

**Qualitative Assessment of Breast Cancer Advocates in Bolivia, Colombia,
Ecuador and Peru**

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Abstract

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Breast cancer mortality is higher in low- and middle-income countries than high-income countries due to lack of awareness about the benefits of early detection and treatment, late-stage diagnosis and limited access to care. Advocacy and education are essential to addressing these underlying causes. We interviewed a total of 15 breast cancer survivors and advocates, and conducted a focus group with 12 advocates from Bolivia, Colombia, Ecuador and Peru to explore local efforts and collaboration between advocacy organizations. We examined advocates' perceptions of challenges across country contexts, socioeconomic status, and financial assistance to determine the state of advocacy groups in South America. Despite the participants' diversity, we isolated four experiences consistent across countries: 1) Advocates observed patients' mistrust around treatment of breast cancer and their role of advocacy in the context of disease; 2) poor data collection on the value of advocacy; and 3) lack of funding and political support hampered efforts to establish and maintain breast cancer advocacy groups. These themes could help informing an action agenda for regional breast cancer advocacy groups, and provide insight for policymakers, program planners, and advocates for improving breast cancer outcomes.

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INTRODUCTION

Worldwide, breast cancer cases have more than doubled over the past three decades -- from 641,000 in 1980 to 1.67 million in 2012. (1, 2) Breast cancer is the most prevalent cancer for women worldwide, and more than half of newly diagnosed breast cancers occur in low- and middle- income countries. (2) Despite lower incidence rates in low- and middle-income countries (LMICs), breast cancer fatalities are significantly higher than in high-income countries. (3) WHO's global cancer projections estimate that by 2015 LMICs will account for 80% of the increase in all cancer deaths. (4) Ignorance of the benefits of early detection and treatment, late-stage diagnosis and limited access to care are associated with higher mortality rates in low-resource settings. (5) U.S. breast cancer outcomes have improved remarkably over the last 60 years because of advances in early detection and treatment. However, the U.S. case-fatality rate declined by 36% before the introduction of mammography and adjuvant therapy, suggesting that LMICs can improve outcomes in the absence of mammography and adjuvant therapy. Specifically, breast cancer data prior to 1974 attribute improved outcomes to increased awareness, effective education, palpable tumor detection and improved diagnostics. (5)

About 114,900 women living in Latin America are diagnosed with breast cancer annually, and 37,000 die of the disease. (2) Age-standardized incidence rates per 100,000 women in Colombia, Ecuador and Perú are 31.2, 30.8 and 34.0 respectively -- a lower incidence than Asia and Africa and slightly lower than Central and Eastern Europe. (2) In Bolivia, 26.57% of every 100,000 women develop breast cancer, and 8.71% prove fatal. (6) Breast cancer has the highest mortality among women's cancers in Latin America, accounting for 14% of cancer deaths. Breast cancer incidence and mortality have steadily increased in the area

during the past 25–30 years (7).

Public health in Latin America has been improving over the past decade due in part to increased access to health care services. However, health insurance coverage and geography affect access to and quality of breast cancer care due to an uneven allocation of resources (e.g. equipment and infrastructure) and a higher concentration of specialists in large urban centers. (8) Differences in access exist even within a particular insurance pool, because patients who do not reside in urban areas are forced to cover non-medical fees (e.g., transportation, temporary housing and meals) whenever cancer treatment is not available locally. (9) In Colombia, public and private sectors are integrated to extend healthcare coverage, which reached 96% of the population in 2013 compared to 85% in 2008. (10) Since 2004, Colombia's mandatory health plan has provided the poor with subsidies for cancer treatment carrying specific entitlements, such as free breast clinical examination and mammogram starting at age 50 and chemo/radiotherapy for cancer patients. Some specialty visits, testing, medications, oncological and reconstructive surgery are also covered along with a small patient co-pay. Homeless, indigenous and displaced populations can access to these health services entirely free. (11) (12) In Peru, 64% of the population depends on public health insurance, (9) which covers breast cancer screening (clinical exam, mammogram but not treatment). Bolivia's national payer system aims for universal coverage. (13) However, cancer prevention, detection and treatment in Bolivia are in their infancy, and palliative care is extremely limited. Services are scattered among major cities, without coordination between oncology units and without reliable national statistics. (6) Ecuador's health sector remains segmented and fragmented, and public healthcare insurance provides only screening for 30% of the population. (14)

