Breast Cancer in Limited-Resource Countries: Health Care Systems and Public Policy

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■ **Abstract:** As the largest cancer killer of women around the globe, breast cancer adversely impacts countries at all levels of economic development. Despite major advances in the early detection, diagnosis, and treatment of breast cancer, health care ministries face multitiered challenges to create and support health care programs that can improve breast cancer outcomes. In addition to the financial and organizational problems inherent in any health care system, breast health programs are hindered by a lack of recognition of cancer as a public health priority, trained health care personnel shortages and migration, public and health care provider educational deficits, and social barriers that impede patient entry into early detection and cancer treatment programs. No perfect health care system exists, even in the wealthiest countries. Based on inevitable economic and practical constraints, all health care systems are compelled to make trade-offs among four factors: access to care, scope of service, quality of care, and cost containment. Given these trade-offs, guidelines can define stratified approaches by which economically realistic incremental improvements can be sequentially implemented within the context of resource constraints to improve breast health care. Disease-specific "vertical" programs warrant "horizontal" integration with existing health care systems in limited-resource countries. The Breast Health Global Initiative (BHGI) Health Care Systems and Public Policy Panel defined a stratified framework outlining recommended breast health care interventions for each of four incremental levels of resources (basic, limited, enhanced, and maximal). Reallocation of existing resources and integration of a breast health care program with existing programs and infrastructure can potentially improve outcomes in a cost-sensitive manner. This adaptable framework can be used as a tool by policymakers for program planning and research design to make best use of available resources to improve breast health care in a given limited-resource setting. ■

Key Words: breast cancer, cancer control, delivery of health care, evidence-based guidelines, health care rationing, health care reform, health planning, health policy, limited-resource countries, resource allocation

In high-resource countries with well-established health care systems, substantial improvements in reducing breast cancer mortality have been made in recent decades (1,2). Compared with low- and medium-level resource countries whose health care systems typically lack core infrastructure elements (3), countries with well-funded health care systems have higher rates of breast cancer incidence, but also have better overall rates of breast cancer survival (4). Early breast cancer detection and comprehensive cancer treatment appear to play synergistic roles in creating improved outcomes in these countries (5). In contrast, breast cancer case fatality rates are highest in economically disadvantaged countries, where survival is worsened due to the advanced stage of disease at initial presentation combined with inadequate resources to provide standard cancer therapy (6,7). Even in the best of circumstances, it is difficult and costly to treat women with late-stage breast cancer, which is more likely to have a poor outcome regardless of the extent of therapy.

Health care ministries from countries with limited resources face organizational, financial, and cultural

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barriers that hinder their ability to create and support breast health care programs. Breast care guidelines from economically privileged regions have limited applicability in limited-resource settings, highlighting a need for modified guidelines that take into account the ubiquitous deficits in infrastructure and resources, substantial implementation costs, and competing health care demands. In October 2002, the Global Summit Consensus Conference was held in Seattle, Washington, to develop recommendations for breast health care in countries with limited resources. Panel member statements noted that within any given health care system, early detection, diagnosis, and treatment are inextricably linked issues (8). Early detection of breast cancer is not helpful if cancer treatment is unavailable. Cancer treatment of curable disease cannot and should not be initiated until a definitive pathologic diagnosis is made (9). Treatment is more expensive and less successful when disease is more advanced at the time of diagnosis (10). Thus systemwide deficits can make breast cancer seem difficult or impossible to treat, despite the proven successes in developed countries with standard therapy protocols combining surgery, radiation therapy, and systemic therapy to reduce cancer recurrence rates by more than half (11).

Early breast cancer detection is a core area of focus, because early cancers have a better prognosis with treatments that are more affordable and less resource intensive to provide. At the 2002 Global Summit, a sequential action plan was proposed, linking early detection to improved outcome: 1) promote the empowerment of women to obtain health care, 2) develop infrastructure for the diagnosis and treatment of breast cancer, 3) begin early detection efforts through breast cancer education and awareness, and 4) when resources permit, expand early detection efforts to include mammographic screening (12). Although this protocol is appealingly logical, its application hinges on the organizational capacity, resource allocation, and institutional "buy-in" of the health care system in which it is applied. For this reason, it was determined that during the second round of guideline development held in 2005, a specific focus on health care systems was needed to better characterize those obstacles so that pathways to improvement can be devised. This report summarizes the work of the Health Care Systems and Public Policy Panel.

METHODS

An international group of breast cancer experts and advocates met at a summit in Bethesda, Maryland, January 12–15, 2005, to formulate consensus recommendations for health care systems and public policy as they apply to breast care in countries with limited resources. In the morning, summit participants gave presentations on related topics and current systems and policies, as well as barriers in parts of the world where resources are markedly constrained. In the afternoon, the Health Care Systems and Public Policy Panel, a subgroup of conference participants, reviewed the current evidence, debated systems and policy strategies under the constraints of limited resources, and drafted preliminary recommendations. The panel, representing nine countries with resource levels spanning the spectrum, followed a process similar to that followed in the first Breast Health Global Initiative (BHGI) summit (8), based on methods initiated by the World Health Organization (WHO) (3) to address cancer care in countries with limited resources (i.e., those with low- or medium-level resources).

One of the panel's aims was to make specific recommendations about resource stratification for health care systems and public policy. The stratification scheme specifies four levels: basic, limited, enhanced, and maximal. These levels refer to the services and facilities to be used in a health unit (e.g., a community, a city, or a region) and not necessarily to a country overall; the different levels were conceptualized as coexisting within a country.

The methods used are described in greater detail in the accompanying overview (13). The final work product of the Health Care Systems and Public Policy Panel is the substance of this report.

FINDINGS

Challenges to Cancer Care

Countries with limited resources face numerous challenges in designing and implementing programs to improve cancer care. Although financial constraints are one obvious barrier to improving breast cancer outcomes, health care ministries face a variety of other barriers, including a lack of scientific and epidemiologic information to guide resource planning, a shortage of trained professionals to provide necessary clinical care, competing health care crises, political insecurity, wars, or combinations thereof that divert attention from long-term health care issues, and social and cultural factors that obstruct the timely and effective delivery of care (3). In particular, efforts aimed at early cancer detection are impeded by public misconceptions about breast cancer that make women reluctant or unwilling to seek care when they notice early symptoms (14).

