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Risk, Activism, and Empowerment: Women's Breast Cancer in Venezuela

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Abstract

The prevalence of breast cancer in Venezuela is particularly alarming, which is attributed to healthcare inequalities, low health literacy, and lagging compliance with prevention methods (i.e., screening and mammography). While the right to health is acknowledged by the Venezuelan constitution, activism beyond governmental confines is required to increase women's breast cancer awareness and decrease mortality rates. Through the development of social support and strategic communicative methods enacted by healthcare providers, it may be possible to empower women with the tools necessary for breast cancer prevention. This paper discusses issues surrounding women's breast cancer, such as awareness of the disease and its risks, self-advocacy, and the roles of activists, healthcare providers, and society. Specifically, it describes a four-year action-oriented research project developed in Venezuela, which was a collaborative work among researchers, practitioners, NGOs, patients, journalists, and policymakers. The outcomes include higher levels of awareness and interest among community members and organizations to learn and seek more information about women's breast cancer, better understandings of the communicated messages, more media coverage and medical consultations, increasing positive patient treatments, expansion of networking of NGOs, as well as a widely supported declaration for a national response against breast cancer in Venezuela.

Keywords

Activism; Empowerment; Physician-Patient Communication; Risk; Venezuela; Women's Breast Cancer Awareness

INTRODUCTION

On May 25th, 2005, the World Health Organization (WHO) recognized cancer as a worldwide public health problem; specifically, breast cancer existing as critical (Cazap et al., 2010). Due to the global impact of this disease, research surrounding its prevalence and impact has become increasingly common (e.g., Althuis et al., 2005; Atkin et al., 2008; Burgess et al., 2009). While breast cancer incidence, mortality, and survival rates differ by ethnicity, mortality rate reduction is associated with early detection and screening practices

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(Kudadjie-Gyamfi & Magai, 2008). This disease has become a serious public health concern especially in developing countries, as the application and effectiveness of early detection and diagnosis programs continue to lag (Modeste, Caleb-Drayton & Montgomery, 1999).

Latin Americans are widely impacted by breast cancer, as it is the leading cause of cancer death among this ethnicity (Abraido-Lanza, Chao & Gammon 2004). Breast cancer research in the United States, especially focused on Latin Americans, has become of primary importance, as these women tend to be diagnosed at more advanced stages than any other ethnic group (Hubbell, 2006). Thus, although Latin American women demonstrate a lower incidence of breast cancer, they are more likely than non-Hispanic White women to die from this disease (Lantz et al., 2006). Several studies demonstrate a higher death rate among Hispanic patients when compared to White women, despite the lower incidence of this minority in acquiring the disease (Holt, Lee & Wright, 2008). While health disparities and low health literacy act as barriers to Latin American women's breast cancer screening compliance, various other cultural and socioeconomic factors interact with this issue.

Venezuela, in particular, has a high level of incidence of women's breast cancer, a high mortality rate, and a high number of "years of potential productive life lost" (e.g., International Agency for Research on Cancer, 2008; MPPS, 2008). Although the government has a National Cancer Program that includes the breast cancer sub-program (Nigenda et al., 2011), the prevalent opinion is that the Venezuelan State has neglected this disease and its overall impact on Venezuelan women and their families (Sociedad Venezolana de Mastología, 2010). When compared with other Latin American countries, Venezuela presents some weaknesses (e.g., the absence of a national policy on breast cancer and the lack of a national breast cancer registry program), even though the country has made progress in the incorporation of civil society actors, including non-governmental organizations (NGOs), in the design and implementation of early detection programs (Nigenda et al., 2011).

This paper aims to discuss issues surrounding women's breast cancer such as awareness of the disease and its risks, self-advocacy, and the roles of activists, healthcare providers, and society. In particular, the paper aims to describe an action-oriented research project[1] that we developed in Venezuela about women's breast cancer, which was conducted over a four-year period of collaborative work among researchers, practitioners, NGOs, patients, journalists, and policymakers.[2] It discusses three key objectives of this project: 1) to facilitate the development of advocacy and spokesperson capabilities of survivors and community activists in order to increase their impact in the fight against women's breast cancer in Venezuela; 2) to contribute to closing the gap in the communication between physicians and patients and enhance the conversation between physicians, patients, and activists to define common goals to promote public awareness and advocacy; and 3) to promote the social

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[1] This action-oriented research project was supported by research grants from the Canadian Institutes of Health Research. It also received additional funding from private-sector donors in Venezuela such as Avon Venezuela, Roche, and Novartis.

[2] This four-year (2009–2012) action-oriented research project was developed by Professor Isaac Nahon-Serfaty and Professor Mahmoud Eid from the University of Ottawa (Canada) in partnership with the Venezuelan Breast Cancer NGO, SenosAyuda, with support from Professors Andrés Cañizales, Alfredo Poggi, José Rafael Briceño, Acianela Montes de Oca, and Néstor Garrido from the School of Social Communication of the Universidad Católica Andrés Bello (Caracas, Venezuela), and the Colegio Nacional de Periodistas, the association representing professional journalists in Venezuela.

dialogue among different stakeholders, including physicians, patients, activists, scholars, and public officials, in order to draft the foundations of a breast cancer national policy.

