

Experiences of Breast Cancer Survivor-Advocates and Advocates in Countries with Limited Resources: A Shared Journey in Breast Cancer Advocacy

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■ **Abstract:** The last decade has been marked by rapid growth in the breast cancer advocacy movement around the world. Today such movements are well established in North America and western Europe, and are emerging and gaining momentum in regions of the world with limited resources—Africa, Asia, eastern Europe, and Latin America. Internationally breast cancer advocates have faced the challenges of dealing with many languages, cultures, countries, and health systems. Because of these differences, existing models of breast cancer advocacy are not always appropriate or reproducible across countries. At the second biennial Global Summit Consensus Conference on International Breast Health Care, 12 breast cancer survivor-advocates and advocates from around the world gave statements describing the experiences of women with breast cancer and with advocacy in their countries, and attended a roundtable meeting to discuss breast cancer advocacy from a global perspective. We used the “long table” method to analyze their comments and identify common experiences. Although participants came from diverse settings, the analysis revealed five common experiences that were consistent across cultures: 1) the experiences and fears of breast cancer survivors, 2) beliefs and taboos about breast cancer that hinder awareness programs and treatment, 3) the need for public education and breast cancer awareness programs in countries with limited resources, 4) difficulty in translating the concept and ethos of advocacy into many languages, and 5) the experiences in establishing and maintaining advocacy groups to promote breast cancer awareness and to inform public policy. These themes constitute an action agenda for breast cancer advocacy groups in countries with limited resources. In addition, they provide invaluable insight for policymakers, program planners, and others undertaking efforts to improve breast cancer outcomes in low-resource settings. ■

Key Words: advocacy, breast cancer, international health problems, language, life change events, life experiences, politics, social support, support groups, terminology

The women’s health advocacy movement began in many countries during the second half of the 20th century. However, organizations by and for patients with breast cancer that provide support and information for patients have been active since the 1950s. In 1952, the American Cancer Society started the Reach to Recovery program. This was a group of women helping women: survivors of breast cancer helping women with newly diagnosed disease. Members of Reach to Recovery, all of whom had had mastectomies, provided a support group for women who had mastectomies. This organization continues today as an international organization supporting women throughout the world (1).

The politics of breast cancer accelerated in the United States in the 1970s and 1980s, when well-known women

such as Betty Ford, Nancy Reagan, Happy Rockefeller, and Shirley Temple Black began to speak out about their experiences with the disease (2,3). As survivor-advocates, these American women helped raise public awareness about breast cancer and the need for early detection programs. Women increasingly identified themselves publicly as survivors. Breast cancer advocacy further developed as dedicated breast cancer advocacy organizations such as Y-ME, the Susan G. Komen Breast Cancer Foundation, the National Alliance of Breast Cancer Organizations, and the National Breast Cancer Coalition added a political dimension to the provision of breast cancer information and support (3). Today, breast cancer advocacy movements are generally well established in North America and western Europe. The movement in the United States, one of the most successful worldwide, provides a good example of the development of a breast cancer advocacy movement and its power to improve breast health care.

During the 1980s and 1990s, organizations that advocate on behalf of breast cancer championed the Mammography

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Quality Standards Act, the establishment of a special fund in the U.S. Department of the Army for breast cancer research, the establishment and expansion of the Centers for Disease Control and Prevention's Breast and Cervical Cancer Early Detection Program, and extensive increases in federal funding for the National Cancer Institute. For example, during the 1990s, federal government funding for breast cancer research increased from \$81 million to more than \$400 million (4,5).

Internationally breast cancer advocates have faced the challenges of dealing with many languages, cultures, countries, and health systems. In particular, in many cultures it is difficult to transcend ethnic and religious differences to break the silence and profound stigma that still surround breast cancer. Because of these many differences, the model of breast cancer advocacy generally endorsed in the United States is not always appropriate or reproducible in other cultures, suggesting the need for alternative models. In addition, the experiences of breast cancer survivor-advocates and advocates in countries with limited resources differ significantly from those in developed countries. Although there is an emerging sense of global breast cancer advocacy, the growth of the advocacy movement in countries with limited resources is somewhat hindered by the difficulty of translating the ethos of advocacy into many languages and cultures. Furthermore, resource-constrained countries have differing financial needs, resource limitations, social barriers, and competing illnesses that frame how breast cancer advocacy can be implemented.

To identify commonalities and differences in the experiences of breast cancer and in the development of breast cancer advocacy movements in limited-resource settings, we undertook a qualitative analysis of statements and comments provided by breast cancer survivor-advocates and advocates at a recent international summit.

