



Perilous equations? Empowerment and the pedagogy of fear in breast cancer awareness campaigns



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SYNOPSIS

Breast cancer awareness campaigns are the major strategy used by public institutions and private organizations to empower women about breast cancer. Yet, drawing on my own research and observations as an academic and activist over the past 9 years in Spain, I argue that these mainstream campaigns are often unaware of, or oversimplify, conceptualisations of empowerment. I illustrate my argument with examples from Spain and North America. I show how the specific goal of empowerment aims to persuade women to comply with biomedical recommendations which include behaviour change and treatment-seeking. Towards this end, their main approach focuses on the use of coercive fear mongering tactics, including misleading information and exaggeration of data on incidence, mortality, survival and treatment efficacy. A further problem is that they allude to assumptions about the reasons for women's compliance: stereotypical moral and gendered responsibilities for one's health and family as well as fear of a horrible death. Some justify this particular use of fear by appealing to the need to target women with a simplified, high-impact message. However, there is evidence that fear creates unnecessary social psychosis and further distorts the decision-making process, conflicting with empowerment intent. I argue that there is an urgent need to stimulate debate about how to improve breast cancer awareness campaigns and propose an alternative approach, grounded in a critical pedagogy paradigm – a model of critical health literacy based on a patient-centred approach that aims to develop critical consciousness and reflection of the social factors that affect breast cancer.

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Introduction

Much of the public and medical literature on breast cancer has celebrated the thriving 'pink culture' as a sign of the progress of women's empowerment with respect to the disease. Indeed, there is no doubt that its advocates have been successful in mobilising public health's main players to bring the disease to the fore in public discourse and to raise money for clinical research and provision of services. Arguably, it has also helped to destigmatise the illness and encourage women to talk about their experiences, making the disease somewhat

less frightening. However, many public health professionals, scholars and health advocates, mainly in North America, have expressed a profound sense of unease about the ways in which breast cancer awareness campaigns have been 'mainstreamed'¹ and how these campaigns have framed the definition of what constitutes empowerment (Goldenberg, 2010). This paper addresses these concerns.

To date, there is little discussion on the recurring use of fear as a pedagogical tool to raise awareness in the North American context (see Sumalla, Castejón, Ochoa, & Blanco, 2013), and still less discussion of the misuse and abuse of the concept of empowerment by these campaigns (see for example King, 2006, 2010). To my knowledge these discussions have not reached the Spanish context yet. Examples from Spain, with which I am most familiar, and also from the United States of

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America, where much of the public and medical literature originated, open a window of opportunity for examining how the pink culture is represented in these contexts. The paper's aim and novelty are therefore to expose the presently neglected links between breast cancer awareness campaigns, conceptions of empowerment and coercive approaches that rely on fear mongering techniques. I argue that in both contexts similar tactics and rhetoric are used to muster women's empowerment. Becoming 'empowered' is perceived as involving two steps: being educated about a reduced number of *facts* and acting upon this knowledge. Towards this end, this article reveals how the main approach focuses on the use of fear mongering tactics, including misleading information and exaggeration of data on incidence, mortality, survival and treatment effectiveness. Fear mongering is powerful because it occurs in a social context. Stereotypes of personal negligence, gendered familial responsibility, and conflation of screening with prevention and cure are used to have an impact on women's compliance. One of the main arguments of this article is that fear mongering is a coercive tactic rather than an educational or/and evidence-based one.

At the outset, I want to emphasise that I am not claiming that my analysis is statistically representative, nor is my intention to point fingers or demonise breast cancer awareness campaigns. In fact, I believe that campaigns can actually be liberating educational tools for women's health. However, it is perhaps most important to unpack current understandings of empowerment and the tactics used to achieve it to reveal several contradictions that health educators and public health practitioners need to consider.

In what follows I frame the specific social context of breast cancer campaigns. I explore some assumptions and social angst underlying these campaigns which include understanding empowerment, the nature and dynamics of gender roles, the benefits of fear mongering tactics and the appeal to risk. Then, I explain the origin and evolution of breast cancer awareness campaigns that sought to empower women by breaking the cycle of invisibilization, stigmas around cancer and dependence on medical authority. I highlight the rise of arguments that justify the pedagogy of fear in public awareness campaigns. I follow this with an examination of some examples of fear mongering tactics to illustrate how disseminating fear is at odds with empowerment intents. Three dominant interconnected messages emerge: discourses that conflate screenings with treatments and cure and the blind faith that many seem to put in all technological medical procedures: gendered familial notions of responsibility, and stereotypes of personal negligence. I conclude by reclaiming the definition of empowerment grounded in a critical pedagogy paradigm – a model of critical health literacy based on a patient-centred approach that aims to develop critical consciousness and reflection of the social factors that affect breast cancer, so it becomes a medium for personal and social change.

So for all the effort made and money invested in campaigns over the last few decades, I hope this article "serve[s] pedagogical purposes" (Inhorn, 2006:347), by echoing concerns raised by activist groups such as the Breast Cancer Action and the Breast Cancer Consortium about the need for a radical shift in the way in which health education is envisioned if we want to decrease the curve of the

epidemic and truly enable women to regain control over their health. Thus, in acknowledging the importance of critical health literacy, I argue that educating healthy and empowered women involves moving beyond the singular focus on risk and individual responsibility to a more holistic approach that gives them a sense of control over their health and that of their communities so they can tackle "the causes of the causes" (Rose 1992 in Marmot, 2005:1102). In addition, I hope this article stimulates debates about the tactics or "processes by which empowerment is generated" (Wallerstein, 2006:3).

Methods

As a researcher, health educator and activist I have been concerned with women's health, empowerment and cancer education for over 8 years now. The account presented here is precisely motivated by a combination of frustration and incredulity due to what has been done in the name of breast cancer and empowerment, which has little to do with giving power to women to control their health, but rather seems to be inadvertently stuck in reinforcing stigmas about cancer and normative gender roles.

Given the ever-expanding number of charities, organizations and public institutions working on breast cancer awareness, it would be nearly impossible to analyse all the 'campaigning work' that takes place. It is important to emphasise that this article is not intended as an exhaustive review and my analysis is not meant to be representative of all breast cancer campaigns. I am drawing on a wide variety of Spanish and North American sources which include journal articles, newspaper articles, weblogs, e-fora, professional debates concerning health education and cause promotion, websites of companies promoting pink merchandising in the name of breast cancer awareness and public health campaigns. My involvement with the Breast Cancer Consortium, the Spanish Network of Women Health Workers and other networks of breast cancer advocates in Spain has been essential to identify materials, trends and debates and to share personal experiences. My analysis is also inspired by data collected in Spain between 2006 and 2008 with women living with breast cancer, their partners and various health professionals, as well as from informal conversations with friends and acquaintances who have undergone, or are thinking of undergoing, different types of breast surgery or diagnostic procedures.

In terms of which data is included in the analysis I have selected those examples and anecdotal evidence which I consider to represent a common thematic pattern: fear mongering as tailored towards (1) stereotypes of personal negligence, (2) gendered familial responsibility, and (3) conflation of screening with treatment and cure.

Given these methodological limitations, I am not claiming that my analysis is statistically representative but, my research and activist experience over the years lead me to suggest that these findings are representative of a wider trend both in Spain and North America. Finally, by public health campaigns I refer to educational materials formulated by public institutions, private organizations – including charities, foundations and corporations – or a combination of both.

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