

Key messages

- In lung cancer, high levels of distress, anxiety, and functional impairment are associated with the symptom of breathlessness
- Evidence on the use of many treatments for this common and frightening symptom is lacking
- Interventions based on psychosocial support, breathing control, and learning coping strategies can help patients to cope with the symptom of breathlessness and reduce physical and emotional distress

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protocol, initiated the study and training of nurses in each centre, and coordinated the study for the first half of data collection. MB coordinated the second half of the study and supported nurses in study sites; was responsible for data management, checking, and entry; and carried out data analysis. RAH was statistical adviser to the project and helped with analysis and presentation of data. MK helped initiate the study, support researchers and nurses, and manage and check data. The Macmillan and specialist nurses listed above collected the data. MB, JC, and RAH wrote the paper. All authors read and commented on the draft paper. JC and BM are guarantors.

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Effect of screening on incidence of and mortality from cancer of cervix in England: evaluation based on routinely collected statistics

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Abstract

Objective To assess the impact of screening on the incidence of and mortality from cervical cancer.

Design Comparison of age specific incidence and mortality before and after the introduction of the national call and recall system in 1988.

Setting England.

Subjects Women aged over 19 years.

Results From the mid-1960s, the number of smears taken rose continuously to 4.5 million at the end of the 1980s. Between 1988 and 1994, coverage of the target group doubled to around 85%. Registrations of in situ disease increased broadly in parallel with the numbers of smears taken. The overall incidence of invasive disease remained stable up to the end of the 1980s, although there were strong cohort effects; from 1990 incidence fell continuously and in 1995 was 35% lower than in the 1980s. The fall in overall mortality since 1950 accelerated at the end of the 1980s; there were strong cohort effects. Mortality in women under 55 was much lower in the 1990s than would have been expected.

Conclusions The national call and recall system and incentive payments to general practitioners increased coverage to around 85%. This resulted in falls in incidence of invasive disease in all regions of England and in all age groups from 30 to 74. The falls in mortality in older women were largely unrelated to screening, but without screening there might have been 800 more deaths from cervical cancer in women under 55 in 1997.

Introduction

Invasive cervical cancer is the second most common cancer in women worldwide, but 80% of cases occur in developing countries. The incidence of the disease has been falling in many western countries, but not in Great Britain, over the past 40 years. The cervical smear test was developed over 50 years ago, and screening began in Great Britain, some Nordic countries, and parts of North America in the 1960s.

Although cervical screening in England started in 1964, for over 20 years it failed to achieve sufficient coverage of women or follow up of all women with

positive results.¹ A national call and recall system was established in 1988.² In 1996, 60% of district health authorities operated a 3 year recall.³ Financial incentives were first introduced with general practitioner contracts in 1990.⁴

To assess the impact of the screening programme in England we examined trends in the numbers of smears taken and other characteristics of the screening programme; age specific trends for both in situ and invasive cervical cancer from 1971 to 1995; and age specific mortality from cervical cancer from 1950 to 1997.

Subjects and methods

The target age group for screening is 20 to 64 years; coverage is defined from 1995 onwards as the percentage of women aged 25 to 64 who had had a smear test in the previous 5 years (for 1988 to 1994, the previous 5½ years).⁵ The cancer registration system has been described elsewhere.⁶ Both the ascertainment and quality of data from cancer registries in Great Britain are generally high.⁷

Data on registrations of in situ and invasive cervical cancer from 1971 to 1991 are based on records of individual cases submitted to and validated by the Office for National Statistics.⁶ Figures for 1992 to 1995 are based on annual data supplied by the regional cancer registries. Information on the stage of invasive disease was not available centrally. We used published data on mortality from cervical cancer for 1950 to 1997, adjusted for procedural changes in the coding of cause of death.⁸

The registrations of in situ cervical cancer are not true incidence because, firstly, the disease is asymptomatic and cases are detected only by screening. Thus any changes over time in the number of women screened in different age groups will affect the numbers of registrations. Secondly, as women are not all screened annually, registrations are a mix of cases diagnosed in women screened for the first time and cumulative incidence since the previous screen for women who have been screened before.

The annual age specific rates for both incidence and mortality were calculated as the numbers of cases divided by the estimated mid-year population. Summary rates for incidence and mortality were directly age standardised by using the European standard population (5 year age bands). Confidence intervals for age specific and age standardised rates were calculated on the assumption that the number of cases followed a Poisson distribution⁹; the figures show typical 95% confidence intervals.

Results

Screening programme

The number of smears taken rose by about 6% each year until the early 1980s, after which the increase was about 8% each year to the end of the decade; since then, about 4.5 million smears have been taken each year.^{5 10-12} The coverage of the target age group in the screening programme rose from 42% in 1988 to 85% in 1994, a level subsequently maintained.⁵ Coverage increased in all age groups, but particularly for older women (55 to 64 years).

