

Stakeholders' positions in the breast screening debate, and media coverage of the debate: A qualitative study

Abstract

Against the backdrop of new research evidence suggesting breast screening causes avoidable harms and that women are not being given enough information to make informed decisions, we sought to explore the positions on breast screening adopted by a range of stakeholders, and coverage of this debate in the media. We sampled material from national newspapers, charity bodies' websites, and official bodies' websites over a two-year period, and analysed this using thematic content analysis. Charities' and official bodies' positions were similar in that they were supportive of the NHS Breast Screening Programme, and tended to defend it against its critics. They acknowledged, and partially explained, the imperfect nature of breast screening but often omitted important information such as simple frequency statistics. There was a tendency for newspapers to cover the screening debate in an oblique way – presenting case studies of 'real' women and celebrities. These were mostly positive accounts of women who believed they had benefited from screening and supported the programme. Engagement with the debate in terms of discussion of the criticisms of the programme was lacking. The debate about breast cancer screening, and the increasing focus on its potential harms, received less coverage in the popular media than might have been expected. Interested stakeholder groups do make publicly available information about their positions on the relative value of screening, but these tend to focus on emphasising the potential benefits and less on the possible harms.

Introduction

The NHS Breast Screening Programme (NHSBSP) has been in operation since 1988 and provides free mammograms triennially for all women aged between 50 and 70 years. However, criticisms of this, and of other breast screening programmes worldwide, concern its effectiveness, the potential harms caused and the information that is provided to women. A Cochrane Review of breast screening suggested that the prolongation of one life came at the cost of a 30% rate of over diagnosis and overtreatment and the screening of 2000 women over 10 years (Gotzsche and Nielsen 2011). Furthermore, there is a lack of understanding of the natural history of breast cancer (Jansen et al. 2009), particularly non-invasive forms such as ductal carcinoma in situ (DCIS). DCIS accounts for 20% of breast cancers detected through screening and is treated clinically as a potentially invasive cancer as it is difficult to predict which will progress to invasive cancers, thus heightening overtreatment (Erbas et al. 2006; Virnig et al. 2010). In addition, the leaflets accompanying invitations to screening have been criticised for not sufficiently enabling informed choice and lacking respect for patient autonomy (Zapka et al. 2006; Gummersbach et al. 2010; Gotzsche and Jorgensen 2011). Finally, concerns have been raised about the psychological impact of breast screening; being recalled for further investigations after an initial mammogram has been associated with both short- and long-term anxiety (Brett et al. 2005).

These points, along with the cost of breast screening programmes - £96 million/year in the case of the English programme (NHS Cancer Screening Programmes 2011), have raised questions about whether screening's benefits really outweigh the harms. Indeed, recent analysis of the data from the original Forrest Report (Forrest 1986), on the basis of which the NHSBSP was initially recommended, supports the Cochrane Review findings that the introduction of breast screening may have resulted in net harm after 10 years. These mounting criticisms led to calls for an independent review and the rewriting of the breast screening leaflet. In October 2011 the National Cancer Director Sir Mike Richards announced, in response to an open letter in the British Medical Journal, that he was heading such a review and commissioning the rewriting of the breast screening leaflet by an independent panel of experts (Richards 2011). The review is not only relevant to the NHSBSP, but to all countries running a

publicly-funded systematic screening programme. The results of the review were made public at the end of October 2012 (Independent UK Panel on Breast Cancer Screening 2012), with the verdict being that screening does reduce breast cancer mortality but with the associated cost of over-diagnosis (meaning that some women will be diagnosed with a cancer that would never have troubled them in their lifetime). The review places the figure at about three over-diagnosed cases identified and treated for every one breast cancer death prevented. The review called for information about the possible costs and benefits of screening to be made clearer and more transparent to women when they are invited to attend for screening, and when making decisions about treatment options. However, even following the publication of the review's findings, critics of screening have criticised the methods used and questioned the robustness of the conclusions drawn (Hawkes 2012; Baum 2012; Thornton 2012).

