

Occasional essay

When statistics provide unsatisfying answers: revisiting the breast self-examination controversy

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When *CMAJ* published a report in June 2001 that questioned the value of teaching breast self-examination (BSE) to women,¹ angry respondents, ranging from breast cancer survivors to clinicians, derided the study as “bizarre” and “lame-brained.”²⁻³ Other commentators, using more neutral language, noted the uncertain nature of the available data.⁴ Because similar debates have erupted in the past with respect to BSE, mammography, radical mastectomy and other interventions for breast cancer,⁵ it might be fruitful to examine the social and cultural factors that lie in the background. By understanding how BSE raises basic questions about the scientific evaluation of screening tests, and about who should have the authority to ascertain scientific “proof,” perhaps we can move past the hostility and hyperbole of the BSE controversy and develop a more realistic perspective on the early detection of breast cancer.

Historical context

The notion of BSE emanated from the theory — popularized by American surgeon William Halsted in the early 1900s — that breast cancer begins as a local disease that is more curable if discovered early. One of its first proponents was New York physician Hugh Auchincloss, who in 1929 wrote that waiting for a lump to appear made little sense.⁶ Ironically, among the strongest early advocates of BSE were Nazi health officials, who viewed the technique as a way to improve the health of Aryan women.⁷ As it happened, it was the defeat of the Axis Powers in World War II that laid the groundwork for the popularization of BSE in the US. Having vanquished the Nazis, America turned its attention to the next enemy, cancer. The first “precision weapon”⁸ chosen for this task was the Papanicolaou smear. Although there were no definitive data proving that the detection of precancerous cells, followed by surgery, lowered mortality from cervical cancer, the dynamic medical director of the American Cancer Society, Charles Cameron, believed that this was the case. He travelled to churches and school auditoriums across the country, urging “for women sere [over 40], a vaginal smear, twice a year.”⁹ The standing ovations he often received reflected the popularity of his message: there *was* something women could do to prevent death from cancer.

This same mindset engendered the push for BSE in the US, Canada and Europe, although even fewer data existed than in the case of Pap testing.⁵ In 1950, the American Cancer Society and the National Cancer Institute introduced a film, *Breast Self-Examination*, that was eventually viewed by more than 13 million women.¹⁰ Accompanying educational material reiterated the point that finding smaller cancers by BSE dramatically improved a woman’s chances of survival. *Look* magazine confidently reported that American women who performed BSE “can virtually conquer the fatal aspects of this disease by their own initiative.”¹¹ By 1951, the Canadian Cancer Society was distributing American Cancer Society leaflets about BSE and generating its own material.¹²

The campaign to promote BSE played on traditional gender roles that placed special responsibility on women for guarding their health.¹³ A woman who permitted a breast lump to grow, wrote one physician, “has committed suicide almost as certainly as if she had blown out her brains with a pistol.”¹⁴ Yet, whether imposed by society or embraced by women themselves, the duty to perform BSE took on special importance when advocated by a supposedly cured breast cancer patient. “My life was saved,” one such woman wrote in 1955, “because I practiced breast self-examination.”¹⁵ Even more powerful were accounts by women who stated that they were dying of breast cancer because they had never performed BSE. Although of questionable validity, such testimonials were hard to contradict.

Breast self-examination received an additional push from the women’s health movement, which emerged in the US, Canada and elsewhere in the 1970s.¹⁶⁻¹⁸ BSE, like other healthful practices, became a mechanism for women to monitor the condition of their breasts and thus become less reliant on the medical system. When the American and Canadian cancer societies developed formal screening recommendations for breast cancer, they included BSE as well as annual breast examinations by health care professionals and screening mammograms. Efforts to promote mammography, like those to encourage BSE, have also conflated the seeming desirability of the test with its demonstrable value. For example, when the American Cancer Society began in the 1970s to recommend a baseline mammogram for healthy 35 year olds, one of its rationales was to instill “good health habits” among women.⁵

Despite the implicit faith in BSE, researchers have attempted for decades to prove scientifically its value in lowering breast cancer mortality. Yet reviews published in the 1980s and 1990s, including those by the US Preventive Services Task Force and the Canadian Task Force on the Periodic Health Examination, found insufficient evidence to recommend the test.^{19–20} More recently published randomized controlled trials conducted in China and Russia also found no reduction of mortality.^{21–22} These studies along with several other trials formed the basis of the controversial review¹ in which Nancy Baxter and the Canadian Task Force on Preventive Health Care lowered the grade for the routine teaching of BSE from a “C” to a “D,” indicating that there was “fair” evidence to exclude such teaching from the periodic health examination of women aged 40–69. Not only was there no benefit, the authors concluded, there was also evidence that it led to harm, including unnecessary physician visits and increased biopsies of benign lesions.

