Challenging Disinformation in Breast Cancer Awareness Campaigns

Problematising disinformation in breast cancer awareness campaigns

Ana Porroche-Escudero

In the current context, pink breast cancer awareness campaigns and initiatives are comfortable for organizers, individuals involved and sponsoring companies, but show clear signs of misinformation. This disinformation blocks the right of people to truthful, objective and complete information that favors free and weighted decision making.

To define the concept of "disinformation" I rely on the recommendations of the Spanish Association Against Cancer (AECC) for good health communication. Thus, I understand disinformation as the provision of erroneous information through "alarmist or morbid headlines, confusing scientific information, creation of stereotypes, invisibility of some groups..."
headlines, confusing scientific information, creation of stereotypes, invisibility of some groups of patients, little social context, inappropriate use, abuse or frivolous terms, and little Preventive information ". Misinformation also includes the omission of valid and relevant information. Let's look at some examples.

Trivialized terms: breast cancer is not sexyEl breast cancer has been defined as a disease sexy simply because the naked bodies of women, pink marketing and solidarity initiatives sell and attract sponsors ². We must remember that the pink ribbons were born as a marketing strategy of the cosmetics company Estee Lauder in 1992. The color pink was chosen because it was associated with femininity and festive spirit ³. The campaigns of British charities CoppaFeel! And Pancreatic Cancer Action illustrate the frivolousness of breast cancer: they not only convey a message that softens the cruelty of the disease, but ignores the lethality of some types of tumors. CoppaFeel! defines self-examination as a technique that "saves lives" while it is "fun" and "sexy". In fact, it stresses that breast cancer is sexy, unlike other cancers, such as testicular. To legitimize his argument invokes Mel B, a component of popular pop group Spice Girls, "which has been photographed topless to support us in October." In the same vein, in 2014, the Pancreatic Cancer Action information campaign said "I wish I had breast cancer," reinforcing the message that breast cancer is not as serious as other tumors.

Inappropriate use of terms: secondary prevention is not primary prevention Frequently confusing early detection with primary prevention, and it is important to emphasize the difference. Primary prevention means preventing the tumor from appearing in the body. Early detection (or secondary prevention) involves finding the tumor as soon as possible to try to avoid its development in order to minimize the impact of treatments. Therefore, neither mammograms nor breast self-examination are primary prevention methods. Messages like "prevention saves lives" or "just 10 minutes can save your life" exemplify how the terms are used interchangeably and erroneous messages are sent to the population.

Confused scientific information: omission of disputes about the effectiveness of evidence

In general, in Spain the campaigns are biased in favor of mammographic screening. It is striking that, despite the fact that millions of euros have been invested in screening programs, and despite scientific controversies about their effectiveness in reducing mortality and its serious health consequences, the population is rarely informed about these controversies ⁴. It is precisely this ambiguity and this answer about the effectiveness of the screening and its
It is precisely this ambiguity and this answer about the effectiveness of the screening and its possible damages or benefits that makes it mandatory to provide complete, clear and unbiased information to facilitate informed decision making. According to the European Charter of Patients’ Rights, providing accurate, reliable and transparent information is a requirement before engaging people in any initiative. A good example is the brochure prepared by the Nordic Cochrane research group in 2008. England, Scotland and the United States also reflect the main controversies about screening. The excellent articles by Martin-Martin and Ojuel and De Michele summarizes clearly the dangers of screening, including overdiagnosis and overtreatment.

The idea that self-exploration prevents cancer has deepened socially through images and messages like "prevention is in your hands." While it is important for women to learn to recognize when changes in the anatomy of the breasts are part of the hormonal and life cycle, and when they alert us to some anomaly, self-exploration does not prevent cancer, it is not a reliable method of early detection and does not decrease mortality. For these reasons, the US Preventive Service Task Force and the Ministry of Health, Social Services and Equality advise against this practice because "there is reasonable evidence of lack of benefit and good evidence of harm."  

**Little context information**

Usually about breast cancer as if it were a single disease progresses linear and orderly manner. That is, it is believed that detecting the package "in time", or when it is small, is a guarantee of salvation. However, there are many types of breast tumors and they do not behave in a linear or orderly fashion. The animal analogy of Barry Kramer, director of the National Cancer Institute's Division of Cancer Prevention, is useful in demystifying the idea that cancer progresses linearly. According Kramer there are at least three types of tumors:

- **Birds**: grow fast (they are aggressive) and metastasize at any time.
- **Bears** can be dangerous because, although they grow slowly, they can metastasize if they are not diagnosed and treated on time.
- **Turtles**: they are tumors of very slow growth that never go to metastasize and sometimes they disappear alone. Diagnosing this type of cancer does not save lives because it poses no threat to the person.

The lack of context in reporting on cancer has three important consequences. One, that
associating the disease with survival is denied that there are tumors that are fast growing and lethal. Two, which create false expectations among the population; for example, a study by the Swiss Medical Board found that 71.5% of women believe that screening reduces mortality by half, a perception that contrasts with the findings of independent studies that indicate there to sift through to 2000 women during 10 years to save a life. And three, as I mentioned before, it is omitted to provide information about the risk of overdiagnosis and overtreatment, "considered the greatest harm of screening for their serious health consequences". Some types of malignant tumors (turtles) pose no health threat, but are treated as if they were invasive tumors once they are diagnosed (overdiagnosed). This causes a healthy woman to become unnecessarily patient, with numerous visits to the hospital for testing, radiation and surgical treatments, periodic check-ups for years, and fear of a lifetime relapse (overtreatment).

