

LIFE AND DEATH Iona Heath

It is not wrong to say no

Why are women told only the benefits of breast screening and none of the possible harms?

I have seen enough women die from breast cancer to know very clearly what a terrible disease it can be and to understand the motivation that drives attempts to promote early diagnosis and curative treatment. It is not possible to take this issue lightly, and yet I have cheerfully declined successive NHS invitations to attend for my own screening mammography. My worry is that I have made this decision on the basis of information that is not readily available to my patients.

In the United Kingdom each mammography invitation encloses the leaflet *Breast Screening: The Facts*, a title that in itself seems to deny any sense of the uncertainties permeating the programme. The unforgivable feature of this leaflet is that, despite protests and promises of improvement, it still emphasises only the benefits of screening and makes no mention of the possible harms. Yet every practising clinician knows that screening always produces harms as well as benefits. The reassuring tone of the leaflet conveys a clear expectation that any rational, socially responsible woman will accept the invitation. In whose interests does this operate?

The Cochrane Review of breast cancer screening and the alternative information leaflet available at www.cochrane.dk describe a situation very different from that implied by *Breast Screening: The Facts*: the evidence review suggests that for every 2000 women invited to screening for 10 years one death from breast cancer will be avoided but that 10 healthy women will be “overdiagnosed” with cancer. This overdiagnosis is estimated to result in six extra tumorectomies and four extra mastectomies and in 200 women risking significant psychological harm relating to the anxiety triggered by the further investigation of mammographic abnormalities. The percentage of women surviving 10 years if they are not screened is 90.2%; it is 90.25% if they are screened. Is this enough of a difference to risk the possibility of significant harm? For me, it is not.

Why, in a service that pays repetitive lip service to fully informed choice, are autonomous adult women not being fully informed about the scientific debate concerning overdiagnosis and the uncertainties about the natural history of ductal carcinoma in situ, when approximately 25% of the cancers detected during screening are this type? My clinical experience is that, since the introduction of national screening for breast cancer, a number of patients on my list have been identified as having “breast cancer” after mammography and have undergone various treatments for this and have subsequently remained very well over an extended period of years. At face value, this is good news; and certainly my patients regard themselves as cancer patients whose lives have been “saved” by the screening programme. But I find myself wondering how many of them have been overdiagnosed, when they had changes that were never going to progress to invasive breast cancer and have been put through the trauma of a cancer diagnosis and subsequent mutilating and debilitating treatment for no purpose. The concerns do not even stop there, because I see the lives of the daughters of these patients being infected with fear as they worry about their family history of breast cancer and their own increased risks.

How many doctors, let alone patients, understand Alvin Feinstein’s 1985 description of the Will Rogers effect (*New England Journal of Medicine* 1985;312:1604-8)? Whenever more people are included within any disease category through stage migration, new diagnostic techniques, extended definitions of disease, or lowered thresholds for preventive interventions, the result is an illusion of improved population outcomes, while there is no difference at all in the outcomes in affected individuals. This comforting illusion has proved very useful to those charged with running the NHS, which perhaps explains to some degree the content of the breast screening invitation.



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The enduring human fear of what the future holds means that it is never easy to decline the promised benefits of screening interventions. Such refusal seems to tempt fate in a disturbingly primeval way. A south London GP, David Misselbrook, wrote in his marvellous 2001 book *Thinking About Patients*: “Consider the numbers needed to treat (NNT) to prevent one bad outcome for most screening interventions. Why do all these people agree to be screened? Partly because we tend to feed them benefit figures based on a relative risk reduction model. But also because it is our modern equivalent to a votive offering brought by penitents to the temple of Hygeia. It is a psychological trick to manage our fear.” Our fear of our inevitable deaths means that psychological tricks are both necessary and prevalent, and it is essential that screening programmes do not escalate these fears in order to promote uptake in an ethically unacceptable way.

In this context, as doctors we need to remember David Sackett’s description of the arrogance of preventive medicine (*CMAJ* 2002;167:363-4): “Preventive medicine displays all 3 elements of arrogance. First, it is aggressively assertive, pursuing symptomless individuals and telling them what they must do to remain healthy . . . Second, preventive medicine is presumptuous, confident that the interventions it espouses will, on average, do more good than harm to those who accept and adhere to them. Finally, preventive medicine is overbearing, attacking those who question the value of its recommendations.”

I have made my own individual decision. Other women, with a different perception of their individual risk, family context, or degree of risk aversion, will quite appropriately make a different decision. It is not wrong to say yes, but neither is it wrong to say no.

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