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Breast screening and ethnic minorities

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Abstract The concern for minority ethnic women is whether they are disadvantaged either in terms of the incidence of breast cancer or because of a lower uptake of screening. There are considerable worldwide variations in the incidence of breast cancer. The lowest rates are found in Chinese, Japanese and Arabic populations and women from the Indian subcontinent, and are 2-3 times lower than that of the UK. This may change in future generations. Although minority ethnic women are not a high risk group for the breast screening programme, in absolute terms breast cancer is a major health problem.

Very few studies have measured ethnic differences in the uptake of screening, and they may be confounded by such factors as socio-economic group. When this is accounted for, uptake by Asian women may not necessarily be lower than by other women in the same area and can be higher for black than white women.

One of the most important reasons for non-attendance is inaccurate screening registers, compounded for Asian women by their return, or extended visits, to the Indian subcontinent. A further organisational issue concerns poor awareness of minority ethnic naming systems, causing confusion over the receipt of invitations.

Comprehension of the concept of screening may be difficult for minority ethnic women yet there has been little evaluation of strategies to promote understanding. However a randomised controlled trial of a linkworker intervention, designed to be feasible for implementation on a population basis, showed no increase in the uptake of breast screening by Asian women. This does not undermine linkworkers' role but suggests that their efforts should be used in other ways. It is essential to assess the relative importance of reasons for low uptake and evaluate measures to meet any unmet need, so that resources can be directed in the most effective way.

Introduction

The NHS Breast Screening Programme was introduced in the UK in 1988, with the target population being women of 50-64 years of age. Women who are registered with a GP are invited to have an examination by mammography once every 3 years, and women aged 65 and over may request it. The aim of the screening programme is to reduce the very high mortality from breast cancer in this country, and breast cancer is one of the diseases for which Health of the Nation Targets[2] have been set. A crucial factor in achieving this aim is the maintenance of a high attendance rate for screening, of at least 70%, in both the prevalent and subsequent screening rounds.[1]

Is there a problem for minority ethnic women? The concern is whether they are disadvantaged either with respect to the incidence of breast cancer or in the uptake of screening.

Incidence of breast cancer

There are considerable variations in the incidence of breast cancer throughout the world,[3,4] as shown in Figure 1, with approximately a 6-fold difference between North America and many parts of Asia. The lowest rates in the world are found in South East Asians (Chinese and Japanese), Arabic women, as well as those from the Indian sub-continent, and are 2-3 times lower than that of the UK. The majority of minority ethnic women of the breast screening age group in the UK are first generation immigrants, and would therefore be expected to have the incidence of their country of origin. There is difficulty in obtaining such information in this country since ethnicity data are not available for recording by cancer registries. The few studies that have been undertaken have mainly investigated 'Asian' populations, which are defined as people originating, directly or indirectly, from the Indian sub-continent (i.e. South Asians), for two main reasons. Firstly these populations can be identified from routine records on the basis of name, which is recognised as an accurate way, at the present time, of identifying people from the Indian sub-continent.[5-7] Under-enumeration of Asian women by this method due to cross-cultural marriage is unlikely since this is currently estimated to be low in Britain,[8,9] especially for women of the breast screening age group. Secondly the Asian population is numerically the largest group in the UK, representing over half of the total minority ethnic population.[10] The studies support the view that the incidence of breast cancer among minority ethnic women in Britain is approximately half that of the indigenous UK population,[9,11-13] and that of Asian women is closer to that in Bombay than the UK overall. Although minority ethnic women are not a high risk group for the breast screening programme, in absolute terms breast cancer is common and therefore represents a major public health problem. There is also evidence that these patterns for a migrant population will alter towards the rates observed in the indigenous population,[11,4] as changes in lifestyle, reproductive patterns and dietary habits change.