Organizational Obstacles to Health Care Delivery Health care systems in countries with limited resources are generally overburdened, inadequately funded, and structurally challenged to meet their intended goals. Although 75% of the world's population lives in low- and middle-income countries, only 6% of the gross national expenditure is spent on health care in such countries (15). Resource-constrained countries suffer from a lack of trained medical personnel, inadequate facilities, insufficient funding for equipment and supplies, and inequity of access to care between rural and urban populations (16,17).

Typically health care allocations are driven by crisis management rather than long- or even midrange strategic planning. Inefficient health care management and disorganized governmental structures contribute to the financial burdens faced in health care (18). In addition, the apportionment of resources is often based on bureaucratic procedures or political goals rather than on coherent public health policy (19). Systematic disorganization in the public health care system makes it difficult or impossible for women to receive appropriate care in a timely fashion, and major components of heath care infrastructure and resources necessary to implement improved breast cancer care are often lacking (20). These multiple barriers combine synergistically to prevent effective cancer diagnosis and treatment in general and in breast cancer care specifically.

Lack of Recognition of Cancer as a Major Public Health Issue Cancer is often not a stated priority for health care expenditures in countries with limited resources. Because infectious diseases typically dominate the health care agendas of such countries, cancer control efforts generally fall behind other priorities of the national health authorities. Although the majority of cancers are curable if detected and treated in the early stages, about 80% of all patients with cancer in the developing world have advanced-stage disease at initial presentation (16).

Limited-resource countries typically lack population-based data on cancer incidence and mortality, aggravating the degree to which cancer is underappreciated as a significant health care challenge (21). Health care ministries have limited evidence-based guidance on how cancer in their countries can best be addressed. Findings from studies performed in populations from wealthy countries may not have much relevance or applicability in limited-resource settings because of differences in social and cultural factors, lifestyles, and available technology (22), among other factors.

Although cancer may have a low priority on the formal health care agenda, resources are inevitably spent on cancer when patients require care for advanced-stage disease. Such unplanned use of resources may not only be associated with poorer outcomes, but may also be more costly than planned, systematic use (23). As infectious diseases become better controlled and the population ages in low-resource countries, cancer becomes an increasing public health problem (2,24). Because cancer is an inevitable social and health care burden, and because its incidence is increasing, the World Health Organization (WHO) recently passed an important and sweeping cancer prevention and control resolution that creates a mandate for member countries and the WHO director-general to address cancer care, including prevention, early detection, diagnosis, treatment, and palliation of symptoms of cancer, around the globe (25). This call for countries to address cancer control is a novel opportunity for ministers to act to address cancer in general, and breast cancer specifically, as a core national health care issue.

Health Care Personnel Shortages Recruitment, training, and retention of health care professionals constitute a very difficult problem in limited-resource countries. Physicians, nurses, and allied health care personnel are few in number and often are most lacking in regions of greatest health care need (26). Funds are insufficient to fully equip hospitals and provide competitive salaries for appropriately trained health personnel. Limited-resource countries are often unable to provide their professionals with an opportunity for career development and adequate remuneration. They lack the infrastructure required for professionals to carry out their work, leading to frustration and disenchantment with the system. Collectively these factors make it difficult to attract new professionals and to retain those who have already been trained.

While manpower shortages span all disciplines in medicine, they are particularly well exemplified in international nursing. WHO reported that in 2004, the nurse:population ratio ranged across countries from fewer than 10 nurses per 100,000 population (Uganda, Liberia) to more than 1000 nurses per 100,000 population (Norway, Finland), a variation of more than 200-fold (27). The average nurse:population ratio in Europe, the region with the highest ratio, is 10 times that of the regions with the lowest ratios—Africa and Southeast Asia—and the nurse:population ratio in North America is 10 times that in South America. Similarly the average nurse:population ratio in high-income countries is almost eight times that of low-income countries (26). The chasm in health care staffing between the "haves" and "have nots" is vast.

Loss of Health Care Professionals by Migration In addition to inherent manpower shortages, there is the problem of health care professionals migrating from rural to urban areas, transitioning from public to private health sectors, and immigrating from poorer to richer countries (28). The loss of trained health care professionals to other countries is often called a "brain drain," as professionals are actively pulled away by wealthy countries offering better opportunities. This loss can also be termed "brain flight," in that professionals are sometimes fleeing from a system that cannot offer them a viable career commensurate with their training and potential for professional growth. Thus both low- and high-resource countries play a role in this migration phenomenon (29).

The outward migration of nurses severely affects some low-resource countries (30). Nursing recruits who cross national borders are often relatively young, well skilled, and expensive to train. Factors pulling nurses to destination countries include better pay, career, and educational opportunities. Factors pushing nurses to leave source countries include low pay, poor career prospects, and in some countries, political instability and violence. Inadequate collection of workforce data makes it difficult to quantify nurse migration to other countries in comparison to unemployment or underemployment of nurses within a country (29).

The practice of active recruitment of health care workers by countries with higher levels of resources has generated controversy in recent years because of its potential to exacerbate migration out of some limited-resource countries (31). In the case of nursing, a driving force for increased international recruitment has been the nursing shortages in developed countries. Shared language, common educational curriculum, and postcolonial ties between countries tend to be the factors determining which low-resource countries are being targeted as sources of nurses (26,29).

Social and Cultural Barriers to Cancer Care A variety of noneconomic barriers impede the early detection and effective management of cancer in limited-resource settings. These include a host of cultural and ethnic beliefs and taboos, which can vary between different countries, religions, and cultures (32). Failure to recognize these internal obstacles can doom the success of any cancer care program, even when adequate resources are provided (14). If patients lack trust in their health care system, believe that cancer cannot be cured, or face discrimination or loss within their community by virtue of having a cancer diagnosis, they will predictably fail to use cancer services, no matter how accessible and affordable they may be. Patients will commonly turn to alternative health care strategies and traditional healers, believing them to have equal or superior ability to address difficult health problems (33). It should be noted that these issues are not limited to low-resource countries. For example, in developed countries, minority ethnic, inner-city women are significantly less likely to participate in free screening mammography programs than are women from the suburbs (34).