Angry responses

Some who challenged Baxter’s study focused on its supposed scientific flaws. These criticisms, well-summarized by Nekhlyudov and Fletcher,⁴ include the claims that the Chinese and Russian studies may not apply to North American women and that the Chinese study is based on insufficient 5-year follow-up. Other critics aptly noted that BSE will never be optimally evaluated until more women learn and practice the proper technique.²³

But a more provocative attack made by many Canadian women was that their personal experiences contradicted the scientific data. BSE had saved their lives, they argued. Without her own “aggressive advocacy,” wrote one woman who had discovered a lump, “I would have clearly been dead.”²⁴ Another woman noted that “taking matters into [her] own hands” with BSE had enabled her to dance at her son’s wedding as a breast cancer survivor.²⁵ Karen DeKoning, president of the Canadian Breast Cancer Network, agreed with these sentiments. Noting that she had twice detected malignancies by BSE, she termed “totally inaccurate” the notion that the technique causes harm. “If lives are saved,” she concluded, “the cost is never too great.”²⁶

It should be noted that Baxter and colleagues did not state that BSE never saved lives. Indeed, it is impossible to know whether or not the claims of these individual women are accurate. The important point is that these survivors believe that their cases do constitute proof, regardless of what population-based analyses of BSE may reveal. As one BSE supporter wrote, “breast cancer is not just a disease but a personal journey.”²⁷

Baxter and colleagues’ detractors also questioned their right to criticize such a trusted and empowering procedure as BSE. “The message of the study,” DeKoning stated, “appears to be that women have no control or knowledge over their own bodies.”²⁸ The authors’ conclusion, regret-

ted another woman, “effectively tells women there’s nothing they can do.”²³ The apparent fatalism of the researchers’ message was especially irksome. “Well, why bother about anything?” asked one woman. “Diet, exercise, wearing a bicycle helmet, looking both ways before crossing a street?”²⁷ Yet, as in the past, such statements said more about the desired or presumed outcome of BSE than about its proven worth. Baxter and colleagues did not deny that BSE might be empowering, only that it did not save lives as advertised.

Finally, critics claimed that discontinuation of BSE was too risky, especially among women under 50, for whom mammography is not recommended in Canada. In advocating the continued use and teaching of BSE, DeKoning opined that “Most women would willingly undergo a needle biopsy or even an excisional biopsy for the reassurance that they don’t have breast cancer.”²⁶ Although this may be accurate, it could also be argued that many women, informed of the current scientific data, might decline to perform BSE on learning that it is apt to result in unnecessary interventions. In any case, the rhetoric of the BSE debate threatened to undermine the ability of women to make their own health care decisions.

Nancy Baxter has become the latest in a long line of Canadian researchers who have generated pessimistic appraisals of popular interventions for breast cancer. Others include Neil McKinnon and Vera Peters, who presciently criticized radical mastectomy in the 1950s and 1960s,⁵ and Cornelia Baines and Anthony Miller of the Canadian National Breast Screening Study, who have repeatedly discouraged the use of routine mammography in younger women.²⁹ Nor is Baxter the first critic of early detection to be publicly vilified. In the 1970s, John C. Bailor of the National Cancer Institute was labelled a “murderer” of women when he objected to a demonstration project of screening mammography.⁵

Conclusion

Additional studies of BSE are ongoing. Although definitive proof of its ability to lower mortality from breast cancer may some day be produced, one may wonder why, if BSE is truly the life-saving procedure that its advocates believe it to be, the existing data are not more promising. Sometimes, good statistics provide unsatisfying answers.³⁰ Research findings should not be disparaged because they conflict with either our expectations or our hopes. Although we might wish otherwise, BSE does not help to save the lives of all — or even most — of the women who find lumps and then survive their breast cancers. Cancers discovered by BSE have likely been present for years and may have silent metastases elsewhere in the body. As such, chemotherapy probably plays a more important role in prolonging survival in these cases than does early detection. But it is also true that Baxter and colleagues’ decision to emphasize certain types of scientific data overlooks other

possible ways to judge the value of BSE. Even though the study of large populations has become the accepted strategy for proving the efficacy of medical interventions, this may not be the type of evidence that many patients desire. Because the stories of individual women have great resonance, and because they at times probably do represent exceptions to population-based generalizations, they constitute an alternative type of “proof” that should not simply be dismissed as “unscientific.”³¹

Similarly, we should respect BSE as a strategy that empowers women who are concerned with having healthy breasts. As one correspondent wrote, the lifesaving potential of BSE may be less important than its ability to give women “some control in deciding what is best for their health and well-being.”³² In this sense, the regular performance of BSE might itself become a desirable intermediate health outcome. If women clearly value breast examination, why is proof of lowered mortality in randomized controlled trials the only appropriate goal to study? Of course, continued support for BSE in the face of lacklustre data remains defensible because of its low cost and minimal reliance on technology (unnecessary biopsies notwithstanding).

In sum, the medical profession owes women the best scientific evaluation possible of breast self-examination. But it also owes them an understanding of the multiple reasons why BSE retains such powerful support despite the existing data. Armed with all of this information, each woman can decide whether BSE is right for her.

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Competing interests: None declared.

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