AWARENESS OF WOMEN’S BREAST CANCER

Several studies indicate lagging breast health and cancer knowledge among various ethnic groups (Ott, Ullrich & Miller, 2009). A lack of awareness is a common problem that prevents women from engaging in productive breast health behaviors. Lagging awareness about this disease among Latin Americans is fuelled by culturally based misconceptions; however, while some women accurately understand its etiology, they misperceive their individual predispositions to breast cancer (Chavez et al., 1995). Therefore, understanding the *risk factors and predictors*, recognizing and practicing *early detection* measures, getting help from *supporting groups*, benefitting from *eHealth* and *awareness initiatives* are of great significance for women toward enhancing their awareness in the fight against women’s breast cancer.

There is no concrete formula to developing or avoiding breast cancer (Canadian Cancer Society, 2004); however, the biggest risk factors are gender (i.e., being female), increased age, family history, and breast density (Breast Cancer Network of Strength, 2008). Others include: lifestyle habits, such as physical activity, diet, and weight (e.g., Courneya et al., 2006; Harvard Medical …, 2007); environmental determinants such as exposure to pollution, pesticides, and tobacco smoke (Plant, 2000); and hormonal factors, such as early onset of hormones, artificial hormones, and reproductive history (Cuzick, 2008). Due to the multitude of risk factors (Eid, 2003), failure to practice breast cancer prevention strategies is considered a risk in itself.

Various interventions and campaigns strive to raise awareness about breast cancer prevention, as early detection through breast self-examination or mammography is a woman’s best chance for survival against the disease. If diagnosed, negative emotions (e.g., anxiety, depression, suicidal ideation, insomnia, and paranoia) can occur, inducing a variety of adjustment problems (Hawkins et al., 2008). Support groups for those facing breast cancer treatments provide an opportunity to talk about their feelings and experiences and obtain information about their diagnosis and treatment (Stang & Mittelmark, 2010).

Patient support resources have become increasingly integrated into cancer centers as more compassionate approaches to healthcare become acceptable and desirable (Eaton et al., 2005). Psychosocial oncology is a branch within breast cancer that deals with the psychological and social aspects of a breast cancer diagnosis. Counselors join forces with oncologists, nurses, and other healthcare professionals to create a cohesive breast cancer team, which focus specifically on the emotional and psychological impact of cancer (Kapusta & Wilcox, 2003). Psychosocial oncology also counters the hierarchical relationships that exist between medical experts and patients, which can elicit a heightened loss of control, illusion of incompetence, and a sense of meaninglessness for people who are in a chronic patient mode (Arntson & Droge, 1987). However, more efforts by medical professionals are required to acknowledge and refer patients to psychosocial branches of breast cancer treatment, as research demonstrates that people who use such resources spend less time with their clinicians, which results in decreased patient care costs and increased patient empowerment (Burns, 2005).

The emergence of eHealth—defined as the use of information and communication technology, especially the Internet, to improve or enable health and healthcare—enables greater access to healthcare information, provides an alternative to breast cancer support groups, and allows for a virtual exchange of ideas and information that is not confined by geography (Ginossar & Nelson, 2010). The Internet has allowed for a rapid increase in the formation of computer mediated support groups for people sharing any number of chronic or acute health conditions. To understand this phenomenon, Shaw and colleagues (2000) explore the Comprehensive Health Enhancement Support System (CHESS)—an interactive computer program providing information, social support, and decision-making assistance to women with breast cancer. Their research indicates the usefulness of this program, demonstrated by the satisfaction, interactive productivity, and knowledge seeking behaviors exhibited by CHESS users.

While the Internet fosters growing breast cancer awareness, activism initiatives have transformed the ways in which this disease is understood, researched, and experienced (Moffett, 2003). Within the communities of people involved in raising awareness about this disease, social cohesion has emerged as an important force (e.g., Brody, Tickner & Rudel, 2005; Herstein, Mitki & Jaffe, 2008). Cohesive groups consist of members who demonstrate a desire to participate in a cause, respect for other group members, and are loyal and united in the pursuit of group’s goals (Figueroa et al., 2002). Thus, as seen in most awareness initiatives, community and social cohesion is necessary for the success of campaigns and efforts with regards to the breast cancer cause (Harvey & Strahilevitz, 2009).

