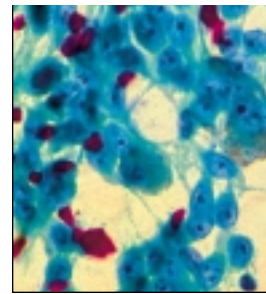


ECONOMIC IMPACT OF THE GROWING POPULATION OF BREAST CANCER SURVIVORS

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Oncology practice and economic realities are inexorably linked today. Developments in cancer economics are explored in this feature.

Introduction

At present, approximately 1.7 million women in the United States have a history of invasive breast cancer; projections suggest that that this number may rise to well over 2 million in the next 5 years.^{1,2} A large proportion of these women were diagnosed more than 5 years ago and some even as long as 25 years ago. This implies not only that the absolute number of survivors is growing, but also that the mean duration of a prevalent case (the number of years on average that women are considered to have survived their cancer) is probably increasing as well. The result is an ever-expanding population of prevalent cases of breast cancer, which has significant implications for clinical practice, public policy making, and the multidisciplinary research agenda in the cancer field.

Perhaps not surprising, some of these implications are economic in nature. One of special interest is that rising prevalence is expected to shift the level and composition of the economic costs or burden of breast cancer. There are good reasons to suppose that these shifts are currently underway, though whether their net effect will ultimately be to decrease the aggregate costs of the disease is far from certain. Since efforts to minimize disease costs (broadly defined) are of increasing importance to providers, payers, and cancer survivors alike, the economic dynamics unleashed by the recent growth in the prevalent population need to be better

understood. The primary aim of this essay is to cast some light on these dynamics.

Potential Economic Impact of Rising Breast Cancer Prevalence

Economists tally the economic consequences of any disease as the sum of attributable *direct* and *indirect* costs.³ Direct costs are defined as the dollar value of all medical and other health care services needed to diagnose, monitor, and care for the patient at the time of initial therapy, at all follow-up points thereafter, and at the end of life. These costs are often estimated by tracking insurance claims data for specific patient samples over time.⁴ Indirect costs are typically divided between *mortality* and *morbidity/disability* losses. Mortality losses are defined as the attributable economic cost of “premature” death, premature being reckoned as the difference in life expectancies at given ages of individuals with and without the disease. Economic valuation of this difference — the dollar value of the number of life-years lost or what some call the economic value of life — has been the subject of intense controversy by economists and others for more than three decades.³ Suffice it to note here that the most common practice is to assign the (discounted) money sum of the market income that an individual would earn over the extra time available to her when premature death is averted. Morbidity/disability losses have roughly

the same meaning. In effect, differences in "work-life" expectancies are calculated for individuals with and without the disease. The valuation of that time is also based on differentials in market earnings, though some also value it in terms of "utilities" or the inherent worth of functional capacities and health-related quality of life.⁵ Many analysts also recognize that the concept of morbidity/disability losses encompasses the effects of disease not only on working subjects but also on the economic activities of the entire family.⁶ Accordingly, indirect morbidity/disability losses include the impact of a disease on reducing work effort, diminishing earnings capacity, and adjusting the work patterns and budgets of other family members.

Up-to-date estimates of aggregate direct and indirect losses attributable either to all cancers or specifically to breast cancer are, regrettably, unavailable. Aggregate, prevalence-based estimates for 1990, the most recent year for which such figures have been published, put the (present) value of the overall economic toll exacted by all malignant neoplasms at approximately \$96 billion, of which roughly \$27 billion is apportioned to direct losses, \$10 billion to morbidity/disability losses, and the residual \$58 billion to mortality losses.⁷ An extrapolation of earlier data suggest that current aggregate losses (in 2000 dollars) are approximately double the 1990 estimate, though so much has happened over the past decade in cancer detection and treatment that this figure is doubtless wide of the

