The role of breast cancer civil society in different resource settings

Gustavo Azenha a, Loyce Pace Bass b, Maira Caleffi c, Robert Smith d, Lauren Pretorius e, Alessandra Durstine a, Cristina Parsons Perez a, *

a Global Health Department, American Cancer Society, 132 West 32nd Street, New York City, NY 10001, USA
b Global Health Department, American Cancer Society, 901 E Street NW, Washington, DC 20004, USA
c Hospital Moinhos de Vento Breast Center, Instituto da Mama do Rio Grande do Sul (IMAMA) and FEMAMA, Rua Ramiro Barcelos, 850 Porto Alegre, RS 90035-001, Brazil
d Cancer Control Science Department, American Cancer Society, 250 Williams Street, Atlanta, GA 30303, USA
e Campaigning for Cancer, Office F15, Balblair Building, Kildrummy Office Park, Paulshof, Johannesburg, South Africa

Abstract

Breast cancer civil society, as represented by non-governmental organizations (NGOs) in this study, can play an essential role in breast cancer control. Their breast cancer-related programs often reflect the breast cancer burden and the resources available for cancer control within the country or region they serve. This report reviews organizational features and program activities of 154 NGOs involved in breast cancer control from 35 countries. Breast cancer civil society in low and lower-middle income countries are most often associated with hospitals and medical professionals and focus on direct medical services, providing information, raising community awareness, and early detection campaigns. In upper-middle income countries, NGOs were likely to be survivor-led and there were more breast cancer-specific organizations. NGOs played a lesser role in provision of direct medical services and had a greater program emphasis on other areas of patient services, including emotional support. In high income countries, they were typically survivor-led, breast cancer-specific NGOs were prominent, and NGOs had a more prominent focus on research, advocacy and legal rights compared to other resource settings.

Introduction

Breast cancer is the second most common cancer in the world and the most common cancer among women.1 Its reported incidence is around three times higher in developed regions than in less developed regions.1 However, mortality-to-incidence ratios for breast cancer are much higher in developing countries indicating different survival rates suggestive of marked disparities in access to, and quality of, information, screening, diagnostic, and treatment services.1 Disparities in cancer outcomes and cancer care are also evident within countries at all resource levels,2 as are socioeconomic disparities in breast care.3

Breast cancer civil society, most often represented by non-governmental organizations (NGOs), plays an essential role throughout the world in addressing the growing breast cancer burden and the disparities in access to and quality of care. Breast cancer NGOs can raise public awareness and educate patients, as well as mobilize resources to serve local needs and provide services not available through government services (e.g., screening and emotional support). They can also help shape public policies and services to be more responsive to patient and community needs.4–8

The level of available health care services can impact the type and quality of care, and varies between countries as well as within countries. The World Bank publishes data on country income level based on gross national income (GNI) as well as health expenditure per capital for countries, dividing countries into low, lower-middle, upper-middle and high income groups.9 This article compares and contrasts the organizational features and program areas of NGOs working on breast cancer initiatives in low, lower-middle, upper-middle, and high income countries in order to better understand the interrelations between resource levels and the presence and scope of breast cancer civil society in breast cancer control.

Keywords:
Civil society
Breast cancer
NGOs
Advocacy
Fatality
Survivorship

© 2011 Elsevier Ltd. All rights reserved.
Methods

A total of 154 NGOs (from 35 countries) that included breast cancer in their mission were grouped by income level using World Bank Country Income Classifications and analyzed for their organizational structure and program activity. While civil society can be considered to encompass other institutions and actors beyond NGOs, this paper uses the terms civil society and NGOs interchangeably.

Organizational features and programs: Each organization was scored for the existence/absence of certain general organizational features (health care professional founded/survivor founded; general cancer organization/breast cancer organization; hospital associated; and coalition/advocacy coalition) and program activity categories (information, community awareness, early detection campaigns, direct medical services, emotional support, research, basic material provisions, advocacy, financial support, and legal support). To ensure consistency between individual evaluators, the organizational and program categories and their definitions were collaboratively developed by the authors (see Table 1 for definitions of programs). Each organization was subsequently scored by one individual with appropriate regional expertise.