METHODS

The second biennial Global Summit Consensus Conference on International Breast Health Care (hereafter referred to as the 2005 Global Summit), sponsored by the Fred Hutchinson Cancer Research Center, cosponsored by the Susan G. Komen Breast Cancer Foundation, and hosted by the Office of International Affairs, National Cancer Institute, provided a forum for the voice of breast cancer survivor-advocates and advocates from countries with limited resources. (For the purposes of this article, survivor-advocates are defined as breast cancer survivors who work in partnership with a community-based group or organization of survivors.)

Each of four sessions of the summit began with a 15-minute introductory statement by a breast cancer survivor-advocate or advocate from a country with limited resources in which she described her own experience or that of women from her country with breast cancer and advocacy. In addition, a 2-hour Advocates Roundtable Meeting provided an opportunity for survivor-advocates and other breast cancer advocates from around the world to discuss breast cancer advocacy from a global perspective. The meeting was facilitated by a representative of the Komen Foundation (D.R.) and was attended by 12 participants, each representing a different country (Belarus, Brazil, Canada, Chile, China, Ghana, Greece, India, Italy, Kenya, Malaysia, and the United States).

In an effort to understand the commonalities and differences in experiences of breast cancer survivor-advocates and advocates from countries with limited resources, we analyzed the introductory statements from the summit sessions and the transcripts from the roundtable discussion for themes. For analysis, we used a low-technology "long table" technique suggested by Krueger (6), which permits analysis of content to identify themes and categorize results.

RESULTS AND DISCUSSION

The introductory statements of the breast cancer survivor-advocates and advocates were a powerful addition to the proceedings of the 2005 Global Summit. The stories of these quietly eloquent women illuminated the connectedness of breast cancer survivors and their advocacy efforts around the world. Similarly, although participants in the roundtable meeting noted some differences between their countries in breast cancer experiences and advocacy movements, the commonalities were striking.

Overall, five major themes emerged from the analysis of the statements and the transcript that reflected common experiences of breast cancer survivor-advocates and of advocates worldwide:

- Common experiences and fears of breast cancer survivors
- Beliefs and taboos about breast cancer that hinder awareness programs and treatment
- The universal need for public education and breast cancer awareness programs in countries with limited resources
- The shared problems with language and difficulty translating the concept and ethos of advocacy into many languages
- Common experiences in establishing and maintaining advocacy groups to promote breast cancer awareness and to inform public policy

Experiences and Fears of Survivors

The experiences of breast cancer survivor-advocates from countries with limited resources were reflected in the statements and transcripts. Participants' comments indicated that the commonality of the experience of breast cancer survivors led to the development of support groups. Specifically, survivor-advocates and advocates recognized the need to provide emotional support and education for breast cancer survivors and to provide testimony "to the power of life." Certain issues are universal for all women with breast cancer, irrespective of age, ethnic group, nationality, or stage of disease, and this universality of the experience of breast cancer was reflected in the comments of survivor-advocates.

I was thinking that breast cancer is the same disease for every woman all over the world, we were survivors. Maybe we felt the same way and we suffer the same, but one of the things I'm taking back home is that we are also different—each country, each culture has a different approach, even when you speak about countries of limited resources.

I'm a breast cancer survivor, five years now, and I am also a breast health advocate. I'm with an organization called the Kenya Breast Health Program. This is basically the only advocacy group for breast health in my country, and I likely got involved with Kenya Breast Health Program at its formation, basically as a result of my experience with breast cancer.

Along with common concerns, experiences, and anxieties, each woman's journey with breast cancer has a unique set of circumstances. A frequent common experience and expression of survivor-advocates was that of fear. They described the personal fear that a woman experiences after receiving a diagnosis of breast cancer, as well as the societal fear manifested in the response by family members and neighbors:

One of the greatest fears expressed by almost all newly diagnosed breast cancer patients is ... am I going to die?

Overcoming fear when alone is not easy ... one feels no longer accepted.... The word cancer terrified me.

A woman's journey in breast cancer in a developing country has a long way to go. For many years, people in developing countries have perceived breast cancer as a frightening disease surrounded by fear and myths.

Avoiding awareness programs and information on this disease as a result of fear has worsened the plight of breast cancer patients in developing countries.

Survivor-advocates and advocates also identified common themes related to the changes in body image associated with mastectomy. In addition, they noted how women with breast cancer must assimilate into their lives the physical scars of treatment, emotional distress, and disruption in family relations. They identified the need for information about prostheses and the need for emotional support for breast cancer patients.

The loss of a breast is a terrifying jolt to one's body image.

Breast cancer creates an identity crisis with the initial loss of body image. Encouragement, hope, and emotional support from loved ones, family, friends, someone with a common experience, and health care professionals can help prevent social isolation and social discrimination, which can be devastating.

