Published in final edited form as:
Int J Risk Conting Manag. 2015 July 1; 4(3): 49–69. doi:10.4018/IJRCM.2015070104.

Ethics, Risk, and Media Intervention: Women's Breast Cancer in Venezuela

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Abstract

Breast cancer incidence and mortality rates are of concern among Latin American women, mainly due to the growing prevalence of this disease and the lack of compliance to proper breast cancer screening and treatment. Focusing on Venezuelan women and the challenges and barriers that interact with their health communication, this paper looks into issues surrounding women's breast cancer, such as the challenges and barriers to breast cancer care, the relevant ethics and responsibilities, the right to health, breast cancer risk perception and risk communication, and the media interventions that affect Venezuelan women's perceptions and actions pertaining to this disease. In particular, it describes an action-oriented research project in Venezuela that was conducted over a four-year period of collaborative work among researchers, practitioners, NGOs, patients, journalists, and policymakers. The outcomes include positive indications on more effective interactions between physicians and patients, increasing satisfactions about issues of ethical treatment in providing healthcare services, more sufficient and responsible media coverage of breast cancer healthcare services and information, a widely supported declaration for a national response against breast cancer in Venezuela, and the creation of a code of ethics for the Venezuelan NGO that led the expansion of networking in support of women's breast cancer healthcare.

Keywords

Breast Cancer; Breast Cancer Screening; Culture; Decision-making; Ethics; Healthcare; Health Communication; Latin America; Media; Right to Health; Risk Communication; Venezuela; Women

INTRODUCTION

The "right to health" in Latin America faces many challenges, which are apparent in the great health disparities present in this region. Thus, despite the World Health Organization's indication of universal health availability by the year 2000, this is not the case for Latin America (Yamin, 2000). Although Latin American women have a lower incidence rate of breast cancer than non-Hispanic women (Cancer mortality …, 2005, October 6), this rate is

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rising faster than any other female ethnic group (Buki et al., 2004). Increasing incidence rates of breast cancer among Latin American women are attributed to lifestyle changes, cultural beliefs, and lagging awareness about the disease (e.g., Andersen et al., 2004; Harvard Medical …, 2007; Schutt, Cruz & Woodford, 2008). The dilapidating effects of health disparities necessitate action from governments and human rights non-governmental organizations (NGOs) as well as media interventions in order to decrease such incongruence and address fundamental health and well-being rights.

The Venezuelan context, in particular, presents several challenges including the fact that poverty is highly prevalent and exclusion on various levels is a reality. Even though the government claims that it has reduced the overall level of poverty, indicators still show that almost 40% of Venezuelans can be considered poor and almost 12% live in extreme poverty (Ponce, 2009). A double-factor of exclusion and marginalization is being both poor and women; hence, unemployment is usually higher among women (Boza, 2004) and their income tends to be lower that the income of poor men (Orlando & Zúñiga, 2000). Exclusion is also a function of geography because some regions in the country present higher levels of birth and mortality rates, showing a clear divide between the center, the east, and the southwest (Freitez, 2003). From a health perspective, 80% of all deaths in the country are related to non-communicable diseases, while the mortality of women from 45 to 64 is mainly due to cervical and breast cancer rather than stroke or diabetes (OPS, 2011).

The 1999 Venezuelan Constitution includes three articles devoted to the right to health. These articles[1] conceive health as a "fundamental social right that must be guaranteed by the state, without discrimination of any kind, as a part of the right to life, expressing the link between health, quality of life, and collective well-being" (Feo & Siqueira, 2004, p. 372). The articles define three mechanisms for enforcing this constitutional mandate to allow for the implementation of these rights into reality: the creation of the Public National Health System, fundamental principles for the direction of the system, and the responsibility of the state to fund the system. The result of this new constitution has provided economic and social resources to populations, improving the health of Venezuelans. While such advancements are undoubtedly beneficial, further development in the realm of legislation and institutional capabilities is still required.

This paper aims to discuss issues surrounding women's breast cancer such as challenges and barriers to breast cancer care, the relevant ethics, rights, and responsibilities, breast cancer risk perception and risk communication, and the media intervention. In particular, the paper aims to describe an action-oriented research project[2] 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.[3] It discusses four levels of ethical interactions and relationships among the stakeholders

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[1] These articles indicate the necessity of state intervention to improve healthcare: Article 83 describes health as a fundamental social right that is the responsibility of the state; Article 84 describes health as a guarantee for all through the state's creation and management of a national health system; and Article 85 highlights that the state will regulate and finance the public health system (Feo & Siqueira, 2004).

