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Review

Assessing the evidence for organised cancer screening programmes☆

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Abstract

The aim of this study was to review the evidence in the literature for organised cancer screening programmes. A Medline search for publications related to organised cancer screening programmes and their components was done. While there is a broad descriptive literature on various cancer screening programmes, there are few published studies that evaluate the impact of organised cancer screening. Most of the evidence to date is from Scandinavian cervical and breast cancer screening programmes. There is a moderate amount of literature that evaluates specific components of cancer screening programmes (such as quality control and recruitment). There is a substantial body of literature on organised cancer screening programmes. However, the studies tend to describe organised screening programmes rather than evaluate their effectiveness relative to opportunistic screening. Furthermore, most studies focus on individual components of organised screening programmes, rather than on the programmes as a whole. More research is needed that directly compares organised with opportunistic cancer screening.

Keywords: Mass screening; Programme evaluation; Neoplasms

1. Introduction

According to data from the International Agency for Research on Cancer, 5 317 905 men and 4 737 646 women were diagnosed with cancer (excluding skin) in the year 2000. In that same year, 3 522 366 men and 2 686 313 women died from cancer [1]. As the population grows and ages, and as more methods of detecting cancer are introduced into practice, the incidence of cancer will increase and the need for comprehensive cancer control strategies will increase.

The opportunity to identify and diagnose cancer early is an essential part of any cancer control strategy. Secondary prevention, or screening, has received considerable attention in many jurisdictions [2]. Secondary prevention initiatives, such as breast, colon and cervical cancer screening programmes, increase the potential to prevent disease as well as cure, by detecting cancer early in its development. While there are many cancer screening tests available, it has been argued that general population delivery in an unorganised manner is inefficient and may not necessarily lead to the best outcomes [3]. Therefore, it has been proposed that organised cancer screening programmes can promote quality, comprehensiveness and accountability [4].

There has been a steady growth of and commitment to organised cancer screening programmes. For example, the Action Plan of Europe Against Cancer Guidelines recommend organised mammographic screening [5]. While all member countries of the European Union (EU) have not yet implemented organised breast cancer screening programmes, there are pilot programmes in all of the countries [6]. In Canada, national recommendations have been made that both breast and cervical screening be implemented in the context of organised programme [7].

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A widely accepted definition of organised cancer screening was put forward by Hakama and colleagues in 1985 [4]. According to these authors, organised screening constitutes programmes that meet the following criteria:

a. the target population has been identified;
b. individual people are identifiable;
c. mechanisms are implemented to guarantee high coverage and attendance (e.g. a personal letter of invitation);
d. there are adequate field facilities for performing the screening tests;
e. there is a defined quality control programme concerning how the tests are performed and interpreted;
f. adequate facilities exist for diagnosis and for the appropriate treatment of confirmed abnormalities;
g. there is a carefully designed and agreed upon referral system, an agreed link between the participant, the screening centre and the clinical facility for diagnosis of an abnormal screening test, for management of any abnormalities found and for providing information about normal screening tests;
h. evaluation and monitoring of the total programme is organised in terms of incidence and mortality rates among those attending, among those not attending, at the level of the total target population. Quality control of the epidemiological data should be established.

Many terms have been used to describe the alternative to organised screening, such as 'opportunistic' (the term we shall use in this paper), 'spontaneous' or 'wild' screening. Some of these terms suggest that this approach is less desirable than organised approaches/screening. Still, in many countries, health systems often directly or indirectly support such modes of delivery, for example, through fee-for-service reimbursement, which pay practitioners for the delivery of specific services. While this may lead to increased screening utilisation rates, it can also lead to inappropriate screening— for example, screening too frequently or in groups for whom screening is not warranted. There are also concerns that quality assurance or follow-up for those found abnormal on a screening test may not be effectively applied under opportunistic screening regimes. Nevertheless, there are often many interests that support opportunistic modes of delivery, usually involving the practitioners. Furthermore, policy-makers usually have to be convinced of the need to invest scarce health resources in the infrastructure required for delivering organised screening rather than the actual screening tests.

While there has been considerable attention to the evidence base to support screening interventions, there has been less systematic assessment of the literature that supports organised screening programmes over opportunistic screening as the mode of delivery for screening services. This paper presents results of a review of the published literature on cancer screening, with an emphasis on organised programmes.

