

Guidelines for International Breast Health and Cancer Control–Implementation

Supplement to Cancer

Guideline Implementation for Breast Healthcare in Low- and Middle-Income Countries

Breast Healthcare Program Resource Allocation

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Breast cancer is serious public health problem in countries of all resource levels. Although major advances in the detection and treatment of the disease have occurred in higher income settings, similar progress has been slow or scarce in most low- and middle-income countries (LMCs). The poorer outcomes in LMCs may relate to the limited capability of their healthcare systems (HCS) to provide successful early detection, diagnosis, and treatment of breast cancer. Impediments to better outcomes include insufficient numbers of appropriately trained healthcare workers, limited access to screening/treatment facilities, inadequate supplies of necessary drugs, and timeliness of treatment after diagnosis. Clearly, these HCS deficiencies are broader than the scope of the Breast Health Global Initiative (BHGI) and are not unique to the issue of breast cancer. To address issues in HCS that hinder the delivery of breast health services, the BHGI Healthcare Systems and Public Policy Panel explored the HCS structures and function needed to operate a breast care program (BCP). Like with all BHGI guidelines, those proposed by this panel were expressed in terms of 4 strata of resource levels: basic, limited, enhanced, and maximal. The current report describes the issues and questions related to HCS that are important to consider when designing, implementing, and measuring the performance of a BCP. Health ministers, other policymakers, healthcare personnel, administrators, and anyone else involved in developing a BCP can use and adapt this framework to improve outcomes and ensure the more effective use of resources. *Cancer* 2008;113(8 suppl):2282–96. © 2008 American Cancer Society.

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Cancer rates are rising around the world. Estimates indicate that, by 2020, 60% to 70% of all new cancers will occur in the developing world.^{1–3} Breast cancer is the most common of all cancers and is the leading cause of cancer deaths in women worldwide,

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accounting for >1.6% of deaths.^{2,4,5} Perhaps predictably, the increase in breast cancer incidence appears to be greatest in areas where previously reported rates were lower.⁴ Data indicate that 45% of new breast cancers and >55% of breast cancer deaths occur in low- and middle-income countries (LMCs).⁶ Countries with better established cancer registries, such as Japan, Singapore, and Korea, have seen breast cancer rates double or triple in the past 40 years, and certain African cancer registries document increases of >50%. Other countries with less developed record-keeping methods, such as China and India, seem to have experienced increases from 20% to 30% in breast cancer incidence over the past decade. Of course, these figures may overestimate or underestimate the true change in breast cancer rates, eg, some of the increase may be caused by better case documentation; or, alternatively, many women who live in remote locations within the theoretical coverage area of a cancer registry may be undercounted.⁶

Although there has been significant progress in reducing breast cancer mortality in high-resource countries, breast cancer remains a critical public health problem because of its prevalence.⁷⁻¹² In LMCs, breast cancer tends to be diagnosed at later, often untreatable stages, leading to poorer outcomes. For example, the ratio of mortality to incidence is about 50% higher in Africa compared with North America.¹³ Thus, achieving breast cancer survival rates comparable to the best in the world everywhere could result in more than 100,000 fewer deaths each year in LMCs.

Healthcare systems (HCS) consist of the facilities, organizations, governments, and healthcare personnel that work in concert to organize, finance, and deliver care. Weaknesses in various parts of the HCS can impact health outcomes negatively for breast cancer as well as other diseases. Inadequate numbers of healthcare facilities, facilities that lack proper equipment, insufficient numbers of appropriately trained healthcare workers, and healthcare financing systems that are prohibitively expensive are examples of issues that may combine to contribute to poor breast health outcomes. The types of problems indicative of poor HCS are far more likely to occur in LMCs, where <5% of the resources needed for cancer control are available and >80% of cancer patients are incurable at the time of diagnosis.³

One indicator of the extent of this problem in LMCs is the lack of radiotherapy facilities and personnel to perform radiation. The International Atomic Energy Agency has documented that only

30% of the world's radiotherapy facilities are in developing countries despite the finding that these countries are home to 85% of the world's population.¹⁴ For example, it has been documented that Arab countries have far fewer radiotherapy centers and radiation oncologists than the United States despite close population numbers.¹⁵ Radiation therapy can benefit at least 50% to 60% of cancer victims in the developing world by prolonging lives and decreasing pain and suffering. However, without adequate numbers of radiotherapy machines, women suffering from breast cancer will be unable to realize these benefits.¹⁴

Reducing the burden of breast cancer around the world in all resource settings will require modifications and improvements to HCS. With the goal of providing guidance for strengthening HCS to improve breast cancer outcomes, the HCS Panel first met at the 2005 Breast Health Global Initiative (BHGI) Summit in Bethesda, Maryland. At the 2007 BHGI Summit in Budapest, Hungary, the HCS Panel expanded and improved the initial guidelines and developed ideas for effectively implementing and integrating these guidelines. The HCS Panel discussed various topics, including financing, insurance, governance, workforce capacity, and informatics. By sharing ideas about what has worked and what has not worked in their own environments, HCS Panel members and discussants identified major barriers to guideline implementation and explored means to surmount these obstacles.