A recently reported trial in the Philippines studying the value of clinical breast examination (CBE) for early breast cancer detection illustrates the critical nature of social obstacles to early detection of cancer (35). The Philippines CBE trial was prematurely closed because a full 65% of the trial participants, while willing to undergo initial CBE in the absence of logistical and financial barriers, and despite coming from a relatively educated population, refused to undergo necessary follow-up diagnostic studies to determine if their palpable lumps represented cancer. The authors pointed out that women attend breast cancer screening in anticipation of having a negative finding (36) and that screening is not a stressful procedure for those with negative mammography (37), but receipt of an abnormal result is associated with considerable psychiatric morbidity (38), potentially leading to a low level of compliance with follow-up. Unfortunately the trial was not designed to determine as a primary end point which reasons led patients to avoid subsequent diagnostic studies after a positive CBE. The authors concluded that culturally related health beliefs can constitute a major obstacle to early diagnosis, and that awareness and access need to be addressed first, both in terms of designing studies and in terms of implementing new programs related to cancer detection, diagnosis, and treatment.

A tragic consequence of advanced-stage cancer presentation is that treatment fails to cure the disease in the great majority of cases, thereby propagating common social myths such as the belief that cancer is invariably fatal, regardless of its extent at diagnosis or treatment (32). If women commonly avoid seeking care until their disease is undeniably extensive, they create a self-fulfilling prophecy by virtue of the fact that the disease is truly incurable at that point (39). Moreover, advanced breast cancer requires more aggressive treatment, including mastectomy, cytotoxic chemotherapy, and radiation therapy, further adding to the fears and barriers that keep women from seeking care. In the worst-case scenario, the public comes to believe that the treatment, rather than the cancer, causes death. These beliefs, which are difficult to shake once established in the social network, can undermine if not shut down any efforts toward early detection programs. Because the social stigmata of cancer can be so powerful, they must

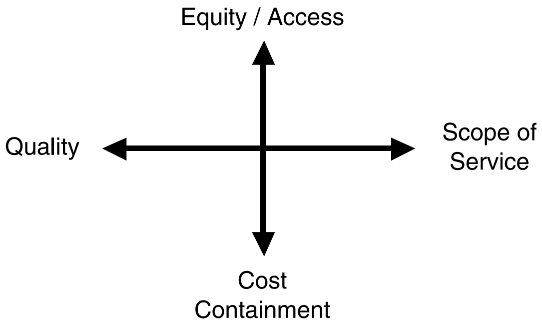


Figure 1. The four universal trade-offs in health care systems.

be fully understood before any improved strategy is implemented within a limited-resource country (14).

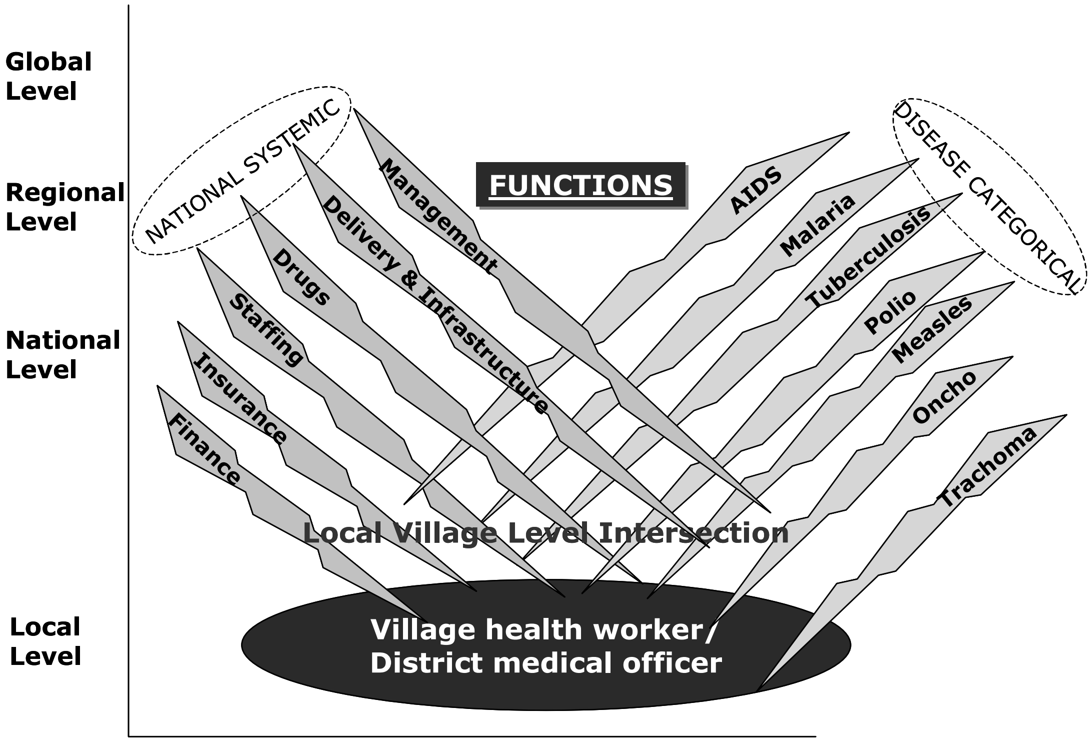
Resource Allocation in Cancer Program Development

Trade-Offs in Health Care System Organization There is no perfect health care system because a system must strike a compromise in meeting the many diverse health needs of the population it serves. Specifically a health care system must achieve a balance among four primary health care system trade-offs (40–43): equity in access, scope of services, quality of care, and cost containment (Fig. 1). Inevitably certain of these needs will be better met than others. Given the diversity of health care systems worldwide and the fact that there is no perfect system, it is inappropriate to rank different health care systems in a single-variable, linear fashion. However, systems can be ranked in terms of multiple care-related metrics, such as equity of access and quality of life, a practice that can be useful because it provides benchmarks for improvement (44,45).

Setting priorities for health care in general, and breast cancer care specifically, is particularly difficult in limited-resource environments in light of the many aforementioned issues. By creating evidence-based guidelines that stratify health care interventions into specific levels and through programmatic proposals based on cost-neutral implementation strategies (discussed in a later section), health care ministries can be offered realistic options for planning the delivery of breast health services within their public health system.

