

Research Paper

Inequalities in cervical screening practices in Europe

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What is known?

1. Cervical cancer is an important public health problem.
2. Cervical screening by Pap smear has an impact on incidence and mortality.
3. Effectiveness (and cost-effectiveness) of cervical screening depends on participation of eligible population (compliance).

What this paper adds

1. There have been inequalities of all kinds among “welfare states” and “countries on transition” in Europe.
2. There has been inequality in access to screening in relation to place of residence
3. Moving of screening services to place of residence, and smear-taking by primary care personnel can equalise the inequalities in access to screening services.

ABSTRACT

Cervical cancer is an important public health problem in Europe. The overall incidence of cervical cancer in Europe is 11.6 per 10⁵ but morbidity and mortality rates differ significantly, country by country, being much lower in Western Europe where prevention programmes are better developed as compared to Central and Eastern Europe where the screening facilities – for several reasons – are underdeveloped. The effectiveness is in close correlation with the intensity of organized screening. Ideally, cervical cancer screening should reduce the burden of disease in terms of death, morbidity, and improved quality of life. Unfortunately,

not everyone benefits equally from the screening due to inequalities of various kinds, such as differences in geopolitical status, diversity in health care systems, access to screening services, socioeconomic and demographic status, lack of knowledge and education. Personal invitation has a major role to play. The acceptance of the offered screening is positively influenced by better access to screening facilities, health consciousness of the invitees, and the quality of pre-screening information. Increasing the uptake of cervical screening remains a challenge in reducing health inequalities in European countries.

Introduction

Since the late 1970s equal access to prevention has been identified as a public health priority by the World Health Organisation through the Alma-Ata declaration (WHO 1978). Notwithstanding, there is an increasing body of evidence about inequality in preventive activities, mostly for cancer screening. Although cancer screening programmes in some countries have achieved good coverage, there are indications that, in others, certain population groups are prevented from accessing services.

Cervical screening by cytology has been on the top of the public health agenda for several decades. This is not because of the epidemiological weight of cervical cancer but because we have all tools for effective prevention in hand: methods of proven effectiveness for early detection, early treatment of both premalignant lesions of uterine cervix and cervical cancer itself (International Agency for Research on Cancer (IARC) 2005).

It is well documented that regular cervical screening can save lives, reduce morbidity, improve quality of life, and provide reassurance to individuals about their health (Arbyn, Antilla, Jordan *et al.*, 2010). This is why the case of cervical screening offers a good opportunity to demonstrate the inequalities prevailing among the countries of Europe.

Mortality from cervical cancer could be substantially reduced if each woman in the high risk age range received and accepted the invitation to regular screening. However, it is fair to say that the potential of cervical screening has remained unexploited, and the full prevention of this preventable disease is nothing but wishful thinking. The reason behind this failure is two-fold. First, there are organisational shortcomings on the supply side. Second, there are obstacles on the demand side because certain sections of the target population decline to use the offered screening. The key-word in both cases is *inequality*.

Inequalities in Europe

In Europe as a whole, there have always been built-in inequalities between countries of the West and East and between the North and South. However, the political division of Europe post-WW2 enormously widened the gap between the affluent states and the disadvantaged ones. Over the past 50 years Europe has gone through dramatic political and socioeconomic changes. This period was an extremely successful period for countries in the West with the development of the common market and social institutions, such as, the Europe against Cancer programme. For Central-Eastern European countries, where two-thirds of the European population lives, the period was not a success and, in spite of the political, economic and social changes in the early 1990s, these countries are still suffering from the polarisation of their societies. Since then, the diverging trends slowed down but continued. (Döbrössy 2002).

Inequalities in overall mortality

There are demonstrable differences in the health status indicators within so-called welfare states, too, based on socioeconomic status (Marmot Review 2010.). There are significant differences in the health status of the populations, particularly in overall mortality rates, between the two halves of Europe (Table 1). For example, let us compare Austria and Hungary, two neighbouring countries with a shared history as part of the former Austrian-Hungarian Empire. As the 1998 curves show, until the late 1960s, cancer mortality rates in the two countries were at a comparable level, but, from the early 1970s, the gap widens: mortality has continually decreased in Austria, while in Hungary it has sharply increased (Figure 1). For explanation, we are referring to tumour-biological facts according to which 10-15-20 years need to elapse from the biological inception of the tumour until its clinical manifestation, and fatal outcome (Figure 2) (Döbrössy, Kovács and Budai 2012). These data permit the assumption that the roots of the deterioration of health status of the population can be explained, at least in case of Hungary, by what Kopp (2008) termed *the state of mind* of the people, the mode of internal processing of historical *happenings* of the *recent past* the use of the easiest, most readily available stress management and coping mechanisms that are now known as lifestyle-related risk factors: smoking, drinking, unhealthy diets etc. (Döbrössy 2002). The same applies to other countries in transition of Central-Eastern Europe.