Advocacy and awareness building are critical to improving access to and implementation of breast cancer screening and treatment. The breast cancer advocacy movement in North America and Western Europe has proven to be a powerful force for advancing cancer control.(15) Advocates and organizations, such as the U.S.'s Susan G. Komen organization, are critical in raising awareness, engaging and educating the public, raising private funds, advocating for legislation for improving cancer care, prevention and increasing funding for breast cancer research and the U.S. National Cancer Institute (NCI). However, funding in North America and Western Europe increased significantly only when advocates joined forces. (15) Coalitions and networks outpaced individual organizations in part because they demonstrated united support for an issue and allowed organizations to collaborate on shared goals by coordinating strategies, resources, expertise and connections. In 1990, the U.S. National Breast Cancer Coalition (NBCC) united hundreds of breast cancer organizations under one umbrella to lobby for policy change. In contrast, South American breast cancer advocacy has, to date, failed to achieve the same level of cohesion. Currently there are over a dozen of breast cancer advocacy organizations in the region, most concentrated in Argentina, Colombian and Brazil. (16) (17) (18) In the Andean region, the development of coalitions and regional networks in advancing cancer control has not advanced quickly. We embarked upon an examination of how local cancer advocates frame the issue, view their scope of work, and engage with other advocacy organizations and stakeholders in order to understand ways to advance cancer advocacy in South America. Interviewing advocates in several countries enabled us to identify common challenges and share strategies for overcoming barriers, lessons-learned and case studies for effective collaboration.

MATERIALS AND METHODS

We employed qualitative methods for this study. We defined advocates as anyone working with breast cancer patient rights, patient representation, awareness building, support and education of patients, survivors and their caregivers. (19) They identify themselves as individuals/organizations that inform the public, the political and regulatory world, health-care providers (hospitals, insurers, pharmaceutical companies etc.), organizations of health-care professionals, the educational world, and the medical and pharmaceutical research communities about breast cancer patient needs. (19) Trained interviewers conducted individual interviews and focus groups in Spanish with Bolivian, Colombian, Ecuadoran and Peruvian breast cancer advocates. We used a semi-structured guide to explore advocates' approaches to advocacy, and collaboration between organizations (Table 1). Advocates also discussed cultural beliefs, attitudes toward traditional or allopathic healthcare providers, their country's cancer-related services, perceived causes of cancer-related illnesses, and anticipated costs of care. All interviews were audio recorded, transcribed and analyzed in Spanish.

Table 1. Interview Questionnaire.

1) What relationships did your cancer work (local, regional, national, international) engender? a. How do you collaborate with similar organizations?
2) Describe your collaborations. a. How were they established? b. What is the purpose/goal of this collaboration? c. What defines the scope of the work? d. In what areas do you collaborate (education, awareness, navigation, support, politics, etc.) and what criteria, if any, govern participation? f. How are collaborations structured/managed? g. What models guide resource collaboration? h. How do you communicate/share ideas?
3) What are your organization's cancer-related objectives (local, national, international)?
4) How do you evaluate the impact of collaborating with other organizations? a. How do you measure impacts and outcomes?
5) Provide success stories resulting from collaborating with those outside the organization.

6) What contributed to this collaboration's success?
7) Tell me what didn't live up to your expectations.
8) What challenges/barriers do you face in working with people or organizations?
9) How would you like to change/improve your efforts? a. What would it take to achieve these changes/improvements?
10) Would connections with cancer organizations in other countries enhance your work? a. Would you like to pursue such a partnership? b. What might be the benefits? c. What could be the disadvantages?

Grounded theory enabled us to identify patterns, and we generated hypotheses as themes emerged. We used a constant comparative method to examine saturation with identified concepts and pinpoint variation among participants. We used nonrandom sampling to include women from different regions (reflecting differing cultural views), and advocacy groups that commonly serve low- to middle-income populations in each country.

We used ATLAS.ti software for thematic analysis of Spanish transcriptions. During the first round of analysis, we identified and qualified common themes and patterns across the narratives using open coding with color highlights. We then conducted a social network analysis of the data to examine how organizational characteristics and inter-organizational relationships related to early collaboration on advocacy activities within coalitions. This analysis helped us describe five types of collaboration among agencies and locate patterns in the data. (20, 21) A network's strength can be measured by network members' commitment to one another as reflected in their engagement in multiple activities. (22) Key informants were survivors or advocates (at least two from each organization) who rated the degree of collaboration from 1 to 5 (five being highest):

“How would you [survivor/advocate] describe the level of collaboration on a scale of 1 to 5

or (1-sharing/communication of information; 2 - cooperation and coordination: joint planning of some projects, 3 - collaboration, joint planning Informal, joint funds, EOM, 4 - consolidation: Formal joint planning, and 5 – funding.”

When two agencies within a network reported that a relationship existed, we considered that to be a strong collaboration. We asked participants whether and how often they engaged in each activity with other agencies in their network and, in the case of information-sharing, referrals, project coordination, and funding sharing, we asked about the frequency and asked them to rank “*Who are the most important people to the success of their work with cancer?*” from 1 – 5 (1 = most support).