This, often heated, debate about the relative value of breast screening predominantly takes place between academic researchers, health professionals, policy makers, and other interested stakeholders. These groups may adopt certain positions, which may influence the nature of the information they divulge to the public. For example, a US-based charity was recently found to have provided unbalanced information in order to persuade women to undergo mammography (Woloshin and Schwartz 2012).

Furthermore, recent evidence demonstrates very limited public awareness of one of the key factors in the debate: overdiagnosis (Hersch et al. 2013). The question of how these debates filter into the public sphere is therefore an important one. While laywomen are likely to gather information about breast screening from the people around them, and of course health professionals with whom they come into contact, publicly available information (for example, on websites and in other media) is also likely to play an important role in shaping their understandings. Although studies have looked at how breast screening is covered in the media (Holmes-Rovner and Charles 2003; Steele and Mebane 2005) and the effects of celebrity breast cancer cases on screening uptake (Yanovitzky and Blitz 2000; Chapman et al. 2005), little is known about how the debate itself, and the key issues within it, has been presented.

This study therefore sought to examine how the debate about the relative value of the NHSBSP was presented by a range of stakeholders, and coverage of this topic by the

media over a two-year period. Importantly, the focus is on the sources of information considered most likely to be accessed by women invited to regular screening through the NHSBSP.

Methods

Data collection

We studied the positions of a range of stakeholders in the breast screening debate, and coverage of this issue in English national newspapers, over a two-year period from 1 January 2010 to 31 December 2011. A two-year period was judged sufficient to ascertain stakeholders' positions and media reporting of this debate, and any shifts in position over time. The period selected included the announcement of the independent review but not the publication of the review's findings. Within the UK, each of the four constituent countries (England, Wales, Scotland and Northern Ireland) operates their own screening programme, although eligibility criteria and screening frequency is currently the same across each of these. While many of the data sources we use are UK-wide, we have where possible sought to limit our data collection to England.

We located websites belonging to official bodies that met the inclusion criteria of being a national governmental organisation with a role in implementing and/or relaying official information to the general public about the NHSBSP. The websites selected were: the NHSBSP, the Department of Health, and NHS Choices. The UK National Screening Committee was excluded as, at the time of searching, there was no information on their position on breast screening except for one statement: “[breast] screening is recommended by the UK NSC” (UK National Screening Committee 2009). Second, we combined a Google search employing the search terms ‘breast cancer charity’ with referral links on the official body websites to identify charity bodies’ websites. The inclusion criterion for these was that they were a national cancer charity. We grouped these by the types of activities they mainly conducted (including: generating funding for research or care, providing support for people with cancer and their families, campaigning and research, and research only). A charity from each group was selected to ensure a diverse sample. The four charity websites included were: Breast Cancer Care, Breakthrough Breast Cancer, Genesis UK, and Cancer Research UK.

We developed search strategies to retrieve data from official and charity body websites, with websites' internal search tools used where possible. Our search terms were 'breast screening' or 'screening', depending on whether the website was breast-specific. These searches were validated with Google search using the search terms: [siteurl]:[search terms] between the dates 1 January 2010 and 31 December 2011. This strategy returned 278 articles from official bodies and 343 from charities.

The sampling frame for newspapers comprised all national (English) daily newspapers. Sampling of newspapers was purposive and guided by the following factors: high circulation figures; a relatively high proportion of female readership; and a wish to ensure a similar number of newspapers from each format type (tabloid/midmarket/broadsheet). The final sample consisted of: The Times, The Daily Telegraph, The Guardian, The Daily Mail, The Express, The Daily Mirror, and The Sun.

We searched these seven newspapers using the e-database Nexis to look for articles between the search dates, with the search terms 'breast cancer' and 'screen!' having to both appear within the same sentence and be found in the headline, lead paragraph or indexing, or simply mention 'mammogra!'. This returned 479 newspaper articles.