mark. While there are no recent estimates of aggregate (direct and indirect) losses attributable just to female breast cancer, some partial National Cancer Institute figures for direct costs alone show those attributable to this disease are greater than any other cancer site, nearly \$7 billion in 1990.⁸ Early studies^{9,10} estimated that the ratio of indirect to direct costs of breast cancer was approximately 3:1. Assuming that this ratio continued to hold until 1990, \$28 billion of the total economic cost of cancer estimated for that year may be attributable to carcinoma of the breast; this number too may have doubled by the year 2000. Circumstances over the past decade in breast cancer treatment and outcomes have also changed dramatically, perhaps more than most other types of malignancies. The broad contours of these changes are worth reviewing for clues about the shifting economic toll of breast cancer.

To begin with, the decade of the 1990s witnessed both a modest but steady decline in the overall rate of breast cancer mortality and the lagged effect of the more dramatic decline in mortality rates for women under 55 years of age that began in the early 1980s.^{11,12} We infer that indirect mortality losses are now falling as a result. Irrespective of how dollar values might be assigned to them, these averted mortality losses are clearly an economic benefit to breast cancer survivors, their families, and society at large. There were, however, still comparatively high incidence rates of breast cancer when mortality

started to fall. In recent years, new cases have just leveled off from their significant spike in the early 1980s. Falling mortality and sustained high incidence means that prevalence spells are longer. We infer from this that lifetime direct costs of breast cancer are now increasing. The additional time enjoyed by survivors adds not only follow-up, drug, and monitoring expenses attributable to the initial tumor, but also more recurrent events and their attending consumption of treatment resources.⁴ Given the expanding prevalent population, the direct costs of breast cancer are now likely to be significantly higher than they were a decade ago. It is unclear at the moment whether the likely decrease in mortality costs is offset to any substantial degree by these likely increases in direct costs, a question to which I will return momentarily.

Despite continuing debate about the determinants of the dramatic upsurge two decades ago in breast cancer incidence, most specialists agree that more extensive screening coupled with new imaging technologies helped to detect not only more tumors, but also at earlier stages of the disease and in younger women.¹³ The evidence on these complex interactions, especially evidence that diagnoses at younger ages is now increasingly common, is hardly straightforward. The age gradient of diagnosed cases is complicated by disease biology, concomitant age-related trends in childbearing and menopause, and the access to and demand for screening, to name just a few.¹⁴ Yet

the age distribution of incident cases does appear to have shifted dramatically after the spike in new cases in the early 1980s. As detailed by Kessler,¹⁵ significantly higher incidence rates in the 45-65 year age bracket are observed after the spike than before it. Moreover, in contrast to the steady jump in age-specific incidence rates over the entire range of ages before the spike, the rates afterward peak at approximately 75 years of age and then *decline* for all older women. This shift implies a drop in the median age at which breast cancer is diagnosed. The well-known analysis of Feuer et al¹⁶ on the lifetime risk of breast cancer (based primarily on data from the late 1980s) puts the median age at diagnosis at approximately 65 years. It is likely, therefore, that the median age has fallen well below 65 years since then.

If true, this strongly implies that indirect morbidity/disability losses from breast cancer have been rising over the recent past. In part, the reason is that there are more prevalent cases now than ever before. However, it is also likely that downstaging and diagnosis at younger ages has interacted with the steady growth in the labor force participation rates of American women to yield even higher losses. Given female labor force participation rates in the critical 45-65 age range of almost 70%, detection of breast cancer at earlier stages and younger ages means the odds now favor that a new case will be a working woman. Women in the labor force may sustain greater losses from their disease than women who are out of the labor

force. This does not necessarily mean that women with breast cancer histories who are homemakers incur no losses; they do, and the past literature on aggregate costs has routinely imputed their dollar value. Employed women, however, may incur *higher* average losses than those imputed to homemakers, which would then clearly generate upward pressure on the indirect morbidity/disability toll of the disease. Since, as noted, the decline in mortality costs may be offset by likely increases in direct costs, this upward pressure may tip the balance as to whether the overall cost of breast cancer is increasing or decreasing. These logical inferences, however, hinge crucially on the assumption that the indirect morbidity/disability effects of breast cancer are both nontrivial and long-lasting. The question thus arises whether breast cancer actually reduces work effort, diminishes earnings capacities, or forces family members to adjust their economic activities in response to the disease. As a result, we turn to a brief appraisal of the available literature bearing on this question.