Inequalities in the health care systems

The economic development of a country can result in inequalities in provision of the health care to the population. There may be differences in the share of total health care expenditure and the proportion allocated to public health. A cancer screening programme requires substantial resources and the economic development of the country is obviously reflected in the quality of provision of screening services. As cervical screening systems are integrated into the health care system, the quality of the health care system has a bearing on the level of provision of screening services and patient follow-up. (Subramaniam, Ekwueme, Gardner *et al.*, 2009). By this measure, Austria, Belgium, France, Germany, the United Kingdom can be considered as highly developed, and the Central-Eastern European countries as less developed countries (Wendt 2009).

Inequalities in cervical mortality

The ultimate effectiveness of a cervical screening programme is measured in terms of reduction in mortality. Across Europe, there are enormous disparities in mortality rates from cervical cancer (Table 2). Finland, for example, has a low mortality rate thanks to a well-organized cervical screening programme having been in operation for decades, with a very comprehensive cancer registry. On the other end of the spectrum are Romania, Lithuania and Latvia, which have the highest mortality rates.

The disease-specific mortality largely depends on the clinical stage at the time of diagnosis and is inversely proportional to efficacy of clinical treatment (Ádány and Sándor 2011). However, the coverage of the female population by screening services in a particular country is an important influencing factor. Evidence from the Nordic countries shows that the degree of reduction of mortality is proportional to the intensity of screening strategy, age range and screening interval, in particular (Läära E, Day NE, Hakama M., 1987.) (Figure 3). Screening of symptomless women is known to advance the diagnosis of cervical cancer, thus it is fair to say that cervical cancer mortality is proportionate to the number of those who decline the offered screening (Spayne, Ackerman, Milosevic *et al.*, 2008).

Inequalities in provision of screening services

Screening can be defined as the application of a simple test to identify early, asymptomatic disease. There is high diversity in the status of cervical screening in Europe. Two types of screening provisions are distinguished, namely the *opportunistic* and *organized* (Hakama, Miller, Day 1986) *Opportunistic screening* makes use of patient-doctor encounters. The symptomless woman, who is assumed to be healthy, might see the health professional for any other reason and be offered the test. Whether or not the test is offered depends on the judgment and oncological alertness of the doctor. The screening is not registered anywhere. Only the number of smears analysed is known: but it is not known who has been screened, and who has not. Opportunistic screening is strongly criticized as it uses community resources without any demonstrable effect on cancer rates (Adab, McGhee, Yanova, Wong and Hedley 2004), and covers only self-selected women. *Organised population screening* is recommended by international bodies such as WHO, IARC and the Union for International Cancer Control (<http://www.uicc.org/about-uicc>). One of the arguments for organized screening is that participation rates are likely to be optimized. It is a provider initiated activity, integrated into the health care system, financed by the health authority or the health insurance system. It uses a notification list, based on authorized population lists to invite each woman in a defined age-range using a personalized invitation letter. It offers repeated screening at defined intervals. The system is served by a dedicated screening registry in data linkage with a population-based cancer registry (Arbyn, Anttila, Jordan *et al.*, 2010). Organized screening is, therefore, a complex, resource demanding public health activity with several sophisticated legal, organizational, personal, methodological prerequisites to meet. Its proper functioning needs to be supported by health education activities. As to the inequalities in the use of cancer screening, these are higher

in countries without organized screening programmes. These results highlight the potential benefits of organized screening (Palencia, Espelt, Rodriguez-Sanz *et al.*, 2010).

Screening strategies differ from country to country. European guidelines recommend three-to five-year screening intervals, depending on the resources available, but there are differences in screening interval and the age range screened across Europe (Arbyn, Anttila, Jordan *et al.*, 2010). The most commonly recommended interval between normal cytological tests is three years. A five-year interval is recommended in Finland, Ireland and the Netherlands. In the United Kingdom, Denmark and Sweden recommendations vary by age. In countries where screening is offered opportunistically, the recommended interval is 1-3 years. As to the age range, most countries recommend screening from the age of 25 up to 64 but, according to the European guidelines, screening is to start at the latest by the age of 30, and definitely not before the age of 20 (Arbyn, Anttila, Jordan *et al.*, 2010).