A random selection of 20 newspaper articles and 10 website articles was selected, and these were preliminarily screened for relevance by the first author (JC). Based on this, we discussed and reached a consensus as a team on relevance criteria. Relevance was operationalized as including a mention of breast screening and an identifiable position as follows: no view of screening; in favour of screening; sympathetic towards both sides of the argument; or containing a critical view of screening. We agreed that articles which did not meet these relevance criteria would be excluded. The full sample of retrieved articles was then screened for relevance by JC using these agreed criteria. After screening out irrelevant articles and duplicates, 157 newspaper articles (35 tabloid, 56 mid-market, 66 broadsheet), 92 charity body website articles, and 28 official body website articles remained.

Data handling and analysis

We used thematic content analysis (Green and Thorogood 2009) to identify the common recurring themes. We decided to use this approach, rather than a more basic content analysis, as we were interested not only in what was being said but also how it was being said, and by whom. First, key themes were identified by JC from a thorough reading of a random sample of 20 articles. These were used to generate a preliminary coding frame, which was discussed and cross-checked by the team. The coding frame was used to code all data, but was continuously revised throughout the process as new themes emerged, in conjunction with regular team meetings. NVivo7 (QSR international), a qualitative data indexing package, was used to facilitate this process.

Results

We present findings organised around several key points. We explore the positions on the value of breast screening adopted by stakeholders (official and charity bodies) as presented on their websites. We explore the engagement of these stakeholders with screening's possible harms, their responses to criticism of the NHSBSP, and their responses to the independent review. We then turn to newspaper reporting of the debate around the value of breast screening.

Stakeholders' responses to criticisms of the NHSBSP

We found that the official and charity bodies tended to defend screening against its critics, and used a range of techniques to rebut criticisms from new research evidence questioning screening's value. We identified two main approaches that were employed: strengthening their own positions, or undermining the critics' positions.

One way of strengthening their positions was by stating commitment to providing women with balanced information about the possible benefits and harms of breast screening. The charity bodies particularly favoured this approach – a typical example can be seen below:

What is important is that women are properly informed about the risks of the screening programme as well as the benefits...

Breast Cancer Care, 16 September 2011

Second, there was a tendency to dismiss criticisms of the NHSBSP by providing and highlighting evidence to the contrary. For example, in order to counter the claim that the NHSBSP had ‘remained largely unaffected by repeated criticism’ (Gotzsche and Jorgensen 2011) a spokesperson detailed the processes the information leaflet had undergone to ensure it was robust in providing information in a way acceptable to women.

The new breast screening leaflet, developed independently of the NHS by a leading team from the University of Oxford, aims to help women assess both the benefits and risks of screening [...] DCIS is now also covered in the leaflet for the first time. A draft of the leaflet was rigorously tested in a series of focus groups...The language used in the leaflet reflects the comments and preferences of those women.

NHSBSP, 29 July 2011

Undermining the critics’ positions was enacted in one of three ways, all of which questioned the robustness of their evidence. One strategy involved highlighting deficits in the studies on which they drew. For example, in response to a publication that suggested breast screening had no significant impact on breast cancer mortality:

...the study did not allow for a substantial amount of non-organised screening that was taking place in the neighbouring country.

Genesis UK, 8 August 2011

A second strategy involved suggesting that critics did not present new evidence, as demonstrated by a charity’s response to the Cochrane review (Gotzsche and Nielsen 2011).

This report fails to provide useful analysis that will help women make informed decisions about this complex issue [...] This report does not present new data and current evidence supports our belief that screening saves lives.

Breakthrough Breast Cancer, 1 September 2011

Similarly, we found the official response was also to dismiss this same paper as ‘trotting out these same criticisms’, (Patnick 2011) implying that not only was the evidence not new, but these authors were publishing the same criticisms time and time again.