Indirect Morbidity/ Disability Losses: A Brief Literature Review

An extensive literature has accumulated over the past three decades on the impact of poor health on labor market outcomes.¹⁷ This literature provides considerable evidence that individuals with chronic health conditions are more likely to reduce

work effort, earn less per hour when they do work, and experience household changes in work patterns than individuals without such conditions, though questions persist about the magnitude of these effects and the degree to which they are involuntary. This literature, however, focuses generally on the impact of a wide variety of health conditions, not just breast cancer, on such outcomes. If that disease is like other chronic, disabling diseases, the literature certainly leads to the expectation that breast cancer survivors will experience poorer labor market outcomes. In fact, there is good reason to suppose that for many women, breast cancer is a chronic, disabling condition in this sense. Diagnosis and treatment by means of surgery, radiation therapy, and even adjuvant chemotherapy produce significant decrements to physical and emotional capacities in many instances.¹⁸⁻²¹ If these decrements are not reversed, they may lead to such adverse outcomes as labor force withdrawal and lower pay. As a result, we anticipate that when studies focus explicitly on breast cancer, they will adduce compelling evidence that the survivor population experiences these outcomes.

Unfortunately, the available evidence is not all that compelling, one way or another. Only a few such studies have been published, and those that have tend to be marred by methodological problems. For instance, two recent studies show that breast cancer does reduce work effort as expected.^{22,23} However, these analyses tracked

changes in work activity over relatively short follow-up periods, in one case only 3 months postdiagnosis, and neither of these studies used a control or comparison group. The time frame of these studies is important, because it is the long-term behavior of survivors that bears on indirect economic consequences of the disease. We expect that women undergoing initial therapy will reduce work activities both in the market and at home. The question is whether, with the passage of time, these women revert to precancer patterns of work behavior or, put somewhat differently, whether the short-term work disruptions that have been observed resolve naturally over time as other social-psychological problems of breast cancer *apparently* do.²⁴

Study designs are even more serious limitations. Consider, for example, that chronic conditions typically strike at a time in the life-course when individuals may be getting ready to withdraw or reduce work effort for other reasons, and when they may be enabled or induced to do so by the availability of pension and other types of transfer income. Economists have devoted considerable attention to disentangling the effects of voluntary and involuntary changes in work effort, and when they do, they find that reductions attributable to poor health are not as great as many suppose.¹⁷ The lesson they have learned is that it is crucial to control for these life-course and choice elements in gauging morbidity/disability losses. The available literature on the labor

market effects of breast cancer generally fails to control for any of these factors, mostly by failing to include a control or comparison group in the study design. Consequently, there is currently little hard empirical evidence that the lingering effects of breast cancer force survivors to reduce their attachment to the work force involuntarily or whether reductions that are detected are changes that would have occurred normally, even in the absence of the disease.

There are many more published papers on the related issue of diminutions in earnings capacity of breast cancer survivors, most alleging that they are subject to such job-related discrimination as outright dismissal, reduced pay, and loss of fringe benefits, especially medical insurance coverage.^{25,26} Design issues surface in this literature as well. Few studies produce any hard data on actual discriminatory practices, and even those that do typically fail to control for the functional capabilities of women. Disease-related diminutions in productive capacity may lead to lower earnings potential of survivors who continue working, but this may not necessarily lead to job-related discrimination. The residual physical limitations noted above, especially the residual effects of axillary node surgery on upper body strength and arm movement, could lead to reassignment to poorer paying jobs for women originally working in higher paying, physically active occupations. Yet the disease may also lead to the *perception* that economic productivity is reduced or compromised even when it is not, thus