Invisibilization of some groups

Pink speeches about breast cancer are characterized by heteronormativity. That is, it is assumed that heterosexuality is the norm. Thus, the needs of lesbian, gay, transgender, bisexual, queer and intersex (LGBTI) are rarely represented in campaigns or initiatives.

People living with metastases are the other forgotten collective. Surprising the invisibility of metastases despite the fact that they are the type of cancer that kills thousands of women and the reason that justifies the emphasis on early detection and access to treatments. It should be noted that only 5.5% of the AECC budget is devoted to research covering some aspect of metastasis. In the United States there are few specific support groups for people suffering from cancer in stage IV, and I am not aware that there are groups and in Spain.

During the celebrations of Pink October, people with metastases may feel like the "elephant in the room " because they symbolize mortality. Moreover, the emphasis on celebrating the survival and abuse of epic terminology ("the struggle", "the battle") can contribute to marginalizing and stigmatizing people with metastases, since it is understood that people who die are losers because they have not beaten cancer.

Little information on primary prevention

Evidence accumulated over decades indicates that cancer is caused by the conditions in which people are born, live, and work. However, breast cancer has traditionally been represented as a disease caused by irresponsible lifestyles (eg, low exercise, high fat diet, negative thinking, smoking, drinking, etc.). According to this logic, women could prevent cancer by making healthy choices. However, recent research indicates that lifestyle factors account for only a small percentage of breast cancer risk.
cancer with adequate information and education to modify their behavior. Numerous studies have consistently shown that interventions to change individual behavior are not effective to prevent certain diseases, such as cancer, because people have little influence to control exposure to harmful conditions in their working and social environment. And they point out that many types of tumors could be prevented with interventions aimed at promoting healthy legal and macro-political advances in living and working conditions, since they have a greater positive impact on primary prevention. Despite all the evidence accumulated, it is surprising that scarce resources are invested to understand, educate and intervene on these social determinants of cancer.

In short, it is time to self-critique the campaigns of the pink ribbon and reconsider the way we approach cancer through awareness campaigns. Misinformation can interfere with people’s critical ability to make thoughtful decisions. As Marshall and Adab point, “a decision which has been taken without access to information is not informed.” Sometimes, women can opt for drastic measures are unnecessary and are also potentially dangerous to your health.

Solutions to address breast cancer go inexorably by: 1) a change in the informational / educational model based on truthful, objective and complete information that enhances both people’s critical ability to analyze medical information and knowledge of Social determinants of health; And (2) a political commitment to primary prevention.

**Authorship Contributions**

A. Porroche-Escudero has drafted the manuscript.

**Financing**

Any.

**Conflicts of Interest**

The author is part of the advisory team of the Breast Cancer Consortium.

**Thanks**

The author thanks Flor Gamboa for her editorial help in trimming the original manuscript, which exceeded the extension limit by far. He is also grateful for the intellectual support of the National Institute of Health Research Collaboration for Leadership in Applied Health.
Research and Care North West Coast (NIHR CLAHRC NWC). The opinions expressed do not reflect the NIHR criteria.

---

**Bibliography**

1. **AECC**  
   Style guide Health & Media: Cancer  
   Spanish Association Against Cancer, (2006)

2. **S. King, Pink ribbons, Inc.**  
   Breast cancer and the politics of philanthropy  

3. **De Michele G.**  

4. **M. Baum, H. Thornton, PC Gøtzsche**  
   Still awaiting screening facts  
   BMJ., 2 (2010), pp. C6152

5. **S. Bewley**  
   The NHS breast screening program needs independent review  

6. **Active Citizenship Network.**  

7. **Cochrane Nordic.**  
   Mammography as a screening method for detecting breast cancer. (Accessed 09/21/2016.) Available at: [http://nordic.cochrane.org/la-mamograf%C3%ADa-como-m%C3%A9todo-de-cribado-para-detectar-el-cancer](http://nordic.cochrane.org/la-mamograf%C3%ADa-como-m%C3%A9todo-de-cribado-para-detectar-el-cancer)

Referring to **Fig.**  

Referring to **Fig.**  

10. **US Preventive Services Task Force.**  
eleven G. Martín-Martín
Periodic mammograms to examine: do they really outweigh the benefits to the detriment in the breast cancer screening program?
MyS Women’s Health., 34 (2013), pp. 20-26

J. Ojuel, G. De Michele
Controversies about the mamografic cribatge: does it save vines or harm the health?
Cicatrius (in) visible. Feminist Perspectives on Breast Cancer, pp. 105-120

Does Michele G. Does The Sun’s Check on Tuesday raise awareness or just set up a sexy breast cancer blame game? Breast Cancer Consortium; March 11, 2014.


N. Biller-Andorno, P. Jüni
Abolishing mammography screening programs? A view from the Swiss Medical Board


C. Valls-Llobet
Influence of health and environment in breast cancer
Cicatrius (in) visible. Feminist Perspectives on Breast Cancer, pp. 93-104


T. Marshall, P. Adab
Informed consent for breast screening: what should we tell women
J Med Screen., 10 (2003), pp. 22-26
Challenging Disinformation in Breast Cancer Awareness Campaigns

Medline

twenty-oneHG Welch

Should I be tested for cancer? Maybe not and here's why


22 Gérvas J. Genes BRCE and preventive mutilations. An excessive response if it is popularized. Health Act; 20 May 2013. (. Accessed 08/20/2016) Available in:


Copyright © 2017. SESPAS