Beliefs and Taboos about Breast Cancer

Several survivor-advocates and advocates identified traditional societal beliefs and cultural taboos that affected women's access to information, early detection, and treatment. They noted how these beliefs may result in social isolation for women with breast cancer. In addition, their comments suggested that cultural attitudes and taboos, especially beliefs of fatalism, may deter breast cancer advocacy efforts:

Traditional beliefs dominate the Asian lifestyle. Negative attitude of society toward cancer can be a greater killer than the disease itself. The woman is made to feel guilty that she has brought "bad genes" into the family. She keeps her disease under wraps just to avoid social rejection and social isolation. In some cases she is isolated from her family members, whereby her dining utensils are separated, fearing that she will "spread the disease to the rest of the family members."

I will never give up to those who suggested that when you get close to a disease or have something to do with it, it will follow or it will affect your family.

Cancer, if you talk about cancer, it comes into your house or if you go to the doctor to be examined for breast cancer, you end up with breast cancer. If you don't go, you won't get breast cancer.

Need for Public Education and Awareness Programs

Breast cancer survivor-advocates and advocates identified the need for culturally appropriate breast health awareness programs and problems with competing for scarce resources in the face of the burden of communicable diseases in countries with limited resources. Participants from such countries had a heightened awareness of disparities in access to diagnostic and treatment facilities that lead to late presentations of the disease:

Most women in developing countries know very little about breast cancer and its warning signs, and as a result go to hospital for treatment when it is rather too late to get cured.

We have a problem with awareness, we have stigmatization, we have all those and end up leading to late presentations, and we have lack of diagnostic facilities, lack of treatment facilities, financing constraints for the women, competition for resources. HIV/AIDS is a major problem, so you talk about breast cancer and say how many people are dying, and they say HIV, they're always quoting figures, 700 people per day, and they say, "Wow, this is the problem. Breast cancer, that's not a problem.

Difficulty in Translating the Concept of Advocacy

Advocacy in the English language is generally interpreted as the art of representing or promoting a cause or purpose on behalf of oneself or others. This may include increasing awareness, influencing policy, affecting legislation, and changing attitudes. Traditionally patient advocacy has involved pleading on behalf of patients' needs. Yet the word advocacy is not directly translatable in many languages (3,4). This difficulty with translation was a theme that emerged from the analysis of comments. Participants in the advocacy roundtable identified the need to develop an international word or language for advocacy that would reflect the broad range of activities and approaches generally interpreted as breast cancer advocacy. In addition, participants noted that in developing countries, women may not have open access to resources, information, or education that empowers them to implement change and promote advocacy.

I must say that the word advocacy is absolutely new for me.

What I'm trying to do is find what the word advocacy means exactly in Spanish. I know what it means, but

I'm trying to find the exact meaning, not the exact word, but the exact meaning.

We still don't have in Portuguese a word for advocacy, and it's a big problem because we cannot say "advogados"—or lawyers, it would mean—because we are not. We must find a word for this, outside English word, because we cannot say "advogados" or something like that. I don't know. We have to think as a group because I'm sure in Spanish and Italian, Latin countries have this problem of the word and we have to make it like an international word.

We don't have a word for advocacy, it's exactly the same as what you say it may mean, that you are a lawyer or something like that, and you have to have that qualification to be one. So the word we use is networking and influencing.

There were not rules that could regulate volunteer work, nobody was talking about social responsibility or advocacy was just out of question. It was a bunch of women that were shouting about something, just no credit whatsoever.

Experiences in Establishing and Developing Advocacy Groups

Although there was apparent difficulty with defining advocacy, breast cancer survivor-advocates and advocates identified common bonds, challenges, and steps that propelled their efforts forward. Their comments reflected the incremental nature of breast cancer advocacy and movement along a continuum from support and education, to developing social responsibility, and finally to influencing change. The burdens and hurdles on the road to breast cancer advocacy were reflected in their comments:

So we decided that we have to work towards some other issues, not just giving support to the women themselves, and from there we started doing a little bit of advocacy work.

We started with six people and this was '93 and things really moved fast, and we start after 2 years we became official Brazilian kind of educational group, volunteer educational group, at that time volunteer work was not accepted in Brazil because we're intruders in hospitals.

So we came up with the idea that we need some form of guideline so that we make sure that everybody is

trying to do something that is normal, or acceptable, so eventually we lobbied the ministry to set up what they call a breast cancer working group.

The message of breast cancer advocacy has been spreading throughout the world. In the early 1990s, EUROPA DONNA, the European Breast Cancer Coalition, was formed. The emergence of breast cancer advocacy throughout Europe can be traced through the development of EUROPA DONNA, a coalition of affiliated groups for countries across Europe (2). Similarly, Reach to Recovery has grown into an international network of survivor-advocates that includes 84 groups in 50 countries. While some are mature groups, the majority are new groups from Africa, Asia, eastern Europe, and Latin America who need help in establishing support services (1).