[2] 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.

(patients, activists, physicians, public officials, journalists, scholars, and private sector representatives) in this project: 1) The basic and foundational physician-patient communication that entails information asymmetry and reveals several human, moral, and emotional dilemmas; 2) The social activism strategies as ways to empower traditionally marginalized actors (poor women and people living in remote areas) and to give voice to those who were voiceless; 3) The right to information and communication in the public sphere with a special understanding of the role of media and journalists in the portrayal of women's breast cancer, the people affected by the disease, and the need to improve access to healthcare services; and 4) The responsible exchange among patients, activists, and journalists in order to have a better understanding of the media's role in shaping public perceptions, expectations, beliefs, and behaviors in relation to breast cancer, and increase the collaboration between these actors in promoting awareness and defining the public agenda.

CHALLENGES OF WOMEN'S BREAST CANCER

Understanding the most important *general*, *socioeconomic*, and *cultural* barriers are of great significance in countering the challenges of women's breast cancer. In general, early detection of breast cancer through screening (i.e., breast self examination or mammography) is the most effective method for increasing survival rates of this disease (Cazap et al., 2010). While public health campaigns can positively influence intentions to seek screening, proper actions are not commonly carried through (Catalano et al., 2003). Lacking compliance is especially prevalent among Latin American women, necessitating the identification of barriers inhibiting such behaviors to aid in the creation of strategic communication methods to mobilize positive changes. A main limitation in the control of breast cancer among Latin American women is related to disease awareness (Schwartsmann, 2001). Knowingness is interconnected with access to education, information, and healthcare, which ultimately impact women's perceived risks (Rogers, Thompson & Robinson, 2002). Lack of knowledge fuels misunderstandings, often resulting in failure to seek proper screening and treatment options (Salant & Gehlert, 2008).

Many barriers associated with unhealthy screening behaviors among Latin American women are related to fear of the disease, resulting in either excessive screening or avoidance (Bowen et al., 2004). Forbearance to seek screening is related to concerns pertaining to the implications of test results on one's family (e.g., Agurto et al., 2004; Barg & Grier, 2008; Harvey & Strahilevitz, 2009; Juraskova et al., 2007), treatment procedures (Howze, Broyden & Impara, 1992), and treatment outcomes, such as hair loss and surgical interventions (Ellingson & Buzzanell, 1999). The stress and anxiety associated with breast cancer can spark emotions of worthlessness, isolation, and loneliness, particularly due to the life threatening nature of this disease (Shaw et al., 2000).

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[3] 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.

Multiple variables interact with breast cancer screening and treatment cognizance among Latin American women; however, socioeconomic and cultural factors are the most prominent. Latin American women face many access barriers that are commonly associated with socioeconomic factors (Lantz et al., 2006). Financial constraints experienced by various sectors of society (e.g., government, institutions, and advocacy groups) impact the quality and accessibility of care for citizens (e.g., Kahn, Yang & Kahn, 2010; Luciani & Andrus, 2008).

Governmental resource deficiencies can create obstacles that hinder or completely impede citizens' access to proper care. Limited funding in developing countries often results in fewer healthcare institutions and insufficient staffing (Bechtel & Ness, 2010). A lack of healthcare practitioners can also illicit various communication barriers related to language, culture, and gender. Given the personal and sensitive nature of women's breast cancer screening and treatment, such barriers can motivate women to abstain from both seeking out and continuing screening and treatment (Montenegro & Stephens, 2006).

Socioeconomic factors, such as income and education, also impact citizens' access to proper healthcare (Herbison & Lokanc-Diluzio, 2008). Impoverished Latin American women face barriers related to proximity and transportation, as distance and inability to physically mobilize to clinics are problematic (Buki et al., 2004). Women also fear the financial burden of breast cancer; not only because it can impede a woman's ability to work, but because of high treatment and medication costs (Kapusta et al., 2005). Low health literacy pertaining to breast cancer is linked to screening and treatment delinquency and avoidance or delay of discussion about symptoms with physicians (e.g., Errico & Rowden, 2006; Holt, Lee & Wright, 2008; Robles & Galanis, 2002). Due to limited health knowledge, Latin American women are commonly "misinformed about the causes of cancers, prevention of cancers, strategies for early detection of cancers, and the optimal treatments for cancers which leads to serious errors, omissions, and resultant health problems" (Kreps, 2008, p. 206). While a preliminary review of the socioeconomic barriers reveal financial support to be a prominent solution to the various issues, it is important to acknowledge the kaleidoscopic nature of such challenges. Beyond the monetary necessities, it appears that limited awareness perpetuated by multiple variables contribute to the lag in screening compliance among Latin American women.