Carcinoma in situ

The registration rate of carcinoma in situ rose broadly in line with the increasing numbers of smears taken, from about 10/100 000 women (2100 cases) in 1971 to 80/100 000 (20 000 cases) in the mid-1990s. The apparent large increase in the rates in 1984 and 1985 is due to the inclusion for the first time of registrations of cervical intraepithelial neoplasia grade III. Since 1987 the trends in registrations in women aged 20-24 and 25-29 have been continually upward, whereas women aged from 30 to 49 have shown no overall increase (fig 1). Registrations for older groups were consistently low and fell with age.

Invasive cancer

From 1971 to the mid-1980s incidence remained between 14 and 16/100 000 (on average 3900 cases a year) (fig 2). It fell for five consecutive years after 1990, reaching just over 10/100 000 in 1995, about 35% lower than in the mid-1980s. The 2900 cases diagnosed in 1995 represented 3% of all malignancies (excluding non-melanoma skin cancer) in women. Age specific incidence has, however, changed differently in the various age groups (fig 3). In 1995, the overall pattern was similar to that in 1990, but the incidence in every age group from 30-34 to 70-74 was substantially (and significantly) lower—by on average 9/100 000 (110 cases).

Incidence varied considerably across the regional health authorities: the crude rates in 1990 ranged from around 11/100 000 (200 cases) in North West Thames to 23/100 000 (280 cases) in Mersey.⁶ Incidence fell in all regions between 1990 and 1995.

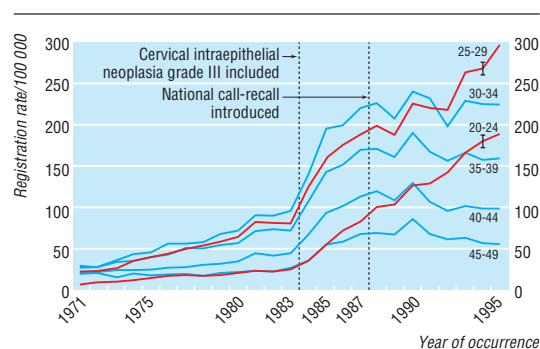


Fig 1 Age specific registrations of in situ cervical cancer in women aged 20-49, England, 1971-95

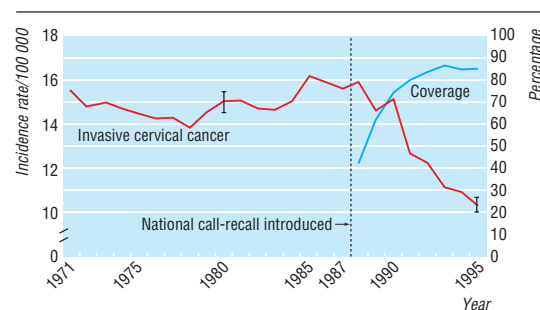


Fig 2 Age standardised incidence of invasive cervical cancer and coverage of screening, England, 1971-95

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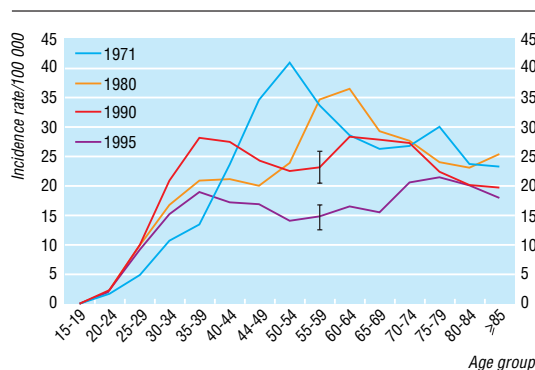


Fig 3 Age specific incidence of invasive cervical cancer in England for 1971, 1980, 1990, and 1995

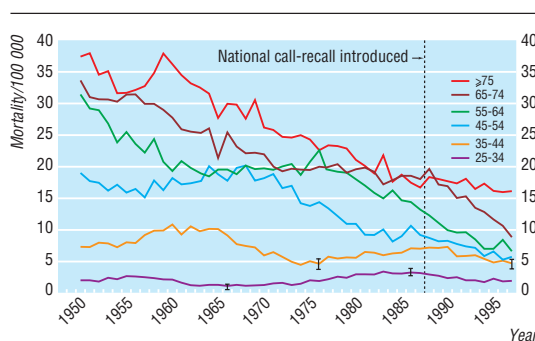


Fig 4 Age specific mortality from cervical cancer, England, 1950-97

Mortality

From 1950 to 1987 total mortality from cervical cancer fell steadily by just over 1.5% each year, from 11.2 per 100 000 (2500 deaths) to 6.1/100 000 (1800 deaths). The rate of fall then trebled, and by 1997 mortality had fallen to 3.7/100 000. The 1150 deaths in 1997 represented 2% of cancer deaths in women and 0.4% of all deaths in women.