Low, lower-middle, upper-middle, and high resource levels: An NGO was scored as servicing low, lower-middle, upper-middle, or high resource region or country using the 2009 World Bank Country Income Classification.9

In addition to the organizational analyses by structure and program activity by income level classifications, discussions draw upon qualitative assessments of NGO organizational capacities and program activities in different countries and income levels. Selected NGO examples across different geographic regions for each resource level are also provided to further illustrate and support the trends observed in this analysis.

Data acquisition

Organizational features and programs: Data for this analysis was provided by the American Cancer Society’s (ACS’s) 2006–2010 international capacity-building initiatives, specifically the ACS University Program, Latin America, Africa and South East Asia Regional Programs (these initiatives capture basic organizational data as part of the grantee selection process). Data was also provided by the ACS country assessments where basic data on civil society organizations engaged in cancer control is captured to identify program opportunities (the assessments were from 2007, 2008, 2009 and 2010).

Program activities

Program activities included providing information, community awareness, early detection campaigns, direct medical services, emotional support, research, basic material provision, advocacy, financial support, and legal rights (Table 2).

The top program activities in low income countries were information (100%), community awareness (90%), early detection campaigns (80%), direct medical services (60%), emotional support (40%) and research (40%). In lower-middle income countries, the most common program activities included community awareness (76%), early detection campaigns (71%), information (65%), direct

<table>
<thead>
<tr>
<th>Program Activity</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community awareness</td>
<td>Organization engages in breast cancer educational and awareness activities in specific communities, including presentations, lectures, meetings, and public events.</td>
</tr>
<tr>
<td>Information</td>
<td>Organization provides print or web-based informational materials to patients and/or general public on breast cancer.</td>
</tr>
<tr>
<td>Direct medical services</td>
<td>Organization provides cancer screening/diagnostic services, treatment (e.g., surgery, and radiotherapy, chemotherapy), and/or medication.</td>
</tr>
<tr>
<td>Early detection campaigns</td>
<td>Organization engages in organized campaigns to promote breast cancer early detection which target a broad public through mass media channels (e.g., television, commercial radio, magazines, newspapers, online media, and billboards).</td>
</tr>
<tr>
<td>Basic material provision</td>
<td>Organization provides non-financial, material support (e.g., bras, wigs, prosthesis, and lymphedema sleeves) to address or ameliorate effects of cancer and cancer treatment.</td>
</tr>
<tr>
<td>Research</td>
<td>Organization is directly engaged in clinical or basic research or provides extramural support for such research.</td>
</tr>
<tr>
<td>Emotional support</td>
<td>Organization provides professional counseling services, organizes group therapy, and/or coordinates informal emotional support from survivors or other volunteers.</td>
</tr>
<tr>
<td>Financial support</td>
<td>Organization provides financial support to cover direct treatment costs or costs incurred as a result of structural barriers to treatment (e.g., housing, travel, or food costs).</td>
</tr>
<tr>
<td>Advocacy</td>
<td>Organization engages in organized legislative, executive, or judicial advocacy activities targeting decision makers that aim for system-wide policy change, and/or the effective and equitable implementation of existing policies.</td>
</tr>
<tr>
<td>Legal rights</td>
<td>Organization provides information or counseling on legal rights, and/or represent patients in legal procedures.</td>
</tr>
</tbody>
</table>
Breast cancer civil society in low and lower-middle income countries

NGOs in low income and lower-middle income countries were found to be broadly similar in terms of organizational features and program emphases. In low income and lower-middle income countries, the few breast cancer-specific NGOs that exist tend to be small, limited-capacity organizations with limited geographic reach. Often NGOs and breast cancer programs are established by health care professionals specializing in the disease, frustrated with the dimension of the problem and convinced that a greater societal response is needed. Breast cancer-specific NGOs in low and lower-middle income countries are often hospital-based, serving the patients accessing the few (or only) breast cancer treatment facilities extant in the country. Active breast cancer programs are also evident in reproductive health NGOs and general health NGOs, where breast cancer is incorporated as part of a larger women’s health agenda and often coupled to cervical cancer initiatives.

