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What makes a screening program ethical?

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What makes a screening program ethical?

Abstract
Ethics, as a discipline, asks "is this decision, situation, program or policy good? Under what circumstances is it good? Why?". This paper applies these questions to screening: "Is screening good? Under what circumstances is it good? Why is it good?". Of course, the answer to these questions depends on how one defines "good". A consequentialist, for instance, will suggest that a screening program is good when it prevents or, at least, reduces harm and suffering1 whereas non-consequentialists are likely to take a rather different approach. In this short paper, I have room only to skate across the surface of these arguments. I will suggest that there are at least two, rather different, sets of responses to the questions above and I will investigate the detail of two of these. The first response states that screening programs are good when they prevent harm and suffering; the second suggests that screening programs are worthwhile because they enhance autonomous decision making.

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SENSITIVITY, SPECIFICITY AND ALL THAT SCREENING JARGON

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Sensitivity and specificity are the measures of a screening test against the "true" results. In other words population screening, which generally uses relatively simple tests so that they can be conveniently used by a large number of people, can only ever provide an incomplete version of the true results.

In population screening there are four groups which result from the screening process; two groups which benefit from the test and two which receive unhelpful information. There are those people who are correctly identified as having the disease after being screened. They are well served by the screening process and receive important health information (the truly diseased group). Those who are correctly identified as not having the disease, have their faith in their own good health supported (the truly healthy group). The other two groups are not as well served by the screening process. They are those who return a positive screening test but do not have the disease (the false alarm group) and those who return a negative test but do have the disease (the missed group).

How well a screening test identifies the truly diseased group, while keeping the false alarm group as small as possible is called the positive predictive value of the screening test, and is broadly regarded as a measure of the efficiency of testing.

However, while a screening test may be efficient in terms of resources, it will fail if it does not have adequate sensitivity and specificity. Sensitivity measures the size of the truly diseased group relative to the sum of the truly diseased and missed groups. A test which misses a lot of people will thus have poor sensitivity and will be avoided in screening programs. Specificity measures the size of the truly healthy group relative to the sum of the truly healthy and false alarm groups. Once again, a test which gives many people false alarms will be rejected as a screening test.

WHAT MAKES A SCREENING PROGRAM ETHICAL?

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Introduction

Ethics, as a discipline, asks "is this decision, situation, program or policy good? Under what circumstances is it good? Why?". This paper applies these questions to screening: "Is screening good? Under what circumstances is it good? Why is it good?". Of course, the answer to these questions depends on how one defines "good". A consequentialist, for instance, will suggest that a screening program is good when it prevents or, at least, reduces harm and suffering[1] whereas non-consequentialists are likely to take a rather different approach. In this short paper, I have room only to skate across the surface of these arguments. I will suggest that there are at least two, rather different, sets of responses to the questions above and I will investigate the detail of two of these. The first response states that screening programs are good when they prevent harm and suffering; the second suggests that screening programs are worthwhile because they enhance autonomous decision making.

Screening to prevent harm and suffering

There is a wide range of guidance available to help determine if a screening program is likely to be able to prevent harm and suffering. Such guidance includes Wilson and Jungner's 10 principles for mass screening programs (see Table 1), which are still cited today when population screening programs are proposed and evaluated.[2] The principles provide a set of straightforward guidelines for screening. The principles are grounded in assessments of the importance of the health problem and the availability and acceptability of screening tools and treatment for the health problem. The principles are also grounded in the scientific understanding of the condition and a favourable economic balance between the costs and benefits of screening.

Each of these principles invites questions, and it is here that the task of ethically evaluating a screening program really begins. For example, Wilson and Jungner state that the condition must be an *important* health problem, judged on the basis of prevalence and seriousness. Candidates for screening programs are more important if their conditions are either prevalent, serious, or both. For example, diabetes, particularly of a mild degree, is an example of a highly prevalent condition; phenylketonia (PKU), on the other hand, is extremely uncommon, but has very serious consequences if not treated early in life; whilst cervical cancer is an example of a condition that is both prevalent and serious.[2] Judgements about seriousness and prevalence are not simple objective measures; they are grounded in specific social, political and cultural contexts. Thus, decisions about which diseases to screen for reflect beliefs about whose

problems matter most; screening newborns is deemed important, in part, because our society places the utmost importance on the health of newborns and children.

Table 1: Principles of Early Disease Detection

1. The condition sought should be an important health problem.
2. There should be an accepted treatment for patients with recognized disease.
3. Facilities for diagnosis and treatment should be available.
4. There should be a recognizable latent or early symptomatic stage.
5. There should be a suitable test or examination.
6. The test should be acceptable to the population.
7. The natural history of the condition, including development from latent to declared disease, should be adequately understood.
8. There should be an agreed policy on whom to treat as patients.
9. The cost of case finding (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole.
10. Case-finding should be a continuing process and not a "once and for all" project.

Source: Wilson J, Jungner G. Principles and Practice of Screening for Disease. Geneva. World Health Organization. 1968.

