Evolution of accesses to information on breast cancer and screening on the Brazilian National Cancer Institute website: an exploratory study

Evolução no acessos à informação sobre câncer de mama e seu rastreio no site do Instituto Nacional de Câncer: um estudo exploratório

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> Abstract Delays in diagnosis due to low Breast Cancer awareness are widespread in Brazil maybe owing to ineffective strategies to raise attention on early diagnosis. As a proxy of collective interest in BC screanning (BCS) we studied the monthly accesses to BC and BCS webpages in INCA's website along 48 months. A log analyzer built a time serie (2006-2009) of BC and BCS monthly means, which oscilations were studied by analysis of variance (ANOVA). We found significant increasing accesses to BC and transient "attention peaks". Enlargement in BC/BCS differences along all period were caused by increasing accesses to BC and decreasing/minor/stable oscillations to SBC pages. These results are consistent with previous reports on increasing interest to BC contrasting with indifference on BCS. In the context of an exploratory study, we discussed some aspects: weakness of a "prevention culture"; lack of confidence in health system and screening programs; "celebrity effect" in the context of media framing; collective perception of risks heightened by perception of social vulnerability. Findings suggest that culture-tailored communication strategies would be necessary to inform Brazilian people about BCS. Future research is needed to study social perceptions and constructions on BC topics.

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Key words Internet, Mass screening, Breast câncer, Health communication, Mass media **Resumo** Demoras no diagnóstico do câncer de mama (CM) são comuns no Brasil, talvez devido à ineficácia de estratégias de divulgação sobre os meios para a identificação precoce. Admitida como equivalente ao interesse coletivo sobre CM, analisou-se a evolução de acessos às páginas sobre CM e seu rastreio (RCM) no site do INCA durante 48 meses. Empregou-se analisadores de log files para construir uma série temporal (2006-2009) de médias mensais de acessos às CM e RCM estudadas por análise de variância (ANOVA). Aumentos significativos e "picos de atenção" transitórios nas CM; ampliação nas diferenças CM/ RCM, por incrementos crescentes nas CM associados à estabilidade nas RCM. Os resultados são consistentes com relatos anteriores que descrevem expressivo interesse em CM e relativa indiferença ao RCM. No contexto de um estudo exploratório, discute-se: a "fraca cultura de prevenção"; falta de confiança no SUS e nos programas de rastreio; "efeito celebridade" no contexto do framing das mídias; percepção de riscos coletivos ampliada por vulnerabilidades sociais. Os achados sugerem que estratégias de comunicação adaptadas à cultura são essenciais à divulgação dos programas de rastreio. Pesquisas futuras são necessárias para estudar com mais detalhe as construções sociais sobre temas relativos ao CM.

Palavras-chave Internet, Câncer de mama, Rastreio de massa, Comunicação em saúde, Mídias de massa

Introduction

Breast cancer (BC) is the most common cancer among women in all parts of the world, wether in high income countries (HICs) or in poor countries¹, accounting for 22% of the 4.7 million new cases ocurring annually among females worldwide^{2,3}. One of the major objectives of the Brazilian Ministry of Health (MH) is to foster the interest in the breast cancer screening (BCS), especially among women at high risk⁴. Strategies have been developed to promote the early identification of BC mainly by the broadcasting of pertinent information⁴. Brazilian BC's mortality rates are increasing with striking variations between geographic regions and several factors might account for disparities including delays in diagnosis due to low BC awareness and gaps in implementation of mammography screening⁵. It is well known that BCS campaigns aiming to increase people's awareness and early detection is related with higher proportion of early clinical stages and decrease in mortality trends. There is evidence that prevention initiatives are much more cost-effective and humane than BC treatment and early detection investiments saves far more lives than late diagnosis⁶⁻⁸. Countries as Netherlands and Sweden, with one of the most effective screening interventions, reach high adherence and have low costs in lives and money for the whole health system. The nationwide breast screening program in Netherlands (1990 to 1997) reached 78.5% of women invited. The stage distribution of screen-detected cancers was more favourable than that of those diagnosed in unscreened women9. Swedish screening programs reduced BC mortality by 16-25%^{10,11} using similar interventions. Nonetheless, from the perspective of poor countries, the efficacy and adherence to BCS is still a global problematic issue from a public health policy perspective¹²⁻¹⁷. Literature describes several barriers such "lack of awareness among women regarding BC", "presence of stigmas", and "lack of proper screening behavior". According to Dey¹⁷, the above is mixed with the apathy and lack of awareness of policy makers regarding BCS and its cost-effectiveness.