Inequalities in access to screening services

There are large variations in the key organisational elements of screening programmes. Data from screening registries show that coverage of the screening test taken within the population-based programme was below 80% in all programmes, ranging from 10% to 79% (Table 3). The screening capacity is satisfactory in most European countries, and there is even over-capacity in several countries. There are also countries which do not yet have acceptable capacity (Anttila, von Karsa, Asmaa *et al.*, 2009). The access to the cervical screening services is uneven. The majority of countries endorse the policy framework set out by the recommendations of the European Council in 2003 (Council of the European Union 2003).

Up to now, the political will to develop such services has been declared by almost all governments (Anttila and Ronco 2009, Arbyn, Autier and Ferlay 2007, Döbrössy 2002). In some countries, such as Austria, Germany, Luxembourg, opportunistic screening is implemented through gynaecological services or the health insurance systems. However, organized screening programmes with full population coverage are implemented only by the United Kingdom, the Netherlands, Finland, Denmark, Sweden, Norway, some regions of Italy.

Two examples of screening practices are given below.

In Hungary, cervical screening began in the mid-1950s and was monopolised by gynaecologists; both cytology and colposcopy were available. Screening was opportunistic and the uptake was low (Kovács, Döbrössy, Budai 2008). Currently, this gynaecologically-based cancer screening is transitioning into the recommended organised cervical screening is in progress: the only screening tool is cytology, the active involvement of primary care personnel in the cervical screening will provide further improvement (Döbrössy, Kovács, Budai *et al.*, 2013).

A mixture of opportunistic and organized screening is evident in Slovenia. Women are invited for a preventive gynaecological examination, including cytology, once every 3 years by a gynaecologist with whom they are already registered. All smear reports from all cytology laboratories are gathered in the central database of the Screening Registry. Invitations are sent by

the Screening Registry to women whose smear has not been registered in the past 4 years (Primic-Zakelj and Repse-Fokter 2007).

The intention to narrow the gap can be traced in the “countries in transition” of Central-Eastern and Southern Europe, but the availability and effectiveness of screening activities are still far below the desirable level (Anttila, Arbyn, Veerus *et al.*, 2010, Arbyn, Antoine, Valerianova *et al.*, 2010, Arbyn, Autier and Ferlay 2007). Cervical cancer prevention policies have been established for the Czech Republic, Latvia, Lithuania, Poland, Romania, Slovakia, Croatia and Serbia (Nicila, Anttila, neamtiu *et al.*, 2009, Arbyn, Primic-Zakelj, Raifu 2007.). A remarkable proportion of women in these countries are not yet covered by the free Pap tests offered either in an organised or opportunistic manner. In some of these countries the establishment of an organized screening programme is not considered a priority because the health authorities are struggling to provide health care systems generally and several other priorities are competing for the scarce resources. As a result, the financial, infrastructural and personal prerequisites of a mass screening cannot be met.

Inequalities in the uptake of offered screening

The uptake of screening largely depends on socio-economic, cultural and behavioural influences (Cancer Research UK 2008). Experience shows that the uptake of organised screening and the coverage of the target population are much higher and social-economic inequities prevail much less than in case of opportunistic screening (Ferroni, Camilloni, Jimenez *et al.*, 2012). However, compliance never exceeds 80% of those invited, partly because a certain proportion of invitees undergo the screening outside the organised programme, or, because the women, for some reason, decline the invitation. Primary care personnel have a role in the recruitment of participants, and in this way can increase acceptance levels (Nieminen, Kallio, Anttila A 1999.)

There are some socio-economic, demographic and behavioural factors which correlate well with cervical screening uptake. The willingness to participate in the offered screening is significantly higher in younger, higher social class, more educated, town-dwelling, well-to-do women who regularly consult a gynaecologist. In contrast, lower social class, lower educated, disabled, unemployed women who do not have the habit of regularly seeing a gynaecologist are less likely to participate in screening. Uptake is highest among married and separated women, and lowest among single and widowed women, thus, the women who are at lowest risk for cervical cancer (i.e. married women) show the highest uptake of cervical screening. (Waller, Bartoszek, Marlow 2009).

There is increasing evidence that health care systems, including screening programmes, can actively alter inequalities in health outcomes, such as morbidity and mortality (Segnan 1997). When a new health intervention, such as organized screening, is introduced into a population, the more prosperous groups use it first and the most deprived, the most in need of the intervention, take it up later and at a lower rate (Sarfarti, Shaw and Simmonds 2010). Reasons for this may include the need to prioritise other more pressing issues, lack of symptoms, lack of knowledge about cancer or about screening or a general lack of health

literacy (Zarcadoolas, Pleasant and Greer 2005). Inequalities in relation to cancer screening programmes manifest themselves in inequalities in cancer incidence and mortality, and so screening participation can be seen as a proxy measure for these distal outcomes, affected by social, economic, environmental and health services factors (Sarfarti, Shaw and Simmonds 2010).