In a sense, the work of the HCS Panel cuts across the activities of the 3 other panels that were convened at the 2007 Budapest BHGI Summit (ie, Early Detection, Diagnosis, and Treatment), because the implementation of any guidance from these panels will take place embedded within a given HCS. For example, the guidelines for early detection recommend diagnostic mammography after a positive clinical breast examination at the limited resource level. However, unless the relevant HCS ensures that women have access to appropriate equipment operated by adequately trained personnel to perform the procedure and that results are interpreted accurately and are acted upon appropriately in a timely manner, the Early Detection Panel's recommendation of diagnostic mammography in limited resource settings cannot be implemented effectively. Because all of the guidelines from each of the other panels will need to be implemented in the context of a given HCS, the 2 guideline tables developed by the HCS Panel, in a sense, must be derivative of the work of the other panels that define the stratified needs in each of their respective thematic areas.

Breast Care Programs:
Human Resource Allocation

Level of resources	Patient and Family Education	Human Resource Capacity Building	Patient Navigation
Basic	<p>General education regarding primary prevention of cancer, early detection and self examination</p> <p>Development of culturally adapted patient and family education services</p>	<p>Primary care provider education re breast cancer detection, diagnosis and treatment</p> <p>Nursing education re cancer patient management and emotional support</p> <p>Pathology technician education re tissue handling and specimen preparation</p> <p>Trained community worker</p>	<p>Field nurse, midwife or healthcare provider triages patients to central facility for diagnosis and treatment</p>
Limited	<p>Group or one-on-one counseling involving family and peer support</p> <p>Education regarding nutrition and complementary therapies</p>	<p>Nursing education re breast cancer diagnosis, treatment and patient management</p> <p>Imaging technician education re imaging technique and quality control</p> <p>Volunteer recruitment corp to support care</p>	<p>On site patient navigator (staff member or nurse) facilitates patient triage through diagnosis and treatment</p>
Enhanced	<p>Education regarding survivorship</p> <p>Lymphedema education</p> <p>Education regarding home care</p>	<p>Organization of national volunteer network</p> <p>Specialized nursing oncology training</p> <p>Home care nursing</p> <p>Physiotherapist & lymphedema therapist</p> <p>On-site cytopathologist</p>	<p>Patient navigation team from each discipline supports patient "handoff" during key transitions from specialist to specialist to ensure completion of therapy</p>
Maximal		<p>Organization of national medical breast health groups</p>	

FIGURE 1. Breast care programs: human resource allocation table. Note that the table stratification scheme implies incrementally increasing resource allocation at the basic, limited, and enhanced levels. Maximal level resources should not be targeted for implementation in LMCs, even though they may be used in same higher income settings.

Findings

Human resource allocation (Figure 1)

To implement effectively any recommendations related to early detection, diagnosis and treatment of breast cancer, there simply must be adequate numbers of competent health care workers. The HCS Panel agreed that it is the responsibility of the HCS, defined either locally or nationally, to ensure that human resources are appropriate in all 3 areas: early detection, diagnosis, and treatment. The first HCS guidelines, Human Resource Allocation (see Fig. 1), includes the personnel needed for patient and family education, capacity building, and patient navigation. Effectively administering services in a sustainable fashion requires that administrators and government leaders develop effective means for building human resource capacity for the complex set of tasks that stretch across the cancer care continuum.

Patient and Family Education

The HCS Panel consensus was that, at all resource levels, it is important to provide patient and family education, because it promotes disease awareness and earlier detection, and it helps to increase the emotional and physical well being of patients and families that are affected by breast cancer. Patient and family education on detection methods and treatments are especially important in developing countries, where misconceptions about breast cancer discourage many women from seeking screening and treatment. For example, in some countries, there is widespread belief that breast cancer is incurable or contagious. These misconceptions, coupled with a fear that the disease will leave them ostracized from community and family, must be reduced and eventually eliminated. Irrespective of the method of delivery, it is important that educational outreach efforts dispel common misconceptions in a manner that is

culturally sensitive, unbiased, and easy to comprehend. Educating women about how to reduce cancer risk through lifestyle changes also may reduce disease incidence.

Implementing patient and family education programs in LMCs requires the formation of materials and messages capable of impacting decisions made concerning breast cancer. Designers should consider cultural norms when developing these materials and messages. For example, outreach for settings in which the affected woman herself is less likely to have control over household decision-making could incorporate messages aimed at educating the decision makers (eg, husbands, parents, in-laws, village leaders, etc) about the disease. In general, culturally sensitive education is more likely to be well received and, thus, more likely to impact behavior.

Many individuals are capable of delivering messages related to breast cancer. These include community health workers, local volunteers, and medical professionals. Community health workers, who reportedly have increased screening and knowledge about breast health among minority populations in the United States, can be trained to deliver these materials and messages.^{16,17} Local, regional, and national breast cancer survivors also can serve as conduits for breast cancer awareness. Because these women may be some of the first members of their community to be diagnosed with and survive breast cancer, they can be especially effective in educating other members of their communities. Famous breast cancer survivors, such as actors, athletes, and community leaders, also can raise awareness effectively. For example, breast cancer awareness in the United States was enhanced significantly when the diagnosis of First Lady Betty Ford was made public. Thus, as it increasingly becomes understood that women do survive breast cancer, and as women and their families become more willing to address the disease, knowledge that changes behavior increases cumulatively within a population.

Of course, awareness about breast cancer does little good if access to services for detection, diagnosis, and treatment are lacking. In some low resource settings, education and outreach activities will be futile, because services are marginal or are unavailable. For instance, women in a population cannot heed advice on the value of seeking a mammogram if the only facility that administers this procedure is not accessible to them either geographically or financially. If a region has very limited capacity, then it may not be able to deal with an influx of women seeking testing and treatment that conceivably could arise because of an effective awareness-raising or

educational activity. Where this is the case, the types of education and outreach activities considered by the HCS must align with community access and capacity.

