

The role of breast cancer civil society in different resource settings

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A B S T R A C T

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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.

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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.

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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).

Table 1
Definitions of Program Activities.

Program Activity	Definition
Community awareness	Organization engages in breast cancer educational and awareness activities in specific communities, including presentations, lectures, meetings, and public events.
Information	Organization provides print or web-based informational materials to patients and/or general public on breast cancer.
Direct medical services	Organization provides cancer screening/diagnostic services, treatment (e.g., surgery, radiotherapy, and chemotherapy), and/or medication.
Early detection campaigns	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).
Basic material provision	Organization provides non-financial, material support (e.g., bras, wigs, prosthesis, and lymphedema sleeves) to address or ameliorate effects of cancer and cancer treatment.
Research	Organization is directly engaged in clinical or basic research or provides extramural support for such research.
Emotional support	Organization provides professional counseling services, organizes group therapy, and/or coordinates informal emotional support from survivors or other volunteers.
Financial support	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).
Advocacy	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.
Legal rights	Organization provides information or counseling on legal rights, and/or represent patients in legal procedures.

Data analysis

Simple descriptive statistics were used to analyze and present the data. The percentage of NGOs within each of the four country income categories exhibiting each organizational feature and program activity were calculated.

Results

Organizational features

Of the 154 NGOs, 10 were in low income countries, 34 in lower-middle income countries, 62 in upper-middle income countries and 48 in high income countries. Organizational features examined included founders, hospital association, type of health focus (i.e., general, cancer, or breast cancer), and engagement in coalitions (Table 2).

Of the NGOs with breast cancer in their mission in low income countries 70% were founded by health care professions. In lower-middle income groups 68% of NGOs were founded by health care professions, while 40% in upper-middle and 31% in high income countries were founded by health care professionals. Breast cancer survivors were more common as organizational founders in high income countries (70%) than in upper-middle (53%), lower-middle (35%), and low income countries (30%). NGOs associated with hospitals were more likely in low (50%) and lower-middle (35%) income countries, than in upper-middle (8%) and high income (10%) countries. The primary focus of NGOs was more likely to be general health in low (50%) and lower-middle (35%) than in upper-middle (11%) or high (2%) income countries, while more likely to be breast cancer-specific in high (60%), than in upper-middle (48%), lower-middle (35%), and low (40%) income countries.

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 2
Organizational Features and Program Activities of NGOs Working in the Breast Cancer Arena by Country Income Classification.

NGO Organizational and Program Features	World Bank Country Income Classification (2009)			
	Low Income	Lower–Middle Income	Upper–Middle Income	High Income
	n = 10	n = 34	n = 62	n = 48
Organizational Features				
Health care professional founded	7 (70%)	23 (68%)	25 (40%)	15 (31%)
Breast cancer survivor founded	3 (30%)	12 (35%)	33 (53%)	33 (69%)
Hospital Associated	5 (50%)	12 (35%)	5 (8%)	5 (10%)
Type of organization focus				
General health	5 (50%)	12 (35%)	7 (11%)	1 (2%)
General cancer	1 (10%)	10 (29%)	25 (40%)	18 (38%)
Breast cancer-specific	4 (40%)	12 (35%)	30 (48%)	29 (60%)
Coalition	1 (10%)	2 (6%)	4 (6%)	7 (15%)
Advocacy coalition	0 (0%)	1 (3%)	4 (6%)	7 (15%)
Program Activity				
Information	10 (100%)	22 (65%)	47 (76%)	36 (75%)
Community awareness	9 (90%)	26 (76%)	47 (76%)	26 (54%)
Early detection campaigns	8 (80%)	24 (71%)	47 (76%)	25 (52%)
Direct medical services	6 (60%)	18 (53%)	16 (26%)	5 (10%)
Emotional support	4 (40%)	15 (44%)	37 (60%)	24 (50%)
Research	4 (40%)	5 (15%)	6 (10%)	23 (48%)
Basic material provision	3 (30%)	14 (41%)	27 (44%)	14 (29%)
Advocacy	3 (30%)	9 (26%)	19 (31%)	22 (46%)
Financial support	1 (10%)	9 (26%)	12 (19%)	9 (19%)
Legal rights	0 (0%)	0 (0%)	14 (23%)	17 (35%)