2. Methodology

MEDLINE was searched from its inception, 1966, through to 06/2002, to identify peer-reviewed articles, in all languages, that pertained to cancer screening. The search strategy used the following terms: CANCER and SCREENING as keywords, and ORGANISED and PROGRAM (and their spelling variants) were searched for as text words anywhere in the citation (title and abstract). The search strategy used was [(CANCER and SCREENING) and (ORGANISED or PROGRAM)]. The search strategy was also repeated on CANCERLIT.

Articles were deemed 'relevant' if they referred to a specific organised screening programme, discussed aspects of cancer screening that are specifically applicable to organised programmes (e.g. population registry, recruitment, recall and follow-up mechanism, quality assurance, evaluation), and/or compared organised and spontaneous screening approaches. Each retrieved abstract was assessed independently to determine if the article was relevant to the review. Full articles were retrieved in all instances where the abstract suggested that it might cover one of the relevant topics.

Of the articles that were identified as 'relevant', the 'related articles' feature in the PUBMED version of MEDLINE was used to identify other potential sources. The reference lists of all articles retrieved were further reviewed for potentially relevant articles.

Each of the articles that met the relevancy criteria was reviewed to determine whether it assessed the question of the effectiveness of organised screening programmes. A description of the organised screening programme was recorded. The design of the study and its results were extracted using a predefined abstraction form.

We originally intended to conduct a meta-analysis of the studies assessing the effectiveness of organised screening programmes. As the studies that we located assessed quite different programmes and used very different designs, a systematic quantitative meta-analysis was not possible. The studies are thus summarised individually according to their key features.

3. Results

The literature that we found can be categorised into three groups. Most of the references were papers that described the components of screening programmes, either proposed or active programmes. Only a small

group of papers described the actual impact of organised cancer screening programmes. Finally, several papers described the impact of individual components of organised programmes, which may help to support the case for organised screening in general. We briefly describe the first group of papers, but our major focus is on the latter groups.

3.1. Components of screening programmes

There is a broad, descriptive literature on cancer screening programmes, particularly with respect to the components of these programme. Most of this literature describes the experiences of cervical cancer screening programmes (particularly in Scandinavian countries) and breast cancer screening programmes. Publications referring to prostate and colon cancer did not involve programmes that took an organised approach with a defined target population and were not included.

The programmes described varied considerably, ranging from very specific programmes, such as those primarily based upon information systems [8,9], to comprehensive programmes that provide all components according to Hakama and colleagues' definition [10–15].

In many settings, it appeared that opportunistic screening occurred in parallel to organised programmes, with little or no information exchange. In other jurisdictions, opportunistic screening was incorporated into organised programmes, with the organised program setting quality standards and guidelines for follow-up and information collection. As a result, no two organised screening programmes are exactly the same. Only a small group of the programmes that were described as organised met all of the Hakama criteria, and most 'organised' programmes included only some programme components (e.g. information systems, quality control) and comparatively few relied on population-based registers.

3.2. Impact of organised cancer screening programmes

Very few of the published studies specifically addressed the impact of organised screening programmes compared with opportunistic screening. Most of these studies pertained to cervical screening. Research addressing the impact of organised breast screening is emerging.

3.2.1. Cervical screening programmes

Ecological studies of comprehensive cervical screening programmes (such as those in Scandinavia) have demonstrated significant mortality reductions. However, there was evidence of considerable opportunistic activity, and so it is not possible to attribute the impact on mortality to the organised screening alone. In Iceland, for example, approximately 16–24% of smears were taken outside of the organised programme. On the other hand, 66–80% of the smears were taken outside of the organised programme in Finland [16]. Both countries include all of the components of organised screening defined by Hakama and colleagues.

The ecological evidence from the Nordic countries provides the strongest evidence in support of organised screening. This has been recently summarised in a paper by Sigurdsson [16]. The Nordic countries have implemented organised cervical screening programmes at different times. Iceland started implementation of a programme in 1964 and completed it by 1969, while Finland started in 1963 and completed implementation in 1970. Sweden also started in 1964 and completed implementation in 1973. Denmark, while it launched a programme in 1962, had achieved only 45% coverage through organised screening as late as 1991. Norway did not begin implementation of organised cervical screening until 1994. The greatest incidence and mortality reductions were observed in Iceland (67% and 76%, respectively) and Finland (75% and 73%). The least reductions are observed in Denmark (54% and 55%) and Norway (34% and 43%), with the pattern in Sweden falling in between these achievements.

