and engaging readers’ imaginations. These readings invite critical examination, a labor of reading and discussion that is inherently difficult but educationally rewarding.

DUKE
UNIVERSITY
PRESS

Volume 1, *Ethics and Cultures of Biomedicine*, examines experiences of illness; the roles and training of health care professionals and their relationships with patients; institutional cultures of bioscience and medicine; health care ethics; death and dying; and resource allocation and justice. Volume 2, *Differences and Inequalities*, explores health and illness, focusing on how difference and disability are defined and experienced in contemporary America, and how social categories commonly used to predict disease outcomes—gender, race/ethnicity, and social class—shape health outcomes and medical care.

We thank our teaching colleagues who helped create and refine all three editions of this reader. These colleagues have come over the years from both within and outside the Department of Social Medicine and the University of North Carolina at Chapel Hill. Equal gratitude goes to our students, whose criticism and enthusiasm over four decades have improved our teaching and have influenced us greatly in making the selections for the reader. We thank the Department's faculty and staff, past and present; students and colleagues from Vanderbilt University School of Medicine and Wake Forest School of Medicine have similarly been instrumental. We especially thank Kathy Crosier, the course coordinator for our first-year class, who assisted with the preparation of the *Reader*. The editors gratefully acknowledge support from the Department of Social Medicine, University of North Carolina at Chapel Hill School of Medicine; the Center for Biomedical Ethics and Society, Vanderbilt University School of Medicine; and the Center for Bioethics, Health, and Society, Wake Forest University.

DUKE
UNIVERSITY
PRESS

Introduction

This first of the two volumes that comprise the *Social Medicine Reader* thematically explores the experiences of illness; the roles and training of health care professionals and their relationships with patients alongside the broader cultures of biomedicine; ethics in health care; experiences and decisions regarding death, dying, and struggling to live; and particular manifestations of injustice in the broader health system. The volume's readings, which include narratives, essays, cases studies, fiction, and poetry, have been "road-tested" in social science, ethics, and humanities classes in health professional schools and graduate and undergraduate programs. They have been used to stimulate debate and small-group interactions or exercises, and they have served as launching points for larger class discussions. We do not cover any content area completely; our goal instead is to provide stimulating selected readings from which to engage students in discussion and deeper investigation.

The eight editors of this volume are diverse in their scholarly backgrounds, expertise, and teaching styles. We each teach the same materials differently and have learned much from each other through many years of faculty meetings focused on teaching and pedagogy. Our collaboration exemplifies the adaptability of the volume's readings to a variety of formats, settings, and approaches.

Beginning this volume with experiences of illness helps to ground the nature and meaning of sickness and healing in the familiar yet uniquely experienced state of being a patient. All health care providers have been, and will be again, patients and family members of patients. Vivid narratives about managing illness in daily life help build understanding of the vantage points of patients and family members who participate in illness experiences. Teachers and students unaccustomed to fiction and poetry in the classroom may be surprised at how readily these materials can stimulate rich and nuanced discussion of profoundly significant issues—especially when read aloud. While the first part of the volume is particularly rich in these forms of literature, such selections appear in most other parts of the volume as well.

In the second part of the volume, medical socialization and the doctor-patient relationship are considered. Social scientists have extensively examined

DUKE
UNIVERSITY
PRESS

the processes that transform medical students into counselors of health and interveners in issues of life and death. Professions, like other social groups, have cultures: they have specialized languages and ways of understanding, norms of behavior, unique customs, rites of passage, and codes of conduct. Students are socialized into the "culture of biomedicine" in a training process that changes the student through direct contact with and knowledge of the most personal aspects of human existence. Many students enter medical school with idealistic views of medicine, its goals, and its basis in evidence. As they learn the ideology and ethics of medicine and uncover the complex evidence base that medicine puts into practice, they may face uncertainty that is too often left unstated in public; they may undergo profound changes in their perspectives and even their identities. These readings promote reflection on the roles of health professional students and practitioners, on the challenges inherent in the physician-patient relationship, and on navigating between professional and personal experiences, values, and truths.

The third part of the volume turns to a more explicit focus on health care ethics. This section includes narratives (fiction and nonfiction) of clinician and patient experiences, as well as theoretical framing and professional guidance. Readings examine moral reasoning and what it means to have a moral life as a clinician in relationships with patients. Fundamental moral precepts in health care practice—truth-telling, informed consent, privacy, autonomy, and beneficence—are addressed in their own right and also presented in cases and stories that pose problems to be unraveled, examined, and debated from a wide range of viewpoints. In this section, complex ethical issues are presented as dynamic: embedded in time, place, society, history, and culture, and entangled in multiple relationships.

The fourth part of this volume employs the prior themes to address decision making, policies, and experiences at the margins of life—including death, dying, and struggling to live. The work of this section includes an effort to clarify concepts; an examination of significant social disagreements and moments in end-of-life decision making; and specific attention to life prolongation, treatment withdrawal, and the ending of life, whether welcome or unwelcome. Questions are raised about the legal, ethical, and practical medical aspects of end-of-life care, the nature and power of medical judgments, and long-standing professional and personal disagreements about the end of life. Poetry, personal narrative, and the voices of patients and their families open the possibility for discussion of morality, meaning, loss, grief, and profound uncertainty in the face of death.

DUKE
UNIVERSITY
PRESS

The final section of this volume approaches justice and allocation through a few examples not commonly addressed in texts on distributive justice in health care. Because there are many more comprehensive treatments of health-related justice issues in other volumes, our goal here is to introduce the relevant concepts and illustrate the wide diversity of ways in which injustice is hiding in plain sight in medicine.

The variety of readings in this volume can be addressed productively from different disciplinary perspectives and in many teaching styles and formats. These readings are readily combined with those from volume 2 of the *Social Medicine Reader*, titled *Differences and Inequalities*. Readings from both volumes can be reshuffled and recombined, stand together or alone, or be supplemented by other literature. A key to using these readings successfully is to approach them with flexibility—as helping to shape the right questions rather than giving particular answers. Our hope is that both teachers and students of materials like these will go on asking questions, and finding different and deeper answers, all their lives.

DUKE UNIVERSITY PRESS