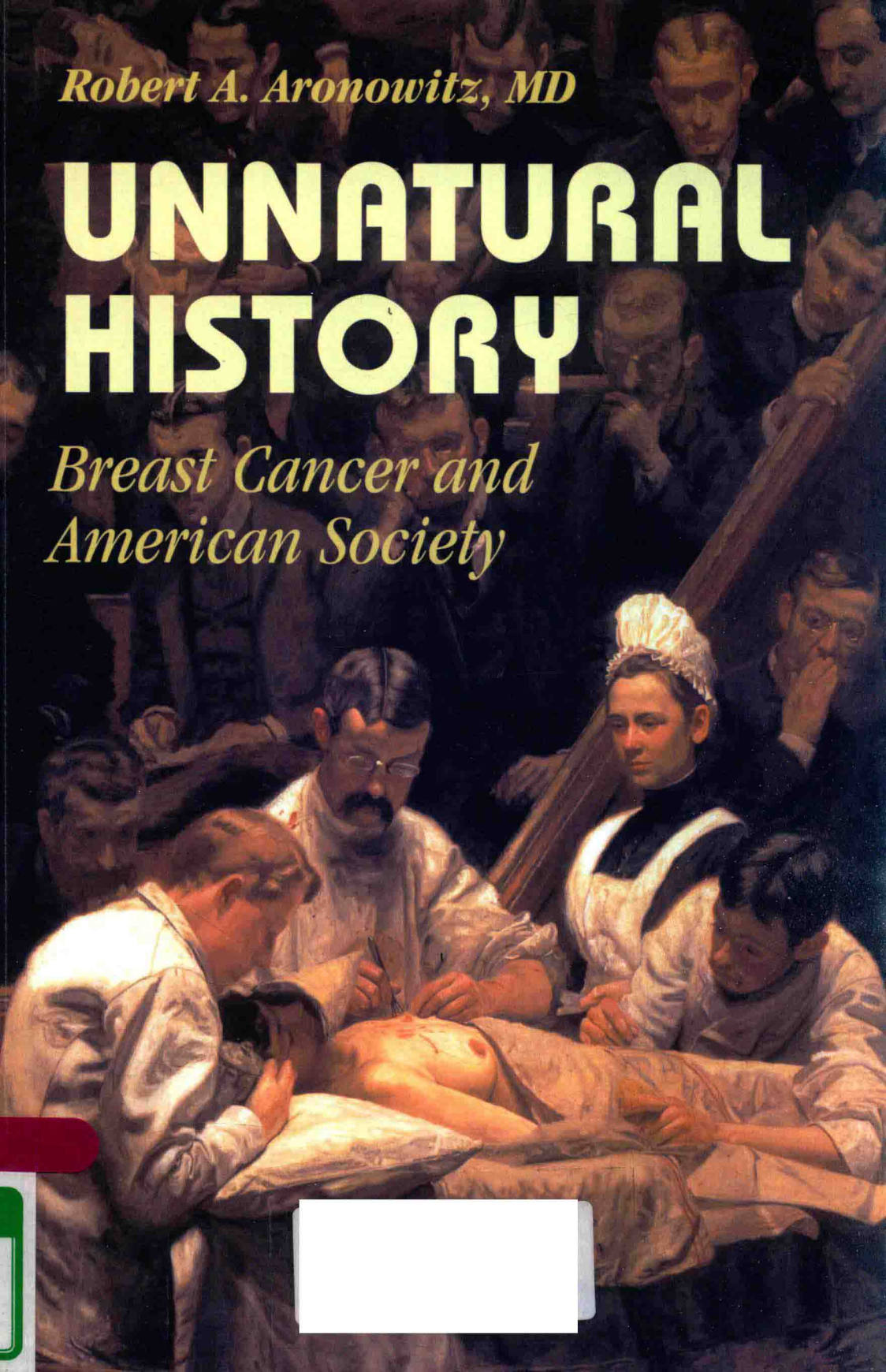


Robert A. Aronowitz, MD

UNNATURAL HISTORY

*Breast Cancer and
American Society*



Unnatural History

BREAST CANCER AND AMERICAN SOCIETY

Robert A. Aronowitz, M.D.

University of Pennsylvania



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UNNATURAL HISTORY

Unnatural History explores the change over the last two centuries from isolated, private fears to an immense individual and collective risk of breast cancer. The book begins with the experiences of a Quaker woman diagnosed with breast cancer in 1812, and ends with our problematic era in which almost every woman is waiting for "the axe to fall." In between, the book traces changes in the beliefs and values of women and their doctors, medical knowledge and technology, clinical and public health practices, and the biological impact of the disease.