Inequalities in prescreening information

There are also inequalities in providing pre-screening information to women. The invitation is an unasked interference into the privacy of healthy or apparently healthy individuals. The intervention is not free of risks as it might entail the risk of diagnostic errors. Harm to an individual might include over-diagnosis and over-treatment, anxiety for those with false positive results and false reassurance for those with false negatives, and various psychological side-effects (Döbrössy B Kovács A, Budai 2007). Participation in cervical screening is voluntary. The invited woman must be regarded as an autonomous person who is capable of making her own decision regarding screening. To this effect, it is an ethical imperative for the provider to give the woman appropriate pre-screening information about what is going to happen, the benefits and possible risks and the meaning and significance of the screening test (Briss, Rimer, Reilly *et al.*, 2004). The information must be evidence-based, honest, straightforward, and easy to understand (Döbrössy B Kovács A, Budai 2007). This information is particularly important for those who do not know about cervical screening, who think the process is unpleasant or do not understand its importance. The information should help to improve unfavourable public images of screening as well as clear up misconceptions and false beliefs about cancer. The information is a tool to combat defeatist attitudes and the anticipated embarrassment associated with screening (Stewart and Wild 2014). However, experience shows that the invitation letter may still have a selective effect, meaning that the better educated may give more credit to it than the less educated ones (Oscarsson, Wijma and Benezin 2008).

Discussion

Cervical cancer is one of the most frequently diagnosed malignancies, and the second most common cause of death worldwide (Ferlay, Steliarova-Foucher, Lortet-Tieulent *et al.*, 2012). Mortality from cervical cancer in western European countries is generally much lower than in Central-Eastern states (Ackerson and Preston 2009). Inequalities in mortality rates correlate with the inequalities of the intensity of cervical screening in individual countries (Läära, Day, Hakama 1987).. It is the responsibility of health care systems to make efforts to reduce the inequalities between countries so that each woman has equal access to cervical screening.

The majority of European countries has or intend to establish nation-wide organized screening programme. However, only the most affluent ones have the organisational and management capacity, professional expertise and informatics necessary to successfully implement population based screening activities. These countries possess the capacity to invite all women in the high risk age groups to attend three-yearly cytological examination, and arrange referral to gynaecological services for those who are in need of clinical verification of test results, and

treatment. In these countries the uptake of organized screening is high (up to 80%) and the outcomes are evident in the reduced burden of disease, incidence and mortality.

Opportunistic screening prevails in other countries where gynaecologists are the traditional gatekeepers of cervical screening. These countries are unable to meet the demands, as the country is unevenly covered by gynaecological services, and a significant proportion of women have no access to screening. The establishment of organized programmes is hampered by the need to address other pressing priorities in health care resulting in unmet needs.

Despite the substantial health benefits of screening, many women who do have access do not get screened, because the benefits of early detection from screening are not fully realised and not shared equally among different segments of the population. The resulting avoidable mortality disproportionately affects poor populations. Lack of uptake could be due to the fact that decision-making regarding participation is affected by emotions: fear of cancer can result in avoidance of risk, or the screening procedure. Even if a woman understands the probability of getting cervical cancer, she may still underestimate her own personal risk, and therefore not undergo screening. The decision about whether to attend or not largely depends on how information is presented. This places responsibility on the providers, on the primary care personnel, particularly nurses, who have close, personal contact with the invited women. Health care providers often overestimate how much information women have and wrongly assume that patients ask for information when they need it. They are in a position to address underprivileged women, to persuade them to accept the offered screening. Furthermore, to advocate for attendance in screening should be one of the main tasks of health education, which should have a wide range of arguments to promote participation in cervical screening.

Conclusions

It is an ethical imperative to minimize the inequalities in cervical screening in Europe. To this effect, socio-economic, organizational and behavioural shortcomings underlying inequalities have to be eliminated (Woodward, Kawachi 2000). Access to organised screening facilities need to improve; social, economic and psychological barriers have to be overcome. Should this happen, mortality rates from cervical cancer in the currently disadvantaged countries would be reduced, resembling those of the affluent states and improving life expectancy for women all over Europe. The ultimate aim of cervical screening is to reduce mortality from cervical cancer via early detection and early treatment of the disease. Theoretically, we have the means to eradicate it.

CONFLICT OF INTEREST

None

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