Approaches to Implementing Disease-Specific Programs There are two general approaches for implementing new disease-specific programs, such as a program to address breast cancer: the vertical approach, whereby the program runs parallel to, but is separate from other disease-based programs, and the horizontal approach, whereby the new program is integrated with the existing system and programs (46). The vertical approach can be beneficial in that specialized care can be implemented because of the disease-specific focus, but it can also be problematic when different diseases end up competing for the same resources. In a purely vertical approach, addressing one disease may compromise the ability to address others when resources are scarce. In contrast, by integrating a new program within a common coordinated structure using existing resources and infrastructure, the horizontal approach allows resource utilization to be optimized at the same time that comprehensive health care needs are met (47). For example, many countries already have infrastructure in place for other services, such as community nurses who visit villages to provide maternal and child care, and a breast health care program may be able to piggyback on this infrastructure (Fig. 2). The combination of the delivery of one intervention with existing successful delivery mechanisms is receiving heightened attention in the international health policy community, although some suggest combined delivery approaches could have a detrimental effect on equity of care unless health care coverage is nearly universal (46).

Macropolicy versus Micropolicy National health care planning directly affects health care delivery at a local level. For example, national health care financing strategies can positively or negatively affect access to health services or health outcomes in communities in limited-resource countries (48). In resource-poor settings, illness imposes high and regressive cost burdens on patients and their families (49). The limited evidence available suggests that, in general, user fees deter health care system use. Conditional cash payments for patient compliance may improve the use of needed interventions, but can create perverse incentives (48). Universal health care provides optimal patient access in that all persons have access to the system. The idea that universal health care is necessarily more costly is not substantiated by experiences in the United Kingdom and Canada (50). However, cost containment in these systems may come in exchange for a limited scope of services provided, slow response to and integration of new technology and pharmaceutical agents, or such prolonged wait times for service that health outcomes are negatively affected (51,52). In some circumstances, certain high-risk populations, such as the poor, may need to be targeted for specific health programs in lieu of a "total population" approach in order to circumvent the otherwise inequitable distribution of health care resources in favor of the economically advantaged (53). Any intervention strategy designed to improve outcome for a given disease must be considered within the context of the health care system in



World Bank, Improving Health, Nutrition and Population Outcomes among the poor: Strategic Options for the World Bank in Sub-Saharan Africa, 2004

Figure 2. Schematic representation showing how vertical disease-specific programs compete for the same scarce resources at various levels. (Copyright 2004, World Bank. Reprinted with permission from the World Bank. *Improving Health, Nutrition, and Population Outcomes in Sub-Saharan Africa: The Role of the World Bank.* Washington, DC: World Bank, 2004.)

which it is being applied to ensure that the strategy is in alignment with financial support and incentives (48).

Effective program implementation also requires that national and international health care policymakers recognize the roles of both macropolicy and micropolicy in health care administration. The health care delivery strategy can affect quality, coverage, cost, sustainability, and equity (46). If well designed and implemented, changes in national-level policy can facilitate improvements at the regional or local level. For example, a health care ministry could define educational programs that allow midwives or nurses in the rural areas, as part of their job, to conduct CBE and teach women breast health awareness. For this reason, senior health care administrators must have a detailed understanding of disease management to understand the broader implications of their policy decisions, or at least need to be well advised as to evidence-based approaches for improved outcome in targeted diseases (54). Health care policymakers need to work closely with informed health care experts to design successful health care strategies, especially in areas of preventive care (55). As such, tailored disease-specific guidelines become a core resource for effective health care policymaking.

Economic Modeling in Breast Cancer Care

Financial Impact of Breast Cancer Care In addition to its human burden in terms of morbidity and mortality, cancer poses a fiscal burden on a nation's health care budget. To use values from a developed country as an example, the U.S. National Institutes of Health estimated the overall costs for cancer to be US$189.8 billion in 2004 in the United States, with breast cancer accounting for 15–20% of all cancer costs (56,57). The economic burden of breast cancer in low-resource countries is largely unknown.

Because health care budgets are always pressured by needs that exceed available resources, interventions designed to improve breast cancer care and outcomes must be not only clinically effective, but also cost effective, to be included in formal clinical practice guidelines. Cost-effectiveness analyses can provide useful information for planning and developing breast cancer control policy. For example, they can be used to inform budget development, to justify the allocation of scarce resources to national breast cancer control programs, and to identify the most efficient ways of delivering screening, diagnostic, and treatment services.

Cost-Effectiveness Analysis in Breast Cancer Many cost and cost-effectiveness analyses have been performed for breast cancer in recent years. A MEDLINE search using the Medical subheading terms "breast neoplasms" and "costs and cost analysis" with a further restriction of "cost" as a title word identified 317 citations. Most of these studies included some sort of simulation modeling approach in which information from different sources is combined to create a simplified version of reality.

Nearly all cost-effectiveness studies have been performed using treatment algorithms and clinical and economic data from developed countries (57). Most of these studies evaluate early diagnosis by screening or evaluate treatment options for specific stages of disease (58). Unfortunately findings of cost-effectiveness studies for developed countries cannot be directly translated to allocate resources or make policy decisions in countries with limited resources. The differences in health care systems, epidemiology of disease, availability of trained personnel and equipment, resource costs, and cultural factors are too great to permit such extrapolation. Furthermore, in many cases the interventions described in these models require a level of breast cancer care that is not available in a limited-resource country. Finally, severe resource constraints in such countries force much more restrictive policies toward the use of new technologies. In these settings, new technologies will not be adopted unless much higher thresholds of economic value are achieved.

Although the circumstances across countries differ greatly, simulation modeling can assist in determining how clinically effective therapies can be applied in cost-effective ways to improve outcomes in limited-resource countries. Recognizing the value of economic modeling, WHO has created a methodology called generalized cost-effectiveness analysis (GCEA) that uses a standardized framework and modeling software (59). This approach differs from the traditional cost-effectiveness analysis, as GCEA requires the analyst to consider what would happen, starting from today, if all resources in the health sector could be reallocated. This situation is called the "counterfactual" against which all interventions should be evaluated. The cost-effectiveness of all possible interventions for a specific disease, individually and in combination, is assessed in relation to this counterfactual (59).

