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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.

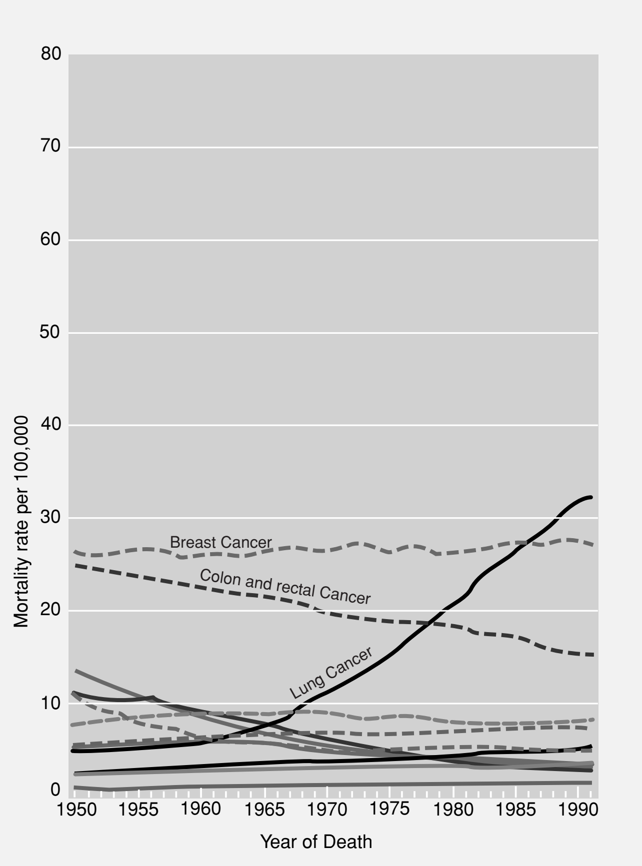

Figure 1.1. Changing patterns for twelve major cancers in U.S. females 1950–1991. Death rates for females, per 100,000, for twelve sites, 1950–1991, age-adjusted to 1970. (Adapted from SEER Data, public use files.)

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

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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

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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.

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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

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mammograms, she had been feeling guilty about not having had one. A few minutes after her mammogram was done, a radiologist asked Janet to come into a consultation room and showed her a 1-inch suspicious mass on the just developed film. The radiologist then called Janet's family doctor, who arranged for her to see a breast surgeon a few days later. The surgeon reviewed Janet's mammogram and then examined her. She thought she could feel something that corresponded to the suspicious area on the mammogram. She did a needle biopsy in the office, which turned out to be benign. After these results became known, the surgeon suggested to Janet, and a few days later performed, an excisional biopsy both to remove any doubts about malignancy and to make it easier to evaluate future screening mammograms.

Janet was shocked when the surgeon called a few days later and told her she had something called "lobular carcinoma in situ (LCIS)." Janet's surgeon explained that LCIS was a kind of precancer, which in her case was probably an accidental finding unrelated to the abnormal mammogram. She explained that "carcinoma in situ" in Latin roughly means "cancer in position" and describes the presence of abnormal, cancer-looking or cancerous cells that are contained within the normal boundaries of the epithelial tissue from which they arose. In LCIS, the abnormal cells are confined to the breast lobules (one of the small masses of tissue within the breast).

Janet was even more puzzled when her surgeon explained that Janet was not "cured" by her excisional biopsy, since the precancerous condition could be present diffusely in both breasts. Her treatment options included doing more vigilant screening, taking an antiestrogen medicine called Tamoxifen, which might help but which would probably bring on menopause and increased her risk of uterine cancer, enrolling in a clinical trial of new agents, or having "prophylactic" bilateral mastectomies (in an earlier era, shortly after LCIS was first "discovered," many physicians recommended mastectomy without reservation). Janet's overriding emotion was regret over having had the mammogram in the first place. But there was no going back, only a series of disturbing questions for which her doctors could not give her satisfying answers: What exactly is LCIS? What were her chances of dying from cancer if she did nothing? Took Tamoxifen?

While Janet's predicament had its origins in medical knowledge and technology, existing medical evidence provided little guidance about what she should do. Some clarification might have come from

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understanding the history of the conflicting values, perspectives, and interests that have contributed to how we classify and name breast and other cancers. Throughout the nineteenth and twentieth centuries, this history has been contentious: What is the proper definition of cancer? What is the relation between clinical and pathological diagnosis and cancer's clinical behavior? Who gets to decide? What is cancer's natural history? How should the circumstances of discovery, diagnosis, and treatment affect the way we name and classify cancer?

Some researchers and clinicians have come to understand LCIS as a risk factor for future invasive breast cancer more than as a pathological entity in itself. In this view, the meaning of a positive biopsy is in what it signifies about future risk rather than the dangers emanating from a localized entity. LCIS thus helps bring breast cancer into the borderland between disease and risk, joining company with many contemporary – and controversial – entities such as osteoporosis and hypercholesterolemia.

In almost every site-specific cancer, there are similar risk/disease complexities. Urged on by her family doctor, a relative of mine in her 70s decided to undergo a full colonoscopy as a screening test for colon cancer. Her gastroenterologist took out a few polyps, one of which was a small villous adenoma, which, while having some definite malignant potential, does not uniformly progress to colon cancer. Shortly after her colonoscopy, she received a letter in which the gastroenterologist congratulated my relative for her decision to undergo screening, since it resulted in the discovery and removal of cancer. With continued vigilance, the doctor continued, she could remain cured of colon cancer. The use of the words *cancer* and *cure* to describe my relative's polyp and polypectomy exaggerated and gave a pseudoprecision to the danger and drama of her screening test and the cancerness of her premalignant condition. This conflation of risk and disease, problematic under ideal circumstances, is especially troublesome when linked to the provision of preventive services, which bring economic rewards to their providers.

In looking at the history of the emergence of such entities as LCIS, I question the taken-for-grantedness of the basic terms and concepts different actors have used to conduct research, structure public health campaigns, and understand their own problems and decisions. Social norms and attitudes, not only clinical and technological developments, have determined how we classify and diagnose cancer. Like the popularization