Uptake of breast screening

The issues of concern for the uptake of breast screening by minority ethnic women are:

- are they less likely to attend for screening than others?
- identification of barriers to attendance where it is low
- evaluation of strategies to meet any unmet need

A low uptake of screening services has been shown in inner-city areas,[15-17] but there is very little information about this in relation to ethnicity, due mainly to the lack of appropriate data. Very few studies have precisely quantified the difference in uptake of breast screening among Asian women as compared to the indigenous population, although some investigators[18-20] have suggested that uptake is substantially less among Asians. Typically uptake of around 50% is reported for Asian women compared with around 73% for non-Asians, shown in Figure 2a. However, the interpretation of these differences is possibly confounded by variation in the distribution of such factors as socio-economic group. As can be seen from the numbers of women in the studies shown in Figure 2a, these reports of uptake may be for several months of screening, covering different types of area, and are not necessarily comparing like with like. For example, it is well known that screening uptake varies markedly in different areas, being much lower in inner-city deprived areas and higher in the more affluent 'leafy' suburbs (Greater Manchester Breast Screening Service, personal communication). It can be argued that area of residence, the type of area that people live in, regardless of ethnic origin, reflects what can be broadly termed socio-economic group. When comparisons have been restricted to relatively homogenous areas, such as, for example, socially disadvantaged parts of inner-city areas, Asian women have not been shown to necessarily have a lower

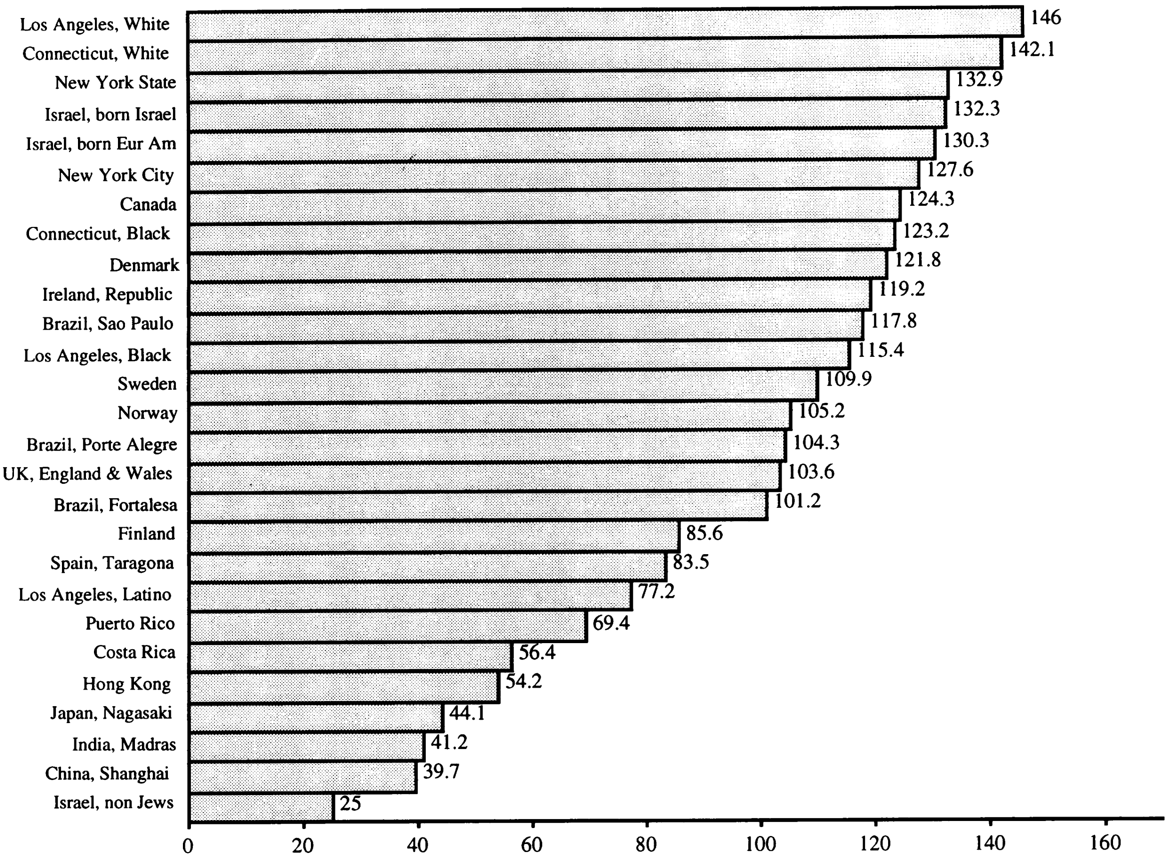

Figure 1 International variations in breast cancer incidence
Selected registries, cancer incidence in 5 continents. Age-standardised incidence rates for female breast cancer, around 1990.
Source: Cancer incidence in 5 continents, Vol V, 1987. IARC: Lyon. Reproduced with permission from Kalache (1992).

