



Breast Cancer – The Hidden Epidemic

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"When I told my husband I had breast cancer, he said, 'I don't want anything to do with you. You can go die.'" These are the words of a 45 year old divorced and homeless woman in Bangladesh. When we think of breast cancer, our image is usually of women seeking treatment in American hospitals, or of loved ones participating in those many fundraising runs that have popped up around the country. It's rarely of the already destitute and downtrodden women of the developing world being further denigrated or cast aside. Yet it is in the slums and villages of the world's poorest places where scientists are only now realizing that breast cancer is a hidden epidemic.

While high-income countries have begun to celebrate significant recent progress toward curing women with breast cancer, the extent and severity of this disease has only begun to be recognized in poorer countries; and the nations of South Asia are particularly at risk. As economic disparities lessen in some areas of the world, the burden of cancer is rapidly increasing.

Globally, cancer now causes more deaths than tuberculosis, HIV/AIDS and malaria combined (8.1 million vs. 4.3 million in 2008). And more than 70% of all cancer deaths occur in low and middle-income countries, such as India and Bangladesh. Once diagnosed, the likelihood of dying of cancer in a developing country is as high as 75%, compared to less than 50% in the United States. This gap is particularly striking for cancers of the breast and cervix, for which early detection and effective treatment greatly influence survival.

The cancer burden is expected to rise to global pandemic proportions, with the greatest projected increase in developing countries. Yet certain age-old barriers prevent us from properly helping those in need, both in South Asia and among South Asians in the West. They are: stigma, shame, cost and undervaluing the lives of women.

The Personal Cost of Breast Cancer

Every one of us has been touched by cancer, whether through personal experience or that of someone close to us. After that of the lung, breast cancer is the most common form of cancer globally, overwhelmingly affecting women, though a small number of men have also contracted it.

The National Cancer Institute estimates that 226,870 women will be diagnosed with breast cancer in the United States in 2012, of whom 39,510 will succumb to the disease. It touches women of all races, with white women exhibiting a slightly higher likelihood of being diagnosed, while African-American women are significantly more likely than all other ethnic groups to die from breast cancer.

Publicly available U.S. data does not distinguish between the racial sub-types making up the general category of "Asian/Pacific Islander," in which most South Asian patients would be grouped. This group experiences the lowest death rate, though is largely represented by Chinese-Americans.

When considering these kinds of data, it's important to consider some of the implicit biases connected with data collection. For example, the fact that African-American women are more likely than others to die from breast cancer may not indicate a biological predisposition toward the disease, but rather a tendency for these women to seek treatment when their cancer is in a more progressed stage, thus making it harder to treat and more likely to result in death.

By the same token, an underrepresentation of South Asian women in the U.S. statistics may indicate reluctance of people in this ethnic group to be screened. And this hints at a continuous thread that is woven throughout the story of breast cancer among South Asians: the unfortunate effects of stigma and denial, and maybe a sense that breast cancer is "not an Indian disease."

One Family's Story

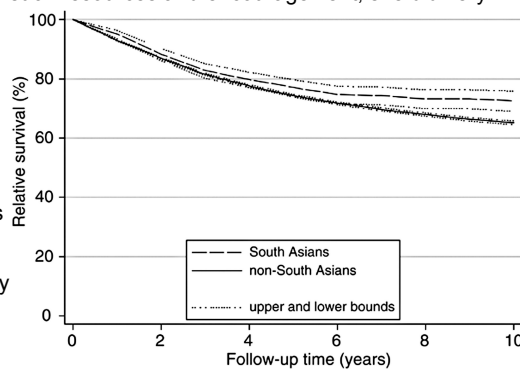
While rates are low compared to other ethnic groups, South Asian women living in North America are definitely at risk. When families migrate to North America, beliefs and attitudes about breast cancer, as well as women's roles and responsibilities, remain, making women from South Asian countries particularly vulnerable to undiagnosed breast disease. Indeed, South Asian women in North America are among the least screened populations for both breast and cervical cancer.

Dr Rita Ghatak, Ph.D., of Stanford University's Medical Center recently lost her mother-in-law to breast cancer. As head of Stanford's Aging Adult Services/Geriatric Health Program, she's often found herself providing navigation to South Asian women regarding management of their disease. In Rita's opinion, the number of women facing breast cancer is on the rise, or so it feels, based on experiences both with South Asians in the United States and those living in India.

Rita's mother-in-law underwent a mastectomy. Though she had great reservations, the American team in California treated her with great cultural sensitivity and she was comforted by the extraordinary care she received. Her aggressive treatment involved radiation and chemotherapy, which left her somewhat dependent on support for daily living. But with such resources and encouragement, she did very well.

Rita's mother-in-law was not prepared to tell anyone—other than her immediate friends and family—about the disease. In Rita's words, "I find that many South Asian women consider this a dreaded disease that attacks their grace and beauty."