SELF-ADVOCACY

The notion of self-advocacy can benefit from the *patient-centered care* model for healthcare communication, *self-efficacy*, *health promotion*, and *coping strategies*. Various studies focus on patient-centered care[3] as the preferred model for healthcare communication (e.g., Albrecht et al., 2009; Bechtel & Ness, 2010; Clayton, Dudley & Musters, 2008; Hay et al., 2009; Kerr et al., 2003). This framework strives to decrease the power divide between doctors and patients, which is achieved through a dynamic process in which both parties understand one another as equals and experts in their own fields (Briggs & Mantini-Briggs, 2009). The idea of a mutual exchange is central to this method, which involves shared decision-making between the patient and physician and the establishment of a common ground and trust (Nekhlyudov & Braddock, 2009). Shared decision-making allows for a relationship of “collaborative informed choice” (DiMatteo, 1994, p. 155), which instigates increased patient satisfaction, as patients tend to feel intelligent, valued, and empowered (e.g., Ellingson & Buzzanell, 1999; Street et al., 2009). Although patient-centered care is often favored, precautions are still necessary. This paradigm requires a patient’s willingness to participate in a specific manner, which can be seen as a challenge that may induce

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[3] Patient-centered care is an approach to healthcare and treatment that places emphasis on patients’ emotions, values, ethics, personal preferences, and needs to empower patients in their healing journey (Venetis et al., 2009).

increased stress and anxiety in patients who already feel overwhelmed by their situation (e.g., Step et al., 2009; Swenson et al., 2004).

Patient support and empowerment[4] is a key priority of physician-patient communication. The role of information is absolutely crucial in patient empowerment (Brashers, Haas & Neidig, 1999); however, physicians are very much responsible for ensuring that patients receive the necessary information specific to their diagnosis (Luker et al., 1995). Patient-empowering communication on the part of the physician has been statistically and significantly linked to increased breast cancer knowledge among women, increased breast cancer screening rates, and higher quality of life for patients undergoing breast cancer screening and treatment (Maly et al., 2008). However, information dissemination must be culturally sensitive to effectively empower patients (Mishra et al., 1998).

The concept of self-efficacy refers to an individual's perceived control over their quality of health. A determinate of self-efficacy in changing behavior is the ability or perceived ability in maintaining behavioral changes; therefore, if individuals do not believe in their ability to maintain behavior changes, they are unlikely to implement these changes (Bandura, 1997). Other factors that affect self-efficacy are cultural precepts, psychosocial dispositions (e.g., depression and anxiety), and mistrust of medical systems (King & Wong, 2008). Self-efficacy is linked to education, knowledge, and empowerment, which can result in healthy breast-screening behaviors (Rutten, Squiers & Hesse, 2006). Therefore, due to limited accessibility to healthcare institutions in countries where breast cancer awareness is limited and technology accessibility is limited or not up-to-date (Witt, 2008), it is increasingly important that communication programs capitalize on the usefulness of messages that instigate self-efficacy (Buki et al., 2004).

Health promotion is defined as "the process of enabling people to increase control over, and to improve, their health" (WHO, cited in Herbison & Lokanc-Diluzio, 2008, p. 303). In the context of women's breast cancer, it has become increasingly important to develop sound promotional strategies to encourage attention to breast health due to the high mortality rates associated with this disease. Communication strategies looking to persuade women must identify and address the deep structure of a woman's psyche, which involves the cultural, social, historical, and environmental factors that influence opinions and ideas about breast cancer (Barg & Grier, 2008). Medical empowerment is one of the best defenses available against the disease; therefore, effective messaging strategies are considered vital in the improvement of public health (Frisby, 2002).

Health promotion strategizing requires attention to the various ways in which women cope with breast cancer. While different people employ different coping mechanisms when faced with this disease, the most prominent methods are related to religion and spirituality, social support, and knowledge. Many females battling breast cancer seek religious and spiritual ventures, which are associated with worship and social activities that provide support, strength, and introspective guidance (Barg & Grier, 2008). Social support can also occur

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[4] In a healthcare context, empowerment refers to feelings of control, confidence, and self-efficacy in one's health and healing, allowing patients to manage their bodies more effectively and make better decisions for themselves (Rohrer et al., 2008).

beyond the confines of organized religion, which is considered equally beneficial for those coping with the realities of this disease (Kapusta et al., 2005). The function of social support in helping women cope with breast cancer is the role of social relationships and the transaction of supportive behaviors among people, such as emotional, instrumental, informational, and appraisal support (Messina et al., 2004). Information "plays a key role in helping patients understand their disease process … enabling them to make informed medical decisions" (Talosig-Garcia & Davis, 2005, p. 53). Obtaining and processing information can increase autonomy and competence among breast cancer patients, as it provides women with a sense of control and empowerment in their treatment journey (Gustafson et al., 2008).

THE ROLE OF ACTIVISTS

Activism in Latin America is fundamental in the fight against women's breast cancer. It is achieved through the *NGO involvement*, the use of *research as an intervention tool*, and the processes of *networking* and *consensus building*. In virtually every Latin American country, some form of constitutional provision validates health as a basic human right. Despite this, the right to health is not guaranteed—it is a goal that is not legally enforceable. Thus, NGOs and community-based programs compliment such deficits, which are driven by social activism and guided by the values of collectivism found in Latin American culture. Health NGOs in Latin America demonstrate positive impacts on the long-term viability and welfare of the communities they operate in; they are considered a part of health activism efforts, which include a variety of roles (Zoller, 2005). These assemblies address some of the economic and social disparities that commonly prevent healthcare equality, which work to provide health, wellness, and lifestyle services to individuals and communities in need.

