

Cancer in Nepal

The Necessity of a Multi-Targeted Approach

Sahaja Acharya

Saint Louis University School of Medicine, St. Louis, MO, USA

The auditorium was bursting with color. Women in vibrant saris and glistening jewelry bustled about, greeting newcomers with a namaste while intermittently catching up with old acquaintances. In juxtaposition to this rich rainbow of color, I was dressed in black pants and a plain white shirt. Mental note to self: next time, spice it up a little. I looked like I was going to a funeral amongst a group of men and women who seemed to be on their way to the biggest party of the year. Yet the occasion was neither festive nor mournful—we were at an obstetrics and gynecology conference in Bharatpur, Nepal. As I sat down to listen to a presentation on cervical cancer, one of the physicians made an interesting observation: young women with cervical cancer are less likely to undergo treatment than older women. This seemed strange. Shouldn't younger women be more educated and thus more proactive when seeking medical care?

Although there is no formal data, it is universally understood that younger, more sexually active women are often abandoned by their husbands at the time of diagnosis based on the assumption that these women will no longer be able to bear children. As a result, these 15- to 40-year-olds do not have the financial and/or psychological support to start or finish treatment, which usually consists of some combination of surgery, radiation and chemotherapy. However, older women in their fifties and above are often brought to places of medical treatment by their children and grandchildren, who not only ensure that treatment is completed but also demand the most aggressive course of treatment. Such barriers to health care represent a significant hurdle in a country where cervical cancer is not only the predominant form of cancer in women but also has the highest age-specific mortality rate.¹ When I asked a radiation oncologist what policies were in place to address the social and cultural barriers to treatment, he looked at me, shrugged and said, "This is Nepal."

The cancer burden in developing countries is rapidly rising; however, it is difficult to accurately quantify this increase because there is a shockingly limited amount of data. In 2006, population-based cancer registries covered only 8% of Asia's population and 11% of Africa's population. To provide some context, in North America, cancer registries cover 99% of the population. Although data regarding cancer incidence and mortality rates in developing countries has become more widely available in recent years, it is inadvisable to compare rates from one point in time to another because methods of estimation vary greatly.^{3,4} However, when comparing data points within a single cancer registry, one can appreciate the magnitude of the cancer burden. In Thailand,

for example, the incidence of breast cancer has doubled over a period of 20 years. Similar trends can be seen in India, China and Brazil.⁵ Nepal does not have a national population-based cancer registry, but it does have a hospital-based registry, established in 2005, which pools data from seven major hospitals. To date, only one analysis set from this database has been published.⁶

Numbers by themselves can be misleading unless the cause of this change is understood. According to the most recent estimates from the International Agency for Research on Cancer (2008), approximately half of cancer cases and two-thirds of cancer deaths occur in low- and medium-income countries. Increases in tobacco use, lack of cancer screening measures and the aging of a growing population, secondary to improvements in life expectancy, are contributing factors. By 2030, low- and middle-income countries will experience a 30 percent increase in population, which is approximately seven- to eight-fold greater than that of high-income countries. Furthermore, the proportion of the population over 65 years, typically the more cancer-prone population, is expected to rise by five to 10 percent in low- and middle-income countries.⁷ From this data, one can reasonably expect the cancer burden in developing countries to become a grave public health challenge.

Compared to cancers in the West, cancers in developing countries are more likely to be related to infectious disease, which explains the relatively higher incidence of liver cancer (Hepatitis B virus), stomach cancer (H. Pylori bacteria) and cervical cancer (Human Papilloma Virus). Of the 500,000 new cervical cancer cases annually, 85 percent affect women from the ages of 15 to 45 in developing countries.⁸ In Nepal, there are over 3,500 cases annually, representing 21 percent of all cancers in women.⁶ However, there has also recently been an increase in non-infectious disease-related cancers, such as those of the breast and colon, in areas where they have historically been absent.⁹ Breast cancer is now the second most common cancer among Nepalese women.⁶

Despite these grim estimates, the international response to the global cancer burden has been lackluster at best. Although Millennium Development Goal 6 (MDG 6) emphasizes the importance of addressing infectious diseases such as HIV/AIDS, TB and malaria, it lacks a similarly vigorous campaign against the rise of non-communicable diseases such as cancer. From 2009 to 2010, more than 50 percent of all development assistance for health in 48 countries was allocated to MDG 6. In 78 countries, MDG 6 represented the largest health aid disbursement. This is in marked contrast to funding for cancer prevention and treatment in developing countries, which represents such a small portion

of the development assistance pie that it is not even listed in the World Health Organization's report for international development assistance.¹⁰ Thus, it is not entirely surprising that cost-effective screening measures for cancer, such as acetic acid visualization to detect cervical cancer, are available to only 32 percent of the population in low income countries (WHO 2012).¹¹ Although combating infectious diseases in the developing world is of utmost importance, there is also a need to anticipate and address the challenge of cancer prevention and treatment.