In these lower resource settings, breast cancer civil society programs typically focus on raising disease awareness, offering information, providing direct medical services, and early detection campaigns. Emotional support programs are also present among many NGOs. Emotional support programs typically follow a group peer-support model where breast cancer survivors speak to women recently diagnosed with the disease, sharing experiences and creating small survivor communities. Basic material provisions are also important given the limited breast cancer services available; NGOs often provide basic patient service programs—managing banks of wigs, prostheses and post-mastectomy bras—and in some cases provide financial support for patients to cover out-of-pocket treatment expenses.

NGOs typically take advantage of their community presence and run community-based awareness programs educating individuals about breast cancer, signs, symptoms, and survivability. Such programs are aimed at breaking down the prevalent myths and misconceptions about the disease through promotion of breast health education, breast self-examination (BSE) and the importance of early detection. In discrete cases, given the medical leadership, screening services may be offered under special initiatives.

In low income and lower-middle income countries breast cancer is often equated to a death sentence due to the bleak prognosis associated with breast cancer late presentation (70% of breast cancers in low-resource settings are diagnosed in advanced stages). A breast cancer fatality cycle (Fig. 1) is observed where breast cancer stigma and fatalism lead to late diagnosis in the population (with patients presenting late out of fear of being diagnosed with a terminal disease). This results in limited numbers of women surviving breast cancer and few survivors to put a public face to their breast cancer story and give hope to others, which in turn propagates the stigma, fatalism and fear. In such situations, breast cancer civil society is working primarily to break this cycle by seedling survivor community networks to empower women to speak up about the disease and to offer hope to others. In doing so, civil society organizations attempt to reduce individual barriers to early detection and diagnosis and disseminate the notion that breast cancer is curable.

Low income and lower-middle income countries were found to share the programmatic emphases described above but did have some differences. The data suggests that financial support was more common among NGOs in lower-middle income countries than in low income countries. Information and research were much more important program areas in low income countries compared to lower-middle income countries. The differences in research may be linked to the greater number of hospital associated NGOs in the low income sample, or perhaps a product of sample bias due to low numbers in this income group.
For examples of specific NGO programs and activities in low income and lower-middle income countries see Tables 3 and 4, respectively.

Breast cancer civil society in upper-middle income countries

In upper-middle income countries, where resources exist but access is inequitable, breast cancer NGOs exist and civil society empowers patients by providing information, raising awareness, and addressing individual, community and structural barriers to care. A more significant survivor community promotes a more robust and patient-centered civil society landscape. Emotional support services are more strongly evident than in lower resource settings. Nascent advocacy programs are observed that tackle inequalities and look to achieve system changes.

In upper-middle income countries, breast cancer-specific NGOs are commonly found. NGOs are often survivor founded; typically by breast cancer survivors from more affluent socioeconomic classes who, having had access to health care services, want to “give back” to society and ensure that women affected by breast cancer have access to quality care and support. Breast cancer programs within national cancer NGOs also usually exist in middle resource countries.

Overall, NGOs in upper-middle income countries have greater capacity than those in lower resource settings, are able to serve and reach more people, have broader geographical reach and broader program scope. Provision of direct medical services by NGOs was much less common than in low income and lower-middle income countries, which is in line with the strong survivor-led character of breast cancer civil society in upper-middle income countries, its weaker direct affiliation with hospitals, and the more developed screening and treatment infrastructure. Despite this difference, strategic collaborations between NGOs and health professionals in programmatic activities are common.

Breast cancer civil society programs in upper-middle income countries usually focus on community awareness, information, early detection campaigns, emotional support, and basic material provision. Breast cancer NGOs in upper-middle income countries commonly engage breast cancer survivors in community awareness initiatives, with survivors presenting information on breast cancer and early detection as well as sharing their personal stories. These direct outreach initiatives often target underserved populations (e.g., low-resource urban communities, rural communities, and indigenous communities).

In upper-middle income countries, NGOs are active providers of breast cancer information on early detection, treatment options, self care and patient rights. They play an active part in breast cancer early detection campaigns, directly engaging the media to raise awareness, break down misconceptions, and undo stigma surrounding the disease; informing the population about breast cancer signs and symptoms, the survivability of the disease, risk factors, and also highlighting the importance of clinical breast examinations (CBE) and mammography.