The third strategy involved suggesting the studies were not specifically related to the NHSBSP, and therefore not applicable. A typical example of this can be seen below in response to a paper reporting breast cancer mortality rates in European countries with varying screening arrangements (Autier et al. 2011).

We can’t comment on screening programmes in other countries but here in England we do know that the best available evidence shows that women aged 50-69 who are regularly screened are less likely to die from breast cancer.
NHSBSP spokesperson, 29 July 2011

Stakeholders’ engagement with the harms highlighted by critics

With regard to the harms of breast screening that are mentioned by critics, stakeholders’ websites did acknowledge, and explain to some degree, that breast screening is not perfect and has potential harms. The possibility of false positives, false negatives and interval cancers was introduced, but detailed information was not given in all articles on all websites, and important information such as simple frequency statistics were often omitted. Rather, they tended to use vague terms such as ‘some’ or ‘not all’ when referring to the numbers of women who had been harmed through screening.

The NHSBSP website outlined some basic details about DCIS, and included the fact that it was benign in itself and had an unknown malignant potential. However, it recommended treatment as a solution to the problem of uncertainty, and there was no mention of the possibility of over diagnosis or overtreatment (NHS Cancer Screening Programmes 2012). The website offered no basic statistical data such as frequency counts regarding DCIS picked up through breast screening. Instead, a link to a document about the uncertainties regarding the management of screen-detected DCIS was provided (NHS Cancer Screening Programmes 2008), but this document is a

formal NHSBSP publication written in dense and technical language that lay women may not find easy to navigate.

The charity websites varied in the level of detail provided about DCIS, ranging from simply defining it and outlining that it is a benign condition with unknown malignant potential, to providing more detail than the NHSBSP website. However, they did tend to outline the points from both sides of the debate regarding the ratio of overdiagnosis and overtreatment to lives saved through breast screening. None of the official or charity bodies gave explicit details about the unnecessary treatments that women may undergo.

In terms of addressing the psychological aspects of screening, we found the official and charity bodies generally agreed that breast screening causes some worry, with the only variation being the *level* of worry. The general view was that women ‘may’ worry, but that this would pass quickly. In addition, the cost of some women worrying was contrasted with the potential benefits for other women.

...out of every 8 women called back, 7 will be fine. These women will have had some unnecessary anxiety. Some people say that the screening programme causes unnecessary anxiety and distress for the 7 out of 8 women called back for more tests who turn out to be fine. But this needs to be balanced against the fact that the programme diagnoses breast cancer early for many women and so saves their families much more distress.

Cancer Research UK, 5 August 2011

Overall, our findings were that official and charity bodies alike downplayed the potential psychological harms of screening.

Stakeholders’ reactions to the review

In reaction to the announcement of there being an independent review in October 2011, responses on charity websites suggested they welcomed it. Response articles tended to reinforce the charity’s own view - that screening saved lives through early diagnosis. They also focused on the fact that the debate could have been causing confusion for women about whether or not they should attend and hoped the review

would resolve this. They emphasised the importance of women having clear and accurate information about the possible harms of breast screening.

The current debate over the pros and cons of screening may be very confusing for women and so we welcome this review. We hope it will mean women are reassured that all evidence has been considered and the information they receive is accurate and balanced.

Breakthrough Breast Cancer, 26 October 2011

Official bodies' responses also welcomed the review. However, in contrast to Sir Mike Richards' depiction of the review as a resolution to the debate, the NHSBSP appeared to present the review as part of an on-going process that always happened, with little mention of the debate itself.

We welcome this review announced by Professor Richards. The NHS Breast Screening Programme has always been based on the best and latest evidence. To ensure this, the Programme has been regularly reviewed over the more than 20 years that it has been running. In that time, where new information has suggested them, changes have been made to the Programme, for example extending the screening age range and using digital mammography, and we look forward to the findings of this latest review.