Brazilian healthcare system is organized as a coordinated conjunction of interventions to promote, prevent and recover health considered at three different levels of complexity. This implies analyzing and meeting all of people's healthcare requirements from the most basic to the most complex. Brazilian National Cancer Institute (Instituto Nacional de Câncer, or INCA) was created in 1990 to plan and support the country's national health policy on cancer, and it is responsible for cancer care delivery, prevention, and early detection. The institute - supported by the Ministry of Health - organizes, manages, and supervises national projects and activities. INCA also produces prevention information materials and promotes events aimed at health professionals, opinion leaders, and the general public18. Working with television broadcasters, print media, and Internet to broadly disseminate information, INCA focuses its efforts to spread the messages of prevention and early detection considering the most vulnerable groups of population¹⁹. INCA's website provides qualified information on cancer prevention and early detection as a primary Web reference for lay public in Brazil^{20,21}. There is a national wide network of diagnostics centers as well as accessible information provided by national campaigns, mostly after 2010 with "Pink October", focused on "breast awareness".

The high prevalence of BC and the increasing attention of mass media have raised attention on this public health problem. Nonetheless, late diagnosis in Brazil may be related (among other causes) to low BC awareness and ineffective strategies to gather attention on BCS in a context of exponential use of Internet as a resource to self care. Web data surveillance hold a strong potential to lead to overlooked phenomenas in health outcomes²²⁻²⁶. Information concerning "prevention interest" might increase knowledge on prevention strategies. A better understanding about the prevalence and preferences of obtaining information on screening might help to identify targeted individuals and design effective strategies. In this context, the objective of the present article is to study oscilattions in accesses to INCA webpages on Breast Cancer (BC) and early detection (BCS) as a proxy of collective interest in BC screanning.

Methods

Recent studies suggest that Internet queries are valid proxies for behavioral changes²⁷, and health outcomes^{28,29}. Web information-queries indicators may be more valid than the commonly used survey questions where respondents describe mere intentions (i.e., "are you thinking about doing mammography?"). Depending on cultural and subjective circunstances, strong influences of "social desirability bias" may mislead to overestimated results³⁰. Data collection timing and analysis - The present results capture a period of significant growth of the use of internet as source of information in Brazil even by low-income groups³¹. The Brazilian National Cancer Institute/INCA website was chosen to be considered the major and most complete cancer-related reference for lay people in Internet³². The comparability of BC and BCS pages was possible along 2006 to 2009 due to unchanged website's archicteture along the 48 months sellected. After 2010 Brazilian Ministry of health adopted other communication approaches like "breast awareness" and "Pink October", which impacts will be analyzed in further works.

The first webpage of interest was "Breast Cancer", which presents detailed and updated content concerning the disease; the growing national and global incidence; correlation with age level; as well as estimates of new cases for the current year and the recorded mortality. Important to mention its highlighted link "para saber mais" (to learn more) which refers to pages on early detection. The second page of interest was "BC Early detection" - with information on the early detection of BC, encouraging breast examination by qualified professionals and mentioning the limited diagnostic value of self-examination. There is a special emphasis on the importance of mammography after age 40. Webpages of interest ("Breast Cancer" and "early detection in SUS") were tracked along an uninterrupted period of 48 months (2006-2009).

A Log analyzer software was employed to collect data and produce reports to construct a time series on pages of interest. We used the WebTrends Log Analyzer software package to record the log files along the selected period and construct reports concerning number of accesses; time spent in each page; most frequent visited pages; between other indicators. This software is frequently used by INCA to assist strategies, support educational products, programs, projects, and activities related to health promotion and prevention²⁰. Log analysis technology is used since 1999 to produce data on public interest in cancer issues²⁰.

Using log files from INCA's website we measured oscillations in number of accesses related to the pages of interest in terms of monthly means. Pages of interest were tracked over the 48 months and the monthly means were compared to annual means by analysis of variance (ANO-VA) assuming a confidence level of 95%. This statistical procedure allows simultaneous comparison of different averages (annual means x monthly means) to determine, by means of a ANOVA test F, if the observed differences were statistically significant or not.