The education of women and their families involves much more than educating the broader community about breast cancer. Education should continue at all points of care. Healthcare workers need to continue to educate patients and families regarding treatment options and about appropriate survivorship or palliative care issues. For this to take place, healthcare workers must be knowledgeable, and have and take the time to perform these educational activities. When limited resources result in excessive case loads or when the desire for maximal throughput results in suboptimal time spent with each patient, the HCS must address these issues to prevent suboptimal outcomes.

Human Resource Capacity Building

Operating a breast care program (BCP) at any resource level requires the effective training and retention of personnel. This is a key part of the responsibility of the HCS. Although the personnel numbers and the availability of highly specialized professionals will vary depending on the resource level, any individual who is charged with administering a BCP must make building human resource capacity a focus of their efforts. The most basic BCP requires having primary care physicians and nurses to provide patients with a continuity of care that effectively detects, diagnoses, and treats breast cancer. Thus, as resources increase, more specialized personnel are used, such as imaging technicians and nurses who specialize in oncology.

There are multiple reasons that the human resources needed to run a BCP typically are lacking in LMCs. First, there is a shortage of health workers generally; according to an estimate, more than 4 million healthcare workers need to enter the market place to meet current needs. Moreover, the global distribution of health workers is not uniform: Some high resource settings having more personnel than needed, and some low resource settings have none. Even in a single country, imbalances can create a workforce unable to meet population needs. For example, a facility in a country's main urban hub may have many specialists, whereas those in outlying areas are understaffed. Migration out of countries also reduces the availability of quality care in LMCs.¹⁸ Other challenges more specific to breast cancer care may include losing personnel within a local setting, such as when staff are recruited to work in better funded, disease-specific programs like those

for human immunodeficiency virus/acquired immunodeficiency syndrome or malaria. These programs often operate vertically, ie, separate from the larger HCS, and may be positioned better to lure staffers away from their current positions with better benefits. It goes without saying that all health needs are important, but it is the responsibility of the HCS to balance these needs with available resources so that it can deal optimally with the constellation of health needs within its jurisdiction.

Problems with recruitment can be reduced through private, public, or public-private initiatives. Research indicates that it often is not physicians but nurses and other healthcare workers that are in shortest supply, something managers need to remain aware of during recruiting and developing retention plans.¹⁹ Because the movement of personnel across labor markets is growing both within and outside of individuals' home countries, managers also have to constantly update and revise strategies, because attrition must be managed to sustain programs.²⁰⁻²² The development of training programs in LMCs can increase supply, because individuals who are trained in their home countries typically have a greater tendency to stay in the area because of family and personal connections. In addition, training programs can stipulate 'service pay-backs' in which trained personnel agree to serve as needed in facilities within a country or region for a specified period in exchange for subsidized tuition or student loan forgiveness.

Depending on the local situation, training community members to serve as lay health workers can free up more highly trained workers by taking on tasks that require less training. There is also evidence that task-shifting among healthcare personnel can be effective in optimizing healthcare delivery, eg, nurse practitioners can safely and effectively provide care that conventionally has been provided by physicians, which reduces costs and increases HCS capacity.²³⁻²⁵ Facility managers should consider training and re-allocating personnel to help alleviate service problems caused by inadequate human resources.

Despite difficulties in filling positions, the HCS needs to ensure that staff has the education and certifications that are required to perform their responsibilities. All healthcare workers should undergo careful screening and reference checks whenever possible. Monitoring and measuring the performance of existing staff also helps to insure the safety and effectiveness of service delivery while providing an opportunity for learning about the employees' strengths, weaknesses, and aspirations. The World Health Organization (WHO) recommends consider-

ing the following 4 dimensions when assessing overall human resource capacity²⁶:

1. Availability—distribution and attendance of existing workers.
2. Competence—the combination of technical knowledge, skills and behaviors.
3. Responsiveness—treatment of patient's and response time.
4. Productivity—producing the maximum health outcomes possible given the existing stock of health workers and reducing waste of staff time or skills.

A low-resourced HCS should not avoid providing any cancer care because of the lack of highly specialized health practitioners; because, even in low resource settings, a team of personnel can be assembled that will allow progress in treating breast cancer. For instance, breast tumors can be removed by general surgeons, and the functions performed preferably by specialized nurse oncologists can be completed by nurses who are trained more generally until others are trained and become available. Over time, the HCS can be improved as resources become available.

The HCS and facility managers in LMCs should use a variety of monetary and nonmonetary approaches to increase staff retention. One approach is to provide continuing education for employees to help keep them engaged and to demonstrate concern for their well being. In addition, facility managers should try to create opportunities for physicians to perform and publish scientific research, which helps them receive acknowledgment, remain connected to the broader scientific community, and increase understanding of cancer in their community. Other approaches, such as providing adequate wages comparable to others with similar training and experience and offering field and transportation allowances, also may improve retention rates. Given the high burnout experienced by many medical professionals around the world, supervisors need to remain cognizant of employee satisfaction and adjust workloads accordingly. Many of the root causes of problems in human resource recruitment and retention cannot be remedied at the facility level. For example, facility managers typically have little control over living conditions in a region, and workers are likely to seek out places to build careers that generally are peaceful and prosperous. Poor conditions lead some healthcare workers to seek posts in government or leave to practice elsewhere. Even at the government level, political unrest and poor living

conditions are not easily correctable and often require considerable investment in infrastructure, changes in political leadership, and many years to improve. Despite the need for broad-based change, a local facility can increase the likelihood that a healthcare worker will stay in the region by implementing the various strategies described, including ensuring decent working conditions and wages and developing a facility culture that recognizes and supports employees.