NHSBSP, 26 October 2011

Of note, the NHSBSP appeared to normalise the review, presenting it as nothing to be alarmed about, whereas Sir Mike Richards had said he would not hesitate to refer the findings on to ministers and the Department of Health if he found screening was not benefiting the women who attended, indicating that there could be substantial changes to the NHSBSP.

Newspaper reporting of the debate

Rather than presenting different sides of the screening debate, the newspapers tended to cover it in an oblique way – by presenting case studies of 'real' women and celebrities. We observed this to be the case particularly in the tabloid and midmarket format newspapers. The articles promoted a sense of 'moral obligation' (Griffiths et

al. 2010) to attend breast screening through the depiction of women who attended screening as health-conscious and responsible. Those who had had a problem identified were typically framed as being 'lucky' as they had been asymptomatic and detected through routine screening. This was characteristic of both laywomen's and celebrities' stories. There was much emphasis on the beneficial outcomes of breast screening rather than any possible harms. A typical example can be seen below.

I've never smoked, I eat a healthy diet and exercise regularly so when, following my routine screening, I was [...] told I had breast cancer, I was shocked and devastated.

The Sun, 27 October 2011

There was little coverage of the criticisms of the NHSBSP. While there were dispassionate articles quoting screening's critics, there was rarely any further synthesis of these as part of a wider debate. Any detailed engagement with these critics' arguments and the uncertainties of the breast screening programme was limited predominantly to the broadsheet newspapers, for example:

The world of medicine reflects the world we live in; constantly in flux with multifarious contradictions. Scientists relish this fact. Hypotheses are proffered, challenged, investigated and proved or disproved in an ongoing, dynamic process [...] The furore around breast screening perfectly illustrates this....

The Daily Telegraph, 31 October 2011

These commentary articles were characterised by their diplomatic writing style where they empathised with both sides of the debate. They went beyond simple reporting by adding their own assessment of the harms and benefits of the debate and attempting to synthesise the information.

Newspaper reporting of screening's possible harms

The majority of newspapers' reporting of the uncertainties and possible harms of screening occurred 'in passing', typically when covering news topics such as breast screening scandals and new technological advancements in screening technology.

Blame was attributed to individual clinicians or technicians in cases of ‘screening blunders’ rather than finding fault with the screening programme per se.

DCIS, overtreatment and overdiagnosis were covered in a similar way across all newspaper format types. The uncertainty around DCIS was partially addressed, but typically not fully explained. Any statistics provided were usually quoted in isolation, making them difficult to interpret. A typical example of this is displayed below, here the prevalence of DCIS is unclear without the provision of other key statistics such as the number of women screened, and the number diagnosed with invasive breast cancer, each year through the NHSBSP.

[DCIS] is mostly symptomless and at least 7,000 British women a year are told they have it after breast cancer screening.

The Daily Mail, 29 April 2010

Newspapers also featured a small number of case studies that focused on women who felt they had not been given sufficient information and so had not been able to make an informed choice. The following extract features a woman who had attended a routine mammogram with little knowledge about possible harms. She was diagnosed with DCIS and subsequently started on Tamoxifen which she could not tolerate. Her experience led her to question the level of information provided with the invitation.

It made me ask, why did I go for screening and why was I not given any proper information about it? Despite promises from the screening service, there is still no leaflet for women which spells out how it [screening] can do a great deal of harm. This public health service creates damaged women...

The Daily Mail, 5 August 2010

Discussion

Our analysis of publicly available sources of information about breast cancer screening demonstrates first how the websites of key stakeholders in the breast screening debate (official and charity bodies) emphasised the benefits of screening, minimised talk of possible harms and responded to the critics, but welcomed the

independent review of the NHSBSP by normalising it rather than anticipating any radical findings. Second, newspapers' reporting of the screening debate itself (as opposed to screening more generally) was limited, but generally balanced. Taken together, the relatively limited newspaper coverage of the debate and the minimal information on official and charity bodies' websites about the uncertainties of breast screening would suggest the debate is less visible in the public sphere (and thus to the women who will receive an invitation) than in the specialist arena occupied by academic researchers, health professionals, policy makers and other stakeholders. It is of course important to note that while these stakeholders and the media are in one sense presenting and commenting on the debate, their statements and the stories they write are also in another sense contributing to and helping to structure the debate. They are participants in the debate as well as commentators on it.