Age specific mortality has, however, changed differently in the various age groups. In the youngest women (25-34 years) mortality trebled from around 1/100 000 (30 deaths) in the mid-1960s to a plateau of around 3/100 000 (100 deaths) in the mid-1980s (fig 4). Mortality in all the other age groups fell, but at different times.

For the cohort of women aged 25-34 in the mid-1980s—that is, women born in the mid-1950s—mortality was three times higher than it had been for women aged 25-34 in the mid-1960s.^{13 14} Cervical cancer mortality in each birth cohort historically increased with age up to 60 years.¹⁴ If the raised risk and pattern of mortality are assumed for women born in the mid-1950s, by 1997 mortality would have increased to around 14/100 000 in women aged 35 to 44, and (with a similar projection based on a doubling of mortality for the cohort born in the mid-1940s) to around 19/100 000 in women aged 45 to 54. These rates are far higher than those actually observed (around 5/100 000 in both age groups (fig 4)). Applying the difference between the projected and actual mortality in 1997 to the number of women in each age group suggests that screening might have prevented 320 deaths in women aged 35-44 and 430 deaths in women

aged 45-54. In addition, mortality in women aged 25-34 in 1997 was one third lower than in the peak in the mid-1980s so a further 50 deaths may have been prevented in this age group.

Discussion

Screening programme

Cervical screening by the smear test meets some of the criteria for screening programmes laid down by the World Health Organisation,¹⁵ but not the two which are probably the most important: cervical cancer in England is relatively uncommon and its natural course is not well understood. Although the effectiveness of screening has never been properly demonstrated in randomised controlled trials, firm evidence comes from the Nordic countries, where the implementation of widely different policies resulted in sharply contrasting trends in incidence and mortality.¹⁶ Even so, many operational features of the cervical screening process in England have been heavily criticised.^{3 17 18 19}

The annual cost of the screening programme is £132 million.³ This is about four times the cost of the breast screening programme, which aims to reduce annual breast cancer deaths in women aged 55 to 69 by 1250. Costs of cervical screening could be reduced substantially, with little loss in effectiveness, by screening all women every five years—there is little benefit but enormous increase in costs in opportunistic screening at shorter intervals than those recommended^{3 16}—and by not continuing to screen women over 50 who have had two or three consecutive normal results.^{20 21}

Effectiveness

Before the introduction of the national call and recall system and of incentive payments to general practitioners the cervical screening programme in England was largely ineffective, owing mainly to problems of organisation.^{1 3 16} Most cytological tests were performed on women presenting for obstetric, gynaecological, or contraceptive reasons. At least two thirds of women with invasive cervical cancer had never been screened; for women over 40 (among whom 70% of cases occurred) over 90% had never been screened.²²

Cook and Draper noted the large increase in incidence of carcinoma *in situ* and judged that screening might have prevented a potential increase in both the incidence of invasive disease and mortality.²³ Parkin et al estimated that, up to 1978, screening had prevented 25% of potential cases of invasive disease.²⁴ On the other hand, Murphy et al related the screening effort in different parts of Great Britain to variations in incidence, mortality, and hysterectomy rates and found no evidence that the burden of cervical cancer would have been higher without the screening programme.²⁵

The NHS cervical screening programme has recently achieved a high coverage of the target age group. It has particularly improved coverage of older women and women in lower social classes, who were most at risk and previously largely unscreened.^{3 26} National guidelines for clinical practice and service delivery have been established, but there have been problems of implementation in inner cities.

If the introduction of national call and recall has had an effect, there should have been some increases in

registrations of in situ disease; a small increase in the incidence of invasive cancer in areas or age groups where coverage was previously poor; a large fall in the incidence of invasive disease across a wide age range and in all parts of the country; possibly a down staging of invasive disease; and lower mortality than would have been expected. Our data show that these changes have occurred.

Registration of in situ disease has increased in parallel with the numbers of smears taken. It is difficult to distinguish increased incidence from improved registration, but changes in completeness are unlikely to produce artefactual trends which affect only particular age groups.²³ There are, however, known problems of misclassification of cervical cancer, and in the North Western region under-registration of invasive disease was about 9% overall.²⁷

The plateau in the overall incidence of invasive cervical cancer up to 1988 concealed a complex pattern of changes in the age specific rates. The patterns suggest a cohort effect. Other analyses (including with age period cohort models)²⁸ have indicated peaks in risk for women born at the end of the 19th century, in the mid-1920s, and after 1950. These women would have been in their late teens and early 20s, and hence becoming sexually active, at the times of the first world war, the second world war, and the introduction of oral contraceptives, respectively.