Patient Navigation

Patient navigators, a relatively new class of healthcare workers, help healthcare consumers (patients, survivors, families, and caregivers) access and navigate the complex HCS by providing reliable and understandable information on treatment options, preventative behaviors, and survivorship. This is especially important because many women who are diagnosed with breast cancer have a strong emotional response to the diagnosis, making it even more difficult to deal with decisions related to treatment.²⁷ It also has been demonstrated that navigators improve a breast cancer patients' adherence to treatment protocols by encouraging and monitoring appointment attendance.²⁸ Examples of other areas in which navigators may become involved include providing service referrals, coordinating transportation for treatment, arranging financial support, providing referral for follow-up services, and ensuring that patient records are available at appointments.

To be successful, navigators need to be knowledgeable about cultural norms and must be familiar with how the existing HCS operates. This includes developing an understanding of treatments and financing mechanisms available to the patient and of the specific shortcomings of the current HCS. Armed with this information, navigators can help to prevent problems commonly experienced by patients in the HCS. Effective communication, compassion, and sensitivity are essential characteristics to look for when recruiting navigators.

More rigorous studies are needed to assess the effects and effectiveness of patient navigation, especially in LMCs. However, existing research does indicate that navigation improves rates of screening and follow-up, improves patient satisfaction, and decreases the number of patients with end-stage disease at presentation²⁹⁻³⁴ By coordinating patient care and providing a sounding board for patients' hopes and fears, it has been demonstrated that navigators improve quality of life and reduce stress, which allows a patient to shift focus from dealing with administrative issues to fighting the disease.³⁵ Other

evaluations also have demonstrated that navigation increases trust between providers and disadvantaged populations.^{30-32,34} Patient navigators also can save the time of other workers who otherwise may be tasked with activities that could be done by the navigator. Navigation is a relatively inexpensive way to improve a breast cancer patient's general experience and health outcomes.

In some settings, nurses or social workers often fill roles as navigators; however, any other individual with knowledge of the health system and treatment options can be trained to fill this role.³⁶ In areas with only basic level resources, it is less likely that nurses and social workers will have the time to take on the role of a navigator, and other personnel can and should be used in these areas; this strategy was proven effective in an American urban center with a large population of underserved cancer patients.³⁷ A hospital can limit the budgetary impact of starting a patient navigator program by hiring a small number of navigators.

Implementing patient navigator programs at all resource levels will help to eliminate barriers to screening, diagnosis, and treatment. Although patient navigation originally was conceived to help the underserved, it also can help individuals in higher resource settings cut through the complex array of treatment options. In addition, taking navigators' observations collectively will expose HCS problems, allowing medical administrators to identify and correct problems in the delivery of care. Like all workers in the HCS, patient navigators require training to perform optimally; once they are established, navigators can train new navigators. Often, former patients who themselves have experienced HCS challenges are motivated to help others by serving as navigators.

Support Systems Resource Allocation (Figure 2)

In addition to human resource allocation, BCP managers must work with a given HCS to determine which services to provide, records to keep, and facilities to invest in developing. The second HCS guideline table shown in Figure 2 addresses these issues.

Services

Getting even the most basic BCP up and running requires developing a service plan. Facility managers, especially those in LMCs, need to determine strategically the types of services that can be provided at their resource level; the Breast Program Resource Allocation guidelines are designed to make these decisions easier. Although there are many services required at even the basic level, including nursing,

**Breast Care Programs:
Support Systems Resource Allocation**

Level of resources	Services	Record Keeping	Cancer Care Facility	Breast Care Center
Basic	Diagnostic/Pathology services Nursing services Oncology services Palliative services Psychosocial services Primary care services Surgical services	Individual medical records and service-based patient registration	Health facility Operating facility Outpatient care facility Pharmacy Home hospice support External consultation pathology laboratory	Breast healthcare access integrated into existing healthcare infrastructure
Limited	Imaging services Peer support services Radiation oncology services	Facility-based medical records and centralized patient registration Hospital level cancer registry	Clinical information systems Health system network Imaging facility Internal pathology laboratory Radiation therapy	"Breast Center" with clinician, staff and breast imaging access Breast prostheses for mastectomy pts
Enhanced	Cancer follow-up Group support Screening programs Rehabilitation services Survivorship services	Resource Room(s) for education/outreach Facility based follow-up Regional cancer registry	Centralized referral cancer center(s) Radiation therapy: low energy linear accelerator, electrons, brachytherapy, treatment planning system	Multidisciplinary breast programs Oncology nurse specialists Physician assistants
Maximal	Universal access to screening Individual psychosocial care	Representative national cancer registry	Satellite (non-centralized or regional) cancer centers	

FIGURE 2. Breast care programs: support systems resource allocation table. Note that the table stratification scheme implies incrementally increasing resource allocation at the basic, limited, and enhanced levels. Maximal level resources should not be targeted for implementation in LMCs, even though they may be used in same higher income settings.

oncology, pathology and surgical capabilities, individuals who are charged with setting up and administering BCPs can look for ways to maximize service provision, such as cross-training staff to perform multiple functions. Another approach is to start with smaller pilot programs that subsequently can grow. Because knowledge about cancer control, especially in developing countries, is incomplete, focus could be placed on a limited geographic area or on a high-risk population, and then services could be scaled up after the pilot programs conclude.³⁸ The knowledge gained from operating at a smaller scale can be used to help inform planning of larger, multifaceted facilities.