The picture that emerges from *Unnatural History* is that our clinical, public health, and societal responses to breast cancer have radically transformed the experience of disease and its apparent societal impact, without necessarily having had much effect on the disease's biological devastation.

Unnatural History suggests that we have oversold both the fear of breast cancer and the effectiveness of screening and treatment, leading to miscalculation at the individual and societal levels.

Robert A. Aronowitz studied linguistics before receiving his M.D. from Yale. After finishing residency in internal medicine, he studied the history of medicine as a Robert Wood Johnson Foundation Clinical Scholar at the University of Pennsylvania. Dr. Aronowitz is currently Associate Professor in the History and Sociology of Science Department at the University of Pennsylvania. He holds a joint appointment with the medical school's department of Family Medicine and Community Health. Dr. Aronowitz was the founding director of Penn's Health and Societies Program. He also codirects the Robert Wood Johnson Health and Society Scholars Program, a postdoctoral program focused on population health. In 2005–2006, he was a Fellow at the Wissenschaftskolleg zu Berlin.

Dr. Aronowitz's central research interests are in the history of twentieth-century disease, epidemiology, and population health. He is the author of *Making Sense of Illness: Science, Society, and Disease* (Cambridge, 1998). He is currently working on a historical project on the social framing of health risks, for which he received an Investigator Award in Health Policy from the Robert Wood Johnson Foundation.

For Jane

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Friends, relatives, and colleagues have supported my unusual medical and social science career. Over the years, I have also profited from discussing with them my evolving views about the history of breast cancer. Fran Barg, David Barnes, Mike Berkwits, Chuck Bosk, Marjorie Bowman, Charlie Brown, Andi Casher, Ruth Cowan, Pete Cronholm, Steve Gluckman, Bob Hedley, Kathleen Hill, Bob Hornik, Pat Johnson, Ralph Kaufman, Riki Kuklick, Susan Lindee, Jun Mao, Ohad Parnes, Harriet Power, Jean Rabinowitz, Scott Schlegel, Joe Straton, Tom Sutton, Ed Viner, and Larry Weisberg have each contributed to the writing of this book. I have also learned a great deal from discussions and close working relationships with too-many-to-mention faculty and fellows at the RWJ Health and Society Scholars Program at Penn and nationally.

Over the years, I have also benefited from comments and suggestions made after talks and presentations. At Penn, I presented parts of this book to the Family Medicine Fellowship seminar, the Religious Studies

Colloquium, the Nursing History Center, the Annenberg School, Presbyterian Hospital Grand Rounds, and the History and Sociology of Science workshop. Other venues outside of Philadelphia have included the Institute for Health Care, Health Policy, and Aging at Rutgers University; the Social Medicine Program at the University of North Carolina; the Foundation Merieux in Annecy, France; the Center for Health and Well Being at Princeton University; the History of Medicine program at the University of Kansas; CERMES in Paris; the National Institutes of Health; the Wellcome Institute for the History and Understanding of Medicine in London; and the Wissenschaftskolleg zu Berlin.

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One consequence of having a project with such a long gestation period is that students who once worked for me as research assistants are now scholars in their own right, such as Elizabeth Toon and Carla Keirns. Elizabeth taught me, an interloper in history from clinical medicine, a great deal about working in archives and organizing research data. She independently researched a lot of material for Chapters 4 and 5, and my ideas about “life at risk” and truth telling evolved partly as a result of our joint efforts to select and prioritize Halsted's vast clinical correspondence. Other students who have worked with me in archives and libraries include Sejal Patel, Tiffany Behringer, Dominique Tobell, Caroline Todd, and Corinna Schlombs.

Part of what I hope is valuable about *Unnatural History* is the close examination of the patient experience of cancer and the doctor–patient

relationship. Those parts of the book could not have been written without the experiences I have had as a doctor and friend to many people struggling with cancer. For reasons of privacy and space, I cannot mention their names, but I will remember here Dianne Barton, Michael Powell, and Marty Bloch. Dianne was the doctor who gave everything to her patients, and she expected the same from the vast network of health care professionals she consulted but never quite let take charge of her care. Michael let me and others who cared for him into the most intimate places. Even at the most desperate moments, he remained a gifted teacher. Both Dianne and Michael came as teachers to my undergraduate classes at Penn and generously imparted a great deal of what they experienced and learned. Marty died before I started this book but his life and struggle with cancer have shaped every part of this project.

