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.
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 (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 project1 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 dialogue among different stakeholders, including physicians, patients, activists, scholars, and public officials, in order to draft the foundations of a breast cancer national policy.