Because of limited availability, rationing of healthcare services within the HCS may be required in many LMC facilities. For instance, a facility may have limited doses of chemotherapy available or may have the capacity to provide radiotherapy to only 10 patients per day. In situations like these, physicians and others involved in HCS planning should develop

general facility-specific guidelines for resource use based on stage of disease. For example, it they could decide to reserve chemotherapy only for women with lower stage disease or to closely monitor the distribution of opiates to ensure they are available for palliation. Although these decisions also will be informed by case-specific circumstances, devising general recommendations will allow facilities to maximize limited resources.

Record Keeping

Accurate record keeping should document care received and help medical personnel protect patients by helping to prevent problems, such as administering inappropriate drugs or duplicating tests. Although patient care and safety are the primary reasons for keeping accurate records, the cumulative value of information gathered in records can help expand understanding of the extent and distribution of breast cancer in a population and allow the HCS

to adapt to the realities of its jurisdiction. The lack of good information on breast cancer tumor types, stage at diagnosis, and breast cancer rates in many LMCs makes it difficult to determine the extent of the public health burden that breast cancer presents. Patient records can be used to uncover trends and develop ideas for future research. Analysis of facility level records also provides the opportunity for managers to gain a better understanding of case mix, treatment patterns, and use of services. Data can be used to support and facilitate research efforts.

The collected data must allow patients to be identified as appropriate candidates for diagnosis and treatment and must document the treatment results.³⁹ The record-keeping capabilities of facilities that provide breast cancer care will vary by resource level. However, the WHO recommends collecting the following information whenever possible⁴⁰:

- Demographic and socioeconomic data (such as the name of the patient [identification], sex, date of birth, place of birth, patient's permanent address, and medical record number) and legal data (including a signed consent for treatment by appointed physicians and authorization for the release of information).
- Financial data relating to the payment of fees for medical services and hospital accommodation.
- Clinical patient data.

Specifically for breast cancer, information on primary tumor site, tumor diagnosis, tumor morphology, stage at diagnosis, and first course of treatment should be collected. Regions and centers can tailor breast cancer programs after well established, population-based registries, such as the US Surveillance, Epidemiology, and End Results Program or the Comprehensive Cancer Monitoring in Europe project in the European Union. The International Association of Cancer Registries also serves as a resource for issues related to population-based cancer registries. The establishment of a population-based cancer registry takes time and requires human and other resources. It is not a 'project' with a beginning, middle, and end but, rather, an ongoing element of disease surveillance.

Establishing a record-keeping program requires determining where records should be stored, who should be responsible for the overall program, and what ethical and legal factors need to be considered. Using the WHO report criteria provides information on each of these questions and may be helpful to many facilities in LMCs looking to establish their own record-keeping system. At the basic level, it is

important that record keeping does not take limited resources away from service delivery; therefore, only individual records at the point of service are recommended. At higher resource levels, as sophistication increases, it can lead to the creation of hospital-based, regional or national cancer registries. It is not necessarily the intention of a national registry to capture every cancer case in the nation but, rather, to make an attempt to register cases such that the records reflect the cancer incidence rates of the nation. For smaller countries, this may require that the registry cover the entire nation; but, for larger countries, a series of registries can provide information sufficient to get a picture of the cancer incidence rates. The process of establishing and administering a population-based cancer registry likely will require the participation of various government officials and requires a significant level of coordination among numerous data sources. Although individual breast care facilities cannot establish such registries in isolation, they can advocate for their creation.

Record keeping is important even in areas that are not covered by a population-based cancer registry. Hospital-based registry of cancer patients in general and breast cancer patients in particular can allow the assessment of caseload and case type that is critical in planning for allocation of resources and infrastructure needs within a single facility or more broadly within the HCS. Regardless of the type of data collected, consistency in the type of information tracked is required to evaluate trends. Teaching physicians the basics of proper record keeping should be standard practice for any facility that delivers breast cancer care. Communicating the critical importance and scientific value of records should increase physician compliance with record-keeping protocols.

Cancer Care Facilities

The sophistication and quantity of cancer care facilities in a country or region will depend greatly on existing infrastructure and resources. In some settings, there exists a range of facilities from local smaller facilities to tertiary treatment hospitals and even specialized cancer centers. Elsewhere, little by way of specialized cancer care exists. Facility planners within any HCS need to consider geographic location when deciding where a facility or group of facilities should be located. The location chosen should take the population features into account, aiming to serve the largest number of patients. Planners should evaluate the modes of transportation available to reach the facility and should plan new facilities close to major roads and public transporta-

tion. At the basic level, a breast cancer care facility will have health, operation, outpatient, pharmacy, home hospice, and external pathology capabilities. Some regions and countries at first may focus on providing cancer care services in already existing hospitals and clinics, because the provision of care in a separate facility is prohibitively expensive.

One of the challenges to HCS is to strike a balance between access and quality. Although having breast cancer services near every woman's place of residence would eliminate the hardships of getting to and from facilities that may be contributing to the under-use of services, later stage breast cancer at the time of presentation, or poor follow-up and compliance in both screening and care, resulting in poorer outcomes. However, it is impractical in many countries or regions in which significant portions of the population live in rural, remote areas; not every village can have the expertise or facilities for surgery, chemotherapy, and radiotherapy. In addition, for certain procedures, there also may be a volume-outcome correlation, in that better outcomes are achieved in higher volume facilities, which almost by definition have to be centralized (usually in large cities). Providing access to these facilities and developing a process of triage, so that services that can be delivered locally are available, and those that require referrals to more sophisticated, centralized facilities are provided. Determination of which services to provide locally and which to provide more centrally must be addressed, and the process of referrals must be examined. Patient navigation, as discussed above, is particularly valuable in working through the process of triage and referral to ensure that women are not lost from the HCS in moving from localized to centralized services.