Due to the large social and economic disparities present within the healthcare system in much of Latin America, the efforts of NGOs have become increasingly crucial; however, both benefits and barriers require acknowledgement. One of the most beneficial aspects of NGOs becoming involved in health processes is their ability to create communicative spaces where the public can engage in education and deliberation about pertinent health issues (De Souza, 2009). Cancer-related NGOs have shown promise in being able to reach communities underserved by the public healthcare system, promoting the early detection of breast cancer (Durstine & Leitman, 2009).

However, some limitations to such involvement exist. With civil society involvement and community-based research that interlink with many actors and variables, there is ample opportunity for political social dynamic clashes (Israel et al., 1998). Additionally, many cancer NGOs are typically too small to enable measurable impacts in Latin America (Durstine & Leitman, 2009). Typically, cancer NGOs also do not collaborate with other NGOs, community organizations, and interested parties, which can diminish their ability to enact policy change. Due to these factors, NGOs are unlikely to fully reach target populations or provide them with the necessary prevention and early detection information.

The development and dissemination of knowledge is integral to effective interventions that strive to instigate healthy behaviors among populations. Health behavior theory is "based on the underlying notion of rational thought in which patients are assumed to be highly motivated to maintain or to return to a universally agreed upon definition of good health" (Barg & Grier, 2008, p. 336). That is, people make decisions about their health based on maximizing benefits and minimizing losses or costs. The theory of planned behavior is also relevant, which "hypothesizes that behavior is a product of three sets of independent beliefs —behavioral, control, and normative—which lead to the formation of attitudes; perceptions of behavior control; and subjective norms, respectively" (Courneya et al., 2006, p. 259).

The model of Communication for Social Change, which refers to an iterative process where community dialogue and collective action synergize to produce social change in a community, improving health and quality of life for all its members is also useful (Byrne et al., 2005). Similarly, the Integrated Model of Communication for Social Change refers to a "dynamic, iterative process that starts with a 'catalyst/stimulus' that can be external or internal to the community" (Byrne et al., 2005, p. 6). Perhaps the most important aspect of this model lies in the goal of knowledge equity; substantial emphasis is placed on the extent to which the knowledge is shared within a community rather than being hoarded or monopolized by just a few.

Research as an intervention tool is integral in healthcare. Focus group discussions (FGDs) in healthcare research are useful for obtaining ideas and perceptions on specific areas of interest in an open, permissive, and nonthreatening environment, which is especially beneficial when the topic of investigation is sensitive in nature (Ferrell et al., 1997). This research method is advantageous because it does not require a high degree of literacy or comprehension; thereby, it encourages participation from a wide demographic (e.g., OMNI Institute, 2004; Slaughter et al., 1999). Successful FGDs regarding breast cancer facilitate a forum that is open to varying backgrounds and beliefs, value all ideas and opinions, and foster intimate and attentive interaction (e.g., McCoy, 2003; National Breast and Cervical …, 2009, January 7). The benefit of using FGDs to address further concerns regarding breast cancer lies in their ability to elicit opinions, perceptions, attitudes, and concerns.

Effective networking exists in the realm of healthcare, thereby producing a wider reach of programs to various communities. Assessment, networking, and awareness of breast cancer incorporate a community perspective where those at the core of this activism are directly involved in program implementation. Participation in health and development communication programs not only strengthens the voice of citizens but also ensures their involvement in decisions that affect them, their families, and their communities (Brasington, Tapia & van Lith, 2007). This approach favors mutual learning rather than top-down practices to change implementation, thereby respecting local traditions and refusing to undermine cultures and values of affected communities. However, careful consideration and planning is required to carry out network relations effectively; network integration must be intensive, involving multiple and overlapping links both within and across the organizations that compose the core of a network (Provan & Sebastian, 1998).

Identification of the facilitative conditions necessary to motivating breast cancer screening among women is paramount to increasing survival rates of this disease. Various studies emphasize the value of social network interventions as a powerful persuasion tool for influencing breast cancer screening among women (Volkman & Silk, 2008). Social connections can facilitate health behaviors due to the influences of naturally occurring social systems, such as family and friends (Allen, Stoddard & Sorensen, 2008). For example, women who engage in conversation about mammography with friends are more likely to get mammograms (Husaini et al., 2001). Therefore, understanding the relationship between social network characteristics and screening practices is vital in the improvement of lagging participation.