Cultural sensitivity is considered a vital factor in encouraging Latin American women to seize ownership of their breast health. It is important to be cognizant and respectful of their cultural beliefs rather than to ignore their perceptions (Chavez et al., 1995). Due to the high value placed on family, Latin American women associate a breast cancer diagnosis with the induction of stress upon their loved ones. This concern is amplified among females due to worries regarding their ensuing incapability to continue household responsibilities and inability to protect their family from the emotional distress caused by the diagnosis (Nápoles-Springer et al., 2009). Such fears create screening barriers, which reinforce secretive behaviors and the stigmatization of cancer, further engendering breast cancer as a taboo subject (Buki et al., 2004). Despite patient fears regarding the well-being of one's family members, loved ones are also prominent sources of support for those undergoing screening and treatment, especially from other female family members (Gonzalez, Gallardo & Bastani, 2005).

Another prominent value in Latin American culture is that of trust (Borrayo, Buki & Feigal, 2005). Specifically, Hispanic women perceive physicians to be less credible and trustworthy than many other demographics, such as Caucasian or Black women, leading them to instill less faith in physicians regarding health information and suggestions (Fox & Stein, 1991). This lack of trust can motivate Latin American women to feel uncomfortable about screening and treatment, which is commonly fuelled by ideas of indecency and embarrassment regarding the exposure of their breasts or discussing breast health with a physician (McCalman, 2003). Respect for their religious beliefs is also important, especially surrounding fate and God’s destiny (e.g., Buki, Salazar & Pitton, 2009; Jandorf, Bursac & Pulley, 2008). If Latin American women believe that their health outcomes are controlled by a higher power, then they may be less likely to proactively seek ways to change life outcomes, seeing them as futile (Otero-Sabogal et al., 2003).

While such challenges, barriers, and other cultural precepts create obstacles that impede proper breast cancer screening and treatment compliance, understanding and sensitivity of these norms can aid in the development of productive communication strategies that can decrease breast health delinquency among Latin American women.

ETHICS, RIGHTS, AND RESPONSIBILITIES

In the fight against women’s breast cancer, issues of ethics, rights, and responsibilities are always encountered. It is, therefore, important to discuss *the right to health*, *ethics in risk communication*, and *responsibilities of public health campaigns*.

Ethical standards and principles related to the healthcare sector are complex, requiring meticulous attention and evaluation. Practitioners within the healthcare industry are responsible for their ethical conduct in care and communication with patients and their families. For instance, in addition to their standard duties, physicians are expected to enact privacy, respect, and trust to encourage autonomy among patients and increase independent and informed decision-making upon those seeking care (e.g., Davidson & Mills, 2005; Kowalski et al., 2009). Thus, health promotion strategies should be based on social values and moral concerns (Lewens, 2010).

A similar macro perspective on the study of healthcare also reveals that medical science is often far removed from the general public due to its complexity and institutionalization. This lapse can be minimized through the creation of deliberative spaces that foster public evaluation and contestations of healthcare practices. The inclusion of the public in the medical system directly pertains to issues related to healthcare ethics, as citizens must be fully informed and active within this realm (Lidskog, 2008). To leverage the decision-making power of the public and draw stronger connections between community members and those in authority, a human rights based approach to public health is deemed useful (Chopra & Ford, 2005). This method prizes community members with the right to health and development, labeling the government and public health agencies as duty bearers, with the responsibility to protect these rights and govern accordingly. Infusing the public with knowledge through effective communication strategies enhances citizen participation and productive social development.

The ethical evaluation of risks and communicating such is exceedingly complex, as it involves many different aspects and actors. Decision-makers assume moral responsibility for exposing others to risk depending on the complicity of those exposed to harm, the reasonableness of the decisions made, and how the harms and benefits are distributed (Athanassoulis & Ross, 2010). Risk decisions must be evaluated in accordance with a comparison to a virtuous ideal based on whether the agent’s reasoning reflects a full and clear view of the issue. These judgments “are not irrational gut reactions, but moral intuitions and emotions that are sources of ethical wisdom that have to be taken seriously” (Roeser, 2010, p. 188). Therefore, risk communicators must strive to educate and advocate for the development of sound and productive decision-making (Bostrom, 2008).