A recent case–control study in Helsinki, Finland, by Nieminen and colleagues is the first we located to address the impact of organised versus opportunistic screening on the incidence of invasive cervical cancer [17]. Cases were drawn from the University hospital, while controls were drawn from the population register for the hospital catchment area. Cervical screening histories were obtained from a self-reported questionnaire. The adjusted Odds Ratio (OR) for invasive cervical cancer was 0.38 (95% Confidence Interval (CI) 0.26–0.56) for having had a papanicolaou (Pap) test through organised screening, while it was 0.82 (95% CI 0.53–1.26) for opportunistic screening. Ever having a visit to a gynecologist had a protective effect greater than the opportunistic smear, with an OR of 0.72 (95% CI 0.42–1.25). As this is a retrospective case–control study, there may be some recall bias in that women seen in the organised programme may be more likely to remember what a Pap smear is.

A recent study from The Netherlands compared cervical cancer screening carried out in the context of an organised programme (79% of smears) with opportunistic screening (21% of smears) [18]. The detection rates of at least severe cervical dysplasia were equal in the two groups; the OR (adjusted for age and screening history) was 0.97 (95% CI 0.84–1.14).

Several studies have suggested that there may be better detection through opportunistic screening. Gustafsson and colleagues, in a Swedish cohort study demonstrated that the adjusted odds of detecting cervical cancer *in-situ* was 1.26 (95% CI 1.09–1.46) for opportunistic versus organised screening [11]. These authors have ques-

tioned the worth of organised screening subsequently [19]. However, they have not reported on the incidence of invasive cancer or mortality in the two cohorts. It is likely that there is greater detection bias in the opportunistic setting, where there is more frequent screening.

In a Dutch study, Kirk and Boon suggested that general practitioners (GPs) were more successful at detecting invasive cervical cancer than an organised cytology screening programme, and achieved better coverage in high-risk women [20]. However, it should be noted that the GP screening was covered by insurance in that setting, while there was a payment required in the screening programme.

3.2.2. Breast screening programmes

There is limited literature comparing organised breast screening programmes with opportunistic screening. One Finnish study examined the impact of organised breast screening [14]. A relative risk reduction for mortality of 0.76 (95% CI 0.53–1.09) was demonstrated among women formally invited to screening compared with those in the same community who were not invited. This mortality reduction is similar to that observed in clinical trials, although it does not specifically compare organised screening with opportunistic screening.

Several studies from British Columbia, the Canadian province with the longest experience with organised breast screening, suggest that there are better process measures, such as the costs being lower, compared with opportunistic screening [21]. Women who had cancer diagnosed in the screening programme had less aggressive disease, were more likely to receive appropriate treatment and had better outcomes [22].

3.3. The potential impact of programme components

The literature was also examined to determine if evidence exists regarding the impact of the different programme components for organised screening programmes. There is a considerable amount of literature examining how the different components of cervical screening programmes affect outcomes. Most of this literature examines the impact of recruitment and recall on screening and detection rates. In general, the evidence supports the finding that systematic approaches can improve coverage, particularly in hard-to-reach populations [23–25]. However, these interventions tend to be expensive, and there is little information on their cost-effectiveness. Since many of these studies are conducted independently of complete organised programmes, they may demonstrate the effectiveness of different recruitment strategies rather than addressing the impact of the organised programmes themselves.

There are also several studies that examine the impact of laboratory quality assurance in cervical screening. One Swedish before/after study suggests that such a programme can improve outcomes [10]. The British Columbia experience also demonstrates the importance of laboratory quality assurance [8,26,27]. However, since only a single cytology laboratory is involved, there is no comparator. The British Columbia experience does suggest that the benefits from cervical screening can be achieved through a programme based on centralised data collection.

4. Discussion

The literature suggests that there is considerable variability in the definitions and implementation of organised screening programmes. Using the terminology and criteria of evidence of the Canadian and US Task Forces on Preventive Health Services [28,29] there is limited evidence, level II-2 and II-3 to directly support the effectiveness of organised cervical screening programmes; and level III for other cancer sites. However, there is indirect evidence from screening trials and other sources which suggests that at least some of the components are important for the intervention. It is important to also recognise that the nature of evidence required for an administrative intervention, such as organised cancer screening, may be quite different from that required to assess a clinical intervention [30]. The concept of levels of evidence may be quite reasonable for a clinical policy recommendation, to screen or not to screen. However, policy decisions on how to organise screening require other contextual factors to be considered, for example, how health services in a region are organised and financed. Nevertheless, the evidentiary basis for organised screening should help to support such decisions.

