Primary care

Screening for cardiovascular risk: public health imperative or matter for individual informed choice?

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The National Screening Committee has recommended a paradigm of informed choice for participants in all screening programmes. Theresa Marteau and Ann Louise Kinmonth examine the potential consequences of applying such a policy to screening for risk of coronary heart disease in primary care

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Current recommendations for the primary prevention of coronary heart disease in groups at high risk depend on screening through primary care and provision of risk related advice or treatment.¹ Criticisms of these recommendations highlight the lack of evidence for the cost effectiveness of multiple risk factor interventions delivered through primary care.^{2 3} We propose that this lack of effectiveness may, in part, reflect how people are invited for screening. The public health approach most often used focuses on maximising participation in screening rather than on informed participation. We consider here the implications of offering primary preventive services for cardiovascular disease within a framework of informed choice.

Methods

We searched Medline and PsycINFO databases for systematic literature reviews relating to informed choice and screening, both in general and in relation to cardiovascular disease. We also drew on personal literature collections, stemming from joint long term interests in risk perception and screening for cardiovascular and other risks.

Current philosophy and practice

A screening procedure is one that is applied to a population to select people at risk of an unfavourable health outcome for further investigation, monitoring, or advice and treatment. A traditional public health approach to screening regards the population benefits of reduced morbidity and mortality as inherent, not to be appraised by individuals before they decide whether or not to participate. In keeping with this, the information accompanying the invitation tends to be brief, emphasising the general health benefits of participation.

A policy shift is occurring in the United Kingdom and elsewhere towards informed choice, as laid out by the National Screening Committee: "There is a responsibility to ensure that those who accept an invitation (to screening) do so on the basis of informed

Summary points

Invitations for cardiovascular screening tend to emphasise the benefits of participation, neglecting the possible harms and uncertainties that such screening entails

A policy shift is occurring towards ensuring that people invited to participate in any screening programme do so on the basis of an informed choice

The impact of conducting cardiovascular screening within an informed choice paradigm is unknown

Presenting the uncertainties associated with the assessment and reduction of cardiovascular risk has the potential to be more cost effective than screening conducted in a traditional, public health paradigm if it results in participants who are more motivated to reduce their risks

It also has the potential to increase inequalities by reducing the number of people most at risk who participate in screening

Evaluation of the operation of an informed choice approach to cardiovascular risk assessment is needed

choice, and appreciate that in accepting an invitation or participating in a programme to reduce their risk of a disease there is a risk of an adverse outcome".⁴ This approach recognises the fact that although screening programmes may benefit populations, not all participants will benefit and some will even be harmed by participation.

Good examples of an informed choice approach to screening are mainly to be found in situations where the penalty of uninformed screening is seen as

unacceptably high. When termination of pregnancy is a possible outcome of antenatal screening, for example, a policy of informed choice is seen as central to individual autonomy and to avoiding eugenic practice.⁵ Authors concerned about the adverse psychological effects of unrealistic expectations of what cancer screening programmes can deliver have emphasised the importance of informed choice.^{6,7} This position is reinforced by increasing litigation associated with the provision of poor quality information to people participating in cancer and prenatal screening programmes.⁸

Screening for risk of coronary heart disease can be said to differ fundamentally from screening for existing disorders such as Down's syndrome or breast cancer. In the first case screening is based on the probability of a future event, and cardiovascular risk is continuously distributed in the population; in the second case a screening test, of defined precision, splits the population into people likely or unlikely to have an existing condition, and this is then confirmed or excluded by a diagnostic test. Although cardiovascular risk may be continuous, however, judgments on how to manage it are binary. Individual risk status is usually confirmed by duplication of measurement of risk factors such as blood pressure, lipids, and glucose. At specified levels of risk, treatment is offered to individuals in an attempt to avert possible adverse future events.

Screening for cardiovascular risk in primary care has also been approached through "case finding." For example, a patient may be identified as having hypertension while consulting about a skin infection. However, qualitative evidence has shown that patients would like choice in this situation and vary as to whether they are ready for the associated lifestyle advice.⁹

Possibility of harm

Categorising individuals as belonging to high risk groups is associated with the adverse effects resulting from labelling. For example, identification of diabetes, hypertension, or hyperlipidaemia creates demands for clinical monitoring and adherence to drug treatment, potentially resulting in a life lived in fear of a heart attack or stroke. Many people do not want to pay these prices for an uncertain reduction in personal risk.¹⁰ However, little or no debate has taken place about the consequences of shifting the focus of screening for specified thresholds of cardiovascular risk from one guided by a population based public health paradigm to one guided by individual informed choice.