Decision-making may be considered one of the greatest ethical concerns faced in healthcare today. Patients are bombarded by information from a plethora of sources (e.g., family, friends, independent research, and healthcare providers), and are expected to appraise various options, understand the risks involved, and enact suitable conclusions. Thus, the relationship between risk management and risk communication is innate to decision-making within healthcare due to the critical nature of such situations (Eid, 2014). Information becomes an inherently critical element in this process, as patients’ understanding of accurate knowledge is necessary for reaching sound decisions (Allen, Petrisek & Laliberte, 2001).

The risk associated with decision-making is not exclusively applied to the decision-maker; it may affect other people (stakeholders), making those affected sometimes at the mercy of the decision-makers. In this, the relationship between those affected by the decision and the decision-makers becomes asymmetrical; stakeholders potentially bear more harm if faced with risks that threaten their values, identity, health, assets, and interests (Boholm, 2008). Risk also exists in the failure not to make a decision, which in many cases can cause greater harm than choosing to make one. In this, uncertainty and value judgments often coincide with risk issues and decision-making, generating varied interpretations (Bakir, 2010).

Closely related to risk in decision-making is uncertainty, which refers to not knowing the precise outcome of the choice enacted. A useful classic model in facing uncertainty and risk when making decisions is the cost-benefit analysis (CBA), which is a rational model. The CBA requires one to weigh the potential costs and benefits of the option and to compare these costs and benefits with all other options or alternatives available (Clarke, 2010). However, it is rare that an individual can ever be fully rational when making decisions, especially when they involve large consequences pertaining to one’s family or health. These circumstances may render the CBA model for decision-making less effective than claimed by its proponents. However, while the CBA may not always seem relevant in patients’ decision making, it is believed that through proper communication with physicians and loved ones and the provision of information patients can reach rational conclusions.

To aid physicians and patients through the subjective path of decision-making, a prescriptive model is proposed that encourages healthcare practitioners to follow a broad ethical framework (e.g., professional code of ethics) to guide communicative actions to patients about decisions (Addington & Wegescheide-Harris, 1995). This allows practitioners to evaluate actions, judgments, and theories, to illuminate the ethical presuppositions founding patients' decisions, and to understand how irrational factors impact conclusion enactment.

Public health campaigns can be used for many purposes; however, there is a barrage of responsibilities and ethical concerns related to these communicative processes. Government and healthcare practitioners face many dilemmas regarding their conduct in public health communication campaigns, necessitating a detailed analysis of such to guide the development of sound and productive messaging. While some ethical concerns can be based strictly on measuring how an audience may be immediately impacted by a message, there are other problems related to public campaigns. For example, while some campaigns may pose obvious ethical issues, harm can also fall upon society inadvertently when campaigns seek to reduce behaviors, which may deprive individuals of pleasure or of significant cultural activities (Guttman, 1997). Additionally, it is also important to understand how messages about health dictate ideals and morals. For instance, some campaigns that advocate certain behavior may (inadvertently or intentionally) tag those who comply with the behavior as “good” and those who do not as “bad”.

Beyond the central focus on overarching values for healthcare, it is especially important to ensure that healthcare communication strategies take into account contextual and cultural factors, such as moral and religious values. Such principles form the foundation of social groups, villages, cities, and nations alike and may affect patient, physician, and authority perceptions and evaluations of healthcare. In a Latin American context, many cultural values need to be considered when developing public health campaigns. For instance, the values of collectivism, family, religion, trust, respect, and interpersonal relationships are deemed significant (Borrayo, 2004). Therefore, health messages must be sensitive to these principles and include content that interacts with or reinforces such values.

RISK: PERCEPTION AND COMMUNICATION

Risk perception can be understood as a “value-dependent process” (Etkin & Ho, 2007, p. 627), influenced by inherent social values that determine which risks are selected for assessment and what tools are to be used in their measurement (Mairal, 2008). Risk assessment also involves emotional and intuitive responses, which impact the deliberation process of how to deal with, or mitigate situations (Roeser, 2010). There are generally two separate ways in which risk is perceived: the first is an affective process, referred to as “the primary evaluative process” that involves a typically instantaneous gut, intuitive reaction to information; and the “secondary evaluative process”, which is deliberative, usually taking place after the initial reaction to information and involves the thinking-it-through period (Visschers et al., 2008, p. 207). While both reactions are to be expected, often the primary, intuitive reaction tends to dominate over deliberation, which can lead to misperceptions of risk. Whether overestimating, underestimating, or simply not understanding one's risk, the results can be detrimental and lead to action or inaction, which may negatively affect one's health.