We found considerable diversity in the components and definitions of organised screening programmes. There is a lack of a consistently applied definition of organised cancer screening in the literature. The models that have been described vary considerably with the degree to which they comply with the widely used Hakama definition of organised cancer screening, particularly with regards to the use of a centralised population registry for recruitment and recall. In order to advocate for organised cancer screening, it is important that consistent definitions be used and that systematic evidence on the effectiveness of programme components, and programmes as a whole, be gathered.

The literature reviewed suggests that organised cancer screening programmes might improve outcomes, such as screening, detection, extent of disease, and follow-up rates, although further work in this area is required. Organised cancer screening programmes may have a significant impact on accessibility, quality and accountability. Organised approaches compared with an opportunistic screening structure can help to ensure that there are appropriate mechanisms to facilitate recruit-

ment and retention of eligible participants. Several studies demonstrate that systematic recruitment strategies, particularly those involving physicians, can improve not only coverage of programmes, but reduce inequities in screening in disadvantaged populations [31]. While such approaches can be implemented outside of screening programmes, they are likely most easily done within an organised approach.

Monitoring the effectiveness of screening programmes is essential to optimise use of resources, to ensure the quality of tests performed and interpreted, and to ultimately produce observable reductions in the incidence of, and mortality from, breast [6] and cervical cancers [32,33]. These observations are based primarily on recommendations of screening authorities, as opposed to empirical evidence that such components improve the outcomes of organised programmes. However, evidence such as that from failure analyses suggests that quality improvement approaches can enhance the delivery of cancer screening programmes [34]. While many laboratories and diagnostic facilities already participate in quality assurance programmes, an organised approach to screening can ensure that all components take considerations of quality into account.

Cancer screening programmes are comparatively expensive to implement and the effects may not be observed for a long time. Accountability for the resources put into such programmes is essential. While we did locate cost-effectiveness analyses based on organised programmes, they did not compare organised screening with opportunistic screening [35–37]. One study, based on a mathematical model, has concluded that compared with opportunistic screening for carcinoma of the cervix, organised approaches are more cost-effective [38].

Another benefit of organised screening programmes is that their information systems help to ensure that the data required for maintaining quality and providing accountability are available. Indeed, one of the reasons why it is difficult to compare organised screening with opportunistic screening is that there is much less data available from the latter.

In addition to the consideration of the impact of organised approaches on incidence and mortality, there are many other important aspects of performance of cancer screening and quality. It will be important for future studies of organised programmes to document their impact on such measures. There are also other considerations such as privacy and consent [39–41] and psychosocial concerns [42–44] that are important to evaluate in the context of an organised screening programme.

5. Conclusions

While there is a substantial body of literature on organised cancer screening programmes, it is primarily descriptive in nature. That is, the studies tend to describe organised screening programmes rather than evaluate their effectiveness relative to opportunistic screening. Furthermore, most studies focus on individual components of organised screening programmes, rather than the programmes as a whole. The literature is focused primarily on breast and cervical screening. The majority of articles describing the impact of organised screening programmes reflects experiences of cervical screening programmes from the Scandinavian countries.

Organised programmes can ensure that services are accessible to the entire population and that they are delivered using a quality approach. They also ensure that the information needed for accountability is collected and available. The challenge is to demonstrate that these benefits are worth the investment. Organised cancer screening may require significant additional investments for many components that, on the surface, appear to increase the cost of organised screening beyond that of opportunistic screening on a per case screened basis. However, such an analysis does not take into account the extra costs of opportunistic screening due to over-screening, and reduced benefits due to poorer quality in screening, follow-up and diagnosis. The true cost-effectiveness of organised versus opportunistic screening should be calculated on a cost per cancer death prevented basis.

In addition to the benefits of organised cancer screening, there is a need to consider the consequences and potential burdens of organised cancer screening as well. For example, organised approaches to cancer screening have the potential to increase financial demands (e.g. through more intensive administration) and the need for a greater number of screening-related health professionals. Thus, it is essential that organised cancer screening programmes anticipate such potential demands and that cost-effectiveness considerations be built into the evaluation mechanisms.

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