These simulation modeling analyses are designed to provide a broad assessment of the cost-effectiveness of a wide range of interventions. The methodology is standardized and thus allows comparisons to be made with recent cost-effectiveness analyses for other health care interventions that follow the same analytic approach (60–63). In terms of breast cancer, a statistical model evaluating the outcomes and costs of different interventions at different stages of disease would be very informative. It would be rational to hypothesize that breast cancer treatment is more cost effective when used to treat early stage rather than late-stage disease, because treatment for the former is simpler and less expensive, and has a better outcome (23). Such a mathematical model could assist health care leaders in identifying cost-effective strategies to reduce breast cancer-related fatality rates given their country's specific characteristics and health budget constraints. This information can be used in government discussions about health care reform and budget allocation.

RECOMMENDATIONS

The 2005 Global Summit panels developed a stratification scheme that maps out a sequential, systematic approach to building capacity for breast health care in the limited-resource setting. This stratification scheme defines an approach for top-down policy reform, according to which services and facilities are assigned to four resource levels:

- Basic—Applies to facilities, services, or activities that are absolutely required to have a breast cancer program (i.e., without these, a health unit is not ready to have a program).
- Limited—Applies to facilities, services, or activities that provide a large improvement in outcome relative to the basic level, particularly as related to cancer survival.
- Enhanced—Applies to facilities, services, or activities that provide a small improvement in outcome relative to the limited level, but may improve important options for patients undergoing cancer diagnosis or treatment.
- Maximal—Applies to facilities, services, and activities that may be used in some high-resource countries and may be recommended by guidelines that assume the availability of unlimited resources, but that should be considered a lower priority than those resources in the basic, limited, or enhanced levels.

These levels refer to the interventions (e.g., pathology services, imaging or treatment facilities, cancer registry) applied in a given health unit (an institution, city, region, or country), and not necessarily to a country overall; different levels can and likely will coexist within the same country. In addition, these levels are incremental; for example, the limited level assumes that a health unit has all the interventions needed for the basic level and now has resources to add more. In this way, the scheme provides

Table 1. Resource Allocation for Health Care Systems and Public Policy

Level of resources	Services	Facilities	Record keeping
Basic	Primary care services Surgical services Pathology services Oncology services Nursing services Palliative services	Health facility Operating facility Pathology laboratory Pharmacy Outpatient care facility	Individual medical records and service-based patient registration
Limited	Imaging services Radiation oncology services Peer support services Early detection programs	Imaging facility Radiation therapy Clinical information systems Health system network	Facility-based medical records and centralized patient registration Local cancer registry
Enhanced	Opportunistic screening programs Cancer follow-up Rehabilitation services Group support	Centralized referral cancer center(s) Population-based cancer registry	Facility-based follow-up systems Regional cancer registry
Maximal	Population-based screening program Individual psychosocial care	Satellite (noncentralized or regional) cancer centers	National cancer registry

a logical, systematic framework for building capacity. The short-term goal is for a health unit to advance to the next level once it has all of the interventions of a given level (i.e., to raise the bar).

The Health Care Systems and Public Policy stratification scheme (Table 1) is based on the recommendations of the other three Global Summit consensus panels (64–66). These stratified guidelines are intended to be used as a flexible framework that can be adapted to individual settings to improve breast health care.

Although a health care ministry may consider their long-term goal to be reaching the maximal level of health care resources, it is critical to recognize that some of the resources at this level are extremely costly and demanding of infrastructure for ongoing support. Maximal-level resources should not be given a higher priority than basic-, limited-, or enhanced-level resources. It is a mistake to purchase expensive tools for purposes of prestige, for example, investing in positron emission tomography (PET) imaging when other fundamental tools are unavailable. The more fundamental resources are needed to make the more expensive tools useful; when obtained out of sequence, the maximal-level resources typically end up being underused or unused.

Roles of Various Sectors in Improving a Health Care System

Improving a health care system so that it can deliver better breast health care can best be accomplished if multiple sectors act in collaboration (67); that is, improvements are most likely to be achieved when health care ministries and governmental agencies, nongovernmental organizations (NGOs), and public and patient groups work together (24,68,69). The relative contribution of each sector will depend on the country's governmental structure, the extent of focus on health care and breast cancer, available resources, the strength of the NGO sector, and the ability of patients, survivors, and advocates to "raise their voices." Women's health advocacy and consumerism have had a direct impact on oncology care in the United States, having the greatest effect when the activities of advocates and health care professionals are coordinated and aligned to guide policymakers toward effective and desirable change (68).

Health Care Ministries and Governmental Agencies In developed countries, government is often an initiator in health care system improvement, both through health ministries and through budget allocations. Mediating reform through government channels is essential because no other organization has the purview to address the often sweeping changes that are needed (24). Typically governmental roles include:

- Enacting legislation for cancer research and control programs.
- Establishing budgetary priorities.
- Training and compensating research and health care personnel.
- Providing and paying for research, health care delivery, equipment, and supplies.
- Constructing and managing oversight programs, and enabling evaluation of programs and outcomes.

- Ensuring the longevity of the initiatives that are implemented.

However, in countries with limited resources, the government may be less likely to initiate system improvements because, at least in part, of the realities of financial constraints, lack of attention to specific populations that do not have political clout, or both. Women may be denied access to services because of a lack of resources and limited mobility (70). Champions for improvement or reform are instead likely to emerge from NGOs, cancer associations within the country, international organizations, or some combination of these (71).

The process of increasing governmental support for health care issues is stepwise. Achieving political commitment from the government requires that it have a rationale for devoting resources to health care and system improvements based on health care data and motivated by public will. Catalysts for cancer control from the nonprofit sector, the public, or patients can provide the necessary attention and impetus for political action by reporting on inequities within a health care system (72). Through such political action, ministries can be authorized to collect data, establish programs, expend funds, oversee activities, train professionals, and evaluate services and outcomes.

Improving capacity has become central to strategies used to develop health systems in low-income countries. Experience suggests that achieving better health outcomes requires both increased investment (i.e., financial resources) and adequate local capacity to use resources effectively. International donors and NGOs, as well as ministries of health, are therefore increasingly relying on capacity building to enhance overall performance in the health sector. A conceptual framework for mapping capacity and measuring the effects of capacity-building interventions can be useful to planners in the design of such interventions and provides a framework for monitoring and evaluating their effectiveness (73).

