



Information Upon Which to Plan Future Service  
Initiatives That Address the 'Human Costs' of Breast  
Cancer Amongst Black Minority non-English  
Speaking Women

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## Introduction

- The National Cancer Alliance (2002) has indicated that black minority ethnic (BME) populations experience difficulties in accessing information about cancer and healthcare services.
- A range of views exist amongst healthcare professionals, voluntary agencies and community groups about the provision of cancer-related information for BME populations in East London (Cox & Lanceley, 2003).
- Statutory and voluntary agencies involved in cancer care need to address the issue of information provision with cultural sensitivity.

# Introduction

- BME women face a number of additional challenges.
- Difficulties in accessing appropriate information as well as dealing with culturally specific (often negative) attitudes about breast cancer. Subsequently the rate of recovery from breast cancer, if treated, is lower amongst BME women in East London.

## Purpose of the Paper

- Findings from the first phase of the research will be explicated. Issues associated with interviewing non-English speaking BME women will be considered. It will be noted that traditional written information has been found to be ineffective at reaching those most in need and does not address more sensitive issues such as the stigma that exists about breast cancer in different communities. Ways to target BME non-English speaking women will be described.

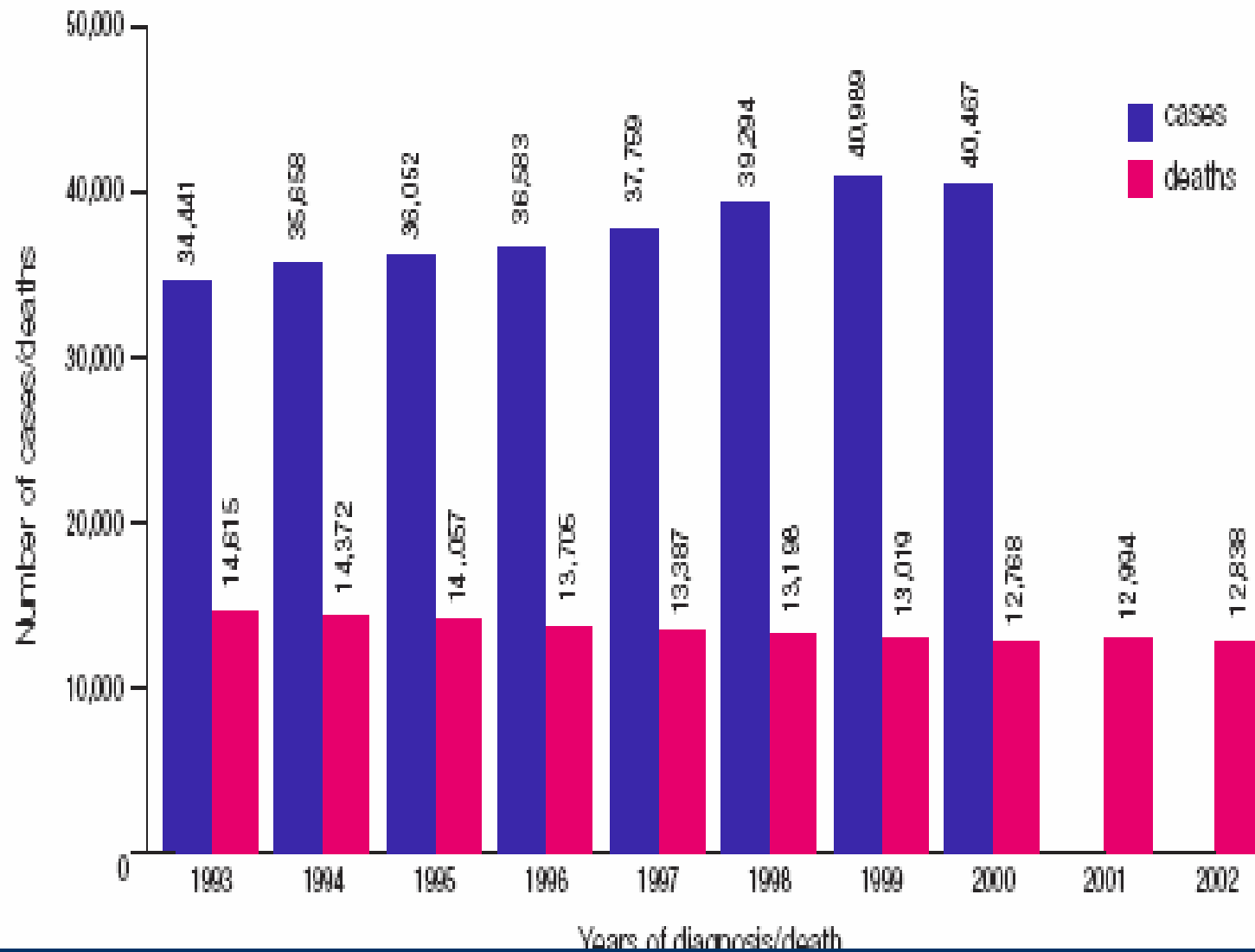
# Literature Review

- Considerable ethnic differences exist in relation to cancer incidence and mortality.
- Members of minority ethnic groups are further disadvantaged when diagnosed with cancer due to lack of appropriate information and support services.
- There is a need to develop appropriate interventions at the 'upstream' national level - as well as at the 'downstream' local level.
- In the UK breast cancer is one of the most common cancers found in women.