Research highlights a vast array of risk perceptions about women's breast cancer, which interacts with lagging breast cancer screening compliance. For instance, patients greatly overrate their risk of developing or dying from the disease (Dubé, O'Donnell & Novack, 2000). Such perceptions are often related to women's misunderstandings of information related to breast health and screening (Wonderlick & Fine, 1997). With so much information to take in, coupled with the stigma and fear surrounding breast cancer, it is unsurprising that misperceptions about one's own risk are common. Common misperceptions about cancer among Latin American women (e.g., cancer is a death sentence, cancer cannot be cured, and cancer may be contagious) illuminate factors that may contribute to risk misunderstandings (Granda-Cameron, 1999). Latin American women are more fatalistic in their perceptions of breast cancer than other ethnic groups and tend to overestimate their risk for getting the disease (Mishra et al., 1998). They tend to believe that it is a symptomatic disease, causing them to greatly underestimate their risk for getting breast cancer, and consequently, they were much less likely to seek screening (Borrayo, Buki & Feigal, 2005). It is, therefore, suggested that accurate risk comprehension and perceived susceptibility to breast cancer is associated with increased screening behavior among women (Williams, Clarke & Savage, 2002). Providing information to women regarding the negative consequences of failing to practice breast screening may increase knowledge of risk and also motivate women to engage in proper screening practices (Meyerowitz & Chaiken, 1987).

Risk communication is considered significant due to the importance of disseminating messages regarding risk to properly inform audiences on the threat of women's breast cancer and potentially mobilize and activate populations to engage in healthy behaviors. Successful risk communication "requires establishing effective communication channels and developing mutually respectful relationships between patients and providers" (Nekhlyudov & Partridge, 2003, p. 236). Thus, techniques should avoid paternalistic and persuasive approaches and focus on fostering open and equal communication when discussing risk. Effective health risk communication is dependent on understanding the information needs of recipients and can directly impact peoples' decision-making in relation to health behaviors, such as mammography practices.

Various studies identify risk communication as a concept that is socially imbedded in different interested communities, such as academics, interest groups, governments, and the public (e.g., Bergmans, 2008; Hansson, 2010; Stoffle & Minnis, 2008; Strydom, 2008). Psychological, cultural, social, and institutional processes are intervening factors that tend to enhance an individual's perception of risk, subsequently influencing risk behavior. Cultural constraints in Latin America include cultural norms of modesty, distrust, and limited familiarity with the healthcare system (Kreps & Sivaram, 2008). Trust, for example, is essential for successful risk communication (e.g., Blennow, 2008; Löfstedt, 2010); it results from transparent and honest communication, which circumvents uncertainty among the public.

Effective risk communication requires collective discussions among all concerned parties. Risk communication can be improved through the integration of potential stakeholders, along with officials, in the definition of the risk problem, aiding in the unification of differing opinions and views about risk and allowing for the discussion of issues associated with the risk from varying perspectives (Brunet & Houbaert, 2007). Despite the introduction of patient-centre care paradigms, physicians still often lack proper training on best practices for effective risk communication (Hanoch, 2004). For example, in communication with female patients about their mammogram results, it is more effective and preferred by patients if communication occurs in person, rather than over the phone or other means, because it allows physicians and counselors to question patients on their perception of their risk in order to avoid misconceptions (e.g., Carney et al., 2009; Quillin et al., 2008). Latin American women are more likely to comply with healthy screening behaviors and exhibit accurate awareness of risk when they are provided with information that they can understand; for instance, through counseling and guided discussions, their perceptions of risk demonstrate increased accuracy and their fears of cancer are decreased (Bowen et al., 2004). Accuracy of risk assessment among Latin American women increases when physicians provide them with social comparison information of other women with higher risk of breast cancer (Dillard et al., 2006). Being prepared to discuss risk to family members is also vital, as one of the greatest fears Latin American women feel is how a diagnosis may negatively impact their family members (e.g., Luker et al., 1995; Macdonald et al., 2008). This fear may act as an additional barrier to women seeking screening for breast cancer. Thus, breast cancer risk should be framed in a way that alleviates women’s anxiety over the health of their family members.