My family members have put up with a lot over the past few years and have helped me enormously. My parents Nat and Eve Aronowitz have selflessly supported everything that I do. My father died just as this book was completed. Up until his last illness, I gave him a progress report in our daily calls that I now miss so much. Over the years, I have learned a great deal from discussing the issues raised in this book with my brother Jerry Aronowitz and sister Sandy Katz. Daniel and Sara, my children, read parts of the book and let me inject risk and cancer into dinner conversations and family vacations. Over the years, they have given me all kinds of frank and often smart advice, more of which I should have heeded. My wife, Jane Mathisen, made too many sacrifices to mention. She read every word of the book and gave me her honest but always supportive suggestions. I dedicate this book to her.

Contents

<i>Acknowledgments</i>	page ix
1 Introduction	i
2 Cancer in the Breast, 1813	21
3 Pessimism and Promise	51
4 Taking Responsibility for Cancer	86
5 Living at Risk	115
6 “Do Not Delay”: The War Against Time	144
7 “Prophets of Doom”: Skeptics of the Cancer Establishment at Mid-Century	163
8 Balancing Hope, Trust, and Truth: Rachel Carson	183
9 The Rise of Surveillance	210
10 Crisis in Prevention	235
11 Breast Cancer Risk: “Waiting for the Axe to Fall”	256
<i>Notes</i>	285
<i>Index</i>	347

ONE

Introduction

I

Breast cancer is all around us: cutting down lives, causing fear, and presenting difficult, often impossible, dilemmas. In the week in which I first drafted this introduction, both my 80-year-old uncle and his 50-year-old daughter-in-law (my cousin's wife) were diagnosed with invasive breast cancer. My then 12-year-old daughter did not think men had breasts; most adults similarly do not know that men get breast cancer. My cousin's wife could have chosen a limited excision of her small cancer but instead decided to have both breasts as well as her ovaries removed. Her mother had died at about her age of ovarian cancer, and her younger sister had recently died of breast cancer. She was "taking no chances." I understood her reasons for this decision and would not second-guess them. But I also knew that even such radical surgery would not entirely extirpate the danger or her fear of cancer.

American women fear breast cancer much more today than they did a hundred years ago when there seemed to be less of it, and it was not such a visible – and contested – public concern. In today's way of talking about and experiencing the fear of breast cancer, we characteristically speak of the increased *risk* of the disease. The central development I analyze in *An Unnatural History: Breast Cancer and American Society* is the historical change over the last two centuries from isolated, private fears of breast cancer to immense individual and collective concern over the risk of breast cancer. I will detail how and why our biological understandings, epidemiological perceptions, clinical and public health interventions, and personal experience and fears of breast cancer have changed so radically.

