Doctors, health pamphlets from national cancer societies, and the Internet all inform women about early detection of breast cancer and the benefits of mammography screening. Thus, women should be fairly knowledgeable about screening. Yet nothing is farther from the truth, as documented by the first European-wide study [1] that included a representative sample of about 5000 women from Austria, France, Germany, Italy, Spain, Poland, the United Kingdom, and Russia (European part). Ninety-two percent of women overestimated the benefit of screening tenfold, hundredfold, two-hundredfold, or did not know; in France, Germany, and the Netherlands, the percentage rose to 98%. Why are women so highly misinformed in Europe? In defence of Russian women, one might note that mammography screening is rare in Russia. Yet the Russian women made by far the most realistic estimates—likely from receiving not more but less misleading information.

What exactly are women told about the benefits of breast cancer screening? Many doctors convey an emotional message: that early detection is a moral responsibility, that women should think of their families and take care of their bodies. Pamphlets emphasize that screening can save lives but rarely provide numbers, which are more likely to be found on Web sites. If numbers about benefits are given, then most pamphlets and Web sites frame information in a format that misleads women, such as relative risk reductions [2]. Women are told that screening with mammography reduces breast cancer mortality by 20% or even 25%. Elsewhere they are told that the 5-year survival rate for women who participate is 98%. This is where Jane Q Public begins to get confused: Does that mean that out of 1000 women, equivalent to 1 in 1000, that is, by 1 in 1000. The fact box also lists the potential harms, which are reported for the same reference class of 1000 women. About 50–200 women without breast cancer will undergo unnecessary biopsies and anxieties due to false positives, and 2–10 women with non-progressive or slow-growing breast cancer will undergo unnecessary treatments such as lumpectomies or mastectomies. For these women, screening provides no benefits but negatively affects their quality of life. A third potential harm, getting radiation-induced breast cancer from the mammography, is not included because only rough indirect estimates (1–5 in 10,000) exist. The simple fact box enables women to come up with informed decisions on an individual basis, according to their priorities.

Fact boxes of this type allow patients to see through misleading information. Consider the 20% risk reduction: from 5 to 4 in 1000, equivalent to 1 in 1000. This 20% figure may be the reason why 27% of women in the U.K. believe that mammography screening saves 200 out of 1000 women from dying from breast cancer, whereas only 7% of Russian women think so [1]. The 98% survival rate is another deceptive tool, given that changes in 5-year survival rates have no reliable relationship to changes in mortality. Yet to the targeted women, higher survival mistakenly implies lower mortality. One reason for this confusion is the so-called lead-time bias: Screening leads to early detection, which in turn inflates the 5-year survival rate, because survival is measured from the time of detection. A second reason is overdiagnosis, that is, screening detects non-progressive cancers that by definition do not lead to mortality, yet their number increases the survival rate [2].
The fact that 92% of European women overestimate the benefits of mammography tenfold, hundredfold, two-hundredfold, or do not know, should give everyone pause for thought. The blame should not be on the women, who are only the last element in a long production line that actively creates and maintains health illiteracy. Physicians, health pamphlets, and journalists contribute, often unawares. For instance, one-third of hundreds of gynecologists I have trained in their continuing education did not even know the benefit of mammography screening but mistakenly believed that a 25% risk reduction meant that 25 or 250 fewer women out of 1000 die from breast cancer [2]. In the European study, we discovered that women who frequently consulted general practitioners or health pamphlets overestimated the benefits even more than those who did not.

Misleading women, whether intentionally or unintentionally, about the benefit of mammography screening is a serious issue. All of those in the business of informing women about screening should recall that medical systems are for patients, not the other way around.

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References


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