inciting various discriminatory practices by employers. Research on this topic thus needs to distinguish carefully between actual and perceived changes in the marginal productivity of working women with a cancer history, and to control explicitly for the functional capacities or abilities of those women. The use of a control or comparison group is one way in which these factors can be taken into account. We know of only one study on this topic that actually uses a comparison group.²⁷ Although it did not introduce functional abilities directly into its design, this study did enhance the likelihood that self-reported discriminatory events were interpreted in context. Additional empirical research based on more rigorous criteria are thus needed before inferences about earnings losses and discrimination in the population of long-term breast cancer survivors can be drawn more precisely.

Finally, we found only two studies specifically focusing on adjustments in household work patterns to breast cancer.^{28,29} This gap may be the most serious of all, because such adjustments may occur irrespective of whether the breast cancer survivor is a working woman. Indeed, the likelihood that other family members will adjust market work over the long-term might well be to substitute for the lost home production of the woman with breast cancer as well as changes in her work effort, if she was a working woman.¹⁷ Clearly, there are related issues such as the impact of breast cancer on family budgets and assets of the cost of the initial treat-

ment itself as well as continuing follow-up expenses. The impact on changes in medical insurance coverage, especially changes that substantially raise out-of-pocket costs for follow-up treatment, must also be examined.³⁰ The issue is increasingly important as cost containment efforts by both public and private payers appear to shift more of the economic burden of health conditions on families during both the acute phase of the disease and the chronic phase thereafter. Whether such adjustments continue over time for long-term survivors is even more important and, to the best of our knowledge, has not yet been extensively studied.

Some Ongoing Research

The gaps in the available literature summarized in the preceding section make any conjecture about current trends in morbidity/disability losses hazardous. Additional empirical research on how breast cancer actually influences the ability of surviving women to continue working, their remuneration, and the work patterns of family members is needed to draw better inferences. Some work is currently underway at our institute that responds to this need. Our study aims to test several (though not all) of the key relationships bearing on the economic consequences of breast disease and to do so in ways that avoid some of the methodological pitfalls described above. More specifically, we are testing whether the economic status of 5-year survivors of breast cancer changes over the period since diag-

nosis more than any such changes observed over the same period in an age/work status matched group of women who never had cancer. Four aspects of the ongoing study are of interest.

First, the focus on women diagnosed at least 5 years ago addresses the issue of whether the lengthening period of breast cancer survival increases the risk of adverse economic consequences. In order to assess the effects on working women, we further restrict the study population to those who were 60 years of age or younger at the time of diagnosis. Because these women are still of normal working age, we will ascertain for those employed at the time of diagnosis whether they are still working or looking for work. We included both working and nonworking women with breast cancer in the sample, though given the age range and the national trends in labor force participation described above, the largest proportion of the sample was comprised of women who were working at the time of their diagnosis. We drew a sample of such women, and then matching on age (within 5 years) and work status (at diagnosis for cases and roughly 5 years ago for controls), we generated a comparison or control sample.

Second, a main outcome of interest for working women is the amount of time devoted to market work and changes in those time allocations over the 5-year study period. Because many in the sample will be at the point in the life/work cycle when individuals

naturally begin to reduce time commitments or withdraw altogether from market work, we will disentangle the effects of the breast cancer from those of normal retirement processes. It should be noted here that the control group, composed of women who have never had cancer, may not necessarily include just healthy women. This means that women in the relevant age group may also encounter chronic health conditions that contribute to decisions to withdraw from the labor market. Thus, we must first disentangle how health conditions and other life-course events interact to produce changes in labor market behavior and then assess the extent to which breast cancer may be implicated in any change differentials observed between cases and controls. Multivariate statistical techniques will be used to ensure that the set of background determinants is taken appropriately into account, so that the net effect of breast cancer, if any, can be detected. The analysis thus requires that we have reasonably good observations on the labor market behavior of cases and controls over the entire study period. Since short-term withdrawal from the work force is expected at the time of initial diagnosis and treatment, we are collecting data on the cumulative total number of hours worked over the 5-year study period. We will then test whether time out of work reverts to old, pre-diagnosis patterns or whether new patterns emerge.