attendance for either the breast[20] (Nott M, Windsor & Slough Breast Screening Service, personal communication) or cervical[21] screening programme, shown in Figure 2b. The latter study is interesting since it was restricted to women of 50-64 years of age who are no longer receiving ante-natal care.[21] These studies were conducted for mainly Pakistani Moslem populations,[20] mainly Indian Hindu populations (Nott), and Pakistani/Bangladeshi Moslem[21] populations. Interestingly another study has shown that uptake by black women was higher than that by white women in the same inner-city area of London.[22] It can be concluded that while uptake of screening is low among minority ethnic women it is not necessarily lower than among women of similar socio-economic circumstance living in similar areas.

Developing familiarity with the Health Services could account forthe finding that the uptake of breast screening is related to the length of time that women have lived in this country.[23] Asian women, regardless of their country of origin, who had lived here for over 5 years were significantly more likely to attend for screening than those who had arrived more recently. This further emphasises an important fact that may be overlooked when considering minority ethnic groups: there must be awareness not only of differences between various ethnic groups but also of similarities between some groups and the indigenous UK population.

There is thus a problem of low uptake of screening in certain areas, and recognition of the relative importance of the factors that affect this is necessary if a realistic assessment of needs is to be made. Organisational issues are important since they may represent one of the most straightforward means of promoting participation. A common problem in many inner-city areas arises

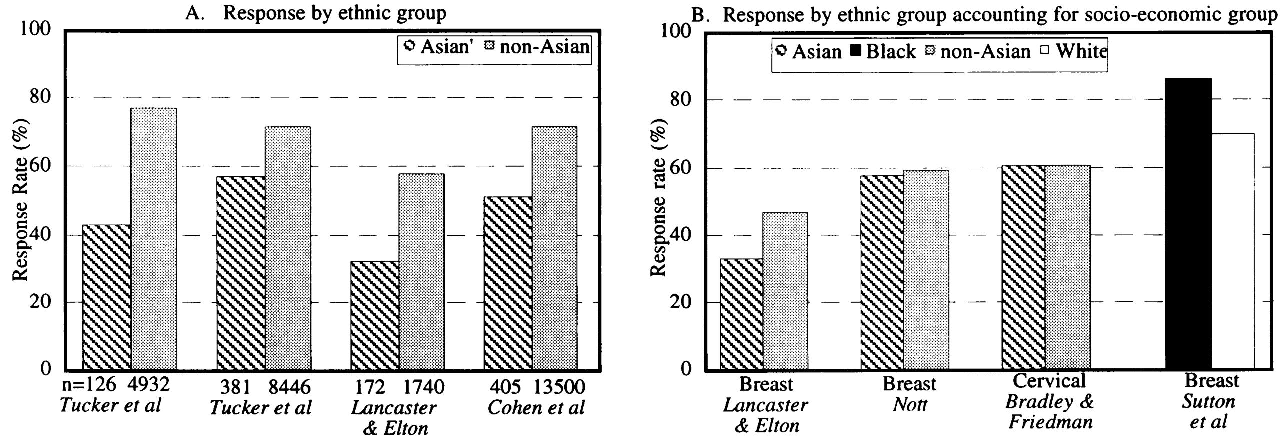

Figure 2 Breast screening uptake

from population mobility[15-17] where invitations are sent to addresses at which women no longer live. Inaccurate FHSA registers, from which screening invitations are derived, are one of the most important factors relating to non-attendance. This is compounded for Asian women by either their return, or lengthy extended visits of several months' or even years' duration, to the Indian sub-continent.[23-26] Thus, even if actually registered with a GP in this country, the women are not in a position to respond to the screening invitation. Between 35% and 40% of invitation addresses were shown to be inaccurate in South-East[16] and West[15] London, and in Central Manchester it was found that 49% of Asian non-attendees were no longer resident at the invitation address.[24] Accessibility of the target population is clearly a problem for screening programmes.