# Literature Review

- Death rates from breast cancer, in the UK, have fallen by approximately 20% in the last ten years (Office for National Statistics 2005, Cancer Research UK 2006). For example, dos Santos et al (2003) examined survival rates for breast cancer and found that women of South Asian origin not only had a lower risk of being diagnosed with breast cancer, but also demonstrated better survival once cancer was diagnosed.

Figure Five: Number of new cases and deaths, breast cancer, females, UK 1993–2002



# Demographics

- 92% of the British population are white with the remaining 8% belonging to people of other ethnic groups (Office for National Statistics 2005). However, non-white sections of the population are concentrated primarily in urban areas, with almost half living in London. North East London, the setting for this study, is characterised by affluence as well as considerable socio-economic deprivation. Importantly, it has the highest BME populations in the UK.

# North East London



# Borough of Hackney



# Provision of Effective Information

- The needs of minority ethnic groups are considered specifically in the development and implementation of policies aimed at reducing socio-economic inequalities.
- The further development of services sensitive to the needs of minority ethnic people and which promote greater awareness in health.
- The needs of minority ethnic groups are considered specifically in needs assessment, resource allocation, health care planning and provision (National Cancer Alliance 2001).

# Race Relations

- *The collective failure of an organisation to provide appropriate and professional service to people because of their colour, culture or ethnic origin (Sir William Macpherson 2005).*

([http://www.cre.gov.uk/gdpract/cj\\_sli.html](http://www.cre.gov.uk/gdpract/cj_sli.html): 1)

# Cancer Policy in the UK

- Cancer policy has been developing rapidly since 1997. Concerns about ethnicity and socio-economic deprivation have emerged as important areas for further development in relation to cancer control. The challenge, however, lies in translating wide-ranging policy recommendations into action in local areas in order to benefit BME patients (Department of Health 1999b).

# Perceptions of Palliative Care

- Perceptions of palliative care staff towards multicultural care provision: Barriers to effective culturally competent palliative care included lack of translation services and negative attitudes or behaviours towards ethnic minority patients (Driver et al 2003).
- Importance of communicating effectively to inform South Asian patients about the nature of palliative care services.
- First generation immigrant populations reported the most communication difficulties and stated that they would like to see more staff being employed from similar ethnicities. The provision of culturally appropriate cancer care, therefore, involves practical issues (such as effective communication or service developments) as well as the promotion of equality based on accurate needs assessment.

# Research Aims

- To identify how/when BME women become aware that they breast cancer.
- To discern the impact of the disease upon the women, their families and communities.
- To understand how BME non-English speaking women obtain information about breast cancer.
- To determine how/when BME non-English speaking women access healthcare services
- To develop strategies for dissemination of culturally sensitive information about breast cancer and access to healthcare services.

# Research Design

- Exploratory qualitative design intended to develop a 'downstream' approach that will raise the awareness of BME non-English speaking women about breast cancer and access to healthcare services in East London.
- Audio taped face-to-face individual interviews and focus group interviews undertaken by research assistants who speak the language of the women being interviewed.

# Findings and Discussion

- Key findings to date have been uncertainty about breast cancer, how to access information about the disease and how to access healthcare services.
- Uncertainty about the disease has been the most common experience reported by women affected with breast cancer.
- One of the reasons for BME women experiencing uncertainty is because even with improved management and advances in treatment options over the last decade, not all cancer cases can be cured (Nelson 1996).

# Findings and Discussion

- Interventions such as education (Wonghongkul et al 2000), self-care promotion and uncertainty management (Braden et al 1998) have been suggested as having a reducing/positive effect on the experiences of uncertainty.
- Braden et al (1998) found that women who participated in the self-care and uncertainty management group performed better in relation to self-care, self-help, psychological adjustment and were more confident in cancer knowledge.

## Findings and Discussion

- Uncertainty in relation to perceived social support and quality of life.
- Perceived social support and uncertainty explain almost a third (27.2%) of the variance in quality of life.
- Lower perceived social support often indicated an increase in uncertainty. Furthermore, a low network size indicated increased experiences of uncertainty whereas in older survivors, positive correlations were found between age and uncertainty.

## Findings and Discussion

- Cancer has been identified as a taboo subject and therefore not openly discussed within the community. Subsequently BME women experience high levels of depression and low levels of well-being.
- Social constraints, such as the perceived notion that other people did not want to know about women's cancer experiences, was observed to link with frequent use of words associated with uncertainty (Cordova et al 2001).

# Conclusion

- Traditional written information has been found to be ineffective at reaching those most in need and does not address more sensitive issues such as the stigma that exists about breast cancer in BME communities.
- Our research will provide information upon which to plan future service initiatives that address some of the 'human costs' of breast cancer amongst BME women.