What would informed choice look like?

An emerging consensus states that an informed choice or decision has two core characteristics: firstly, it is based on relevant, good quality information; and, secondly, the resulting choice reflects the decision maker's values. This can be viewed in practice as a choice based on relevant knowledge, reflecting an individual's value system, and behaviourally implemented.¹¹ The General Medical Council has produced guidance on the information that should be provided to people offered screening.¹² This includes information on the condition for which screening is being

Screening programmes may benefit populations, but only a few individuals will benefit and some may even be harmed by participation

offered, as well as information on the likelihood, meaning, and implications of all possible test results. Such guidelines do not, however, tell us how much information should be provided or how it should be presented in order to facilitate choices that are informed.

The national service framework for coronary heart disease and the joint British recommendations on prevention of coronary heart disease propose that all patients with a 10 year absolute risk of a coronary event (non-fatal myocardial infarction or death from coronary heart disease) of over 30% should "be targeted and treated."^{11,13} People meeting or exceeding this threshold may be viewed as "screen positive." If such patients take effective drugs for hypercholesterolaemia and high blood pressure they can, as a group, reduce this risk by about 30% over 10 years (estimated from studies over five years).^{14,15} This might reduce a 10 year risk of 30% to one of 21%. Thus a patient identified as being at high risk by the screening criteria in the national service framework has about a 9% chance of benefiting (and a 91% chance of not benefiting) from 10 years of treatment. To put this another way, 11 patients at high risk must be treated for 10 years to avoid a coronary event in one of them.

How will individual patients respond to different representations of their predicament? The information could be presented in general terms—for example, "this treatment will reduce your risk"—or more specifically in terms of reductions in relative or absolute risk or in terms of the number of patients who need to be treated for one person to gain. The consequences of treatment can also be expressed in terms of the number of people who will be inadvertently harmed. Each of these different ways of presenting similar information can affect choices in other contexts,¹⁶ but we do not know how different combinations affect choices about participation in screening for risk of coronary heart disease or about subsequent treatment and changes in behaviour.

What might be the consequences of achieving informed choice?

Uptake

Educational interventions aimed at increasing uptake of screening seem to have, at most, only small effects on uptake.¹⁷ However, the content of these interventions was probably more positive than negative, given that such interventions are generally aimed at increasing uptake rather than promoting informed choice. Evaluations of some information systems aimed at helping men to make informed choices about screening for prostate cancer show a decreased uptake in screening after provision of information about the uncertain and adverse effects of such screening.¹⁸ This, however, is for a screening test that is a weak predictor of a condition for which treatment is of unknown benefit. It may not hold for cardiovascular disease, for which the impact of preventive drugs on risk reduction is well documented and may be judged as large in the groups at highest risk.

Emotional impact of screening

Participating in screening after having made an informed choice to do so is likely to be associated with more realistic expectations of screening, with corresponding lower levels of emotional distress and false reassurance. Interventions that increase understanding about a screening test and subsequent interventions lead to lower levels of emotional distress among people learning of increased risks of disease and lower levels of false reassurance in people receiving a negative result or one indicating a low risk.^{19 20}

Motivation to change behaviour

Change in behaviour after participation in cardiovascular screening programmes designed to reduce the risk of coronary heart disease has been disappointing.²¹ Change in behaviour is most likely in people who are motivated to make such changes.²² Ensuring that people accepting an invitation for screening do so on the basis of relevant information may lead to the motivation to make changes to reduce any risks identified being higher than has been observed hitherto, resulting in larger effects on health.

Impact on equity and population health

A policy of informed choice might inadvertently foster inequities in two ways. Firstly, a detailed invitation to participate in screening may lead to high levels of fear in people aware of their increased risk, an emotional state that can lead to avoidance behaviour, including not attending for screening.²³ Secondly, a detailed invitation to participate in screening may be less accessible to people with low literacy skills, who may also be at high risk of heart disease. Development of materials that do not induce very high levels of fear and are comprehensible to most of the population may go some way towards minimising these potential sources of inequity.

Conclusion

The net effect of any population based preventive strategy depends on the number of people participating, their baseline levels of risk, and the changes in risk achieved by their actions after testing. Although a policy of informed choice may reduce the likelihood of the public health objectives of screening being achieved, it may also increase the effectiveness of interventions

among people who choose to participate and may prove at least as cost effective as current efforts. If people are unmotivated to achieve the gains that risk assessment and subsequent intervention can result in, this would be another instance of informed patients behaving in ways that are at odds with prevailing medical opinion, an increasingly recognised consequence of patient centred care.²⁴ Whatever the population outcomes, a policy of informed choice could place primary care back in partnership with patients seeking help to change their behaviour, as opposed to being faced with a responsibility for improving the health of the public, regardless of the motivation of individual patients. Studies are now needed to evaluate the impact of a policy of informed choice on reducing cardiovascular risk in high risk populations identified by screening.