Since the introduction of national call and recall in 1988 there has been an overall fall of 35% in the incidence of invasive cervical cancer, reflecting falls in the age specific rates for all women aged from 30 to 74 years and in all regions of England. Studies based in the regional cancer registries indicate that since 1988 the distribution of stage has shifted towards earlier stages.²⁹ And a retrospective case-control study of invasive cancers diagnosed in 1992 has suggested that without screening there would have been 2000 (57%) more cases,³⁰ although this may be an overestimate.¹⁹ We therefore conclude that the fall in incidence is directly related to the increased coverage of screening.

Mortality

Interpretation of trends in mortality data presents several problems. Firstly, mortality may be affected by changes in survival. But there have been no significant improvements in treatment for cervical cancer over the past 20 years, and there is no evidence that stage specific survival rates have improved substantially. Secondly, recording of cause of death may not always be accurate, and attempts to improve death certification may lead to artefactual changes. Thirdly, the proportion of deaths ascribed to "cancer of the uterus, site unspecified" has varied²³ and will have decreased as death certification improved.

For mortality, as with the incidence of invasive disease, the long term downward trend which accelerated after 1988 concealed a complex pattern of changes in the age specific rates. These changes reflect the cohort effects in incidence.^{15 14 31} Little, if any, of the observed long term fall in mortality up to the late 1980s can be ascribed directly to screening because relatively few women dying from cervical cancer aged over 55 years would have been screened, and it was in these women that the mortality was highest and the falls were largest.²² The situation for younger women, however, is

Key messages

- The coverage of the NHS cervical screening programme has increased greatly but several problems remain
- Rates of in situ cervical cancer have continued to rise in women aged 20-29
- Improvements in the screening programme have led to a 35% fall in incidence of invasive disease
- Reductions in mortality over the past 40 years in women aged over 54 are not related to screening, but in women under 55 screening may have prevented 800 deaths in 1997

different. Raffle³¹ estimated that for women born since 1930, screening prevented about 660 deaths in 1995. The latest data indicate that for women aged 25 to 54 screening might have prevented 800 deaths from cervical cancer in 1997.

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Short version 1

Narrowing social inequalities in health? Analysis of trends in mortality among babies of lone mothers

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Editorial
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Abstract

Objectives To examine trends in mortality among babies registered solely by their mother (lone mothers) and to compare these with trends in infant mortality for couple registrations overall and couple registrations subdivided by social class of father.

Design Analysis of trends in infant death rates from 1975 to 1996 for the three groups. The data source was the national linked infant mortality file, containing all records of infant death in England and Wales linked to the respective birth records.

Setting England and Wales.

Participants All live births ($n = 14.3$ million) from 1975 to 1996; all deaths of infants from birth to 12 months of age over the same period ($n = 135\ 800$).

Main outcome measures Death rates in the perinatal, neonatal, and postneonatal periods and for infancy overall.

Results For the babies of lone mothers infant mortality has fallen to less than a third of the 1975 level, with a clear reduction in the gap between the mortality in these babies compared with all couple registrations: the excess mortality in solely registered births was 79% in 1975 reducing to 33% in 1996. Most of the narrowing of the sole-couple differential was associated with the neonatal period, for which there is now no appreciable gap. For couple registrations analysed by social class of father, infant death rates have more than halved in each social class from 1975 to 1996. The reductions in mortality were greater in the late 1970s and early 1990s. Infant death rates in classes IV-V remained between 50% and 65% higher than in classes I-II. Differentials between social classes were largest in the postneonatal period and smallest in the perinatal and neonatal periods. The gap in perinatal and neonatal mortality between the

babies of lone mothers and couple parents in social classes IV-V has disappeared.

Conclusions The differential in infant mortality between social classes still exists, whereas the differential between sole and couple registrations has decreased, showing positive progress in the reduction of inequalities. As the reduction in the differential was confined to the neonatal period these improvements may be more a reflection of healthcare factors than of factors associated with lone mothers' social and economic circumstances.

Introduction

Infant mortality has long been accepted as an important indicator of a population's health, with evidence of any social differentials in this indicator regarded as particularly unacceptable and a spur to action. The traditional way of analysing social trends in infant mortality, often limited to births inside marriage by social class of father, has, however, become increasingly problematic as growing numbers of infants are excluded from such an analysis, not least the babies of lone mothers.

Over the past 20 years there has been a clear reduction in the proportion of births registered within marriage in England and Wales,¹ and this trend has been accentuated in manual social classes (table A on the *BMJ's* website, www.bmj.com).

A second distinct group commonly excluded from the traditional analyses of social trends in mortality consists of babies registered outside marriage solely by their mothers. The size of this group has increased from 5% of births in 1975 to 8% in 1996 (table B on the *BMJ's* website, www.bmj.com). The social class of the father is not available from these records, and it has not been possible to assign a social class on the basis of the mother's occupation to most births until the last few years as