Ethical consideration - Data have been collected as information aggregates, not reflecting individual perspectives and considering absolute anonymity between authors and individuals. Comparing risks and the study outcome, we consider that benefits overcome risks. The project was conducted considering Ess & Association of Internet Research protocols (Ethical Decision -Making and Internet Research Recommendations from the AoIR Ethics Working Committee (Version 2.0) and was approved by INCA's Research Ethics Board.

Results

There was a significant increasing in accesses to "breast cancer pages" (Trend line "Breast cancer") which overcame accesses to "Early detection" in the beginning of 2006 and keep increasing audience until the end of 2009 (Figure 1). There was an enlargement in differences over time caused by increasing access to BC pages associated with the fall of the audience to SBC pages.

Short and transient "attention circles" were registered as major increases (most of them within the SD – Table 1) in the number of accesses to BC pages. There were significant annual peaks (beyond SD limits) in "breast cancer" pages in November (2006-2009) along the "National Day Against Cancer" campaigns (27th November) but with lower and stable accesses to BCS pages.

There was a steady growing along three years with a slight plateauing in 2009 (Figure 1). Nonetheless, these massive accesses to BC pages contrasts with minor oscillations and - comparably - scarce accesses on "early detection" pages. Information on BC screening tends to be less accessed along the four years. There were significant annual peaks (beyond SD limits) in "breast cancer" pages (although just in 2006 and 2009 to "early detection" pages – Table 1) observed in November. It was also observed a consistent annual decrease in BC screening pages from December to February along the four years.

Discussion

Results show that collective interest in information on BC (as a disease) is increasing gradually (although in a not stable way) in contrast to BCS,

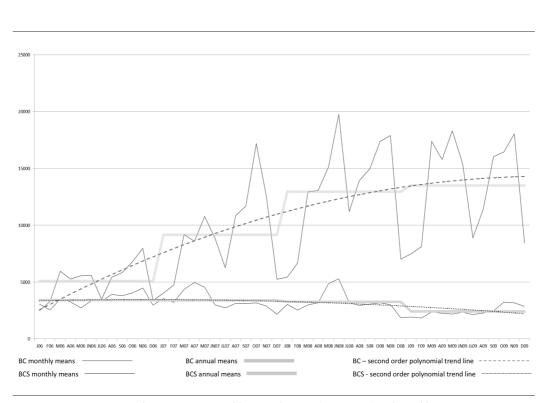


Figure 1. Accesses to BC and BCS pages - monthly/annual means (2006-2009) and trend lines.

which are steadily falling down. These findings are coincident with increasing access to internet observed in Brazil and higher incidence of new cases of BC, as well. Nonetheless, people didn't search further on early diagnosis information by clicking the link that leads to screening pages. In other words, the rising number of queries towards symptons and mortality was not coherently directed to pages concerning actions related to early identification of such a severe condition. Considering Internet queries as valid proxies for attitudinal changes²⁷ these findings may be interpreted as a relative weakness in terms of campaigns planning. Transient "attention circles" on BC pages, not observed in BCS pages, may be consistent with previous works which describe media driven misbeliefs on BC associated to low adherence to BCS³³. Several authors contend that lack of evaluation skills to understand lay media reports undermines public decision making concerning health risks^{22,33,34}. Nevertheless, successful examples in terms of BCS point out some sociocultural peculiarities that intervene in effective outcomes. Positive results in Netherlands and Sweden, according to several authors, may express a culture of interest in early identification of diseases in addition to the strong confidence in health systems⁹⁻¹¹. In addition to the "culture of prevention" associated with trust in the health care system, several factors which can influence public opinion with regard to screening campaigns have been described.

Public health campaign evaluations generally highlight the role of variables controlled by campaign organisers in explaining changes in participation in BCS. Nonetheless the "Kylie Minogue effect" (Australian singer who disclosed her BC diagnosis) on BCS program described by Chapman³⁵ indicates that unplanned influences, although usually relegated to a background "noise" status, can also have profound effects on such outcomes. Unplanned public events, like prominent people disclosing their breast cancer, influenced significantly media coverage and moments of intense public interest³⁶. Concerning this topic, celebrities' endorsements have been increasingly employed, although considered separately from their sociocultural contexts and based simply on the common sense perception that they can be useful in promoting health behaviors such as