Some groups advocate for privatization of care as a method for improving health care delivery (74). It is often argued that the private sector is more efficient than the public sector in the production of health services and that government reliance on private provision would help improve the efficiency and equity of public spending in health. A review of the literature, however, shows little evidence to support these statements (75). Privatization will be unlikely to improve the equity of access because, by definition, this care is market driven. Furthermore, privatization of health care is typically directed at treatment rather than prevention. Because the financial incentives that drive treatment interventions are typically absent in preventive care programs, such programs need strong government involvement to be successfully implemented (76).

Medical facilities in low-resource countries are frequently established and funded by charitable organizations, often with excellent organizations and efficiency. In Senegal, Catholic health posts were shown to be significantly more efficient than public and other private facilities in the provision of curative and preventive ambulatory services at high levels of output (75). As resources become available, health ministries may increasingly provide key planning and funds for building, staffing, and maintaining cancer care institutions. Such institutions, with the support of NGOs, and eventually the government, can provide training for health care professionals. Governmental involvement and support of research, another important facet of health care improvement (discussed subsequently), should also increase as resources become available for this activity.

Nongovernmental Organizations NGOs can play a key role in initiating and supporting improvements in health care (71). Such organizations can create programs that provide the best available evidence to inform the public, can keep cancer control on the public agenda, and can pressure governments and decision makers on issues related to cancer control, either directly or indirectly, such as via the media. NGOs may serve as a catalyst for dialogue and collective action within national and local cancer organizations, both governmental and nongovernmental. Ultimately, well-coordinated public-private partnerships can greatly enhance national health care for specific diseases (77). In some limited-resource countries in eastern Europe, NGOs are beginning to be formed to advocate for increased resources and services for core areas such as reproductive health (78). Services for family planning, abortion, infertility, cervical and breast cancer, and violence against women are underdeveloped in these countries and represent areas of common interest for NGOs advocating for women's health.

Because NGOs can drive policy by providing independent funding, consideration must be given to issues affecting an NGO's motivations to ensure good alignment with the interests of the health care system overall (79,80). Case examples have been provided in which NGO participation was less helpful than anticipated. According to one study in Mozambique, a deluge of NGOs and their expatriate workers contributed to local health system fragmentation, undermined local control of health programs, and contributed to growing social inequality. Because national health system salaries plummeted over the same period as a result of structural adjustment, health workers became vulnerable to financial favors offered by NGOs seeking to promote their projects in turf struggles with other agencies (81). Thus collaboration between NGOs and governmental health agencies needs to be an interactive "two-way street" where common goals are identified and coordinated.

There are several core activities within the NGO purview for cancer control. The first is creating information resources based on the scientific evidence base and developing support for information storage, access, and dissemination to both professional and lay audiences (79). A second core activity is advocacy to influence public policy (82). A third area of focus is lobbying for the education and training of professionals in all fields of cancer control and through direct support with fellowship grants, support of conferences and workshops, and provision of materials that can be adapted to be locally relevant. With all of these activities, emphasis is placed on collaboration between organizations, agencies, and groups working in similar areas to leverage resources.

Rapidly improving breast cancer care in countries that have limited resources or lack comprehensive cancer control programs, or both, may be accomplished by focusing on three areas that NGOs can partly address: early detection, adequacy and quality of treatment, and supportive care. Rates of early detection can be improved with a pair of strategies: screening (performing systematic examination by professionals of all individuals in a healthy targeted population) and early diagnosis (increasing the awareness of women and health professionals about early symptoms to facilitate rapid diagnosis). NGOs can actively address these strategies in four ways:

- Lobbying governments for optimal high-quality goods and services; to advocate for rational and strategic decision making based on needs and resources assessment; to implement or improve organized, proven, population-based intervention (either screening or early diagnosis); and to ask for quality assurance and equity.
- Raising public awareness about initial symptoms, the availability of care, and the potential for cure if the disease is detected early and treated appropriately through public policy advocacy; by creating and conducting public information campaigns; and by ensuring widespread distribution of carefully designed communication materials.
- Training professionals in the proper conduct of CBE, mammography, cytology, biopsy, treatment, and supportive care to implement only evidence-based interventions, and to accept quality control and evaluation processes.
- Supporting research and the adaptation of proven protocols for the level of resources available, to design more efficient strategies adapted to economic level and health systems.

Nongovernmental organizations can also promote caring for the practical and emotional needs of patients by creating structures such as welcome centers in hospitals, patient committees, support groups, phone services, or "hope lodges," where patients may find an alternative to hospitalization. Cancer patients in many countries are often faced with formidable practical hurdles, such as the distance to treatment centers and the prohibitive costs of hospital stays and palliative care. In addition, patients and their families frequently experience a chronic lack of moral and psychological support. Hope lodges, which already exist in some countries, help resolve practical problems by allowing patients to undergo therapy as outpatients at little or no cost for room and board, and by offering the benefits of shared experiences with fellow patients, and in some cases, professional psychological support. Although not unique in serving this role, NGOs can be primary drivers in supporting patients with cancer and their families by decreasing financial constraints that limit cancer care in many countries and by encouraging the adaptation of cancer control strategies in the face of these constraints.

Nongovernmental organization interventions may require adaptation by the public in order to be successful. In 1997, a consortium of NGOs in Bangladesh began to implement health sector reform measures intended to expand access to and improve the quality of family planning and other basic health services (83). The new service delivery model entailed higher costs for clients and required that they take greater initiative than in prior programs. Clients had to travel farther to get certain services and pay more for these services than they did under the previous door-to-door family planning model. Beyond the need for establishing an appropriate pricing structure for these services, barriers to access, such as social concepts about gender, class, entitlement, the role of government, and obligations among people to participate in their own care require consideration and adaptation. Change was necessary for attitudes related to charging and paying for services, along with the institutional policies and practices that support them (83).