THE ROLE OF HEALTHCARE PROVIDERS

Healthcare providers play an essential role in the fight against women's breast cancer through the processes of *intervention* and *communication*. Interventions led by healthcare providers are considered an effective method in increasing breast cancer screening compliance among women (Rogers, Thompson & Robinson, 2002). The positive influence of healthcare providers in motivating women to engage in breast cancer screening is consistently demonstrated in literature examining this correlation. Perhaps the most important aspect of this linkage is the vital role of interpersonal communication (Dakroury & Eid, 2012) that can occur between a woman and a healthcare provider (Jones, Denham & Springston, 2006). While this area of communication offers hope for creating effective messaging strategies to encourage breast cancer screening and prevention, it includes confounding variables and complex issues. Overall, healthcare providers have the ability to educate women and motivate them to take control of their breast health. Therefore, it is important to understand the relational dynamics involved in this correlation to effectively harness the immense potential of these tendencies.

Healthcare practitioners must be aware of their vital function and be trained to interact proficiently with patients[5] to maximize the effectiveness of their messaging techniques (Diefenbach et al., 2009). Effective communication by physicians results in a plethora of positive effects, increasing patients' satisfaction of the healthcare experience and their overall health outcomes (Robinson et al., 2008). Communication that fosters the idea of humanism and an empathetic approach that treats patients as complete human beings with emotions and social needs is essential to effective physician-patient interactions (Butler et al., 2005).

Physicians play a pertinent role in the dissemination of information about breast cancer to patients (Lewis et al., 2009). Therefore, physicians need to focus on presenting clear and accurate information to aid the patient through their journey and instigate a relationship of trust, which is tied to an increase in compliance with physicians' recommendations (e.g., Kowalski et al., 2009; Paulsel, McCroskey & Richmond, 2006). Physicians are expected to recognize the contingent nature of medical visits, as patients have different informational needs at different times; physicians can address these needs in a way that avoids professional jargon[6] and is accurately understood by patients (e.g., Eheman et al., 2009; Thompson,

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[5] Patients' reluctance to communicate effectively with a physician is not necessarily a failing of the patient, but of the improper communication skills and training of the physician (e.g., Hanoch, 2004; Huijer & van Leeuwen, 2000).

[6] Medical language can often seem foreign and complex to patients, with jargon clouding their understanding of diagnoses and treatment options (Lee & Hawkins, 2010).

2009). Increased agency through decision-making, facilitated by the provision of information from physicians is beneficial for patients, as it is associated with increased participation, self-efficacy, and heightened trust (e.g., Arora et al., 2009; Vogel, Leonhart & Helmes, 2009).

Serious concerns are often associated with a diagnosis of breast cancer, necessitating strong physician-patient communication (Carney et al., 2009). Women tend to be more comfortable dealing with female physicians, especially when dealing with reproductive health issues, such as breast cancer, because of the perception of sharing a common female experience (Borrayo, Buki & Feigal, 2005). Women desire emotional support from their physicians more so than men, especially if they do not have strong familial support at home (Han et al., 2005). Physician-patient communication in this context often faces heightened complexities in developing countries, as resources are limited, breast health literacy is lagging, and access to properly trained staff and equipment can be challenging (Kreps & Sivaram, 2008).

Cultural competency in physician-patient communication is positively associated with improving women's abilities to make decisions regarding cancer treatment (Hawley et al., 2008). When dealing with Latin American women and breast cancer, physicians need to be actively aware of their patients' background, beliefs, and culture (Meeuwesen et al., 2007). Latin American women are less likely to trust their physicians as reliable and credible sources of information; therefore, they are less likely to follow their recommendations regarding screening practices (Otero-Sabogal et al., 2003). Especially in the Latin American context, the training of physicians may benefit from a family-centered rather than individual patient-centered approach to remain in alignment with the emphasis placed on family in Hispanic culture (Beckman & Frankel, 2003).

THE ROLE OF SOCIETY

Society has crucial impacts on patients in their experiences with breast cancer through two main influences—*familial* and *cultural*. Familialism is a crucial value in Latin American culture; it is the main source of support, especially in the presence of illness (Granda-Cameron, 1999). One of the most prominent roles that the family takes on is to provide emotional and social support[7] for female cancer patients, which can help to reduce the many negative psychological and psychosocial impacts of a breast cancer diagnosis (Nápoles-Springer et al., 2009). Loved ones are often the primary source of hope, encouragement, and emotional support; without this social support, the trauma women face may be devastating (Harris et al., 2009). Therefore, diagnosis of cancer does not only affect the patient; it affects the entire family.

This is especially true in Latin America where the protection of family members from harm is a strong belief (Mystakidou et al., 2004). Family also plays a role in how patients seek out and interpret information. Women often receive information about breast cancer from their loved ones (Washington et al., 2009). Women tend to feel as though they, not the physician,

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[7] Latin American women understand social support as providing women with informational guidance, emotional support, empathy and caring, and tangible help such as bringing women to appointments and picking up medications (Gonzalez, Gallardo & Bastani, 2005).

bear the responsibility to inform family members of their genetic cancer risk, which may also increase anxiety about a diagnosis (Macdonald et al., 2008). However, although the family may be the primary support-providers for women, this does not diminish the physician's responsibility to ensure that women are receiving support, whether from the family, the physician, social support groups, or online support groups (Levy & Strombeck, 2002).