				2	006							
	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC
Breast cancer	2478	3283	5956	5262	5545	5607	3492	5421	5849	6770	7983	3405
Annual mean: 5088 (SD = 16	13)											
Screening pages	3071	2558	3509	3266	2722	3344	3321	3901	3792	4033	4488	2973
Annual mean = 3415 (SD = 5	63)											
				2	007							
Breast cancer	4013	4750	9169	8598	10784	8843	6255	10842	11697	17179	12495	5237
Anual mean = 9155 (SD = 37	84)											
Screening pages	3555	3220	4352	4965	4563	3008	2732	3124	3101	3171	2892	2181
Annual mean = 3405 (SD = 8	16)											
				2	008							
Breast cancer	5447	6661	12939	13068	15123	19755	11198	13934	14957	17348	17899	7031
Anual mean = 12947 (SD = 4	611)											
Screening pages	3039	2531	3002	3171	4866	5298	3198	2964	3055	3171	3016	1868
Annual mean = 3265 (SD = 9	31)											
				2	009							
Breast cancer	7494	8100	17373	15784	18314	15397	8896	11421	16026	16451	18047	8437
Annual mean = 13478 (SD =	4255)											
Screening pages	1921	1845	2367	2267	2201	2351	2145	2284	2471	3244	3186	2866
Annual mean = 2429 (SD = 4	49)											

smoking cessation, safe sex and avoiding illegal drugs37-40. A good example of intensive use of media, celebrities and fashion in Brazil can be seen in the campaign "Fashion Targets Breast Cancer" promoted in 1995 by the IBCC (Brazilian Institute Against Cancer) and supported by the biggest Brazilian media names. It is a long-standing belief that famous persons are capable of influencing health care behaviors and searching for information on early signs and prevention, which is described as a "celebrity effect"^{35,41,42}. There are evidences that describe how spotlights on public disclosures pose a positive major advance in terms of how celebrity cases are leveraged for public health impacts^{37,38}. At the first glance, celebrities' disclosures may reinforce awareness on screening programs (taking in account the growing availability of proper resources for early detection in Brazil).

Concerning our findings, there were major peaks above annual means (October/November 2006) when the American singer, Sheryl Crow⁴³ and Cynthia Nixon, a popular American actress publicized their diagnosis. The same happened in May/June 2008, after Cynthia Nixon's disclosure⁴⁴. In fact, within the studied period (2006-2009) BC diagnosis was disclosed by several top celebrities - Joanna Fomm, a renowned Brazilian soap opera actress at that time (in 2007); Joyce Pascowitch (a prominent Brazilian journalist and writer); Maggie Smith (very famed English actress); Christina Applegate (American actress); Norma Blum (an illustrious Brazilian actress); and Elba Ramalho (one of the most well-known Brazilian singers), had her BC disclosed between 2006-2009⁴⁵⁻⁴⁷. Several authors believe that publicized personal experiences by famous people may amplify public expectations and latent interest on identification of diseases^{35,41,42,48}. Important to consider that our findings can not be linearly comparable between themselves in terms of magnitudes of public events. Accesses to webpages are subject to multiple and complex influences of difficult correlation to an unique cause, although are relevant to raise interesting questions. Nonetheless, it's not implausible to believe that higher oscillations observed in a random pattern may be also related to transient interest on celebrities' disclosures broadcasted by TV shows, internet and magazine interviews at different moments.

At a first glance, regarding the present results, the assumption of the "celebrity effect" may confirmed its influences - if real, the impact on sear-

ch behavior for information concerning BC was impressive. Nonetheless, our main point is - despite the massive interest on BC, a proportional impact was not observed on BCS pages, although information being at a distance of just one click in the same webpage. Therefore, the premises that the collective interest raised by celebrities would leverage people to search information on early BC detection were not here confirmed. These findings refute recent papers which report significant impacts on primary and secondary prevention of diseases after public revelations^{35,41,48,49}. In a recent work, Ayers compared smoking cessation awareness events with Google queries related to Brazilian President and smoker Lula da Silva's laryngeal cancer diagnosis announcements⁴¹. According to the authors, Lula's disclosure increased public awareness and drive those online to professional evidenced-based cessation programs. Authors debated that public health professionals should promote primary and secondary cancer prevention by buying advertised links on Google, asking celebrities to work in planned media campaigns, in short, using public narratives to motivate legislative action⁴¹.

