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## Position Paper

# ‘Breast awareness’ and ‘breast self-examination’ are not the same. What do these terms mean? Why are they confused? What can we do?

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## ABSTRACT

The terms ‘breast self-examination’ and ‘breast awareness’ are often used loosely, causing general confusion, with potential to cause women harm. To explore this confusion, we begin by defining their current meaning. We trace the history of these methods of early detection over the last half century, which has seen considerable cultural, social and attitudinal changes. Breast self-examination is not recommended. We caution that uncertainty exists about the value of practicing breast awareness: evidence is currently lacking to determine whether the benefits outweigh the harms: globally-aware research is needed. We believe that a clear and universally agreed definition of the term ‘breast awareness’ is needed, and that the confusion needs to be further exposed and debated. Meanwhile, we advocate ‘sensible alertness’.

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## 1. Introduction

There is confusion, and sometimes disagreement, about the meaning of the terms ‘breast awareness’ (BA) and ‘breast self-examination’ (BSE). The authors of a Cochrane review concluded that BSE cannot be recommended.<sup>1</sup> A meta analysis obtained similar findings.<sup>2</sup> Because BA has become the current advocated policy, we believe it is important to attempt to define the terms, understand the differences and find ways to deal with the confusion. We should like to explore the historical reasons for this confusion of terms and consider the current fundamental attitudinal differences that exist behind the concepts of these two different activities. As we shall see,

BSE preceded BA, which is currently the preferred term and preferred activity in the United Kingdom (UK), despite uncertainty about the balance of benefit to harm.

## 2. Background – evolution of breast self-examination (BSE)

The concept of breast self-examination (BSE) was promoted in the 1950s by Cushman Haagensen, a Breast Surgeon from the United States of America (USA), at a time when mammography was yet to be developed, and many women were diagnosed when the tumour had become large and inoperable. Haagensen hoped that encouraging breast self-examination

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would help catch tumours earlier when they were still treatable, and when amenable to surgical excision without the need for the more disfiguring operation of mastectomy. To challenge mastectomy, the accepted standard operation at that time, was also contentious.

Haagensen appeared in a public education film 'breast self-examination' released by the American Cancer Society (ACS) and the National Cancer Institute (NCI) in 1950.<sup>3</sup> A series of educational leaflets were also produced. In 1955, Good Housekeeping reported that over five million women had viewed the educational film. By 1967, 13 million women had seen it. But even then, the ACS, NCI and the medical profession were aware of the potential pitfalls of promoting routine BSE. Haagensen instructed women to examine their breasts only once every two months 'to prevent the development of an abnormal fear of cancer'. Other doubts were voiced by both physicians and by the women themselves. There were criticisms covering many aspects of promoting and undertaking the practice with respect to the language used, and of the pictures of attractive, healthy partly-clothed young women used in the literature that were a clear and shocking departure from clinical descriptions and illustrations of diseased breasts in medical textbooks.<sup>4</sup>

The notion of the profession engaging in attempting early detection of a disease by these 'popular' means, engaging with women themselves through the media, rather than in just treating and curing it, caused a shift in the public perceptions of the medical profession and its rôle at that time in the 1950s. Haagensen wisely and correctly forecast that the practice could result in exacerbation of the fear of cancer.

### 3. What is breast self-examination (BSE)?

Breast self-examination is a regular, repetitive monthly palpation to a rigorous set method performed by the woman at the same time each month. Women who perform BSE should be properly trained.

BSE was evaluated for the first time in a randomised controlled trial in Shanghai in 1997. This large study, involving 260,000 women, followed up over a five-year period, did not demonstrate a survival benefit in doing regular BSE.<sup>5</sup> Since then, a Cochrane review has been undertaken of regular self-examination or clinical examination for early breast cancer to determine whether these interventions reduce mortality and morbidity from breast cancer.<sup>1</sup> The authors concluded that, using data from two large population-based studies (388,535 women) from Russia and Shanghai that compared BSE with no intervention, their findings do not suggest a beneficial effect of screening by breast self-examination, whereas there is evidence for harms in terms of increased numbers of benign lesions identified and an increased number of biopsies performed. They concluded from this that breast self-examination cannot be recommended.