Culture can seriously influence one's decision-making with regards to health behaviors. Factors such as religion and belief systems are woven into perceptions about healthcare, and thus are considered very important when looking to understand barriers related to proper breast cancer screening. An examination of Latin American cultural interactions with breast cancer reveals the prominence of fear and anxiety related to the disease. That is, Latin American women fail to engage in screening and prevention practices due to the secretive and shameful perception of breast cancer, which is fuelled by embarrassment and shame likely associated with their limited knowledge of the disease (Hedeen & White, 2001). The lack of information exchange occurring at home is instigated by anxiety about discussing women's bodies—as this topic of conversation is considered private and inappropriate (Buki et al., 2004).

Religion and spirituality interact with Latin American women's views on breast cancer screening and treatment (Holt, Lee & Wright, 2008). While church-based health communication may not be at the forefront of screening compliance strategizing, it is considered an important tactic for some niche demographics that place a strong emphasis on the synergy between health and faith (Frisby, 2006). For instance, in their analysis of the effectiveness of a spiritually based approach to education on early detection of this disease, Holt, Lee, and Wright (2008) found that spiritually based interventions could be highly effective if properly strategized. Thus, interventions and communication techniques that demonstrate sensitivity to religious precepts can facilitate increased compliance to proper breast health practices.

ACTION INITIATIVE IN VENEZUELA

Action-oriented research is a collective, self-reflective, and participatory enquiry undertaken by participants (stakeholders) in social interactions to improve some condition in which they are all involved. It is "a methodological approach for doing collaborative research with practitioners and community partners that can inform practice, programs, community development, and policy while contributing to the scientific knowledge base" (Small & Uttal, 2005, p. 936). It promotes a critical consciousness that exhibits itself in political and practical action to make some type of change. Its agenda mainly includes "producing research that can address practical concerns" (Small, 1995, p. 942), aiming to "have some type of change" (Small & Uttal, 2005, p. 938). It helps to: 1) increase the closeness between the day-to-day problems encountered by practitioners in specific settings and the theories used to explain and resolve the problem; and 2) assist practitioners in lifting their veil of clouded understandings to better understand fundamental problems by raising their collective consciousness (Berg, 2009; Eid, 2011).

Action-oriented researchers “believe that the process of conducting research should be empowering for research participants” (Esterberg, 2002, p. 141). They “value collaboration with nonresearcher participants” in that while they bring “to the research process theoretical knowledge, experience, and the skills of conducting social science research, the participant collaborators bring practical knowledge and experience about the situations that are being studied” (Small, 1995, p. 942). Together, researchers and community partners “combine their different kinds of knowledge and skills to produce insightful and usable findings” (Small & Uttal, 2005, p. 938). Ultimately, action-oriented research aims to “generate knowledge that can be used to address practical concerns of local communities, organizations, and groups and incorporate local understandings of specific practices and issues” (Small & Uttal, 2005, p. 938).

In Venezuela, we developed an action-oriented research project in collaboration with SenosAyuda, a Venezuelan NGO that supports women with breast cancer and advocates for the early detection of the disease and better access to healthcare services, as well as a group of physicians, patients and survivors, journalists, and policymakers. This project aimed at helping SenosAyuda in the creation of a national network of breast cancer volunteer organizations while facilitating the acquisition of communication and advocacy skills and capabilities of breast cancer survivors and community activists. Our research has been guided by the “ecological perspective” (Street, 2003) that proposes an integration of the different levels in health communication (interpersonal, organizational, and social), and highlighting the potential emancipation role of health communication according to the pioneer of the field, Luis Ramiro Beltrán (1994).

The project was implemented in a very particular political and social environment. Since 1999, when Hugo Chavez became president after winning a democratic election, Venezuela has lived under a highly and virulent social and political polarization. The divide between the Chavez’s followers and the opposition has translated into political violence, attacks to the freedom of speech, and a discourse of hate from both sides. However, the Chavez regime has put a strong emphasis on social programs in order to help the poor and expand the access to services, including access to healthcare, specially through its flag program *Misión Barrio Adentro* (Inside the Neighborhood Mission) with the help of the government of Cuba (Briggs & Mantini-Briggs, 2009). The overall performance of the *Misión* is far from the positive results announced by the government; this program has even contributed to an increase in the historical fragmentation of the Venezuelan healthcare system with a negative impact on the overall financing of the public sector (e.g., Díaz Polanco, 2006; Nahon-Serfaty, 2005). Social challenges in Venezuela include general resistance from the public to learn about women’s breast cancer, shortage in physicians’ availability, lack of training of spokespeople on behalf of patients, survivors, and foundations, shortages in the logistics of organizing public events, absence or reluctance of volunteers and advocates, and deficiencies in activity evaluation and feedback measures.