Similars results were found after news coverage of Kylie Minogue's diagnosis, which caused an unprecedented increase in bookings for mammography³⁵. Other authors also contend that a focus on primary prevention around celebrity diagnoses may also lead to salubrious public health benefits via health policy initiatives⁵⁰. Different settings and outcomes are profuse in literature suggesting that a celebrity spokesperson can have a substantial impact on public participation in preventive care programs^{39,40,48,49}. In a recent systematic review, public figures and celebrities disclosures about cancer diagnosis or death was described as significant events in public life and cancer-oriented outcomes. Jade Goody, Kylie Minogue, Nancy Reagan, and Steve Jobs were the most commonly studied public figures and the most common cancers were breast (53%), cervical (21%), and pancreatic (21%) cancer. Results fairly consistently associated cancer announcements as meaningful effects (despite its short term) on many, if not most, of outcome variables⁵¹.

A recent paper, on public figure announcements and opportunities for cancer communication, portrays a theoretical model reasoned by: announcements (related to celebrities' public status and age) and mediators/moderators (media coverage x audience factors) and intermediate outcomes (cancer information seeking; interpersonal communication; changes in beliefs); behavioral outcomes (prevention/screening/detection behaviors and decisions); and disease outcomes (cancer detected and controlled)⁵¹. Despite its comprehensiveness, it is interesting to note how this perspective is similar to the exposure/outcome models commonly used in epidemiological research which simplifies the understanding of collective phenomena. Nevertheless, beyond the linear truth of exposure factors and outcomes, influences of media framing in culture are subject to multiple and subjective variables - so familiar to social scientists and health communication researchers. Causal models may pose the risk of linear perspectives that might obscure cultural peculiarities influencing announcements, mediators, and outcomes⁵².

Culture holds relevant influences over public communication outcomes, modulating and positioning messages under different media framings. A good example of cultural driven modulations in a complex scenario is the scarce public disclosure of cases of prostate cancer⁵³, despite its high prevalence (comparable to cases of breast, cervix and lung cancer) they are not present in Noar's review⁵¹. In other terms, celebrities suffering from prostate cancer don't call the spotlights, maybe influenced by taboos linked to masculinity. Interviews and focus groups revealed, despite satisfactory literacy test scores, a limited understanding and misconceptions concerning early detection and relevant risks⁵⁴.

Most of western cultural systems, like Brazilian, deal with cancer under the taboo of the "inescapable sentence", framing the drama of famous persons with cancer as life histories of overcoming after tragic fates. It is relevant to note that cases of Brazilian celebrities only became publicly available in recent decades, perhaps under the influence of slow changes in social representations involving the disease and its increasing healing potential (maybe reinforced by new communication technologies).

In successful programs, sustained high level of participation in BC screening are attributed to policies that are implemented in a climate of trust in authorities. In this regard, apparently individual decisions about health behaviors are tightly woven with societal ideas and values¹¹. The ease of attending means that governments are able to shape behavior with no coercion, and public uncertainty about the benefits of the screening program is reduced. The ideas about cancer, risk, and about the value of health technologies all contribute to the high level of acceptance of health control programs such as mammography screening¹¹. Wider availability of better quality information has helped patients' increasing ability to reach tough decisions, taking account of perceived risks and their own beliefs. Women want to be committed to healthy behaviors including mammography screening as part of a good health regime. This belief and commitment is facilitated and sustained by proper policies of screening. Having an organized approach to BC screening reinforces the importance of mammography in the minds of the population. Nonetheless, in a complex society there are subtils, though also powerful, tacit messages sent by media concerning personal histories of famous people.

Our results may be consistent with previous papers that report strong interest related to cancer (as a disease) after institutional campaigns in Brazil, in contrast to relative indifference concerning its prevention or early detection^{18,20,21}. A maybe simplistic first hypothesis should draw attention to the lack of collective confidence in Brazilian public screening programs related to the problem. Perhaps the belief in public system ineffectiveness in supporting women (with or without premonitory symptoms) could explain the collective apathy towards information on screening programs. At this point of discussion is pertinent to raise questions concerning empirical observations of internet queries as 'intermediate outcomes'.

Personal Drama vs. "Breast awareness" perspectives

Maybe another layer of understanding could be useful in the interpretations of these results. In the past, BC prevention campaigns were breast self-examination centered, as proposed in the 1950s by Cushman Haagensen, an American breast surgeon at a time when mammography was not yet available. At that time most of women were diagnosed when the tumour had become large and inoperable⁵⁵.