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- 1 Department of Health. *National service framework for coronary heart disease*. London: Stationery Office, 2000.
- 2 Rouse A, Adab P. Is population coronary heart disease risk screening justified? A discussion of the national service framework for coronary heart disease (standard 4). *Br J Gen Pract* 2001;51:834-7.
- 3 Toop L, Richards D. Preventing cardiovascular disease in primary care. *BMJ* 2001;323:246-7.
- 4 National Screening Committee. *Second Report of the UK National Screening Committee*. Departments of Health for England, Scotland, Northern Ireland and Wales, 2000. www.doh.gov.uk/nsc/pdfs/secondreport.pdf (accessed 7 Jun 2002).
- 5 Andrews LB, Fullerton JE, Holtzman NA, Motulsky AG. *Assessing genetic risks: implications for health and social policy*. Washington, DC: National Academy Press, 1994.
- 6 Raffle AE. Cervical cytology screening 10 years on. *Trends Urol Gynaecol Sexual Health* 1998;3:14-6.
- 7 Austoker J. Gaining informed consent for screening. *BMJ* 1999;319:722-3.
- 8 Petticrew MP, Sowden AJ, Lister-Sharp D, Wright K. False-negative results in screening programmes: systematic review of impact and implications. *Health Technol Assess* 2000;4(5):1-120.
- 9 Stott NCH, Pill R. "Advise yes, dictate no." Patients' views on health promotion in the consultation. *Fam Pract* 1990;7:125-31.
- 10 Misselbrook D, Armstrong D. Patients' response to risk information about the benefits of treating hypertension. *Br J Gen Pract* 2001;51:276-9.
- 11 Marteau TM, Dormandy E, Michie S. A measure of informed choice. *Health Expect* 2001;4:99-108.
- 12 General Medical Council. *Seeking patients' consent: the ethical considerations*. London: GMC, 1999.
- 13 British Cardiac Society, British Hyperlipidaemia Association, British Hypertension Society, British Diabetic Association. Joint British recommendations on prevention of coronary heart disease in clinical practice: summary. *BMJ* 2000;320:705-8.
- 14 Shepherd J, Cobbe SM, Ford I, Isles CG, Lorimer AR, MacFarlane PW, et al for the West of Scotland Coronary Prevention Study Group. Prevention of coronary heart disease with pravastatin in men with hypercholesterolemia. *N Engl J Med* 1995;333:1301-7.
- 15 Jackson R. Updated New Zealand cardiovascular disease risk-benefit prediction guide. *BMJ* 2000;320:709-10.
- 16 Edwards A, Elwyn G, Covey J, Matthews E, Pill R. Presenting risk information—a review of the effects of "framing" and other manipulations on patient outcomes. *J Health Commun* 2001;6:61-82.
- 17 Jepson R, Clegg A, Forbes C, Lewis R, Sowden A, Kleijnen J. The determinants of screening uptake and interventions for increasing uptake: a systematic review. *Health Technol Assess* 2000;4(14):1-133.
- 18 Flood AB, Wennberg JE, Nease RF, Fowler FJ, Ding J, Hynes LM. The importance of patient preference in the decision to screen for prostate cancer. *J Gen Intern Med* 1996;11:341-9.
- 19 Shaw C, Abrams K, Marteau TM. Psychological impact of predicting individuals' risk of illness: a systematic review. *Soc Sci Med* 1999;49:1571-8.
- 20 Marteau TM, Senior V, Sasieni P. Women's understanding of a "normal smear test result": experimental questionnaire based study. *BMJ* 2001;322:526-8.
- 21 Ebrahim S, Davey Smith G. Multiple risk factor interventions for primary prevention of coronary heart disease. *Cochrane Database Syst Rev* 2000;(2):CD001561.
- 22 Armitage CJ, Connor M. Efficacy of the theory of planned behaviour: a meta-analytic review. *Br J Soc Psychol* 2001;40:471-500.
- 23 Witte K, Allen M. A meta-analysis of fear appeals: implications for effective public health campaigns. *Health Educ Behav* 2000;27:591-615.
- 24 Smith R. The discomfort of patient power. *BMJ* 2002;324:497-8. (Accepted 11 April 2002)