In the late 1990s, the Komen Foundation began to develop international affiliates in countries that were interested in implementing Komen activities, such as the Race for the Cure. Today the Komen Foundation has three international affiliates—in Germany, Italy, and Puerto Rico—that fund grants and carry out breast cancer education programs. In addition, the foundation has made grants to nongovernmental organizations (NGOs) in more than 30 countries to support a range of breast cancer education, outreach, and support programs. Representatives from several of these organizations participated in the advocacy roundtable discussion and shared their experiences. They remarked that financial support from foundations and NGOs had been helpful in furthering their activities

So you need some luck in life, and my lucky occasion came in 1998 when I had the privilege and fortune to cross roads with the Komen Foundation, very, very early when they were starting to become an international organization or at least to start some international efforts.

And we have had really the fortune to look at a wonderful model that in the United States has created, really a switch in the way breast cancer is addressed and see how we could apply at least some part of this model in Italy, through innovation and new strategies, trying not to duplicate efforts that were already there, but creating new opportunities. And in 5 years, we have been able to become self-sufficient, we generate money that allows [us] to fund, we have supported 50 programs of other breast cancer groups in Italy, in small possibly groups that would have good ideas but not have access to funding, so that at the local level, the community

level, this is helping women with breast cancer to have something more to face this disease better.

CONCLUSIONS

The last decade has been marked by rapid growth in the breast cancer advocacy movement around the world. There has been a shift in the activities of survivor-advocates and advocates as breast cancer advocacy campaigns have increased in intensity in regions with limited resources including Africa, Asia, eastern Europe, and Latin America. The practice of breast cancer advocacy has increasingly become international, with sustained, effective collaboration among groups. The goals and methods of these campaigns may vary with the social, economic, and cultural circumstances of the countries and women involved. Despite this diversity, survivor-advocates and advocates at the 2005 Global Summit voiced a set of common themes in international breast cancer advocacy that reflected their shared journey with breast cancer.

By virtue of their personal life experiences, breast cancer survivor-advocates possess unique insights regarding the complex sociocultural issues that may hinder the implementation of breast health awareness and early detection programs in countries with limited resources. Survivor-advocates and advocates at the summit expressed common themes pertaining to the experience of breast cancer, including societal fear of the disease, cultural taboos and myths, and a lack of adequate educational resources. Their statements indicated that these factors can be major barriers to breast health awareness and early detection programs in countries with limited resources. Their experiences are consistent with the findings of several studies that have documented that fear, perceptions, and lack of knowledge are obstacles to breast cancer screening (7–9). To successfully recruit women to breast health awareness and early detection programs, such programs must take into consideration women's perceptions and cultural beliefs about breast cancer. Participants' comments indicated that these perceptions and beliefs vary among countries and population groups, necessitating a tailored approach to program design. The impact of effective programs is potentially large, as participants' comments expressed confidence that such programs could contribute to improved survivorship for women with breast cancer.

Although the word *advocacy* is not directly translatable in many languages, the role of breast cancer survivor-advocates and advocates appears to be universal. Participants in the Advocacy Roundtable strongly believed that

with the assistance of governmental and NGOs, breast cancer advocacy groups can continue to create change. In partnership with organizations such as Reach to Recovery International, the Komen Foundation, and the medical community, survivor-advocates and advocates may be instrumental in establishing effective breast health awareness programs as well as breast cancer research programs that cross social, economic, and cultural boundaries in countries with limited resources (9).

Breast cancer advocacy can have a marked positive influence on societal awareness of and attitudes toward the disease, on breast health care services, and on funding for research (3). However, establishing and expanding advocacy groups in countries with limited resources may be especially challenging. Resource-constrained countries have limitations in financial support, social barriers, and competing illnesses that frame how breast cancer advocacy can be implemented. Comments made by survivor-advocates and advocates at the summit indicated that they have a deep understanding of the barriers to developing breast cancer advocacy in such countries. These individuals are nonetheless motivated to integrate their insights and experiences to support and maintain advocacy groups. Given the potential of advocacy movements to improve breast health outcomes, the founding and growth of advocacy groups should be fostered in countries with limited resources.

Taken together, the five themes we identified constitute an action agenda for breast cancer advocacy groups in countries with limited resources. In particular, the survivor-advocates' and advocates' comments revealed barriers and challenges to breast health care and breast cancer advocacy, but at the same time suggested potential strategies for overcoming them. The themes also provide invaluable insight to policymakers, program planners, and others undertaking efforts to improve breast cancer outcomes in such settings.

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