### 4. What is breast awareness (BA)?

Being Breast Aware is currently defined as a woman becoming familiar with her own breasts and the way that they will change throughout her life. It encourages women to know

how their own breasts look and feel normally so that they gain confidence about noticing any change which might help detect breast cancer early. The changes that should be looked out for are

- Size – if one breast becomes larger, or lower.
- Nipples – if a nipple becomes inverted (pulled in) or changes position or shape.
- Rashes – on or around the nipple.
- Discharge – from one or both nipples.
- Skin changes – puckering or dimpling.
- Swelling – under the armpit or around the collarbone (where the lymph nodes are).
- Pain – continuous, in one part of the breast or armpit.
- Lump or thickening – different to the rest of the breast tissue.<sup>6</sup>

'Being breast aware' is gaining increasing acceptance the world over, signalling a move away from the popularly held belief that it is wise to practise rigorous BSE. In 1991, the UK abandoned systematic BSE. This policy was based on the work done by Cancer Research, UK,<sup>7</sup> who confirm that breast awareness is important, and detecting a cancer at an early stage may increase the chances of successful treatment.<sup>8</sup> The UK information and support organisation, *Breast Cancer Care*, clearly describes breast awareness.<sup>6</sup> The NHS Breast Screening Programme also produces a leaflet.<sup>9</sup> This refers to the evidence that shows 'that a formally taught, ritual self-examination, performed at the same time each month' is not beneficial.

But some websites still carry information about what BSE is and how to practise it.<sup>10</sup> There is even money to be made by companies who market special gloves for women to practise BSE.<sup>11,12</sup>

Coining a new term, 'BA', and advocating a new attitude, perhaps reflected the desire to move towards avoiding the 'development of an abnormal fear of cancer' that Haagensen so perceptively predicted. But if we are using this new term, everyone should know what is meant by it, clearly convey what is meant when they use it, and acknowledge there are uncertainties about its overall benefits and harms.

### 5. Practice in the clinics

Many women attending breast clinics in the UK are confused about the term 'breast awareness' and, because it involves touching the breast, equate 'breast self-examination' with 'being breast aware'. Closer uniformity of definition is now used by organisations in the UK in their advice to women.<sup>6–8</sup> Breast care nurses, who do much of the counselling in breast clinics, can allay women's anxieties and take opportunities of correcting misconceptions that women may have about these terms. Many breast centres in the United States, however, still actively advise rigorous BSE despite changed policy directives, and evidence for the harms that can result from its practice. It can be difficult for clinicians to give anxious women the counter-intuitive advice that BSE is not recommended.

But 'touching and finding' can occur in different situations motivated by different attitudes of mind. 'Chance detection'

can occur when women who are sensibly alert are showering, bathing or dressing; 'deliberate detection' can occur when women purposefully practice BA with the intention to check for abnormalities.

## 6. Chance detection by 'sensible alertness'

Women who are 'breast aware' can find breast cancers not detected during mammographic screening. Most cancers are found by women themselves<sup>8</sup> rather than by mammographic screening, which only detects between one third and a half of breast cancers.<sup>13</sup> Most women who find the cancer themselves do not routinely practice self-examination.<sup>14</sup> It is likely that the more relaxed group of women who are 'sensibly alert' to the possibility of finding an abnormality by chance will be less anxious than those who deliberately practice BA.

## 7. The effects of shared responsibility in a changing society

There have not only been cultural changes in society, but also changes in the way that medicine is practiced, and in the doctor–patient relationship. Automatic patient acceptance without question of doctor's recommendations that obtained a few decades ago has been replaced by various degrees of shared responsibility for decision-making.<sup>15,16</sup> This, coupled with wider availability of better quality information and of decision aids,<sup>17</sup> has led to patients' increasing ability to make trade-offs, taking account of perceived risks and their own values.