Medicine is complex, and oncology epitomizes such complexity. It requires an orchestra of physicians from various specialties playing the same melody, a melody that is always changing as the array of chemotherapeutic agents, radiation modalities and treatment protocols evolve. Many countries have already invested in cancer hospitals designed to provide multidisciplinary cancer care involving medical oncologists, pathologists, radiologists, surgeons and radiation oncologists, all of whom play a part in treatment.¹² Getting these centers to deliver the best value care at the lowest cost will not only require financial support and medical expertise but also the ability to overcome social, cultural and logistical barriers to health care. Examples of such barriers include poor health literacy, lack of women's empowerment, uncoordinated treatment efforts between medical specialists and lack of effective communication between health care workers and between patients and health staff.

When Deepa, a middle-class woman in her fifties, presented to BP Koirala Memorial Cancer Hospital (BPKMCH) in Nepal, she had already been diagnosed with breast cancer and treated with a lumpectomy followed by chemotherapy at an outside hospital. She wanted to know if radiation would provide any further benefit. According to Deepa's pathology report, the disease was localized to her left breast without any evidence of metastasis to lymph nodes; however, the size of the tumor was unclear as two conflicting measurements were reported. This poses a problem because breast cancer is staged according to the greatest dimension of the tumor; a larger tumor would upstage a patient and potentially require a different treatment. Furthermore, a larger tumor dimension translates into a smaller tumor-free surgical resection margin. Multiple studies have shown that margin status and pathologic tumor size, among other factors such as age, hormone receptor status and lymph node status, are prognostic for recurrence.^{13,14,15} The risk of recurrence must be carefully weighed against the side effects of radiation and/or chemotherapy in order to effectively battle cancer and still maintain an acceptable quality of life. This is especially important in resource-poor settings where most patients do not have access to routine screening measures that can detect recurrences at an early stage or genetic profiling assays, such as Oncotype DX, to individualize recurrence risks. Hence, obtaining an initial accurate pathologic diagnosis and formulating an appropriate risk-benefit ratio, keeping in mind that recurrences will likely be fatal, is of the utmost importance to a patient's survival and quality of life.

Facilitating inter-specialist and inter-hospital communication would be one way to avoid the blunder in Deepa's case. Pathology reports are of varying quality, some providing insufficient or ambiguous information, and it is almost impossible to have the pathology specimen forwarded to the next hospital for a second look. Furthermore, although Deepa had brought all of the necessary records with her, not all patients provide such a wealth of information. Sometimes post-operative patients show up without an operative report or imaging, making it difficult to know what was surgically removed, how extensive the disease was or even if the disease represented a first cancer diagnosis or a cancer recurrence. BPKMCH has a telemedicine center with video conferencing ability that could be used to communicate with major referral centers and clarify ambiguities. Alternative communication routes include Skype, Google Talk or

even a simple landline.

Just as essential to patient care as communication between health professionals is communication between patients and physicians. There is generally a health literacy gap between patients and physicians, and this is even more pronounced in countries such as Nepal, where the adult literacy rate is 59 percent.¹⁶ As a result, patients require extensive instruction, not only about the disease process and treatment options, but also concerning logistics—where to go for treatment, what paperwork to bring and what to expect. More often than not, this is overlooked and patients are left wandering halls, frightened and confused. Only those bold and persistent enough to seek out this information can master the system. Aastha was one of them. Her story exemplifies how easily patients can get lost amidst the chaos of the hospital even when they belong to the 59 percent of the population that is literate.

It was late morning when I first noticed Aastha. It wasn't her appearance that struck me, but rather her perseverant character. I was with a group of physicians in one of the treatment planning rooms when she walked in. Like so many patients I had seen before, her soft brown eyes expressed both confusion and anxiety, but she spoke with confidence, clearly articulating her words and making direct eye contact, something I soon learned only comes with education. "I need to have this signed," she stated, handing a sheet of paper to one of the physicians. She was told that she had the wrong form and was asked to leave. Instead of being shooed away, she stood there adamantly, waiting for further instructions. She wasn't afraid to ask questions, even though the responses were curt. Once she gathered all the information she needed, she left. I ran after her.

From her demeanor, I could tell Aastha was at least a high school graduate. She happened to be a pharmacy student at a college nearby. She had come with her father, Ramesh, who had noticed a change in his voice months ago and subsequently developed difficulty swallowing rice. After a course of antibiotics and multiple biopsies, he was eventually diagnosed with cancer of the larynx. When I asked both father and daughter what the greatest challenge had been so far, their responses were uniform: navigating the system.