Nongovernmental organizations often play an important role in developing cancer research programs, collecting charity money, and establishing a research strategy. Because research is generally given a low priority in limited-resource countries, a significant part of a research unit's budget is derived from charity grants. Accordingly, such organizations may have a strong influence on the orientation of cancer research. NGOs can be full-time partners in cancer control and consequently they must apply the same scientific rules and evidence-based strategies used by other partners involved in cancer control efforts. Data suggest that stakeholders have different agendas, and that donors predominate in determining the research portfolio. High-level consensus building at the national and international levels is necessary to ensure that the diverse agendas play a complementary role in support of health system objectives (84). Because of their direct impact on the population, such organizations can play a major role in convincing governments to create relevant cancer services and strategies, they can implement their own demonstration projects, and they can give important economic support to translational research. As such, the NGO becomes a link between public health care research and health care policy reform.

The Public, Patients, and Advocates The public, patients, and advocates also play both central and supportive roles in improving a health system so that it can deliver better health care. Community participation in health offers various advantages in health care and development, among which are helping communities to develop problem-solving skills, encouraging them take responsibility for their health and welfare, ensuring that the needs and problems of the community are adequately addressed, ensuring that the strategies and methods used are culturally and socially appropriate or acceptable, and enhancing the sustainability of successful programs (85). Once organized, public health care advocacy groups can catalyze internal political action and system reform. However, it should also be recognized that these groups, which are common in individualistic societies with developed health care systems such as the United States, may find more obstacles to change in the hierarchical societies with unmet demand for regulated health care commonly found in low- and medium-level resource countries (86).

Health Care System Reform

Undeniably, moving a limited-resource health care system toward the goal of improved breast health care is a difficult endeavor requiring not only the initial commitment to change, but also ongoing effort toward that goal. Most often, system improvement is gradual and incremental rather than rapid and radical. Efforts are most likely to succeed when they are tied to specific goals (3). Of note, successful reform has implications beyond improved breast cancer outcomes; that is, it can serve as a model for better management of other diseases that also require multidisciplinary care.

Approaches to Reform To improve a health care system, efforts and resources can be applied with a top-down approach (i.e., starting at the minister or policymaker level) or with a bottom-up approach (i.e., starting at the grassroots/community level). Participatory models of care, in which the public is empowered through collective action, can be successful in motivating health care reform (82). Both approaches can be used at the same time to synergistically improve breast cancer outcomes.

There are two important components in any national initiative to improve health care: a policy component and an implementation component. The former entails setting government policy on the issue, while the latter addresses how that policy will be put into action. The policy component is typically addressed with policymakers, such as health ministers. They must be convinced that there is a need for a health care program based on data on the incidence and mortality of breast cancer, and that what is proposed is attainable and implementation is feasible within the budget constraints of their country. Policymakers obtain information on issues from multiple sources, therefore they may best be able to discern the need to consider a breast health care program if they are presented with a simple business case packaging the clinical, epidemiologic, and economic picture into a coherent plan to improve outcome. This case should tie economic terms to endpoints. For example, if reducing case fatality rates is the endpoint, models suggest that the down-staging of breast cancer at presentation (in the context of at least basic treatment) is the most cost-effective way of achieving the goal (23).

The implementation component may be addressed with policymakers, government agencies, NGOs, or other groups, and can be outlined in guidelines. Specifically, guidelines should delineate options for health care reform and propose ways of addressing the various constraints (manpower, education, equipment) to such reform in the limited-resource setting. However, guidelines can only generally address implementation because each country must tailor its own approach based on its unique circumstances. Of note, in some limited-resource countries, implementation may fail due to inefficient health management and corruption. External donors, on the basis of previous experiences, may prefer to start projects or programs with an NGO; however, this approach may lead to verticality, with resultant discontinuation of the program if the NGO does not continue its funding or if a political regime change occurs (84). Continuity is an important consideration in any health policy change.

Working with Changing Leadership A major obstacle to health care reform for countries with all levels of resources is the short-term political obstacle of changing leadership. Because health care ministers commonly change more often than do political parties and leadership in power, health care ministers may be reluctant to undertake a long-term effort that could not be realistically achieved in a single term in office. They may be more amenable to undertaking a multistep plan of small interventions, so that visible progress can be made even in the short term.

Integrating a Breast Health Program into the Existing Health Care System To be effective and to ensure continuity and viability, a breast health care program should be integrated into the existing health care system whenever possible. Most limited-resource countries, especially middle-level ones, already have at least minimal health care infrastructure in place, and a breast health program should be integrated into that infrastructure. For example, nurses or midwives providing maternal and child health care in rural areas can also be trained to educate women on breast health and to carry out breast examinations. Unfortunately some health care systems are dysfunctional and unresponsive to the urgent needs of their populations. In such cases, it may not be possible to work within the system; that is, the system may need fundamental changes to be able to deal with breast cancer and other diseases.

National Cancer Centers as a Hub for Cancer Care Centralized centers of excellence serve as a core resource for a health care network, both for providing tertiary care of complex referred patients and for supporting the development of satellite cancer centers that can deliver care to peripheral regions of the country. Every country should strive to establish at least one center of excellence (i.e., a national cancer center). Such centers have the necessary expertise, facilities, and equipment to train health care professionals and to help coordinate and implement a cancer control program. When deciding where to locate such a center, as well as the smaller, linked health units (e.g., hospitals and clinics), consideration should be given to ensuring that they are readily accessible to the public.

Although establishing cancer centers and linked health units is an important step, it must be acknowledged that this approach will not solve problems for many women living in rural areas who cannot travel far to receive care. In limited-resource countries, referral from primary care to secondary- or tertiary-level facilities can be a relatively rare event (87). To meet the needs of such women, a program must also consider outreach approaches such as using visiting nurses and other physician extenders.

Breast health care requires multidisciplinary care including surgery, radiation therapy, medical oncology, pathology, and radiology. The breast unit concept, an approach to organizing multidisciplinary care, is a cost-effective way of managing breast cancer (88). As such, this concept may be a viable strategy in certain limited-resource settings. However, staffing breast units may be a major hurdle, and referring women to such units may be impractical because of factors such as transportation barriers.

Some limited-resource countries already have fairly well-established health care systems, but the public is reluctant to use them, in part because of system-related barriers such as long wait times, insensitivity of staff, or lack of female medical professionals. However, public use of such systems would likely increase if those barriers were reduced or removed. Therefore health care leaders should work to identify and dismantle barriers that deter the public from using existing facilities.