It is important that patients and GPs realise the importance of correct information in their records. While scrutiny of lists by GPs, before invitations are sent out, is crucial, it may be unrealistic to expect that the travel movements of Asian women would always be passed on, if indeed they are known.

An appreciation of minority ethnic naming systems by health professionals could affect the response to screening invitations. Asian women may use a 'title' such as 'Begum or Bibi', equivalent to Mrs/Miss. FHSAs add 'Mrs' or 'Miss' to names and then screening offices may abbreviate them. As can be seen from Table I below, this has the effect of sending an invitation to 'Mrs, Mrs'.

Table I Comparison of naming systems

GP Record	FHSA List	Screening Office Abbreviation
Jane Smith	Mrs Smith, Jane	Mrs J Smith
Soraya Bibi	Mrs Bibi, Soraya	Mrs S Bibi
Fatima Begum	Mrs Begum, Fatima	Mrs F Begum

When several Asian women live in the same house it is not surprising that a major problem faced by radiographers is whether a woman, if she attends, is indeed who they think she is (Greater Manchester Breast Screening Service, personal communication). Women apparently well outside the screening age range attend,[23,25] with implications for radiation hazards for young or pregnant women.

Among a range of attitudinal factors affecting attendance for screening it is clear that comprehension of the concept of screening apparently well women for detection of disease may be difficult for minority ethnic populations.[24,26] Women, and their families, see themselves as fit and well and can see no reason for a medical invitation to improve their health. Illness may be perceived as a situation in which symptoms exist, and then treatment sought. The invitation can even induce anxiety because of a belief that a medical invitation must mean that they are indeed ill. With a low level of literacy among some minority ethnic women[23,25] where someone else is required to read and explain the invitation, the issue may not be given priority. This 'gatekeeper' effect results in women being unaware of the invitation.[23-26] Interviews with the women have shown their isolation, their dependency on others and a lack of understanding of what the invitation was for and why they had been invited.[24,26]

There has however been little evaluation of strategies designed to promote understanding about screening. A personal approach with leaflets or a video was shown to be effective in persuading those Asian women who were resident, and who had never had a cervical smear test, to then have a smear.[27] That study was however conducted before the introduction of the call/recall scheme inviting women for cervical screening, so it is not surprising that almost none of the control group went for a smear. Furthermore the authors concluded that this type of intervention would be too lengthy to be feasible in practice to cover all invited women in the community. Building on this experience, and from positive indications from a study of Asian non-attendees,[26,28] an investigation was carried out to determine whether more could be done to increase the uptake of breast screening for the minority ethnic population than by the accepted methods of health promotion alone.[23] It was found that despite dedicated health promotion work in this district, none of the women had heard about breast screening.[23,25] The randomised controlled trial of a link worker intervention among Asian women invited for breastscreening was designed to be a model that could reasonably be implemented on a population basis.[23,25] In this study women in the intervention group were visited by link workers and given a talk and encouragement in their own language about screening, whereas the control group received no visits. A disappointing outcome was that there was no difference in attendance between the two groups.

Accessibility of the target population was a problem in this breast screening study with only 60% of the study population able to be contacted; over a quarter of the women were either temporarily (on visits) or permanently (not resident) unable to respond to the screening invitation. This also resulted in an ineffective outcome for a scheme to visit all non-attendees for cervical screening in Liverpool.[29] An important caveat to the conclusion from the breast screening study however is that it does not undermine the valuable role that link workers play but suggests that their resources should be used in other ways.

Conclusion

It can be concluded therefore that while minority ethnic women are fortunately currently at lower risk of breast cancer than the indigenous UK population it remains a major health problem. The uptake of screening appears to be low among minority ethnic women but it is not necessarily lower than among women of similar socio-economic group. For any substantial section of the community where uptake is low and factors associated with this can be recognised there is scope for action directed towards meeting the need. A major organisational problem to be addressed is that of screening list accuracy, compounded by long-term visits or return abroad. For minority ethnic women there may be the attitudinal issue of a lack of comprehension of the concept of screening. For interventions to improve uptake to have an impact they must cover all the target population. Interventionsare not without costs, and must be rigorously evaluated so that resources are directed in the most effective manner.

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