Principle 2, in table 1, directs our attention toward the outcomes of screening. The basic principle is that screening is only desirable when a better prognosis is given by identifying a condition, or its precursors, earlier. Clearly, screening for conditions for which there is no treatment available at all is hard to justify ethically. Usually, however, the problem facing the public health practitioner is more complex, as the evidence that screening "makes a difference" is not always available or may be difficult to collect. It is accepted practice that we ought not screen in the absence of evidence of effectiveness.[3] However, if a screening program has become accepted practice in the absence of adequate evidence of its effectiveness, it would be difficult to discontinue such screening for this reason alone. For example, clinical examination of the hips of newborn infants is routinely performed as a screening test for developmental dysplasia of the hip, despite little firm evidence to support its value.[4] However, as a Scottish health technology assessment report noted: "this screening has become such an accepted part of newborn health care that it would be almost impossible to discontinue it without compelling contradictory evidence".[5]

Ethical analysis of the issues raised by principle 2 will also go beyond debate about the scientific evidence for screening and the need to consider other intended outcomes of screening. Screening tests give rise to false positives and negatives, and such events carry with them the potential for considerable anxiety and distress. For example, screening tests for herpes simplex virus 2, even in high prevalence populations, will have false positive rates of the order of 10%.[6] The impact of learning that one has a sexually transmitted, life-long, incurable condition, particularly if one has no symptoms, is likely to be profound. An ethical assessment of a screening program needs to build an awareness of these types of outcomes into any analysis.

Principle 3, in table 1, emphasises the point that screening must only occur if people found to have a condition are able to access the treatment they then need. How "available" does treatment need to be for it to be ethically acceptable? Lippman, for example, notes that PKU testing is supported across the United States, in part because there is a well established and accepted diet for children diagnosed with PKU.[7] However, in only four states are health insurers required to cover the costs of the special foods that children with PKU need. Closer to home, one might argue that screening for diabetic retinopathy amongst indigenous people is only worthwhile if we are prepared to provide the culturally accessible and appropriate services that will be needed to make a difference to those with the condition.

One could go on, examining each of the principles and identifying and analysing the extent to which population benefits result from screening. As noted in the introduction, the underpinning ethical theory in this approach is consequentialist in orientation. However, some scholars writing about the ethics of screening have noted that there is a second set of arguments about the ethical acceptability of screening programs, which is not based on a preventive principle. These arguments focus instead on information and autonomy, suggesting that screening can be regarded as "good" because it enhances people's capacity to make their own decisions about their own lives, and that this is a worthwhile aim in itself.[8]

Screening to promote individual autonomy

"Autonomy arguments" for screening are not grounded in the classic public health principle of benefit for the health of populations. Rather, they reflect an individualistic orientation by suggesting that, quite outside their role in preventing or reducing disease, screening programs can offer individuals the opportunity to take more control over their lives. Screening tests provide information, and information is a worthwhile aim in itself, regardless of the outcome. Stone and Stewart go so far as to suggest that this "information" aim represents a "paradigm shift in the philosophy of screening".[8]

Views such as these are typically found in debate about the ethical acceptability of prenatal screening.[7] Prenatal screening is presented as an option that increases women's reproductive choices and control. Much has been written about this issue and I will raise only three points. First, the information women have available to them when they make choices about reproduction is socially, historically and culturally determined. Only some conditions can be tested for; indeed, Lippman suggests, rather provocatively, that women have had little control over which conditions warrant screening tests at all. Instead, this has been determined by the geneticists who provide the tests, something, she

posits, that reflects "almost exclusively a white, middle class, perspective".[7]

Second, the options available to women once they have test results are, in reality, quite limited. Their capacity to control their circumstances may be restricted to a simple decision about whether to continue with a pregnancy or not. One can imagine ways in which we might expand the available choices, for example, by ensuring that whatever diseases or conditions a child is born with will be treatable and/or manageable by available resources.[7]

Finally, even if we accept that there is a demand for information, particularly in the burgeoning realm of screening for genetic conditions, how much people actually understand about the conditions for which they may be screened is unclear. How well are people able to interpret information about genetic status, particularly if that information includes complex statements about risk and susceptibility to disease? If we are contemplating mass screening for genetic conditions, we need also to factor in the possibility that those who provide information about screening may not be competent to explain the nature of screening to their patients, or to answer questions before and after test results are available.[8]

Conclusion

The principles that guide screening have been well described for almost 40 years. For most of this period, ethical debate about the interpretation of these principles has focused on the extent to which screening programs can prevent or reduce the burden of disease. More recently, some screening programs, particularly in prenatal and genetic testing, have been justified in terms of their capacity to enhance personal autonomy. This paper has suggested that neither the preventive nor the autonomy enhancing rationale can be taken at face value. In both cases, arguments about whether a screening program is, indeed, "good" will need to be made on a case by case basis, with careful attention to the circumstances and context of the individual program.

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THEORETICAL AND CONCEPTUAL ISSUES AROUND *EQUITY IN HEALTHCARE*: APPLICATION TO CERVICAL CANCER SCREENING IN SOUTH AUSTRALIA

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Introduction

Across the world, terms like "inequalities", "disparities" and "inequities" are often used interchangeably in academic and policy literatures.[1] Even when they are defined, there seems little consensus about their meaning or measurement.[2,3] The rationale for this paper is to distinguish "inequity" from both "inequality" and "disparity" and to go on to highlight how we might measure and monitor the equity of healthcare provided to groups or populations. The paper is divided into two main sections. The first section focuses on the definition, measurement and monitoring of the equity of healthcare. The second section uses actual data on cervical screening rates in South Australia to highlight issues around the inequitable uptake of preventive services. Throughout both sections of the paper, we outline some of the suggested reasons for inequitable healthcare services and suggestions for future research.

Whilst much of the public health research literature on equity focuses on *equity in health* (i.e. in terms of morbidity, mortality, and proxies of illness/wellbeing using measures like quality adjusted life-years, disability adjusted life-years, SF36, etc), this paper focuses attention on *equity in healthcare*.

The definition of healthcare used in this paper is fairly wide, and includes preventive services (e.g. cancer screening, women's health clinics), treatments (e.g. prescribing), acute and chronic services, and services provided by a vast