*Bold indicates top programs.

medical services (53%), emotional support (44%), and basic material provision (41%). For NGOs in upper-middle income countries, information (76%), community awareness (76%), early detection campaigns (76%), emotional support (60%), and basic material provision (44%) were the most common programmatic activities. Lastly, the most common program activities for NGOs in high income countries were information (75%), community awareness (54%), early detection campaigns (52%), emotional support (50%), research (48%), and advocacy (46%).

Discussion

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 existent 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, prosthesis 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).¹⁰ A *breast cancer fatalism 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 seeding 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.

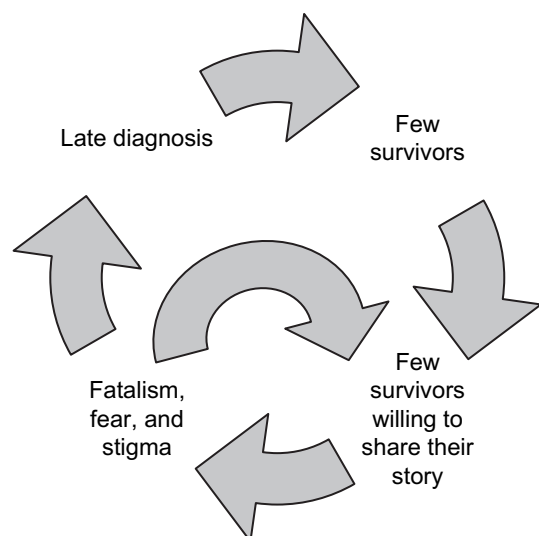


Fig. 1. Breast cancer fatalism cycle.

Table 3
Examples of NGO Breast Cancer Programs in Low Income Countries.

Community Awareness and Information—Tanzania
The Medical Women Association of Tanzania <i>Founder:</i> Health care professionals. <i>Collaborator:</i> Public health association of Tanzania. <i>Activities:</i> Educates journalists and disseminates evidence-based cancer information to increase public awareness on common cancers in Tanzania (including breast and cervical cancers), breaking down myths and misconceptions and promoting health-seeking behaviors.
Direct Services—Ghana
Breast Care International <i>Founder:</i> Specialist in breast pathology. <i>Collaborator:</i> Peace and Love Hospital. <i>Activities:</i> Counseling center (help dispel myths about breast cancer; connects survivors with newly diagnosed patients) and education (breast cancer and BSE); CBE center and mammography and treatment center.

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

Table 4
Examples of NGO Breast Cancer Programs in Lower-Middle Income Countries.

Early Detection Campaigns, Information, and Direct Services—Thailand
Queen Sirkkit Center for Breast Cancer <i>Founder:</i> Breast surgeon. <i>Collaborators:</i> Community leaders. <i>Activities:</i> Breast cancer survivors work with breast nurse counselors and gynecology nurses to visit Bangkok slums, liaising with community leaders to teach breast and cervical cancer awareness and offer CBE and cervical cancer screenings.
Survivor Support and Early Detection—Philippines
ICanServe <i>Founder:</i> High profile journalist breast cancer survivor. <i>Collaborator:</i> Mayor of Marikina city. <i>Activities:</i> Empowers women by leveraging survivors and provides information to enable patients to have a voice in their health care. Publishes a resource guide for breast cancer survivors. Provides a directory of cancer support groups, hospice care and community resources. Breast cancer screening program 'Ating Dibdibin' promoted breast cancer early detection; measured awareness and attitudes of Marikina women regarding breast cancer, launched an awareness media campaign led by a local celebrity, trained local medical staff and community health workers on early detection techniques, collaborated with the local medical center and diagnostic services to screen women with CBE for free.
Direct Services, Financial support—Nicaragua
Fundacion Ortiz Gurdian <i>Founder:</i> Breast cancer survivor. <i>Collaborators:</i> Hospital Berta Calderon Roque, Ministry of Health. <i>Activities:</i> Financial assistance for the chemotherapy and hormonal therapy treatment (for a defined number of women in need).
Early Detection, Direct Services (referrals), Advocacy—Nigeria
Preventive Healthcare Initiative <i>Founder:</i> 5 member Board of Trustees (i.e. retired School Teacher, Medical Practitioner, Lawyer, Banker and Social Scientist) <i>Activities:</i> Early detection, including health worker trainings. Recruited nurses in Port Harcourt to participate in workshops on CBE resulting in increased confidence in performing CBE and commitment to training colleagues. Breast cancer survivors resulting of the initiative have proposed starting a breast cancer NGO.