In many LMCs, there are few places that a woman can go to for detection, diagnosis, and treatment of breast cancer. Establishing new cancer programs in remote areas will reduce the burden of cancer; however, facilities in remote areas may not have enough beds or medicines to treat all women in need, or a BCP may need to refer certain patients to a different facility for more specialized treatment. A physician in Sri Lanka experienced this limitation firsthand, noting that, in a cancer unit with only 70 beds, greater than 100 outpatients visited the clinic every day, and there was a desperate demand for both the support of both treatment and patient services.⁴¹ In these situations, facility managers need to develop guidelines determining which patients will be treated at the facility and which will be referred for treatment elsewhere in a coordinated fashion. Referring a patient to another place for treatment may

be unsuccessful, especially if the other facility is difficult or impossible for the patient to reach and/or if treatment is unaffordable.

Deciding which patients to treat and which to refer also can be based on volume-outcome measures. For certain procedures, especially procedures that are performed infrequently and highly risky procedures, the volume-outcome correlation appears to be particularly strong. However, for common, cancer-related surgical procedures, the results from an Institute of Medicine comprehensive review indicated that some studies showed no correlation, whereas others showed significant, but small effects.⁴² With this in mind, facilities with fewer resources may decide to perform surgical tumor removal whenever possible but will not administer chemotherapy. However, smaller facilities in remote areas need to work with larger facilities to ensure that the number of referrals is reasonable, because sending too many patients can flood that system with more patients than it is capable of serving.

Regardless of the sophistication of a facility, adherence to cancer care guidelines and safety requirements must be a priority. By keeping in mind the limitations of their facility, healthcare personnel and administrators can focus on ensuring that the care they are able to provide is of the best possible quality and will not harm the patient. In many cases, a cancer care facility will need many years if not decades to reach the highest level of sophistication; however, planners should not be discouraged, because the services provided in the interim can lengthen life considerably and can reduce the pain and suffering of countless women who otherwise would go unserved.

Breast cancer services are often delivered in existing cancer care facilities but also may be administered in freestanding programs devoted solely to breast cancer care. Breast screening facilities often are freestanding and highly specialized with referrals rather than providing a full range of breast health services. In some cases, even mobile clinics in the form of mammography vans are used. Freestanding programs should integrate services into the existing healthcare system, which will require sharing information across healthcare delivery organizations, increasing knowledge and awareness of breast cancer, and improving consistency of patient care. Each facility that delivers breast cancer care should reflect local strengths, interests, needs, and resources.

Insurance systems: Obstacles to timely care

The BHGI guidelines outline the support system and human resources that are required to run a BCP. However, implementation of all of these guidelines

does not guarantee that a facility will be able to detect and treat breast cancer successfully; success also depends heavily on the affordability of care both in LMCs and among disadvantaged populations in higher resource countries. An inability to pay for services, or the fear that seeking services will lead to economic devastation has an impact on a woman's decision to seek care, her ability to obtain care, the quality of care she receives, and the financial impact receiving care has on her and her family.

Lack of resources to pay for care prevents individuals from seeking treatment in both high- and low-income countries. For example, a recent study in Cameroon, Africa demonstrated that a common reason for presenting with very advanced cancer was the inability to pay; other research has indicated that individuals who are ill are more likely to seek care if they are wealthy and that insured patients, especially at lower income levels, are more inclined to seek care.⁴³⁻⁴⁵ In the United States, several studies have established a link between the inability to pay, usually because of the lack of insurance, an increase in the severity of disease at diagnosis, and a decrease in use and quality of care received.⁴⁶⁻⁵⁰

An inability to pay can lead to catastrophic health expenses, causing severe changes in daily living or pushing a family into poverty.⁵¹ A survey of data from 59 countries demonstrated that catastrophic health payments are common in middle-income countries, countries in transition and several low-income countries. Predictors of catastrophic payments are high rates of poverty, groups excluded from financial risk protection mechanisms (such as social insurance), and moderate to high levels of healthcare access and use.⁵² Coping with the costs of illness is especially difficult for individuals who barely have enough to meet minimum food needs.⁵³ To afford medical costs, households employ a variety of coping techniques, including using savings, borrowing from others, selling food stores and livestock, and reducing consumption on nonessential and then essential items.⁵⁴ Because reducing poverty is a slow process, approaches to insulating women who receive care from these catastrophic payments need to be employed.

There are various financing approaches that can be used protect women from the high out-of-pocket payments (also known as user fees) often associated with breast cancer care. In HCS in which individuals have to pay a large portion of the costs out of their own pockets, the poorest members of a society are unlikely to receive care.⁵⁵⁻⁵⁸ Therefore, the most effective financing mechanisms will reduce user fees to a point that even the country's poorest members

can afford to use health services. In many high-income countries, universal coverage greatly reduces or eliminates user fees primarily by providing publicly financed health insurance. This type of financing model can be employed in some countries but will be difficult to implement in all LMCs because of the limited availability of public revenues, the inability to collect revenues because the country has a small formal employment sector, and institutions that are incapable of administering a program.⁵⁹