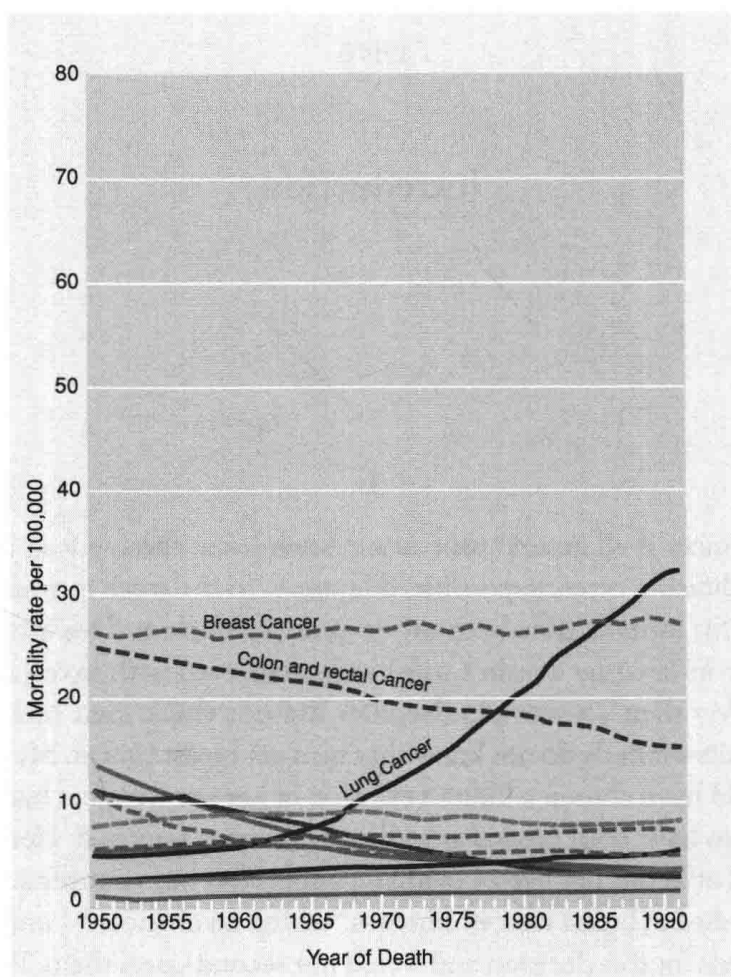


Figure 1.1. Changing patterns for twelve major cancers in U.S. females 1950–1991. Death rates for females, per 100,000, for twelve sites, 1950–1991, age-adjusted to 1970. (Adapted from SEER Data, public use files.)

The change from a disease that was hardly visible to anyone who was not directly affected by it to the highly publicized statistic that women in the United States have a lifetime risk of 1:8 of being afflicted with the disease is not simply a reflection of more and worse disease. Epidemiologists have observed that the age-specific mortality from breast cancer – the odds of women of a given age dying from breast cancer – in the United States remained essentially unchanged from the time minimally adequate aggregate data were first collected in the 1930s until around 1990 (see Figure 1.1), when it began to decline.¹ Epidemiologists use age-specific mortality to make valid historical comparisons – in this case, to factor

out the increase in breast cancer deaths due only to more people surviving into older ages (when breast cancer is more common). It is possible that efforts at early detection and progress in treatment had just kept up with an increasing tide of new breast cancer cases, resulting in a mortality standoff for most of the twentieth century. A more economical explanation is that we have detected a large amount of disease not destined to seriously harm or kill and – until quite recently – have not made significant progress in treating cancer.

Unnatural History's terrain is the chasm between our medical and cultural understandings of breast cancer and its direct biological impact. Starting with the experience of breast cancer in the early nineteenth century, I examine the *social* forces and developments that led to a radical transformation of breast cancer's impact and meaning in American society.² Some readers and medical colleagues will probably be surprised and challenged by my emphasis on underlying social rather than biological causes of the historical shift in both the perception and lived experience of breast cancer in the United States. For example, I will argue in Chapter 6 that the widely perceived improvements in breast cancer survival rates in the middle decades of the twentieth century largely resulted from changed health-seeking behavior and diagnostic practices rather than more effective means of prevention and treatment. I want to redress an imbalance that follows from the priority generally given to biological over social explanations in cancer and many other diseases. Pushing social explanations as far as they might plausibly go also has considerable heuristic value. Cancer and other diseases look different when social factors are in the foreground, rather than evoked only to explain what cannot be attributed to biologically mediated changes.

At the same time, I do not assume that breast cancer, as a purely biological process in the bodies of American women, has had an unchanging clinical expression or population impact. It is highly probable, for example, that the real incidence of breast cancer (number of new cases in a given time period) was rising during the nineteenth and early twentieth century America. This change most likely resulted from social and economic shifts that led to earlier onset of menstrual periods, older age of first childbirth, fewer children, and later menopause.³ Neither do I assume that our clinical and public efforts have had little or no impact on breast cancer as a biological process. The declining breast cancer mortality in the United States since 1990 has probably resulted from more

use of effective treatment, especially hormonal therapy and chemotherapy given to women who do not have clinical evidence of cancer spread, and to a lesser extent, the identification of cancers through screening.⁴

Unnatural History is not a polemic about medical and popular misunderstanding of breast or other cancers' natural history and epidemiology, and the exaggerated claims of efficacy by supporters of current efforts at prevention and treatment. There already exists a sizeable literature that uses the tools of clinical epidemiology and "evidence-based medicine" to critically analyze current concepts and practices.⁵ While this literature often points out important limitations of many beliefs about cancer and treatment practices, it does not try to systematically account for how we arrived at our present situation. *Unnatural History* is a *history* of how we incrementally arrived at our present state of belief and practice. This narrative involves choice, change, and continuity in medical and lay beliefs about cancer and the body, the felt experience of cancer and fear of cancer, the nature of relations between patients and doctors, and the assumptions patients and doctors have used in making clinical decisions.