More recently, a different approach, known as "breast awareness", encourages women to gain confidence and avoid fear about noticing any change which might help detect early stages of BC^{55,56}. As stated in Pink October website (a worldwide campaign to increase awareness on early identification of BC) "while most people are aware of breast cancer, many forget to take the steps to have a plan to detect the disease in its early stages and encourage others to do the same"⁵⁷. In other terms, "Breast Aware messages" could be summarized in how a woman becomes familiar with her own breasts and the way they change throughout her life⁵⁸. The objective of coining this new motto was advocating a new attitude to help women to move beyond, avoiding paralyzing fear of cancer⁵⁶.

In the present case, beyond simplistic perspectives concerning the lack of confidence in Brazilian public health support, the assimetric attention towards diseases and its early detection may have its origin on attitudes which are blocking the way of queries on BC screening. In fact, it's not possible to know the real intentions of people - why are they searching on those websites; what are they doing after? We just know that they visit those webpages but not how they react later on. The "breast awareness" approach (which development involved considerable cultural and attitudinal changes in several countries) may have been misled by public disclosure of celebrities framed as personal dramas. Such different approaches needs to be further exposed and debated, mainly by social scientists and health policy makers.

A recent debate was aroused by Angelina Jolie after her opinion piece concerning a preventive double mastectomy due to her family history of cancer related to BRCA1 gene42,59-62. Media coverage was extensive, but the influence of what message public opinion took (and what decisions would come after) from this personal health story is still not clear^{63,64}. Maybe the common low educated women consider celebrities as goddess - famous, rich, having the best chances and deserving the best treatment available at any cost. The same media messages may affect women in different ways depending on several aspects, like the perception of their own vulnerability65,66. Maybe celebrities could talk about their experiences in a different framing, stressing the role of prevention. In their statements the terms "battle against cancer", "fighting the disease" or "defeat cancer" are constantly employed. Not a single word about prevention is mentioned⁴⁵⁻⁴⁷. The disclosure of a celebrity give people a chance to talk about this taboo, although related to a distant person, just to admire her fight against cancer (that maybe happens in better conditions that they would have). While celebrities' histories can bring heightened awareness to health issues, driven by a 'prevention behaviour', it can also lead (if in a context of overwhelming vulnerability) to postpone important decisions, self-denying the possibility of get sick. If so, more sophisticated criteria in health communication are needed to

understand misleading in public understanding on the prevention messages that these stories convey⁶⁵⁻⁶⁷. Multi-cultural research on breast awareness is needed and evidence is currently lacking to determine whether its benefits outweigh the harms of "personal drama framing" over cultures self-perceived as vulnerable.

Limitations and Future Research Directions

The present investigation, as na exploratory study, tried to describe a fragment of a complex mosaic concerning patterns of queries and information-seeking. In other words, it is oriented to a problem that has not been clearly typified by literature in terms of conceptual distinctions. In this sense, foreseeably, there are several limitations that should be taken into account. First, it is not possible to draw an accurate populational segmentation in terms of socioeconomical status since it follows an "echological study" design. Time frame is restricted to 2006-2009, thus missing longer range trends involving other aspects of breast cancer news – to be analyzed in further works.

Although developed to low-literacy readers and considered the most consulted reference source in Brazil, the study just examines IN-CA's website. The sample is restricted to those who reached it, certainly not considering very low-income populations. Important to add that detailed socioeconomic profiles can be accessed by SISMAMA - information system introduced by INCA in 2009⁶⁷ - which might provide segmented populational studies concerning access inequalities.

Brazilian Ministry of health is increasingly using other communication approaches, like "breast awareness", and future works may study changings after 2010 (when a breast awareness approach started to be used).

The log analyser software can not produce reports considering Brazilian heterogeneous educational levels - the capacity to understand and interpret the relevance of BC early detection will be studied in future projects using a qualitative approach.

Future research is also needed to thoroughly examine issues involving public capacity to absorb complex information on various breast cancer topics. BC risk perceptions are socially constructed based on experiences of relatives and closer people as well as learning from fictional pieces and commercial messages. In this sense, analysis of contextual risk information may be useful in future works. Broader explanations could be applied to the current findings if also centered in social representations theories.

Collaborations

PR Vasconcellos-Silva – idealization, collection and interpretation of data, writing and review. T Sormunem and AG Craftman – interpretation of data, writing and review.

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