Overcoming Societal Barriers to Improving Breast Cancer Care In developing a health care system to address breast cancer, it may not be enough to simply establish a system and expect the public to use it. It may also be necessary to provide the public with the rationale for why they would want to use the system, especially in societies where there are substantial barriers to seeking care for cancer, such as a lack of awareness, fatalism, stigma, and fear. Societal barriers can be overcome by educating the public and including a message of empowerment for women to take charge of their own health.

Several parties can help overcome social barriers to breast health care. A potentially very effective way of promoting public participation is by involving the public itself or trusted community leaders to give the public a sense of ownership (53). In many communities in the developing world, the decision for intervention for women's health rests with men (14). For this reason, men may need to be involved in interventions such as efforts to promote early detection.

A third influential group is breast cancer survivors. Survivors play a key role by showing, through their very existence, that breast cancer is not invariably fatal, which is a critical step in convincing women to seek care. Moreover, these survivors can act as advocates in raising their voices to policymakers. Survivors also provide insight into obstacles related to a cancer diagnosis and reasons why women may feel disenfranchised from health care (89,90).

Research as a Tool to Improve Health Care Outcomes

In the limited-resource setting, the potential for establishing a regional or national research program grows over time and with economic development. Basic research laboratories are established, whether newly created or as an expansion of activities in existing institutions. Clinical research provides for protocol-driven care in which intervention suitable to the population and resource level can be tested and adopted.

Overcoming health care constraints and obstacles in the limited-resource setting requires novel thinking and creative approaches. When new ideas are developed, they must be implemented in ways that allow researchers to determine if the approach improves outcomes. For example, in countries where limited availability of pathology prevents prompt cancer diagnosis, one solution in remote areas may be cytopathology services using commonly available communication technologies to transmit images to centralized facilities. This intervention—cytologic diagnosis using telemedicine—and similar ones need to be studied in appropriately selected limited-resource countries, preferably with intervention and control arms.

Situational Analysis and Needs Assessment Different countries will require different solutions for the same health care problem, depending on their resources, their populations, the prevalence of disease, and other factors. Thus performing a situational analysis in a country is necessary before introducing any new intervention. Situational analyses may allow researchers and health care ministries to identify ways in which an existing system can be used to implement solutions for which the system was not originally designed.

A related form of research, needs assessment, should be considered in multiple areas. The availability of data to inform cancer control efforts should be assessed. Data registries, whether they are as broad as regional and national cancer registries or as limited as study-specific registries, are required to measure outcomes and the impact of interventions. Further needs assessment includes determination of the availability of manpower, training, and core equipment; the distribution and support of facilities; and the availability of funding for consumable supplies. It is also relevant to perform needs assessments in the general community and in the medical community, including asking the public and health care professionals, respectively, what their needs are and what problems they face. This type of research is efficient and allows the tailoring of programs to a specific health care setting, but it can become expensive when it requires the hiring of skilled research professionals.

Economic Analyses New interventions designed to improve breast health outcomes must be both economically feasible and cost effective compared with alternative uses of limited funds. As previously noted, few if any cost-effectiveness studies related to breast cancer care have been conducted from the perspective of countries with limited resources. It is less expensive to treat early breast cancer than to treat locally advanced or metastatic breast cancer, yet the costs of identifying cancers at earlier stages must be weighed against the savings afforded through early detection (23).

Demonstration and Pilot Projects Demonstration projects (which show how an intervention can be applied on a small scale) and pilot projects (which test a research hypothesis on a small scale) can be vehicles for health care reform. For example, these projects might be used to evaluate the effectiveness of various approaches for the down-staging of disease at presentation. Screening by mammography was introduced in a pilot project in one territory of the Ukraine, a country in which about 30% of breast cancers were of stage III or IV at diagnosis at that time (20). The project found that 9% of cancers detected by mammography were in situ, while most were T1b (20%), T1c (48%), or T2 (22%), which represented a marked improvement in comparison with historical controls.

Outcomes Analyses It is important to monitor the efficiency and effectiveness of a breast care program. Although a policy may be present, implementation may not have been carried out, and even if the policy was implemented, for various reasons, it may be having no impact on outcome. Outcomes analysis can therefore be helpful in modifying policy and implementation. In countries with limited resources, two possible outcomes of interest are a decrease in the stage of the disease at presentation and a reduction in mortality from breast cancer. Of course, monitoring outcomes also requires resources, and these costs must be factored into the cost of the program.

Establishing data collection, including a cancer registry and a health information system, is key for outcomes analysis and will usually reside in the hands of governments, although NGOs may also provide guidance and support (21). Unfortunately, in most limited-resource countries, there are few accurate data on the incidence and mortality of breast cancer. Regional and national cancer registries are nonexistent, very rudimentary, or are only hospital based.

Improving outcomes through guidelines hinges on guideline interventions being well implemented. To this end, countries must establish a structure and program for implementation, identify provider targets for the program (e.g., nurse practitioners), identify individuals who can assist in implementation (e.g., key opinion leaders), and develop measures of evaluation, quality control, and feedback to those who are to follow the guidelines. In this sense, implementing guidelines in limited-resource countries is very similar to doing so in wealthy countries. Nevertheless, resource limitations will force decision makers in countries with limited resources to be creative in following the steps of guideline implementation.

Research into best practices for guideline development and implementation in countries with limited resources is still in its infancy. Whenever possible, those developing and implementing guidelines should document their processes as well as their methods for implementing and monitoring outcomes. Ideally these documents should be published in peer-reviewed literature, but the Web also allows posting of documents on sites devoted to this cause. NGOs or groups such as WHO may consider hosting Web sites on which guideline developers and implementers from limited-resource countries can share their methods and experiences.

CONCLUSION

Health care systems provide the framework for improving outcomes for women with breast cancer in limited-resource countries. The barriers to reform are numerous and sometimes difficult to clearly identify; nonetheless, a firm understanding of the obstacles within these systems is a necessary initial step. Women themselves are stakeholders in the outcome and as such are an invaluable resource. Through education and organization, they can help facilitate needed change and save lives. Stratified breast health guidelines become the road map for addressing and curtailing the devastating morbidity and mortality of breast cancer.

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