MEDIA INTERVENTION

Breast cancer has attracted notable media coverage, which is likely attributed to the growing prevalence of this disease and to society’s heightened fixation on risks and fear regarding health issues (Cookson, 2010). Exposure to media regarding women’s breast cancer screening practices is shown to encourage effective uptake of this behavior among women (Wang et al., 2008). The use of storytelling in the media is employed as a method of conveying the experiences of this disease in society and how it impacts the lives of women and their surroundings (Kreuter et al., 2007). The vast majority of stories about breast cancer provide citations of specific individuals, typically experts or women experiencing the disease; a process of personification through narratives that allows the audience to connect to breast cancer on a unique level, characterizing its realities and reifying survivors (Atkin et al., 2008). However, debates over the representations of the fusion of women and breast cancer in the media face criticism. Breast cancer is a disease that impacts women globally; women of all different demographics face the burden of this disease in some capacity. Despite this, mainstream media representations tend to leave out the dynamic nature of the people who are affected by breast cancer—often failing to incorporate “the complexities of age and beauty as they pertain to specific groups of women” (Cartwright, 1998, p. 131).

Agenda-setting theory posits that the media play a pivotal role in shaping public thought and discussion on breast cancer screening behavior compliance (Eid & Dakroury, 2012). It may be possible to promote changes in health behaviors with the help of media strategizing, as journalists and media practitioners have the ability to impact public health in a positive manner due to the power of agenda setting, potentially resulting in opinion changes (Dakroury & Eid, 2012; Jones, Denham & Springston, 2006). For example, a study about the impact of exposure to newspaper coverage on breast cancer screening practices among female college students and their mothers revealed that “the quantity of mammogram screening coverage in newspapers contributes to mammography utilization” (Atkin et al., 2008, p. 6). Media coverage of public figures and their experiences with breast cancer and widely publicized events that draw attention to this disease and the importance of screening can be an opportunity to persuade women to engage in health behaviors, such as breast self-examination and mammography (Fink et al., 1978).

Activism and advocacy efforts have also attracted significant media coverage due to growing community involvement in breast cancer awareness (Cartwright, 1998). Communication “through the local media can be an invaluable resource for mobilizing community support and activity” (Figueroa et al., 2002, p. 10). Agencies and organizations that specialize in cancer research or awareness often work to establish relationships with media outlets with the intention to promote knowledge on the nature, detection, and treatment of breast cancer (Catalano et al., 2003). However, while the media are said to be an important health communication tool in the dissemination of information about women’s breast cancer, it is also important to acknowledge the limitations involved in holding expectations of this transmission vehicle’s standards. The media may fail to provide audiences with sufficient information, resulting in distorted understandings or conceptions of the disease. Thus, while media coverage on this topic is inevitable, it is important to note that not all is considered helpful in breast cancer health communication ventures. For example, the news media rarely provide sufficient information regarding pertinent topics related to breast cancer, such as prevention methods and encouragement of healthy dietary practices (Atkin et al., 2008). Also, while the Internet is considered a valuable tool with regards to communicating information about breast cancer as women can seek knowledge about the disease or interact in virtual communities to obtain information or support, there are many limitations associated with information acquisition via this medium, such as the lack of trust regarding the credibility and accuracy of the information (e.g., Bernhardt et al, 2002; Elliott, 2007; Lee et al., 2008; Winzelberg et al., 2003). Thus, in exploring the analytical agenda of media involvement in health communication associated with breast cancer, it becomes clear that further investigation on the role of the media is required.

METHOD & OUTCOMES: INITIATIVE FOR ACTION IN VENEZUELA

Action-oriented research 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). As “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), 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.

Action-oriented researchers "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). They "believe that the process of conducting research should be empowering for research participants" (Esterberg, 2002, p. 141). Aiming 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), action-oriented researchers and community partners "combine their different kinds of knowledge and skills to produce insightful and usable findings" (Small & Uttal, 2005, p. 938).

We developed an action-oriented research project in Venezuela in collaboration with SenosAyuda, an 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. 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). 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.

The project was implemented in a very particular political, social, and cultural 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. The media have played an important role in the dynamics of polarization. The Chavez's regime has contributed to this polarization by promoting what the government calls the "new media hegemony" through the control of a vast network of radio and TV stations, newspapers, and Internet websites that are part of a huge propaganda machine (Bisbal, 2009). On the other hand, 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 increase 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).

The various social challenges in Venezuela include insufficient and irresponsible media coverage of women's breast cancer and the relevant healthcare services and information, 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, deficiencies in activity evaluation and feedback measures, and incompetence in the physician-patient interactive relationship.