The data analysed came from sources that women who are invited to regular screening through the NHSBSP are most likely to come across either on a daily basis (newspaper articles reporting the debate about screening) or when searching for information after receiving an invitation to attend for a mammogram (websites providing information about breast cancer and screening). Thus, the analysis provides a good picture of the level and type of written information and opinions on breast cancer screening that reaches the targeted population.

Stakeholders featured in our study, as well as prior researchers, have expressed concern that the debate about breast screening may lead to confusion among laywomen, and that this may lead them to bring questions about the harms and benefits to their local clinicians (Holmes-Rovner and Charles 2003; Steele and Mebane 2005). Our findings indicate that newspaper reporting of the debate may not be as visible to women as previously thought, and may be *relatively* balanced. However, our finding of the unbalanced nature of information on charity and official bodies' websites about both the debate and the uncertainties of breast screening emphasises the need for clinicians to be aware of *how* breast screening is presented across a range of media sources as this may influence the beliefs of the women consulting them.

While we acknowledge that the data sample was limited to a 2-year period, the sample allowed sufficient analysis of the stakeholders' positions and newspapers' reporting of the debate. Indeed, within the period six major academic research papers were published that added evidence to the screening debate, the independent review was announced (although we did not capture responses to the review's findings), and three celebrities diagnosed with breast cancer were profiled across the range of newspapers. Although this study focused on the NHSBSP, this enabled a focused study of a clearly defined dataset of media and website sources. Furthermore the findings are likely to be relevant further afield; the NHSBSP is arguably of worldwide importance due to its status as the first systematically implemented programme, but also due to the continuous scrutiny it receives (most recently in the form of the independent review).

This is the first study of its kind to identify positions of a sample of major official and charity bodies from their websites, and to assess reporting of the screening debate in a purposively-selected sample of newspapers. Previous research has focused on press coverage of key milestones in the breast screening debate and has thus analysed shorter time periods or non-UK sources (Holmes-Rovner and Charles 2003; Steele and Mebane 2005). In terms of internet coverage, our findings about the unbalanced nature of information on stakeholders' websites concurs with the only previous study we are aware of that examined internet coverage about breast screening (Jorgensen and Gotzsche 2004). While a direct comparison is not appropriate given the different websites studied, our findings do indicate *some* improvement in the way that harms are discussed on such sites.

In terms of further research, responses to and media reporting of the announcement of the independent review results would provide further relevant data in this area. Furthermore, it would be useful to investigate the impact of newspaper and website reporting of the debate on women's understandings and behaviours in relation to breast cancer screening. Coverage of celebrity cases of breast cancer have been linked with an increase in bookings for mammography for non-screened age groups and for higher referral behaviour by clinicians for biopsy (Chapman et al. 2005; Kelaher et al. 2008). Thus, an in-depth study of women's views would provide insight into the impact of press coverage, in terms of how they interpret information, and use this to

inform their decisions. Recent coverage in the medical journals, including editorials and opinion pieces (for example, Baum 2013; Kirwan 2013), indicate that the debate itself shows no signs of ending in the immediate future. Thus, research into the impact of the debate on the perceptions and behaviour of the target population will remain equally important.

Conclusions

The debate about breast cancer screening, and the increasing focus on its potential harms, has received less coverage in the popular media than might have been expected. Interested stakeholder groups do make publicly available information about their views and positions on the relative value of breast screening, but these tend to focus on emphasising the potential benefits of screening and focus less on the possible harms.

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