Making Sense of Illness

Cambridge History of Medicine

Edited by
CHARLES ROSENBERG, Professor of History and Sociology of
Science, University of Pennsylvania and
COLIN JONES, University of Warwick

Titles in the series on page following index

Cambridge University Press
978-0-521-55234-9 - Making Sense of Illness: Science, Society, and Disease
Robert A. Aronowitz, M.D.
Frontmatter
More information

Making Sense of Illness

Science, Society, and Disease

ROBERT A. ARONOWITZ, M.D.
Robert Wood Johnson Medical School

CAMBRIDGE
UNIVERSITY PRESS

CAMBRIDGE UNIVERSITY PRESS
Cambridge, New York, Melbourne, Madrid, Cape Town,
Singapore, São Paulo, Delhi, Tokyo, Mexico City

Cambridge University Press
The Edinburgh Building, Cambridge CB2 8RU, UK

Published in the United States of America by Cambridge University Press, New York

www.cambridge.org
Information on this title: www.cambridge.org/9780521552349

First published 1998
First paperback edition 1998

A catalogue record for this publication is available from the British Library

ISBN 978-0-521-55234-9 Hardback
ISBN 978-0-521-55825-9 Paperback

Cambridge University Press
978-0-521-55234-9 - Making Sense of Illness: Science, Society, and Disease
Robert A. Aronowitz, M.D.
Frontmatter
More information

For Sara and Daniel

Contents

Cambridge University Press
978-0-521-55234-9 - Making Sense of Illness: Science, Society, and Disease
Robert A. Aronowitz, M.D.
Frontmatter
More information

Preface

This book of essays has had a long gestation. Before I became a doctor, I was a graduate student in linguistics. I thought this background would prepare me for a clinical and research career in neurology, focusing on language disorders such as aphasia, but instead it helped me make sense of my uneasiness with how we generally classify, talk about, and find meaning in disease. In the first days of medical school, I elected to take the "clinically relevant" biochemistry elective, which was organized around specific diseases – such as sickle-cell anemia – whose ultimate cause was a molecular defect and whose sequelae could be described in terms of disturbed organs and physiologic systems. While this scheme made biochemistry more interesting, I was bothered by my teachers' priorities: molecular mechanisms of disease were deemed more important than common clinical problems; biochemical explanations of disease were more valued than social ones; and molecular researchers generally enjoyed higher status than clinical researchers and clinicians.

These priorities were not usually talked about directly. When they were, they were often rationalized by the idea of progress. The foreword to my biochemistry course's syllabus began ". . . for example, the recognition and elucidation of the molecular mechanism for the excessive purine synthesis in a rare neurological disorder, the Lesch-Nyan syndrome, has contributed more to the understanding of the basic molecular pathology of the far more common disease, gout, than the past 23 years of detailed clinical and laboratory descriptions of the disease."[1] This description of progress is not only debatable on its own merits but is also a tautology – molecular research leads to more molecular insights than nonmolecular research. This type of circularity excluded or gave less emphasis to other insights and perspectives on illness. And these priorities had important consequences, both by influencing the career decisions of medical students and by shaping the way students would later practice clinical medicine.

On the wards, I was enthusiastic about finally taking care of patients, but I sometimes felt alienated by the medical culture of which I was rapidly becoming a member. As an intern, I briefly took care of an elderly woman, I.R., who was legendary for the dislike she inspired in the house staff who cared for her. I.R. refused to leave the comforts of her private hospital room and her attending physician was determined to get her out of the hospital one way or another. There was some question that her heart failure and survival might be improved with an operation to replace one of her heart valves. A preoperative cardiac catheterization was scheduled despite the fact that I.R. would never consent to any surgery that might be recommended on the basis of this test. Her attending physician gave her an ultimatum – either get the catheterization or leave the hospital immediately. Under duress, I.R. consented to the catheterization.