The Ethics Committee and the University of Washington Institutional Review Board approved this study. We used an approved script to explain the research and collect participants’ verbal consent.

RESULTS

Participant Characteristics

Fifteen people took part in interviews or the focus group. Participants generally worked with public hospital oncology units in major cities in their home countries, which happened to be state capitals. All identified as breast cancer survivors or cancer patients' relatives. Ages ranged from early thirties to late sixties, more than half had professional degrees and two-thirds worked solely in cancer advocacy. Table 2 outlines detailed demographic information.

Table 2. Demographic Characteristics of Breast Cancer Survivors/Advocates.

Age	<40 = 2 40-50 = 4 50-60 = 5 >60 = 4
Sex	F = 15 (100%)
Urban vs. Rural	Urban = 15 (100%)
Highest education level	Post-secondary = 2 University = 10 Post-graduate = 3
Number of years working as advocate	< 5 = 2 5-10 = 8 >10 = 5
Position within organization	President = 13 Staff = 2

Barriers to Advocacy Work

Theme 1: The participants reported that poor, rural and ethnic minority patients with whom they work often attribute breast cancer to non-biological causes. Such women are often single mothers caring for more than two children, parents or close family members. Breast cancer education does not remove the fear of the non-biological components that it would endure to their family of a diagnosis (financial burden with out of pocket expenses). However, our findings are limited to the population we assessed:

“Patients usually arrive with [perceived cause] rooted on religion; they say they are possessed or someone has cursed them somehow. They also have misconceptions about the treatment, friends and family tell them chemotherapy is going to kill them anyways, once they noticed no one is there to support them, they decide it’s better not to do anything at all.”

Theme 2: Participants expressed concern for the future of their organizations — The government allocates inadequate resources to cancer advocacy, most organizations depend on donations from family and friends, fundraising events, items they sell (i.e. wigs, kerchiefs), pharmaceutical companies and private companies:

“The government doesn’t help, unless you have friends in politics.... Help usually comes from the donations made by family friends or oncologists. Every October, we organize a walk or a fundraising dinner and we are fortunate to have enough to fund our projects for the next year. Pharmaceutical companies provide a lot of partial grants: They usually fund 30% of the project, but we need to find the rest. The other 70% has to be split between private companies that might be willing to help.”

Theme 3: Monitoring and evaluation to measure advocacy impact is lacking locally and nationally —Participants recognized they do not have the training to collect data that could be used to: (1) show progress, (2) enable more or diversified funding, (3) help nonprofits to make more strategic decisions; (4) decide what to advocate for and not just how to do it and (5) to constantly assess their progress and effectiveness:

“The only thing I have is database with basic information about the patients, their demographics, their relationship with the families, how long they stay with us and few more things. We haven’t set specific goals nor measured our outcomes. We rarely review the data we collect [satisfaction surveys]. We play by ear and adjust depending on the resources we have... I’ve never heard of impact evaluation.”

Theme 4: Public education to promote widespread breast cancer awareness is essential — Countries must establish consistent messaging that extends beyond at-risk populations to

generate widespread knowledge of breast cancer. Some advocate groups have incorporated breast cancer awareness into media campaigns:

“We regularly have outreach programs covering self-examination, education and awareness to the healthy population. I also give my testimony to patients who have been diagnosed with metastatic disease. Since I’m in charge of the Foundation’s website, I also do a lot of patient education in Social Media using either Facebook or Twitter.”

Importance of Social Interaction and Networking

Theme 1: Advocates benefit from national and international networks — Advocates value interacting and sharing information. Creating joint initiatives where planning and budgets are available impact the community more effectively. Advocates value when governments and funding agencies acknowledge their work.

“We have a WhatsApp group and communicate with each almost every week asking for advice. We also meet every three months to share experiences not only about education and awareness, but ways to navigate the complicated health system that we have. Sometime, patients are denied certain medications, one of our senior advocates is well regarded at the national level, she knows a lot of people and is a fierce champion. She makes things happen.”

Theme 2: Social interactions and collaborations start by word-of-mouth — More than a dozen advocacy groups are in the region and are usually one degree away from knowing another group. Technology seems to play a role in maintaining these relationships, especially between groups in different countries:

“We developed a strong connection with a Foundation in Ecuador, they reached us initially via e-mail because someone told them we were the largest advocacy foundation in Colombia. They were looking for survivors to model in a runway show they were organizing. This year they’re planning on launching the same event in Los Angeles, I’m very excited about it because it would give our foundation the visibility we need internationally.”