Early detection educational programs and awareness campaigns are often coupled with provision of CBE and/or mammograms for the population, as civil society also takes on the role of tackling community and health system barriers (by increasing system capacity for screening, providing financing, running mobile mammography units, training health care professionals, transporting patients to healthcare centers, etc.).

It is common for early detection awareness initiatives to be coupled with the provision of free or reduced cost screenings, through collaborations with local government, health care services and providers. This collaborative capacity is also reflected in initiatives where NGOs train health care professionals to increase early detection system capacity, such as: educating community health workers in breast cancer early detection guidelines, training health care professionals in CBE, and training primary care doctors on referral pathways.

As in lower resource settings, basic patient services, such as emotional support and provision of wigs and prostheses, are available and important program areas, however, patient services are broader in scope than in lower resource settings and include patient navigation, assisting patients with the health care system and accessing available resources in the community. Patient services also reflect the larger numbers of women living with the disease, and the resulting need to address a wider range of survivor-specific issues (e.g., education on nutrition, living with
Examples of NGO Breast Cancer Programs in Upper-Middle Income Countries.

Breast cancer NGOs of larger collaborative capacity have nascent advocacy programs which aim to influence public policy in a more targeted fashion. Collaborative relations and involvement in diverse programmatic activities that address individual, community, and systems barriers give NGOs the strategic systems insight, technical knowledge, and social networks that serve as the foundation and impetus for expansion into advocacy initiatives. In a small number of cases, NGO networks with an advocacy-specific focus have formed.

For examples of NGO programs and activities in upper-middle income countries see Table 5.

Table 5
Examples of NGO Breast Cancer Programs in Upper-Middle Income Countries.

<table>
<thead>
<tr>
<th>Country</th>
<th>NGO Name</th>
<th>Founder</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Argentina</td>
<td>MACMA</td>
<td>Breast cancer survivor</td>
<td>Provides emotional support programs for breast cancer patients, including a support group for metastatic breast cancer patients to discuss topics specific to their unique needs (quality of life, symptom management, depression, feelings of failure, interactions with loved ones and caregivers, boosting self esteem, and conflict resolution).</td>
</tr>
<tr>
<td>South Africa</td>
<td>Campaigning for Cancer (C/CC)</td>
<td>Co-founded by a breast cancer survivor in 2008 as a result of her experience with health care coverage and legislation that threatened to limit her access to treatment options. Provides information and resources to patients and decision makers. Empowers individuals to request optimal services; creates an environment in which quality affordable and sustainable cancer-related health care is available for all South Africans affected by cancer. Advocacy includes convening multiple stakeholders (government officials, private medical funders, survivors, health care practitioners and service providers to discuss gaps in costs or delivery of cancer care). NGO challenges cancer-related policies and proposes more effective, alternative legislation or policies.</td>
<td></td>
</tr>
<tr>
<td>Mexico</td>
<td>Mexico Fundación Cím*ab</td>
<td>Two high profile breast cancer survivors who had access to private health care. Collaborators: Collaborates with the Mexican National Commission for the Development of the Indigenous People. Partnered with other NGOs to launch the Mexican breast cancer advocacy coalition, COMESAMA. Activities: Early detection activities include an initiative targeting rural indigenous women. Developed a video on breast cancer early detection in the náhuatl dialect, engaging indigenous midwives. Rural indigenous women were offered CBE and access to a mobile mammography unit. Advocacy includes working to improve mammography coverage in Mexico.</td>
<td></td>
</tr>
<tr>
<td>Brazil</td>
<td>IMAMA/FEMAMA</td>
<td>Breast specialist</td>
<td>Collaborators: In 2006 founded FEMAMA, a Brazilian advocacy coalition (in 18 states and with 44 member NGOs). Activities: Strategic advocacy engagement. Members participate in Brazilian Universal Health System councils. Coined the term 'vitoriosa', culturally adapting the term survivor. Produced a national breast cancer media campaign to pass a federal law on breast cancer early detection and treatment. Advocated to pass legislation to create municipal 'Committees on zero tolerance for breast cancer mortality': multisectoral entities to oversee the implementation of local breast cancer policies.</td>
</tr>
</tbody>
</table>

Breast cancer civil society in high income countries

In high income countries, breast cancer civil society is strong with significant organizational and program capacity. Breast cancer NGOs are prevalent and commonly survivor founded, with the

Table 6
Examples of NGO Breast Cancer Programs in High Income Countries.

