Informed choice in screening needs more than information

In The Lancet, Jolyn Hersch and colleagues report on a randomised controlled trial of two decision aids for women approaching the target age for starting breast screening (age 48–50 years): an intervention decision aid that included information about the most severe harm of breast cancer screening (overdiagnosis); and a control decision aid that did not have this information.1 The aim of the trial was to see if including information on overdiagnosis would help women make an informed choice about breast screening. We could argue that to do a trial in which half of the participants are not given information about the harms of an intervention is ethically unacceptable. However, most breast screening programmes do not include information about overdiagnosis or other relevant harms of screening in their invitations,2 which is why this study is so important. Of 409 women who received information about overdiagnosis in their decision aid, 99 (24%) were judged to have made an informed choice, the trial’s primary endpoint, compared with 63 (15%) of 408 women who received the control (difference 9%, 95% CI 3–14).1

Paternalistic discourse is apparent in research on screening: several studies have been done with the explicit agenda to increase uptake in screening, without consideration of whether participation is based on informed choice or not.1 Contrary to this previous work, Hersch and colleagues1 chose the proportion of women making an informed choice as their main outcome. This shift of perspective, from paternalism to respect for women’s autonomy, is one important step towards an approach consistent with contemporary ethical values. It is noteworthy that Hersch and colleagues investigated the effect of only one type of harm of breast screening. However, other important harms might affect many more women; for example, false-positive results have serious psychological consequences3 that are typically downplayed or left unmentioned in screening invitations. The findings by Hersch and colleagues underline the need for a reassessment of invitations to current screening programmes, not only those for breast screening. Adequate information on all important benefits and harms should be added, in addition to an acknowledgment that non-participation might be as rational a choice as participation.

Balanced comprehensive information is important from an ethical perspective; however, it might not have a substantial effect on the ability of women to make truly informed choices. In the study by Hersch and colleagues,1 a woman was judged to have made an informed choice if she had sufficient knowledge and made a decision consistent with her personal preferences and values. We agree this definition of informed choice is useful in a research context, but it assumes that information speaking to people’s intellect is easily integrated into understanding of risk. Yet research suggests that our understanding of risk relies mainly on emotions and that cognitive comprehension has little effect on decision making.5,6 Furthermore, if emotionally charged messages have formed our perception of a particular risk, which is certainly the case for breast cancer, subsequent information is unlikely to change our understanding of that risk nor our attitudes or behaviour.6 Therefore, emotional factors are likely to have a greater effect on women’s decisions about participation in breast screening than is information in decision aids.

Many women will probably trust that an invitation from health authorities strongly indicates that the intervention is worthwhile. This assumption is emphasised by widespread use of prebooked appointments (versus opt-in alternatives), which short-circuit the decision process by indicating a seemingly correct and expected choice.7 Furthermore, the harms of screening receive little attention in media coverage whereas advantages are typically portrayed through case studies of women and celebrities who claim to have benefited from screening,8 although the value is effectively impossible to measure for any particular individual. Such stories have a strong emotional effect, and attendance at screening is sometimes expressed as a moral obligation.1 Websites of key stakeholders (official authorities and cancer charities) emphasise the benefits and downplay the harms of screening.8 Clinicians have unfounded faith in the value of screening.9 Moreover, harms are systematically under-reported in randomised controlled trials of cancer screening,10 and research on psychological harm of screening is generally insufficient,11 which means that the information on which policy makers base their decisions is biased in favour of screening.
In this context, balanced information in invitations to screening seems merely a small step towards true informed choices based on personal preferences. Equally important is a better understanding of the benefits and harms of screening among journalists, clinicians, researchers, editors, and policy makers and a more nuanced debate about screening in the media.

Personalised risk communication has been proposed as a means to increase informed choice about screening. Although appealing, are such methods sound from a public health perspective? Should we use scarce resources to maximise informed choice among healthy individuals when money could instead be spent on people with the greatest need: those who are already ill?

We would also like to raise a note of caution. Informed choice must not be used to justify the introduction or continued use of screening programmes in which the balance between benefits and harms is doubtful, and informed choice does not remove the responsibility for offering such screening programmes from health authorities. True, informed choice remains utopic in our cultural context and does not solve the fundamental dilemma of screening; is it ethically acceptable to cause serious harm in some people to improve the prognosis of others?

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