We are also analyzing changes in the functional capacities of working women and the amount

that they earn as a means of testing, among others, whether there is discrimination against breast cancer survivors in the labor market. As noted earlier, evidence of economic discrimination requires that cancer survivors have the same set of productive capabilities as other workers but be remunerated at a lower rate, if at all. We are defining remuneration or “pay” relatively broadly so as to include fringe benefits, especially medical care insurance coverage. Controlling for other factors that increase or decrease the likelihood that such coverage will be obtained on the job, we will test whether changes in coverage occurred, whether similar changes are observed in the comparison group, and thus the net likelihood that breast cancer survivors experience these various forms of job discrimination relative to the control group. Supplementing this analysis will be more detailed accounts of actual *behaviors* that women might have undertaken in the face of discriminatory practices. For instance, in addition to subjective accounts of having been discriminated against by an employer, we will ascertain whether these women engaged in relevant behaviors in response to the discrimination (eg, whether they filed an Equal Employment Opportunity Commission complaint under the Americans With Disabilities Act [ADA]).

Finally, we are measuring labor market attachment and earnings of all members of the households of cases and controls, using detailed job and earnings probes to characterize the temporal profiles of

hours worked and earning per hour over the study period. Cumulative market earnings of the households of cases and controls can be computed, and differences between these values will, as before, be tested by statistical means.

Policy and Clinical Relevance

Our study will establish a fairly rigorous standard for judging whether long-term breast cancer survivors incur significant economic losses. For one thing, we are relying primarily on documented behavior rather than subjective reports of adverse consequences. For another, the control group includes women with other chronic health problems, so the economic losses of breast cancer survivors will be judged relative to average women, including those who have had, for instance, a heart attack or have severe arthritis. While detecting such losses is sufficiently important in its own right, we will also be able to tell whether there are interaction effects. For example, we should be able to assess whether the losses of women with both breast cancer and severe arthritis are additive or even multiplicative. We should also be able to tell whether specific demographic subgroups (eg, African American women who for unknown reasons tend to have poorer breast cancer outcomes) incur disproportionately higher economic losses, and so forth. Put differently, we will learn whether detectable losses are distributed more or less equally over the sample of prevalent cases or

whether instead they are concentrated in only a small fraction of women who incur catastrophically large ones.

Findings from this research, as in other research on the economic burden of cancer, may help policy makers to refine priorities for research, including the need for longer-term follow-up studies of patients with breast cancer and other cancers. The dollar value of the indirect costs may be used either alone or in combination with other indicators to assess the effectiveness and efficiency of various types of medical and cancer control efforts. Policy makers may also find that the character of the losses suggest the need for new or redoubled public sector efforts. To illustrate, discriminatory job practices are already subject to legal action under, among others, the ADA. If such practices are detected, efforts must be made to ensure that cancer survivors are aware of their legal rights and responsibilities under the ADA.

New figures on the economic losses attributable to breast cancer are needed, but the estimation of these losses is only an organizing device for (perhaps even just a metaphor for) the host of problems that may afflict breast cancer survivors and thereby impinge on the decision making of clinicians who care for them. Most clinicians understand that women diagnosed and surviving the disease have many problems for which careful follow-up is needed, including the social/psychological aspects of survival.²⁴ Clinicians are already

advised to inquire about mood disorders, anxiety, and the like arising from stress over the potential for recurrence. If economic consequences are also serious, clinicians should be advised to inquire about the economic well-being of the patient and her family. Responses might be used to fashion a rehabilitation plan. Practitioner-backed requests to employers for flex time, job reassignment, or other types of work-related accommodations may help to sustain work effort and the productive capacity of working survivors. Assistance of medical social workers and other professionals in making up losses for those unable to work in the application of disability insurance and other public assistance programs may also be needed.

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