LMCs instead may find success in reducing user fees through government financing, private donors, or nongovernmental organizations, whereby women pay nothing for breast cancer care. Although this type of financing system may be unsustainable and is applied more easily at a smaller scale, it can be a first step toward preventing catastrophic costs. Strategies for cooperation and allocation of public resources are an important function of ministries of health, especially in LMCs. Governments and facility managers also may want to consider introducing community-based health insurance (CBHI) as an initial step toward reducing user fees. In this model, individual and household resources are pooled to cover unpredictable health costs, thereby reducing out-of-pocket payments. It has been demonstrated that CBHIs substantially improve access to care, although it also was reported that CBHIs are ineffectual in helping the poorest members of a community.^{60,61} Despite these mixed reviews, CBHI is a strategy that should be considered, especially in LMCs where tax revenues are limited. In addition, CBHI can serve as a transitional mechanism if there is little public funding and can become a supplementary form of financing when public funding increases.⁶² Planners must carefully consider the unique characteristics of their jurisdiction when developing any type of financing and insurance system. Successfully implementing and sustaining any financing and/or insurance model requires a strong understanding of the interplay of the political, social, and cultural characteristics that shape the region.

Pharmaceutical Delivery

In many LMCs, patients do not have access to the standard drugs used to treat breast cancer in higher income settings. Not only is access to more sophisticated drugs like trastuzumab unavailable for most patients, but common palliative drugs often remain out of reach. Remedying drug distribution problems and reducing the cost of prohibitively expensive drugs are difficult to achieve at the facility level and

often need to be addressed by the government, which can work to improve drug donation programs, obtain better prices from pharmaceutical companies, and obtain permissions to manufacture generic drugs. In addition, the corruption that sometimes accompanies deals between ministries of health and pharmaceutical companies needs to be addressed and prevented.

More specifically, government and health officials need to focus on addressing problems particular to opiate availability and distribution. Preliminary estimates indicate that 4.8 million individuals per year do not receive treatment for moderate to severe pain caused by cancer.⁶³ Another measure of the availability of palliative treatment is the consumption of morphine; developing countries consume only approximately 6% of the world's morphine, despite housing >80% of the world's population.^{64,65} Increasing the availability of opioids requires reducing attitudinal, access, and legal barriers. For example, health officials need to be educated on the value of opioids and dispel myths that addiction is unpreventable. Altering basic understanding of pain medicines will encourage facilities and governments to make them more available by increasing orders and empowering clinicians to prescribe these medicines. In addition, regulations that limit dosage amounts or make dispensing opioids illegal need to be reviewed to ensure they are not overly prohibitive. Finally, delivery of these important medications will not improve in developing countries without dramatic reductions in price, which currently greatly limits access.⁶⁶

There is also broader concern that research and development of cancer drugs are driven mainly by commercial considerations rather than public health priorities, leading to the creation of drugs that are unlikely to reach populations in less developed countries. The future development of targeted, genetically based drugs is likely to exclude large portions of populations in LMCs. For example, recent studies indicate that some African populations are more likely to develop breast cancer, possibly because of different genetic make-up.⁶⁸ It is less likely that a drug company would invest in creating a drug targeted to this group if the return on investment, because of the inability of patients to pay, is considered relatively low.

Economic Modeling and Metrics: Tools for Decision Making

Modeling and metrics are useful tools that health ministers and facility managers can use to track progress and to inform future decisions. Economic modeling that employs cost-benefit analysis may reveal the most cost-effective improvements in the HCS.

Without metrics, it is difficult to determine the success of a BCP. The BHGI suggested metrics that are very basic and are intended only to provide a general orientation to metrics and models. Specific measurements will need to be designed at the local level, where an intricate understanding of the available resources and program goals can inform their creation and use. Generally, the sophistication of metrics will increase with the level of resources; however, it is possible that certain metrics can be used at many levels of resources with outcome expectations changing as resources levels increase. In many LMCs, the collection of even rudimentary measurements will be difficult. Despite these difficulties, LMCs should engage actively in creating and employing, at a minimum, some basic metrics that can be integrated easily into existing practices. In addition, improving the quality and quantity of metrics will benefit from efforts like the Health Metrics Network, which is a partnership of the WHO that is focused on strengthening general health information systems.

Measuring overall HCS performance is difficult given the many inputs and outputs. Instead, it is easier to create a general picture of how a health system is functioning by looking at a combination of other discrete factors; for example, detection/screening, diagnosis, treatment, and human resources. For more details please, see Figure 3 (Core Process and Outcome Metrics for LMC Breast Health Care Programs).

Detection/screening factors include:

- The percentage of the total target population that has been screened in the past year.
- The percentage of patients who present with tumors at stage 3 or 4 (can also use tumor size instead of stage).

Diagnosis factors include:

- The percentage of patients diagnosed using tissue/pathology report.
- The percentage of patients that receive a multidisciplinary assessment of their case and receive a case plan.

Treatment factors include:

- The amount of time elapsed from diagnosis date to beginning treatment.
- The percentage of patients that receive treatment (including palliative care) compared with the number diagnosed.
- The percentage of patients that receive treatment compared with the estimated number of individuals estimated to have breast cancer in the facility treatment area.