The narrative alternates between detailed "grain of sand" case studies of individual patients and overviews of important developments in medical thought and clinical and public health practice, from the early nineteenth century to the third quarter of the twentieth century. I do not consider in any detail case studies or medical developments after 1977. This is in part arbitrary, but also reflects my belief that the major elements of what I consider to be our current era of breast cancer risk (subject of the concluding chapter) were in place at that time. The detailed case studies give texture to the felt experience of affected women. I similarly use the writings and clinical records of selected doctors to provide a close up view of the often subtle continuities and changes in medical assumptions about breast cancer. The larger picture that emerges is thus potentially distorted by my selective sampling, but I hope that this limitation is balanced by the book's wide historical sweep and the advantages of examining in detail how breast cancer was experienced and decisions were made in different eras.

In the many casual historical overviews of breast cancer, which have appeared in such diverse places as patient accounts, newspaper articles, medical review articles, and grand round talks, there are typically three recurring motifs: (1) the post-World War II movement away from radical mastectomies toward more localized surgery, led by a few researchers

who tested their original ideas in robust clinical trials whose results then influenced practitioners to change their practice; (2) the important role women played in this and other changes in cancer treatment; and (3) the declining paternalism and increased honesty in doctor–patient interactions surrounding breast and other cancers. While these overviews capture some important developments, they are incomplete and partly reflect the problematic assumptions, priorities, and visions of their narrators. They assume a basic stability in what breast cancer is and means as well as that significant therapeutic progress has and is being made. They tend to ignore countervailing contemporary trends, such as the increased frequency of radical surgery for breast cancer risk, and deeper continuities, such as the desire of both physicians and patients to maintain hope and avoid stark confrontations with mortality.

Apart from a skeptical reading of epidemiological trends, there are reasons to believe that the many historical changes in the magnitude, meaning, and significance of the risk factors for breast cancer are not a simple reflection of the disease's increased deadliness. Risk, as many anthropologists, sociologists, historians, and others have reminded us, is a cultural construct that bears a problematic and often indirect relationship to death rates or other “objective” markers of danger and bad outcomes.⁶ In our contemporary response to breast cancer, risk is an elusive term with different meanings and uses. It may be used to describe a quantitative assessment of disease incidence or mortality in a defined population upon which policies such as annual screening mammography are built or it may describe a highly individual, subjective sense of danger, which might influence lifestyle “choices” such as the timing of a first child, the use of oral contraceptives, or starting a low fat diet.

Epidemiologists, doctors, and laypersons often use terms such as *risk factors*, *risk reduction*, and *risk assessment* in a way that implies or assumes that the important causes of breast cancer are mostly a matter of individual – rather than social or communal – concern and responsibility. There is also often a problematic quantification in some risk-factor discourse that makes it appear that we know more than we do about the precise causes of breast cancer and the relative impact of different putative risks. While existing risk factors sometimes help mediate the gap between aggregate data and individual decision-making, they are hardly an unfailingly wise guide to lifestyle, clinical, and policy choices. They can obscure as much as clarify.

Thus we should not understand breast cancer risk ideas and terms as a merely logical or self-evident way of conceptualizing and communicating about danger, choice, cause, or responsibility. Modern risk discourse often reveals more about our present and past assumptions, priorities, and investments than it expresses new etiological, preventive, or therapeutic insights.

Nothing seems more new, objective, and insightful than recent developments in the genetics of breast cancer. In the early 1990s, molecular biologists identified mutations in two “susceptibility” genes for hereditary breast and ovarian cancer (*BRCA1* and *BRCA2*), and epidemiologists began to correlate genetic mutations with particular ethnic groups, most notably the association between specific mutations and Ashkenazic Jewish women.⁷ These discoveries have already led to widespread genetic testing and risk assessment, prophylactic surgery for some genetic mutation carriers, and ethnicity-based disease advocacy and community programs. It is likely that lay and biomedical interest – as well as finite economic and intellectual resources – will shift in a problematic and disproportionate manner from the much more common sporadic cases of breast cancer to the seemingly more certain, mechanistically rationalized, “genetic” cases. The test for a breast cancer susceptibility gene is likely to be one of the first of many such tests that will transform our view of individual health from a complex group of consequences of one’s heredity, environmental exposure, lifestyle choices, and chance to a more specific, precise, and frightening “at risk for” consciousness.

