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.

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 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

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the disease (e.g., Andersen et al., 2004; Harvard Medical ... 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 than 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 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 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. It discusses four levels of ethical interactions and relationships among the stakeholders (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.
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