<table>
<thead>
<tr>
<th>Country</th>
<th>NGO Name</th>
<th>Founder</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>American Cancer Society</td>
<td></td>
<td>Advocates policymakers on cancer-related issues including access to health care; cancer research funding; tobacco control; cancer early detection. The organization has extensive training programs for grassroots advocates. It lobbies decision makers, educates the public and media, organizes candidate forums, hosts debates, produces voter guides, aims to get every lawmaker and candidate on the record in support of laws and policies that help people affected by cancer. Example: As part of a campaign to block a Senate bill that eliminated guaranteed insurance coverage for mammograms, ACS CAN used innovative media advocacy to run a 'red bra' ad stating &quot;Don't let the Senate leave women exposed&quot; in the congressional districts of Senators that were going to approve the bill. The ad asked local grassroots to contact those Senators and request that they block the bill. Grassroots sent over 167,000 emails and made over 8000 phone calls to Senators. The bill was blocked.</td>
</tr>
<tr>
<td>Korea</td>
<td>Breast Cancer Coalition</td>
<td></td>
<td>Advocacy—Europe—UK</td>
</tr>
<tr>
<td>Korea</td>
<td>Europa Donna</td>
<td>Founder: The founder had a personal experience of a breast cancer misdiagnosis. Activities: Lobbies European Parliamentarians in Brussels to ensure breast care is kept on the agenda. Addresses coalition demands, such as the strengthening of research, job protection for breast cancer patients, and European directives for breast care nurses. Launched the European Parliamentary Group on Breast Cancer (EPGBC) and the European Parliament Breast Cancer Resolution.</td>
<td></td>
</tr>
<tr>
<td>USA</td>
<td>USA, National Breast Cancer Coalition (NBCC)</td>
<td>Founder: Founded by a breast cancer survivor. Activities: Advocates for public policies that impact breast cancer research, diagnosis and treatment. Played a critical role in: promoting increased government research funding; strengthening the role of women in defining relevant policies and funding decisions; increasing access to screening and treatment. It trains breast cancer advocates in the science of breast cancer (Project LEAD - Leadership, Education and Advocacy Development) so that advocates can better critically analyze breast cancer research and influence research committees and other breast cancer decision making bodies.</td>
<td></td>
</tr>
<tr>
<td>USA</td>
<td>Young Survival Coalition</td>
<td>Founder: 3 young breast cancer survivors. Activities: Dedicated to the critical breast cancer issues unique to young women (under the age of 40); advocates to influence the research for improved treatment options and better health legislation; educates young women about the importance of breast awareness early detection; creates networks of young women with breast cancer.</td>
<td></td>
</tr>
</tbody>
</table>

Please cite this article in press as: Azenha G, et al., The role of breast cancer civil society in different resource settings, The Breast (2011), doi:10.1016/j.breast.2011.02.005
existence of specialized organizations that target specific niche constituents with unique breast cancer needs. Collaboration and support from the private sector is more prominent in these settings, with NGOs engaging in cause-related marketing as a way of raising awareness, engaging grassroots, strengthening their brand and garnering support for the cause.

Overall, breast cancer civil society in high income countries is an active and influential player in all stages of the breast cancer continuum, with programs focusing on community awareness, information, early detection, research and advocacy. One notable differentiating factor between NGOs in middle and high income countries is the more active involvement of breast cancer research through funding of and/or participation in its design and implementation.

Breast cancer civil society in high income countries provides more varied breast cancer information, with specialized materials on a myriad of breast cancer issues (including available clinical trials). In several cases, information provision is complemented with tools and calculators (such as treatment decision and individual risk assessment tools), to support and empower patients and the general public to make informed health care decisions.