The civil society organizations emerged in Venezuela as a way to fill the void left by the public sector in the provision of healthcare, especially to the poor populations. The oldest organization, the *Sociedad Anticancerosa de Venezuela* (the Cancer Society of Venezuela) was created in 1948 to lead the efforts to educate and provide medical care to those lacking financial means or insurance coverage. Recently many NGOs working specifically in breast cancer have been created: SenoSalud, Funcamama, Fuccam, Famac, Fundamama, Fundaseno, Senosestima, Unicam, and SenosAyuda, among others.

SenosAyuda was created to address the problems and deficiencies that women are facing with breast cancer issues, and promote nationwide long-term action programs. In 2007, the NGO initiated the Organizational Capacity Building Program (OCBP) directed to collaborate with other social development organizations involved in the fight against women's breast cancer in Venezuela. The OCBP objectives were: 1) to contribute to the development of such organizations in three fundamental phases of their evolution: to be born and established, to progress, and to be consolidated or redefined; and 2) to educate the leadership hands-on learning methodologies and provide the social development organizations with the managerial tools that allow them to manage their associations efficiently.

Within the context of the OCBP initiative, our project was based on six guiding principles: *inclusion and equity*, *gender sensitivity*, *dialogue and interaction*, *social change*, *networking*, and *ethical standards*. Inclusion and equity are fundamental because all the stakeholders should have a voice in defining their priorities and needs, and all have the potential of becoming advocates and spokespersons of their own cause. Gender sensitivity takes into account that on top of all the traditional barriers to access proper healthcare services, women in Venezuela face additional obstacles due to cultural and social obstacles as they are frequently the subject of a double marginalization process (being poor and women). Dialogue and interaction are ways to promote an open conversation about the goals, strategies, and tactics of the project, inspired by the conviction that communication is a two-way and horizontal process (e.g., Eid & Dakroury, 2010). Social change is understood here as a gradual process that entails the development of capabilities and abilities of the individuals and organizations to improve their access to information, healthcare services and participation in the policy decision-making. Networking is a way to promote solidarity among different actors, including those who were marginalized (i.e., regional activists) and to create synergies among them. Ethical standards are essential to respect human dignity, promote transparency, encourage responsibility, and demand accountability of all the stakeholders (e.g., Eid, 2008; Eid & Nahon-Serfaty, 2008).

Collaborators of this action-oriented research project have engaged in discussions through four annual collective workshops in Caracas and continuous national events and activities throughout the four-year period (2009–2012). The workshops essentially helped participants to be spokespeople for their organizations and to understand how to use communication as a tool to plan and achieve the given activities. The workshops provided skills of composing and communicating messages about breast health that help promote changes in attitude and behavior. They discussed the situation of patients living in regions with no access to healthcare services, the confusion caused by the debate about breast implants, and the need to secure humane and dignified palliative care. They helped also in how to determine the importance of having volunteers and thanking them for their contributions, use techniques of group discussions, target the audiences and select the strategies to reach them, and conduct social mobilization. Social mobilization involves how to work together to create visibility of the problem and achieve support of the government, opposition members of the council, and community members.

Events and activities were numerous. Collaborators have been active in conducting and participating in events and activities in order to promote breast cancer health awareness. October 19th was the day dedicated to promoting breast health. In particular, "The Pink Walk" was an important event where breast cancer survivors and other activists from the community could walk the streets, raising awareness. In addition, posters and banners were put up in public places such as bus stops and taxi and moto-taxi stops. Activities include the production of materials, such as the "Pink Recipe," which discusses the four "to-dos" for breast health: self-exam, breast echography, mammogram, and consultation with a physician. Other materials were newsletters, letters asking for contributions and thanking sponsors and volunteers, and website updates and maintenance. Essentially, the most significant activities involved getting the messages of breast health out to the public, the media, and even physicians. The publics were reached through direct talks (such as the ABC's of breast cancer—talks about the organization, activities, and early detection and prevention), distribution of pamphlets, information, and pink ribbons. For example, the talks with the Mission Mothers of Barrio helped reach women in poorer communities. The creation of clubs called, "Prevention and Early Diagnostic of Breast Cancer", involved different talks about breast health, the creation of billboards and newsletters, and even theatre presentations.

One of the major outcomes of our action-oriented research project has been the expansion of the networking base of SenosAyuda with different stakeholders including other NGOs from different regions, physicians, scholars, journalists, and public officials from state and municipal governments.[8] For example, a direct outcome celebrated in May 2011 after the third workshop of our project was the declaration "*For a Consensus Vision for the formulation and implementation of a National Response against Breast Cancer in Venezuela*" which was subscribed by an initial group of 20 participants. A year after, in May 2012, the document has been signed by 101 organizations, including 8 breast cancer advocacy organizations, 6 major medical associations, 4 human rights NGOs, and important social actors, such as the Red Cross and the National College of Journalists.