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

breast cancer, sexuality, and dealing with lymphedema). Compared to low income and lower-middle income countries, upper-middle ones have more survivors available (and willing) to champion and participate in more robust peer-support programs. As a reflection of this, emotional support provided for patients is more prominent and tends to be more expansive, including support groups for women with metastatic breast cancer. Legal support programs to defend individual patient rights, which were found to be absent in low income and lower-middle income countries, are present in upper-middle income countries.

Taking patient advocacy one step further, in some cases, 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.

Emotional Support—Argentina
MACMA <i>Founder:</i> Breast cancer survivor. <i>Activities:</i> Provides emotional support groups 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).
Information and Advocacy—South Africa
Campaigning for Cancer (C4C) <i>Founder:</i> 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 own access to treatment options. <i>Activities:</i> 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.
Information, Early Detection Campaigns, and Advocacy—Mexico
Mexico Fundación Cim*ab <i>Founder:</i> Two high profile breast cancer survivors who had access to private health care. <i>Collaborators:</i> 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. <i>Activities:</i> 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.
Advocacy and Information—Brazil
IMAMA/FEMAMA <i>Founder:</i> Breast specialist. <i>Collaborators:</i> In 2006 founded FEMAMA, a Brazilian advocacy coalition (in 18 states and with 44 member NGOs). <i>Activities:</i> 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': multisectorial entities to oversee the implementation of local breast cancer policies.

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.

Advocacy—European Countries
Europa Donna <i>Founder:</i> The founder had a personal experience of a breast cancer misdiagnosis. <i>Activities:</i> Lobbies European Parliamentarians in Brussels to ensure breast cancer 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.
Advocacy, Information, Research—UK
Breakthrough Breast Cancer <i>Founder:</i> The NGO was founded in memory of a breast cancer patient. <i>Activities:</i> Dedicated to advocacy, research and education. Grassroots advocates campaign on local and national issues. Organizes an annual lobbying event, the Westminster Fly-In, where advocates are trained (practical campaigning skills, specific breast cancer issues, speaking to the media) and meet with their elected Members of Parliament to put forward specific breast cancer policy asks. Occupies different channels for civil society participation in local and national decision making. Grassroots are also leveraged to input into the organization's research agenda and intramural research. Provides information on patient services available by legal right.
Advocacy—USA
American Cancer Society's Cancer Advocacy Network (ACS CAN) <i>Activities:</i> 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. <i>Example:</i> 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 "Don't let the Senate leave women exposed" 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 8600 phone calls to Senators. The bill was blocked.
Advocacy—USA
USA, National Breast Cancer Coalition (NBCC) <i>Founder:</i> Founded by a breast cancer survivor. <i>Activities:</i> 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.
Advocacy, Research—USA
Susan G. Komen for the Cure® <i>Founder:</i> Founded by the sister of a breast cancer patient. <i>Activities:</i> Funds breast cancer research. Offers community grants that focus on breast health education, screening and treatment for the medically underserved. Sponsors 'Race for the Cure', a community walk. Raises funds through partnerships with businesses (cause-related marketing) where a percentage of product sales revert to the NGO.
Advocacy and Information—USA
Young Survival Coalition <i>Founder:</i> 3 young breast cancer survivors. <i>Activities:</i> 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.

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 in 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 spokespeople. 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.³ 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 health from international development and donor agencies; 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

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