Theme 3: Partnering with clinicians and researchers helps establish relationships and legitimacy — Interpreting medical literature is challenging, especially when dealing with

highly trained clinicians and researchers who share language, research interests, and sometimes collaborations. Social events, such as fundraisers or cancer walks, provide advocates with valuable opportunities to connect with clinicians and researchers:

“Cancer doctors are good to us, they help us preparing our talks and explain to us medical concepts. When they come with us to one of our events, people take us seriously. However, finding willing doctors isn’t easy. We have to knock on many doors first, people don’t believe in foundations, they think we are using it as a shortcut to avoid taxes or to steal.”

Theme 4: National strategies are needed to improve organized advocacy — Advocates bring a perspective to policy development that many policymakers lack, due to the close relationships between advocates, patients and survivors. Advocates are familiar with the system as they often have had personal experiences with cancer (either themselves or relatives):

“The government doesn’t understand our work. Every year I go to governor, to ask for support for our October walk. They instantaneously say ‘no, we don’t have for that,’ they say is not cost-effective, they’ll have to invest money to get nothing in return. For them create breast cancer awareness within the community is not a priority, they don’t seem to get that the event isn’t about the money but the people.”

DISCUSSION

This study reveals some strengths and challenges of cancer advocacy programs in the Andean region. Most participants collaborate with well-established oncology units at public hospitals. Some have structured cancer awareness programs focused on prevention. Identified areas for improvement were: awareness campaigns around treatment benefits, public financing, advocates' training in monitoring and evaluation to establish the necessity and benefit of advocacy, and further integration of patient advocates in medical treatment. Recent literature demonstrates the cost-effectiveness of involving cancer advocates at all phases of breast cancer care and research. (23) Participants' objectives and histories of success indicate that they have a role in individual patient care. In contrast, few advocates reported elements that indicate effective policy advocacy work. For example, their sense of agency was limited by the difficulty of getting public policies passed.

Significant indicators of successful advocacy include understanding their hospitals' organizational culture, having clear short- and long-term objectives, and a well-designed implementation strategy that takes into account the current political context, civil society mobilization, organizational power and leadership development, as well as monitoring and evaluation. This study reinforces that progress is needed to address barriers to advocacy program implementation, such as cultural barriers (treatment is associated with a body mutilation procedure), problematic national data collection (absence of advocacy indicators and poor methodology evaluation), financing inequities (political willingness and public regional/state funds), education (illiteracy and poverty rates), and lack of involvement in medical treatment and policy decisions. (24) (25)

Notably, human resources were not identified as primary limitations. Experts agree that participants striving to implement large-scale, culture-changing maneuvers need to experience early “wins.” (26) Thus, the status of the region’s breast advocacy groups may be most effectively addressed by increasing the real and perceived efficacy of their efforts, specifically by instituting collaborations with clinicians and researchers, giving advocates an valuable role in allocating research funding, disseminating research results to the community, and overseeing health policy implementation.(23) (27)

Hospital staff and political leaders’ inadequate training and effort were underscored as critical barriers to successful breast cancer advocacy by these key stakeholder groups. Ministries of health and hospital administrators could prioritize advocacy, if provided time specifically dedicated to those activities. Moreover robust databases or advocacy organizations that match clinicians /researchers to local and regional advocacy organizations could help engage advocates in cancer care and research processes. Hospitals should allow for a budget to support advocate training, meeting attendance, and compensation.

Advocates are enthusiastic about their experience with social interaction and networking. (28) This suggests that working together may be useful for new programs and regional collaborations given their common language, Spanish colonial history, topography and, more recently, political and economic pact (UNASUR). (29, 30) Ideally, participants favor a regional initiative where seasoned research advocates would train a pipeline of new advocates. However, given the four countries’ economic and demographic differences, advocates need exposure to others’ experiences in indigenous and other marginalized communities, displaced populations and rural areas with limited healthcare access.

Representing diverse experiences, providing greater understanding and appreciation of diversity of beliefs, will ensure cultural competence, which would engender more effective breast cancer care. (31)

LIMITATIONS

The qualitative nature of this study, sample size and potential bias inherent in participant self-selection limit our results. We acknowledge a mistranslation risk in presenting data in English rather than Spanish; however, we analyzed the transcripts in Spanish to minimize bias and translated outstanding quotes into English for manuscript preparation.

CONCLUSIONS

This study of breast cancer advocacy groups in the Andean region of South America provides information important to thinking through steps needed to improve the effectiveness of advocacy organizations in the region. More rigorous monitoring and evaluation must be instituted to assess the value of involving advocates in comprehensive treatment of breast cancer patients. Collaboration with local support groups that have successfully implemented action-oriented advocacy/policy programs may aid in advocacy program maturation as well as publication of successful work in low resource settings. On a global scale, expanding breast cancer advocacy programs internationally could help empower local providers to participate in their health systems as planners, system-thinkers, and agents for change.

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