When I argued against the procedure with I.R.'s cardiologist, he simply could not hear my objection to coercing I.R. and reiterated the rationale for the catheterization in terms of pressure gradients across a heart valve. From the cardiologist's point of view, what mattered most were the objective and universal facts about I.R.'s heart pathophysiology, not the idiosyncrasies of her fears and preferences. As it turned out, I.R. died the evening after the catheterization as a result of complications from the procedure. I.R.'s tragic experience seemed to me as much a result of the way we typically name and classify suffering, which in this case contributed to understanding her problem as a valvular lesion rather than as a fear of life outside the hospital, as an inhumane medical system. Both I.R.'s cardiologist and attending physician, after all, were caring and competent physicians.

I began to record and rework my medical experiences as the starting points for a historical study of the changing meanings of disease, especially chronic disease, in the twentieth century. In fact, all of the chapters on specific diseases or disease meanings (Chapters 1–6) had their origins in my medical training or later clinical experiences as a practicing general internist. The first three of these essays were written as separate pieces with specific, largely medical, audiences in mind, not as parts of a book for a general audience. Although I substantially revised these earlier essays to reduce redundancy and make the medical details more understandable to lay readers, it was not possible to expunge all traces of earlier stages of my intellectual and professional development that now seem to me simplistic or misguided. Chapter 2, most notably, reflects my reactions to normative medical beliefs and practices about disease at a time when I knew little about contemporary social science scholarship.

Cambridge University Press
978-0-521-55234-9 - Making Sense of Illness: Science, Society, and Disease
Robert A. Aronowitz, M.D.
Frontmatter
More information

The three coronary heart disease essays (Chapters 4–6) have not been previously published and bear a closer relation to each other.

I want to thank Richard J. Wolfe at the Francis A. Countway Library at the Harvard Medical School, Victoria Harden at the National Institutes of Health, and the staff of the College of Physicians of Philadelphia for their help in guiding me to appropriate primary and secondary sources. I also want to thank Rutgers University Press, Raven Press, and the Milbank Memorial Fund for permission to adapt previously published material into what are now Chapters 1, 2, and 3. Although I talked to many colleagues and medical experts at different times in the genesis of this book, I want to especially thank Allen Steere, William Kannel, Meyer Friedman, and Ray Rosenman for allowing me to interview them. Hans Pols and Carla Keirns worked as research assistants in the finishing stages of this book, and I thank them for their resourcefulness and organizational skills.

I am grateful to the many friends and colleagues who read and commented on different chapters of this book. Steve Martin, Barbara Rosenkrantz, Leon Eisenberg, Edward Shorter, Matt Liang, among many others, had thoughtful reactions to oral presentations and previously published portions of this book. Rosemary Stevens, Tom Huddle, Charles Bosk, David Asch, and Chris Feudtner each offered constructive criticisms on drafts of one or more chapters. Allan Brandt, Sankey Williams, and Joel Howell read earlier drafts of the entire book and had many helpful suggestions about style and content. Knud Lambrecht not only read many of these chapters in earlier drafts, but contributed to the genesis of this book by constant and unwavering friendship and support. Howard Spiro was my advisor for my medical school thesis on the psychosomatics of ulcerative colitis. That thesis and an article we wrote for a clinical audience formed the basis for Chapter 2. I am especially grateful for his help in keeping me on a less-than-straight course when I was a medical student. Charles Rosenberg read and commented on many different drafts of every part of this book. He has played many roles – teacher, career mentor, and series editor at Cambridge University Press, to name but a few – in addition to continually challenging me to be more precise and brief.

I also want to thank the chairman of internal medicine at Cooper Hospital, Edward Viner, and the two former chiefs of general medicine, Steve Gluckman and Bert Keating, for their emotional and material support in the many years in which I have juggled clinical and teaching responsibilities with my efforts at research and writing. I have been

Cambridge University Press
978-0-521-55234-9 - Making Sense of Illness: Science, Society, and Disease
Robert A. Aronowitz, M.D.
Frontmatter
More information

generously supported by both the Robert Wood Johnson Foundation (RWJF), formerly as a RWJF Clinical Scholar and currently as a RWJF Generalist Physician Faculty Scholar, and by the Charles E. Culpeper Foundation, which supported me as one of their Scholars in Medical Humanities.

My wife, Jane Mathisen, not only encouraged me to live out an atypical and sometimes insecure medical career, but believed that I was up to the task of writing this book.