Culturally, *machista* chauvinist prejudices still dominate the public debate about breast cancer, as shown for example by the controversy prompted by soccer fans protesting because their team decided to wear pink shirts during the breast cancer month in October 2012. According to a news report, the suspension of the game between Deportivo Táchira and Atletico Venezuela was ordered by representatives of the Venezuelan Football Federation after fans refused to leave the field for 40 minutes "to protest the pink shirts being worn in support of the fight against breast cancer, led by the Fundación SenosAyuda" (Bailey, 2012, October 29).

As a way to fill the void left by the public sector in the provision of healthcare, especially to the poor populations, the civil society organizations emerged in Venezuela. *Sociedad Anticancerosa de Venezuela* (the Cancer Society of Venezuela) was the oldest organization, 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.

To address the problems and deficiencies that women are facing with breast cancer issues and to promote nationwide long-term action programs, SenosAyuda was created in 2007. This 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 aimed to achieve four main goals: 1) to develop and enhance the communication capabilities of activists in order to increase their impact as spokespersons of their cause; 2) to identify needs and gaps in the communication between different stakeholders (i.e., physicians, patients, activists, journalists, and public officials); 3) to promote open discussions and debates about the ethical issues relevant to women's breast cancer in order to achieve more transparent, symmetrical, and empowering engagement and action among stakeholders; and 4) to create networking opportunities in order to expand the impact of social civil organizations and activists in the public discourse about breast cancer and the need for a national policy.

Through four annual collective workshops in Caracas and continuous national events and activities during the four-year period (2009–2012), collaborators of this action-oriented research project have engaged in discussions. The workshops essentially helped participants to be spokes-people for their organizations in the media and to understand how to use communication as a tool to plan and achieve the given activities. The workshops provided skills of ethically and responsibly composing and communicating messages about breast health that can help promote changes in attitude and behavior. They helped with ethical media relations and how to define the goals of interviews and to target the audiences and select the strategies to reach them. The workshops also included discussions on 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.

During the workshops, discussions have highlighted the media influence in the fight against women's breast cancer. It has been noted that although patients generally prefer screening information supplied by primary care providers, their providers actually play a limited role; most information come from media sources. Media campaigns impact awareness of mammography as a screening tool, knowledge of mammography guidelines, intention to be screened, and motivation to seek first time and subsequent mammograms. Criticisms of media practices include that news coverage of preventive actions focuses mainly on what women can do at the individual level rather than portraying actions at the family or societal level. Also, news media present almost no information to educate parents about how to protect their daughters from environmental risks. Useful and successful media practices were suggested, such as that message strategies that include testimonials from real-life survivors of breast cancer significantly affect participants' willingness to seek early detection for breast cancer. The workshops' discussions have emphasized fundamental ethical principles that are necessary for the media to abide by when covering issues surrounding women's breast cancer. These principles include independence, accuracy, integrity, truth, fairness, and serving the public interest (Eid, 2008). Moreover, protecting the patients' privacy, showing respect, and correcting mistakes were discussed.

A wide range of events and activities were conducted by collaborators 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. Another event was a fashion show where breast health was promoted at both the regional and national levels (television coverage by the station TELEVEN). Other events included tennis tournaments to raise funds and support the foundation, funding campaigns, and the design of a project to strengthen the development of breast health education.

Activities include the production of materials, such as "If you read me, you take care of yourself and you touch yourself", which was distributed to the public. Also, 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 public was 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. The media were beneficial through conducting interviews to help get the messages out, and the physicians were of assistance in providing information as well as being spokespeople to help further convey the importance of breast health.

A major outcome 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.[4] 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 a 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. Moreover, the declaration has contributed to highlighting some of the major ethical issues in breast cancer information and care, particularly the need to communicate messages associated with the solutions available to the public and adapted to their needs and socio-cultural realities, the role of the state in securing financial protection to every person affected by breast cancer through public and private healthcare insurances and funding, and the provision of palliative care as part of human, moral, and ethical duties towards people suffering from breast cancer.