What distinguishes Rita's family's experience in California from those of women in less resourced parts of the world is the degree, availability and quality of care received. "Care here was so culturally appropriate and so tender and from countless emergency room visits, trips to her primary care doctor, oncologist and her infusion areas, I think that my mother-in-law could not have experienced better treatment and better support."



But more importantly, she feels that the tendency for breast cancer patients to lose contact with their primary care doctors is a gap in our system. In the process of navigating our complicated network of expensive specialists, clinics and examiners, our system sometimes misses the importance, both in terms of efficiency and emotional cohesion, of "the big picture" and continuity of care.

The Fiscal Picture

A 2009 study published in the journal *Pharmacoeconomics* reported that in the United States, lifetime per-patient costs of breast cancer ranged from \$20,000 to \$100,000. With medical costs sadly being the cause of many bankruptcies, it is not surprising to learn of stories like that of New York's Natasha Pierre, who in 2007 related to reporters her inability to pay the \$1000 fee for her lumpectomy, and the monthly \$500 co-pay for her chemotherapy, both of which drove her into poverty.

These high prices are likely the driving force behind the reluctance of some largely low-income demographic groups, such as African-American women, to delay seeking care until the disease is well entrenched. As much as this phenomenon affects the poor in America, it is recapitulated and enhanced amongst the very poorest in the developing world, for whom wages dip well below \$1 per day.

A recurring trope in the study of global health is that when the impoverished must make health choices, it is often women's health that is least considered, due in part to a belief that priority must be given to children and to husbands for their economic value to the household. The effects of the high cost of health care, then, disproportionately disadvantage women, and are particularly enhanced when the disease in question is primarily a woman's disease. Pervasive sexism and poverty combine to complicate all attempts to address disease on the global stage.

David Bloom of Harvard University reports that the total cost of treating breast cancer in the Americas is well over \$150 billion per year (in 2009), a figure that includes economic costs due to the loss of productivity of people unable to work because of the disease (accounting for about 27% of the total). The same year, costs in Asia were under \$50 billion, based on the same criteria. Unsurprisingly, there is a strong worldwide correlation between how much money you have and how likely it is that you will survive your experience with breast cancer.

Over the next 20 years, chronic diseases which include all cancers will cause a projected economic loss in poor countries of \$100 billion to \$2.8 trillion, according to scientists at the World Economic Forum in 2011. This is clearly not the stereotypical expectation that many of us in the wealthy part of the world have of the so-called developing world. Images of malnourishment, natural disasters, water shortages, homelessness and plagues of viral and bacterial diseases are our more common health impressions of low income countries, not cancer and diabetes.

While such stereotypical images reflect the continued truth of the existences of millions of people, they are no longer wholly accurate. Yet

these impressions drive both our attitudes toward these countries and our investments in health interventions aimed to reduce suffering and improve economic stability. In fact, less than 5% of global spending on cancer is in low income countries, yet such countries bear 80% of the global cancer burden, when considered in terms of total numbers of people affected. The rise of chronic disease demands a reconsideration of our global health spending priorities.

The Rise of Breast Cancer in South Asia

Clearly, the new battle ground against chronic diseases in general, and cancers in particular, are the low-income, developing nations; and breast cancer is the most common type of cancer and the most common cause of cancer-related mortality among women worldwide. One in ten of all new cancers diagnosed globally each year is a cancer of the female breast. According to a 2004 study, more than 1.1 million cases are diagnosed and more than 410,000 patients die of it all over the world. Its incidence is increasing almost everywhere. However, its burden and death rate are not evenly distributed. In general, the incidence of breast cancer is high (greater than 80 per 100,000) in developed regions of the world and low (less than 30 per 100,000), though increasing, in developing regions.

In South Asia, breast cancer is second only to cervical cancer in some of the more remote populations. With improved access to cervical cancer screening and treatment, as well as the recent availability of low-cost vaccines against human papilloma virus (HPV, the primary cause of cervical cancer), breast cancer will soon emerge as the most prevalent cancer and commonest cause of cancer-related death among all women in South Asia.

It is estimated that each year 76,000 women die of breast cancer in South Asia, and over 50,000 in India alone: almost double the number in the United States. This is undeniably a dramatic underestimate, given our inability to detect a great many cases, and a tendency for causes of death to not be fully ascertained, particularly among poor villagers.

The prevalence of breast cancer in the region is expected to grow due to a combination of population explosion and, perhaps ironically, some of the more positive effects of economic development, including increased life expectancy, delayed child bearing and fewer numbers of children. Add to this the decreased duration of breast feeding and the adoption of “Western” lifestyles (higher fat diets, overweight and obesity, and reduced activity), and it is projected that global breast cancer cases will grow from 1.4 million in 2008 to over 2.1 million cases by 2030, due in large part to the increase in cases in South Asia.

Despite the high quality of cancer care in some urban centers, such as the Tata Memorial Hospital in Mumbai, where more than 70% of patients receive treatment at almost no cost, many people suffering from cancer in India are simply unable to attend such a facility. A recent, high-profile study of Indian cancer mortality highlighted key differences in cancer deaths between urban and rural settings.