Breast cancer organizations engage the media on large scale awareness campaigns, leveraging survivors and celebrities as campaign spokespersons. Given the existence of universal health coverage (with the exception of the USA), it is unusual for NGOs themselves to offer screenings, instead organizations focus on advocating for local health care services to meet the local demand and empowering the population to exert their rights to these services.

In high income countries, breast cancer civil society is actively involved in organized advocacy, monitoring policy implementation, mobilizing grassroots activities, agenda setting with the media, and building local, national and regional advocacy coalitions.

Breast cancer civil society exists in a highly developed and competitive landscape with diverse emphases and specialized missions that attend to diverse constituent needs. Many NGOs have strong grassroots networks, robust advocacy programs, and mobilize sophisticated campaigning strategies (often collaboratively). Civil society is a powerful and vocal actor in breast cancer control, including policy and research.

For examples of NGO programs and activities in high income countries see Table 6.

**Conclusion**

The breast cancer landscape varies markedly according to resource setting and development status as a result of disease epidemiology, wider public health burden, socio-cultural factors, health care services availability and capacity issues. Given that civil society addresses pressing community needs and complements government services by filling in the existing gaps, breast cancer civil society also varies according to the breast cancer landscape and resources available. In addition, the profile and scope of breast cancer civil society in a specific context is a product of the unique local history of breast cancer civil society, itself shaped by: the existence/absence of formal channels for civil society participation in the health care system; the extent and type of investment in the health care system; the extent and type of investment in the health care system; and political climate/legal regulations that impinge on NGO formation, scope of activities, and fundraising possibilities.

The findings and analysis put forth in this study are exploratory ones based on descriptive methodology and qualitative analysis, which have their inherent limitations. Although the sample size of NGOs scored in this study was robust, the methods for defining the sample of NGOs and countries may have introduced biases and limitations to our results and conclusions. Further studies are necessary to better understand the relationship between the organizational features and programmatic emphases of breast cancer civil society organizations, and the socioeconomic and political contexts in which they operate.

Similar studies with larger samples of NGOs in greater numbers of countries, combined with appropriate statistical analysis would be a fruitful avenue of inquiry to provide more detailed insights into the important and context-specific roles of NGOs in breast cancer control. Additionally, conducting future studies with the use of more fine-grained resource classification systems that are health care system-specific and/or breast cancer-specific (e.g., a system based on BHGI’s distinctions between basic, limited, enhanced, and maximal resource levels) might yield more nuanced and novel insights.

Despite the limitations of the data and methods employed in this study, it provides an unprecedented, broad scale exploration of breast cancer civil society in different resource scenarios. By understanding the profile and scope of breast cancer civil society in different resource settings it is possible to support and leverage its contribution to effective breast cancer control. Strong breast cancer civil society promotes survivorship and patient empowerment, fosters a more patient-centered understanding of and approach to breast care, and progressively politicizes the personal breast cancer experience to drive system change. Unlocking its potential and bolstering the breast cancer movement will help raise awareness and increase the political will—and funding—necessary to shift resource levels and subsequently improve breast cancer health care services and rights, as well as address disparities in access to care and outcomes.

**Contributors**

GA conceptualized and designed the paper, collected and analyzed data, drafted methods, part of the introduction and results, case studies and conclusion. LPB drafted case studies relating to Asia and Africa, collected and analyzed data, helped conceptualize the paper and offered feedback on the manuscript. MC wrote the case study on IMAMA, offered feedback on the manuscript. RS drafted part of the introduction and revised the manuscript critically. LP wrote the case study on Campaigning for Cancer and offered feedback on the manuscript. AD conceptualized and designed the paper, drafted summary, offered feedback on the manuscript. CPP conceptualized and designed the paper, collected and analyzed data, and wrote part of results and discussion. All authors approved the final manuscript.

**Conflict of interest and funding statement**

The authors report no conflict of interest. The NGO projects that serve as the basis for the analysis of this article were supported by a wide range of funding sources, none of which played any role in the development of this article, and the results and conclusions set forth herein.

**References**