Another major outcome of our action-oriented research project has been the creation of a code of ethics for SenosAyuda. In light of the NGO's mission, this code aims to emphasize a commitment to: 1) maintaining social responsibility; 2) upholding human rights; 3) increasing breast cancer awareness; 4) ensuring transparency; and 5) maintaining corporate responsibility. These major ethical principles have been emphasized through detailed relevant ethical standards and guidelines. To maintain social responsibility, SenosAyuda

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[4] 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.

serves the communities within which it operates with a focus on helping those affected by breast cancer, upholds the reputation of communities it represents, complies with all government regulations, adopts a positive and proactive role in the community, and takes an active role in the creation and moderation of breast cancer care services. To uphold human rights, SenosAyuda respects and acknowledges the dignity and worth of all individuals involved, respects cultural, individual, and role differences among people, upholds the individual’s rights to privacy and maintains the confidentiality and security of their information, recognizes the individual’s innate dignity as a human being and respects their autonomy and freedom of choice, and ensures that donors, beneficiaries, members, and others are free from undue pressure arising from personal relationships, financial or gift incentive or disincentive, and other forms of coercion. To increase breast cancer awareness, SenosAyuda’s education and information materials and programs are created for, aimed at, and made accessible to those affected by breast cancer in the community. SenosAyuda retains transparency (Eid & Nahon-Serfaty, 2008) in all of its dealings with the government, the public, donors, partners, beneficiaries, and other interested parties, presents information in a fair, accurate, and unbiased manner, is obliged to disclose conflicts of interest whenever they appear, and provides accurate and timely information on the procurement and management of donations received. Finally, to maintain corporate responsibility, SenosAyuda uses all funds solely for the purpose of continuing its mission, actively seeks out new donors and opportunities to raise funds for its cause, and uses donations in accordance with the commitments it has made to contributors.

CONCLUSION

To conclude, this paper describes an action-oriented research project that we developed in Venezuela to help women reduce the risk of breast cancer by discussing several levels of ethical interactions and relationships among the stakeholders (patients, activists, physicians, public officials, journalists, scholars, and private sector representatives) which are currently social-cultural obsticales towards this goal.

The key to reducing the risk is to foster positive health attitudes and behaviors among women to understand what is effective in removing general, cultural, and socioeconomic barriers to seeking screening or treatment. Important barriers for Latin American women related to screening are anxiety about the procedure, cost, embarrassment, fear of the pain of mammography, and fear of being diagnosed with breast cancer, which may be perceived potentially as a death sentence or serious issue for their family. Also, due to the high value placed on modesty among Latin American women, and the fact that with time and experience they become increasingly comfortable touching their breasts for self-examination, they may benefit from physicians and nurses showing them how to conduct a breast self-exam. Therefore, in the promotional efforts for breast self-examination, it is essential to understand and be sensitive to these cultural beliefs and feelings and not simply attempt to educate these beliefs away. The physician-patient discussion of breast cancer and screening is a strong factor in the likelihood of women’s adherence to breast exams (Smith et al., 2009). In this physician-patient relationship as well as many other interactions and practices relevant to women’s breast cancer, ethical principles, rights, and responsibilities are fundamental to reach positive outcomes.

A perception of risk is a prominent driving force to seek breast cancer screenings and practice healthier behaviors (Hubbell, 2006). In creating strategic risk communication messages that can encourage breast cancer early detection for women, it is essential to frame messages in a manner that address cultural constraints such as women's modesty, religion, distrust of physicians or the healthcare system in general, and low socioeconomic status, which may all prevent women from seeking breast cancer screening (e.g., Kreps, 2008; Kreps & Sivaram, 2008). Messages for Latin American audiences should also recognize the heterogeneous and diverse nature of this population and demonstrate cognizance of communities with low health literacy rates (Buki, Salazar & Pitton, 2009).

Despite the fact that governmental efforts strive to improve healthcare accessibility and promote equality, deficiencies and disparities persist in the status of breast cancer among Venezuelan women. This issue is of specific importance, as lagging health literacy about the disease and growing incidence rates can result in increased mortality. In the fight against women's breast cancer in Venezuela, it is suggested that public health campaigns work to raise awareness on the value of screening behaviors and government strives to facilitate increased accessibility to public prevention and treatment facilities. This goal requires the acknowledgement of the barriers that impede Venezuelan women from complying with productive breast health practices and an assessment of their risk perception.

It is possible to develop effective risk communication strategies through media interventions that can influence persuasive and useful public health campaigns regarding women's breast cancer. The media coverage of this disease is specifically useful, as health beliefs and ideas are intrinsically linked to media depictions. As a result of the workshops, events, and activities of our action-oriented research project in Venezuela, there has been positive indications on more effective interactions between physicians and patients, increasing satisfactions about issues of ethical treatment in providing healthcare services, and more sufficient and responsible media coverage of breast cancer healthcare services and information.

Biographies

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