They often received conflicting instructions from different doctors and were reprimanded for not bringing certain files or for bringing the wrong files. When there is no system to organize the flow of information or to assist patients with paperwork, things get lost, miscommunications occur and mistakes happen. More often than not, it is the patient who bears the consequences.

Both Deepa and Aastha exemplify the diverse barriers to appropriate cancer care, ranging from medical inaccuracies to communication and logistical challenges to issues relating to health literacy. Yet, there is an additional barrier, often unaddressed but persistent throughout all socioeconomic classes of Nepal—the marginalized status of women in society. Marginalized women are less likely to receive appropriate medical attention, especially when long-term follow-up care is required. The issue of women's rights is inseparable from that of health care, and the status of women in society will inevitably affect cancer treatment and prevention efforts. How? Take Srijana's story, for example.

Srijana was a 16-year-old girl from a village in the terai, the southern plains of Nepal, and had only a fifth-grade education. I met her somewhat unexpectedly. I was on my way to the cafeteria for lunch when one of the doctors called out to a girl standing by the entrance of the inpatient ward. "Hey, why did you leave in the middle of treatment?" he asked. She smiled, pulled her shawl over part of her face, looked at her feet and mumbled something inaudible. Srijana had been diagnosed with cancer of the vagina months ago, and after starting treatment, she disappeared. This is not uncommon, especially for young girls who have gynecologic cancers. In a conservative, patriarchal society, these girls are embarrassed by their disease and often abandoned by their families. Although Srijana had

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returned months later to resume treatment, her disease had progressed, and the chance for cure was thus reduced.

Great improvements in patient outcomes can be achieved by focusing on cooperation, health literacy and women's rights; however, financial constraints can be frustrating when it comes to maintaining and upgrading technology. Last month, when BPKMCH was in the process of upgrading to intensity modulated radiation therapy (IMRT), physicians were overwhelmed with the task of troubleshooting the new system. One physician explained, "I am the radiation oncologist, the engineer, the physicist and the electrician." Most physicians do not have formal training in engineering or physics, and learning how to do things on the job means working late nights with little progress. Although an engineering team from Palo Alto-based Varian Medical Systems visited the center last month to perform the upgrade, the service was expensive and short-lived. More sustainable solutions are needed—for example, a virtual help desk connecting engineers in cancer centers throughout South Asia. The initial challenge to such a solution would be to identify cancer centers with similar equipment, as there may be very few centers with IMRT technology, and they may all struggle with limited expertise.

Deepa, Srijana, Aastha and the physicians at BPKMCH all exemplify how various, seemingly unrelated social, cultural,

logistical, medical and financial barriers intertwine to affect cancer care. As developing nations such as Nepal strive to meet the needs of a growing cancer burden, they will require much more than financial assistance and medical/technical expertise—they will require a restructuring of the concept of medicine from one that focuses solely on the physician to one that is multi-targeted and addresses the non-medical barriers to health care, including deficiencies in health literacy, women's rights, coordination between medical specialties and communication. Each component represents an essential spoke in the wheel that must keep turning to catch up with the already overwhelming cancer burden. Let us not fall too far behind.

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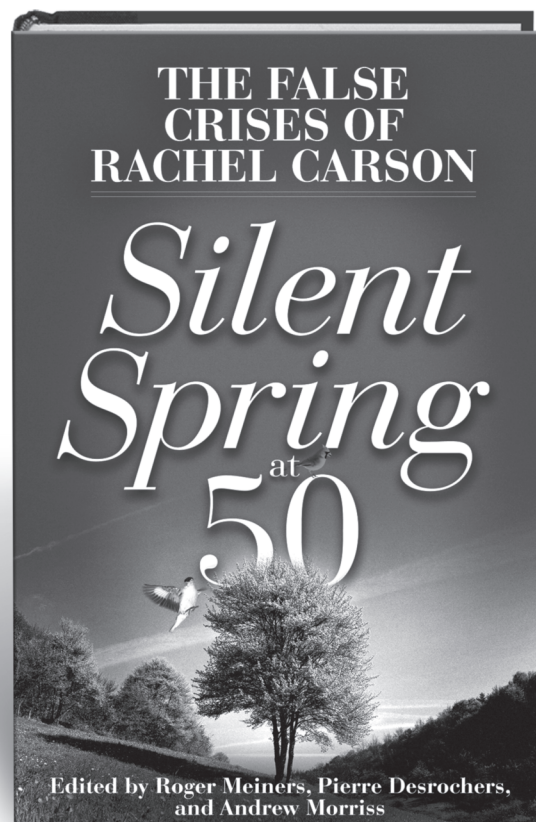
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