The composition of the stakeholders who now have an input into how breast cancer is researched, managed and treated has changed: it has altered the power dynamics, influencing the shape of 'knowledge-making'.<sup>18</sup> This process began in 1950 with the first attempts of the medical profession at encouraging women to take some responsibility for earlier detection, coinciding with the birth of women's advocacy movements; use of formal methods of prospectively evaluating interventions; changes in social attitudes and changes in the doctor–patient relationship. Many women were, and are, no longer content to be the passive recipients of healthcare.

## 8. Repercussions of 'breast awareness' promotions

Breast cancer support and advocacy organisations have a high public profile and exert considerable influence over large numbers of women. It is essential that they recognise their responsibilities.<sup>27</sup> For example, intense promotional activities, such as 'breast cancer awareness month', every October, result in dismayed clinicians finding their clinics overcrowded with the 'worried well' to the detriment of patients with breast cancer.<sup>19,20</sup> These organisations should help curb the over-enthusiastic damaging practice of BSE; advocate an approach that recommends 'sensible alertness' to finding abnormalities and advocate for better evidence.

## 9. Research; ethical aspects

It is important that methods chosen for obtaining evidence are the most appropriate<sup>21</sup> and include both health economic and psychological studies. A broad perspective and understanding is required if we are to help women globally. There are considerable inequalities of resource availability between rich and poor, both between countries and within countries. A global perspective shows that although breast cancer incidence is substantially higher in the more affluent developed countries, breast cancer mortality rates are similar.<sup>22</sup> Firm agreement is needed about what constitutes a competent self-examination, how often it should be carried out,<sup>23</sup> together with transparent methodologies.<sup>24</sup> Compliance must be thoroughly monitored, not just of the practice itself, but also with respect to women with abnormalities to determine whether they pursue diagnosis and treatment.<sup>25</sup> Measurement of outcomes can be problematic in a range of social climates ranging from affluent regions that strongly believe in prevention and screening to others where there is little awareness and fewer resources. How applicable are findings from studies in one region or continent to another?

Ethical aspects of distributive justice should be considered when planning any evaluation of the usefulness of different modes of early detection to reduce mortality from breast cancer. BA or clinical breast examination may be a more just and appropriate method of early detection in the developing world than mammographic screening which diverts scarce resources away from interventions that might give greater benefit in that society.<sup>26</sup> Financial cost/benefit ratios and the benefit/harm ratios of the various methods of early detection are different in resource rich and resource poor countries.

## 10. Conclusion

BSE continues in spite of evidence that it cannot be recommended.<sup>1</sup> Efforts should be made to halt the promotion of this damaging practice of rigorous breast palpation as a screening tool in 'well women'. Promotions – on websites; by companies selling gloves; by misguided advocacy groups, etc. – do women a disservice, misleading them about what is best for their well-being. The consequences of practicing BSE, both to the individual and to health services, are not trivial.

We must also remember that there is overall uncertainty about the balance of benefit to harm in the intentional practice of BA generally. We do not know whether, on balance, BA is beneficial or harmful. No intervention is harmless: we need to determine the ratio of harm to benefit. BA might be more worthwhile in some regions of the world than others. Meanwhile, there should be honesty – with kindness – in explaining this uncertainty in promotions to the general public, and to individual women in breast clinics. More precise and accurate use of 'breast awareness' is needed if harm and confusion are to be avoided. Summary points

- Breast self-examination (BSE) is not recommended (Cochrane review<sup>1</sup>).
- Uncertainty exists whether the benefits of breast awareness (BA) outweigh the harms.

- A clear and universally agreed definition of BA is needed.
- The confusion needs to be further exposed and debated.
- More research is needed.
- Meanwhile, 'sensible alertness' is suggested.
- The practice of BSE should be discouraged.

### Conflict of interest statement

None declared.

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