Process Metrics for LMC Breast Healthcare Programs

Level of resources	Early Detection	Diagnosis	Treatment	Programmatic
Basic	# Pts with documented H&P / # Pts evaluated <i>Description: The ratio of the number of patients who have a recorded history and physical examination within the target group to the number of patients who were clinically evaluated within the target group for a center or program providing organized breast healthcare.</i>	# Pts with tissue dx / # Pts with suspic. mass <i>Description: The ratio of the number of patients who receive a tissue diagnosis (benign or malignant) to the number of patients who had a "suspicious mass" (finding on CBE that the clinical examiner considers abnormal and therefore warranting further evaluation).</i>	# Pts treated for ca / # Pts with tissue dx ca <i>Description: The ratio of the number of patients who receive cancer treatment of some fashion (surgery beyond surgical biopsy, radiation tx and/or systemic tx) to the number of patients who had a tissue diagnosis of cancer.</i>	Median pathologic tumor size <i>Description: The median pathologically determined size of invasive breast primary tumors within the target group for a center or program providing organized breast healthcare.</i>
Limited	% Pts with CBE-detected abnormalities who undergo breast imaging for work-up	% Pts with biopsy-proven cancer diagnosis who have documented TNM stage	% Pts with ca diagnosis who start treatment within 120d of tissue diagnosis	% cancer Pts who have TNM stage I or II disease at initial biopsy-proven diagnosis
Enhanced	% Pts age 50-69 who had screening mammogram within past 24 months	% Pts with biopsy-proven cancer diagnosis who have documented HER-2/neu status	% Pts treated by lumpectomy starting XRT within 120d of last surgical procedure	% cancer Pts who have TNM stage I or II disease who at 5 yrs have no evidence of disease recurrence
Maximal	Maximal category process metrics determined based upon standards of care in high-income countries	Maximal category process metrics determined based upon standards of care in high-income countries	Maximal category process metrics determined based upon standards of care in high-income countries	Maximal category process metrics determined based upon standards of care in high-income countries

FIGURE 3. Table of process metrics for breast healthcare programs in low-and middle-income countries. Pts indicates patients; H&P, history and physical; dx, diagnosis; suspic., suspicious; CBE, clinical breast examination; ca, cancer; tx, treatment; TNM, tumor classification system; HER-2/neu, human epidermal growth factor receptor 2; d, day; XRT, external beam radiotherapy. Note that the table stratification scheme implies incrementally increasing resource allocation at the basic, limited, and enhanced levels. Maximal level resources should not be targeted for implementation in LMCs, even though they may be used in same higher income settings.

- The percentage of patients that complete a standard protocol of treatment.

Human resources factors include:

- The percentage of healthcare personnel with training and/or experience in breast cancer care.
- Percentage of physicians employed with ≥ 5 years of experience.
- The ratio of medical personnel (such as pathologist, breast surgeon, nurse) to either the number of patients served or the total population.

Conclusion and Perspectives

The BHGI HCS guidelines in their entirety are intended to help facility planners and health ministers make decisions regarding the provision and planning of breast cancer services. There are signifi-

cant opportunities for those working in higher income settings to lend support and assistance to their colleagues in LMCs by either formalized institutional relationships (eg, twinning) or, less formally, as caring individuals. Sadly, most individuals who are equipped to provide such support/assistance have full-time duties at their home institutions, they often already are struggling to handle the volume of these duties, and they find themselves immersed in an HCS 'reward system' that is not geared toward providing professional advancement for these types of efforts.

There is ample evidence that HCS weaknesses, even when they occur in otherwise rich countries, contribute to poorer health outcomes. For example, lack of access to care increases the number of individuals who delay or forgo treatment, leading to poorer healthcare outcomes, and previously uninsured indi-

viduals who obtain insurance have better health outcomes.^{49,67-71} Research indicates that, compared with privately insured patients, Americans without insurance present with more advanced disease and have lower rates of survival.^{72,73}

The weaknesses in HCS that impede optimal breast health obviously are broader than the scope of the BHGI. Such issues as shortage or maldistribution of healthcare workers and inadequate availability of pharmaceuticals and other supplies clearly are not confined to the delivery of services related to breast health, and it is unlikely that these issues can be addressed effectively as they relate to breast health in isolation. Similarly, the issues related to access to services and ability (or inability) to pay transcend the issues of BHGI, because they are truly systemic. It is most unlikely that risk pooling strategies to assist those unable to pay will occur absent a broader approach as it relates to healthcare overall. The importance of this concept is illustrated by the observation that capacity building in a disease-specific manner actually can lead to the deterioration of other healthcare activities by creating competition for scarce human resources and management capacity. The goal of any activity aimed at strengthening the HCS involved in breast cancer detection, diagnosis, and treatment should occur with horizontal integration in view. For a broader perspective on the strengthening of HCS more generally and for further discussions on the points raised here, the reader is advised to consider the content of *Disease Control Priorities in Developing Countries* and, in particular, the chapter by Mills et al.⁷³

The discussions that took place at the BHGI Summit of 2007 in Budapest have shaped the content of this report. One of the most striking aspects of these discussions is the repeated reference to the paucity of locally generated evidence upon which to base improvements in HCS for breast health. Of course, health services research conducted locally is an ideal to be sought; however, given the shortage of such research, HCS planners should analyze and use research done elsewhere while attempting to adapt those findings to their local situation. The expectation of a '1 size fits all' solution to relieving HCS weaknesses clearly is unrealistic, but the ideas generated in research around the world can inform and guide progress in many countries. HCS planners should not be paralyzed by the lack of locally conducted HCS research, or the absence of functional local cancer registry, or even the absence of a national comprehensive cancer plan. The building of new breast health facilities or improving the quality of existing facilities should move forward based on

applying what is known from other settings. Likewise, attempts to improve physical and financial access in an equitable way to the range of services that currently are available should be a priority.

Facility managers can use the guidelines to help set priorities and should work to make incremental improvements in service provision. Planners in LMCs likely will face many of the problems outlined throughout this article. Despite these hardships, the establishment of BCPs is a worthwhile undertaking, because even the most rudimentary facilities can extend life and reduce pain and suffering while increasing understanding of the disease.

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