Yet, however profound these changes may appear, they cannot be understood as direct, unmediated consequences of new genetic knowledge. There are many continuities between the seemingly revolutionary impact of genetic insights and earlier experimental, pathological, epidemiological, and clinical insights. For example, the enthusiastic medical and popular reception of genetic insights and the rapid deployment of genetic tests reflect a historically familiar calculus of change. Clinicians and laypersons have often made fundamental decisions – to encourage or consent to some type of cancer surveillance, to consult a doctor for a breast lump, to choose one type of therapy over another, or to promote this or that educational message – because of the vision of the future with which they most closely identify. Promise more than evidence from clinical trials or the lived realities of disease and clinical practice has repeatedly played a determining role in many personal, clinical, and

policy decisions and developments concerning breast cancer. Knowledge of these historical continuities can help clinicians and patients respond more thoughtfully to the many clinical and policy conundrums presented by genetic tests, screening mammography, lifestyle interventions, and prophylactic surgery and chemotherapy.

II

But why an *Unnatural History*? The choice of title partly goes against – and distinguishes my approach from – the more fashionable trend of emphasizing the natural, that is, the biological and adaptive, basis of complex behaviors and social structures, in paper, book, and lecture titles, for example, the natural history of parenting, sex, alcoholism, fear, and so on. But the history of the meaning, perception, and experience of breast cancer in the nineteenth and twentieth centuries can be thought of as “unnatural” in several other ways. First, for much of breast cancer’s modern history, we have radically transformed breast cancer’s epidemiological, clinical, and personal meaning, often without significantly changing its natural history, that is, its destructive course within the body. Second, the most important initiators and mediators of these transformations are best understood as social (e.g., lowered thresholds for seeking medical attention for breast lumps or expanding definitions of cancer) rather than biological/natural. Finally, there is the historical contingency of the natural history concept itself. In each era and setting, researchers, clinicians, and laypersons have often meant, assumed, or focused on different basic identities and definitions of breast cancer – macroscopic or molecular, one disease or many, constitutional or local, a disease from within or without, predetermined or treatable, discrete from or continuous with “premalignant” and benign conditions. “What is breast cancer?” has been a recurrent, central, if often unarticulated, question just below the surface of so many controversies about cause, prevention, treatment, prognosis, and policy. It also lies just below the surface of many individuals’ difficult decisions.

Students frequently ask me how physicians and patients could use the word *cancer* in the era before microscopic descriptions of abnormal cells and in clinical situations where nothing remotely like twentieth- or twenty-first-century diagnostics were done. They also question any historical comparisons between whatever we mean by cancer today and these older entities. I often respond by pointing out that categorizing and

diagnosing cancer is contingent on tools, medical knowledge, and the social and medical uses of labels, in the past and now. To bring this point home, I imagine a future medical world where students wonder how early twenty-first-century physicians and patients accepted chemotherapy for small “breast cancers” and surgery for some “prostate cancers” when they did not yet have the XYZ test that predicts with a high degree of certainty which tumors will be lethal and which will be slow-growing and unlikely to metastasize.

I am a doctor as well as an historian, and my clinical experiences and training have shaped my historical approach. I have been influenced by teachers and mentors who have had a skeptical, empirical, and quantitative “evidence-based” approach to clinical practice and health policy. My clinical experiences and those of my patients, friends, and family members, some of which are discussed in this chapter, have often reinforced my skepticism about many existing public health and clinical strategies in breast and other cancers. But at the same time I worry about the implications of this skepticism. It has been personally difficult, for example, to reconcile my belief that past and present prevention and treatment efforts in breast cancer are less effective than widely believed with my responsibility for the health of patients, friends, and family. I recently talked with a friend in her 40s who said that she was still not getting screening mammograms “thanks to you.” I immediately protested that our previous conversations were about my historical research and not meant to suggest specific courses of action in the here and now. But I also knew that I was on thin ice. Like the many historical actors whose actions and beliefs I closely examine here, I would like to eat my cake (in this case, draw general historical implications for the present) and have it too (not be tied to specific clinical recommendations, especially since the evidence is often unclear and almost always changing). One result of this awareness has been to redouble my efforts to approach the different actors in historical and contemporary controversies in an empathetic, balanced, and nonpolemical manner.

III

Naming and Classifying Breast Cancer

My friend Janet was 47 years old when she made an appointment for a screening mammogram. Although her family doctor had told her that medical opinion was divided over whether women in their 40s needed