The declaration has also contributed to set additional goals of networking and consensus building for SenosAyuda, the organization that is leading the initiative, including the collection of 10,000 signatures by the end of 2013 in order to support a National Response against Breast Cancer in Venezuela, the launch of national media campaign to raise public awareness about the need of a consensus, and the celebration of public forum all over the country to discuss the principles and objectives that should guide a national policy for the disease. The declaration has also served as a framework to define the priorities of a future national policy on breast cancer:

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[8] A total of 121 people participated in the four workshops (June 5–6, 2009; June 11–12, 2010; May 20–21, 2011; and February 24–25, 2012). They were 50 activists representing different NGOs and including survivors and patients, 23 physicians, 28 journalists, 9 scholars, 5 public officials, and 6 representatives from the private sector.

- Educate and train healthcare personnel specialized in the diagnostic, treatment, and integral support of breast cancer patients;
- Develop a national system to compile, analyze, and facilitate the access to reliable data that show the real impact of breast cancer on the population as a way to draft evidence-based policies and actions;
- Establish the mammography as a key procedure for an accurate diagnosis that also contributes to articulate the different players in the healthcare system;
- Communicate messages associated with the solutions available to the public and adapted to their needs and socio-cultural realities;
- Secure financial protection to every person affected by breast cancer through public and private healthcare insurances and funding;
- Promote the integration of public and private services in order to improve access to proper diagnosis procedures and treatments at the national level;
- Provide palliative care as part of human, moral, and ethical duties towards people suffering from breast cancer.

CONCLUSION

Breast cancer continues to plague female populations around the globe, necessitating awareness initiatives designed to increase participation in prevention techniques, such as screening and mammography. The prevalence of women’s breast cancer in Venezuela is particularly alarming, as it is attributed to healthcare inequalities, low health literacy, and lagging compliance with prevention methods. While the right to health is acknowledged by the Venezuelan constitution, activism beyond governmental confines is required to increase breast cancer awareness and decrease mortality rates. Although a simple recipe has yet to be discovered that results in breast cancer, a wide variety of risk factors and predictors are involved in breast cancer diagnoses. However, through social interactions facilitated via support groups and online forums, it is possible for women to exchange ideas and knowledge regarding this disease. In addition, awareness initiatives organized and facilitated by a variety of groups aid in women’s breast cancer consciousness-raising efforts.

Individuals who face the burden of breast cancer are bombarded by a variety of factors that interact with one’s disease path. Patients are forced to wade through their own emotions and those of others, information regarding treatment, and a multitude of healthcare practitioner personalities. While this process can be extremely daunting for many women, the enactment of certain behaviors and social mechanisms can act as useful coping techniques. These tactics are intrinsically linked to empowerment and are centralized around one’s ability to enact self-advocacy, which are facilitated through patient-centered care, self-efficacy, and strategic health promotion and coping strategies. Such empowerment can boost feelings of self-efficacy, which may promote healthy preventative behaviors (Errico & Rowden, 2006). Particularly in Latin America, NGOs are involved in the instigation of these endeavors; however, they commonly face obstructions to their success. Thus, research surrounding health behaviors is identified as a useful tool in guiding health interventions. The techniques and ideologies extracted from such research are subsequently complimented by networking, which fosters interactions and community involvement necessary for breast cancer awareness among women.

Activism initiatives function with the help of both healthcare providers and social influences. Healthcare providers play a unique role in activism and raising awareness, as they have the ability to interact with patients on a personal and intimate level. However, this opportunity for enacting satisfaction and healthy behaviors among patients relies on healthcare providers' communicative abilities. A detailed analysis of physician-patient communication reveals the highly complex nature of such interactions and the need for ongoing training and development. The role of society, specifically familial and cultural influences, has a strong impact on women's breast cancer awareness, ultimately affecting how breast cancer patients choose to navigate their healing journey. In fact, Latin American women respond more positively to physicians and outreach that is sensitive and attuned to their specific cultural context (e.g., Larkey, 2006; Warren, Londoño & Wessell, 2006).

As a result of the workshops, events, and activities of our action-oriented research project in Venezuela, there has been an increasing interest among community members to learn and seek more information, a higher level of awareness of the concerned organizations, a better understanding of the communicated messages, an increase in the media coverage and the number of medical consultations, and positive satisfaction reports about how patients were treated in the provided healthcare services. Breast cancer risk factors have been communicated through positive messages such as those of support, the colour pink, lifestyle changes, keeping health as a determining factor for life, fighting and winning life, and knowing your breasts. The decree of the Municipal Council includes data about mortalities from breast cancer, about access to healthcare services and risk factors, and of promoting October 19th as "Breast Cancer Day". The idea of solidarity and social responsibility in that health and well-being have an influence on families and communities was successfully communicated through the increase of awareness and promotion of social change.

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