Distance, education, language, awareness and even psychological barriers persist in preventing those suffering from seeking and receiving appropriate care. Misconceptions about the origins and implications of cancer abound, muddying any potential public education initiatives. Much like other diseases discussed openly in the West, in many South Asian communities, stigma remains a daunting barrier to both measuring the problem and treating it.

Inconceivably, unfairly and tragically, shame has entered the equation, often preventing sufferers from acknowledging their conditions or even sharing their status with loved ones. This is all the more tragic for breast cancer because it is a treatable and often curable disease.

Experiences in Bangladesh

Our recently published work in rural Bangladesh, in a region of about 15 million people, just 80 miles from Kolkata, taught us that most women do not seek care for a serious breast problem until it is too late. More than 80% of new cases we see at our small breast center—Amader Gram (Our Village, in Bengali)—are at a very advanced, generally incurable state. When we ask these women why they apparently waited for months and even years before seeking care, most said that they were aware that they had a serious problem, even a life-threatening disease, but told us they had “no choice” but to wait. Almost all reported a financial, geographical, or family-related obstacle to seeking care. And most of them viewed breast cancer as a curse and a death sentence, a sentiment seemingly shared by their communities, since women who do seek treatment often risk divorce or abandonment. As a consequence, many women die without ever seeking care.

These women’s words were as heartbreaking as they were concerning. Their incorrect perception of breast cancer’s treatability is reflected in one woman’s stark statement that, “No one getting cancer gets saved.” Another suggested a demonic origin to the disease: “It is evil. Once it visits your house, it kills.” But a prevailing attitude is one of shame and guilt, as in one woman’s belief that “It’s a curse from God for wrong-doings.”

There are, of course, other reasons that South Asian women are not seeking or receiving care. One widely-reported trend is a basic mistrust of doctors, or a desire to only see a female doctor, which is difficult to accommodate. This has led to many patients turning to alternative medicine, such as homeopathy, Ayurveda and spiritual healing, none of which has shown any success. As a 28-year-old patient

told us, “The homeopath prescribed me many drugs and gave me some injections ... but my breast lumps didn’t go away.”

These words are recapitulated in the experiences of Dr. Rita Ghatak’s mother-in-law in California. Before her death, her relatives in India suggested that she, too, seek homeopathic or other kinds of unproven traditional methods, suggesting that the cultural aspects of addressing breast cancer among South Asians have a global reach.

As in all communities without socialized medicine, especially those with pervading poverty, the potential for a serious disease to financially ruin a family is tangible. As discussed, this is the cause of many bankruptcies in the United States. It may also compound the stigma, as many women fear that their husbands would sooner abandon them than shoulder the immense financial burden that cancer treatment may entail. This has accelerated the turn to cheaper, though unproven and possibly harmful alternative treatments.

Even when the husband and in-laws are supportive, the money just might not be there. As a 30-year-old patient reported, “Two years ago I noticed a lump. The homeopath prescribed a paste that made my skin burn like a spice and now I can’t touch my breast because it’s so painful. My husband earns Taka 150 (US \$2) per day ... he wants me to go see a good doctor. But it will take time to save up for this ... My last visit to the doctor cost Taka 3000 (US \$43).”



Problems and Solutions

How do we address this simmering epidemic, when so many cultural, financial and logistic barriers conspire to deny care to those most in need? The entangled threads of disease, poverty, and sexism are complicating enough; but the situation is exacerbated further by structural failures in nations’ formal health systems. Doctor absenteeism, reported by one study to be over 70% at smaller clinics in Bangladesh, and doctor malpractice (either as a result of incompetence or greed) contribute to the perception that modern, Western medical care is ineffective and corrupt, and that cancer is “a death sentence.”

Furthermore, services that should be very low cost or free have been co-opted by individuals seeking to make a profit from an overstressed medical system, such that many services required for standard breast cancer care are unnecessarily unaffordable by the average family. The problem of breast cancer in South Asia is a combination of cultural, social, infrastructural and political issues. It’s in the latter arena that an impact can be most immediately felt.

Tedious bureaucratic systems, lack of collaboration across the health sector, and poor governance have contributed to delaying advances in health care solutions throughout South Asia, and must be minimized for significant progress to be made. A commitment to this aim alone could have major implications for advances and cost savings in not only breast cancer care, but many other infectious and chronic diseases, as well.

Despite the gloomy picture that our story paints, there is reason for hope. In October of last year, the Global Task Force on Expanded Access to Cancer Care and Control (GTF.CCC), published “Closing the Cancer Divide,” which explores specific opportunities to affect the global burden of cancer.

Percolating through these strategies, though, must be an awareness of the need to empower women to advocate both for their health and their deserved status in society and in the home, to better shrug off the bite of stigma. Effective and affordable treatments for breast cancer do exist. Our inability to care for so many stricken South Asian women is evidence that it is us, not they, who should be ashamed.

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