Black and Minority Ethnic (BME) Cancer Experience

Introduction

This briefing paper provides a round-up of the current data and research findings regarding ethnicity and cancer. It builds on recent data releases, research findings and survey data, to provide an insight into the current data and information available. It does not include all available data, but brings together some of the emerging knowledge to date.

Cancer Incidence Levels in BME Communities

The National Cancer Intelligence Network (NCIN) published its first major report on ethnicity and cancer in 2009; it brought together data from difference sources and allowed for analysis by ethnicity and cancer type. This report has some limitations as it does not identify the Irish community as a separate ethnic group and at the time of the report over 20% of the data source were of unknown ethnic origin. This aside, the report offers for the first time, real insight into the differences in cancer incidence rates by ethnicity. The report identified that people from BME communities generally have lower rates of cancer than the wider white British population. However, the data does show that there are a number of exceptions where incidence rates for some BME groups are substantially higher than the rates of the white British population.

- Incidence rates of prostate cancer for African and African Caribbean men are around twice as high as the rates for white men.
- Incidence rates of stomach cancer for both African and African Caribbean males and females are around 50% higher than the rates for white males and females.
- Incidence rates of liver cancer for both African and African Caribbean males and females are around twice as high as the rates for white males and females.
- Incidence rates of myeloma for both African and African Caribbean males and females are around twice as high as the rates for white males and females.
- Incidence rates of liver cancer for Asian males and females are around twice as high as the rates for white males and females.
- Incidence rates of mouth cancer for Asian females are around 50% higher than the rates for white females. For females aged over 65, rates are around twice as high.
- Incidence rates of cervical cancer for Asian females aged over 65 are around twice as high as for white females aged over 65.

Mortality Rates

Work by the NCIN, has identified there are some differences in mortality rates for BME communities, however more recent figures are needed. African and Caribbean women have lower incidence rates for Breast cancer, they do have higher mortality rates (NCIN 2009, Bowen 2009 and Wild 2006). Research carried out by Harding S, Rosato M, Teyhan A (2009) indicates that the Irish community in Britain have had high rates of cancer mortality for several decades and this pattern persists for several cancer types.

Cancer Awareness

Awareness levels amongst people from BME communities are generally lower than that of the white population, poorer awareness may lead to both later presentation and more advanced disease.

- Both African and African Caribbean women have a lower knowledge of the signs of breast cancer than white women (Breast Cancer Care, 2005)
- 65% of BME women compared to 73% of white women thought cervical screening is a necessary health test (Jo’s Cervical Cancer Trust, 2011)
- Knowledge of the signs and symptoms of cancer is poorer among the Irish than White British (Scanlon et al, 2006)
• Just under half of the BME women in the ‘same difference campaign’ reported they never practised breast awareness (Breast Cancer Care, 2005) compared to 11% of respondents from the general sample (Breast Cancer Care, 2011)

Screening Uptake

The NCIN reported that screening uptake is generally lower in minority ethnic groups than in the population as a whole and this is evidenced in take up of all three cancer screening programmes, Breast, Cervical and Colorectal (NCIN, 2010).

A recent YouGov survey by Jo’s Cervical Cancer Trust (2011) found a number of factors impacted on the low take up of cervical screening by BME women. This study found:

• More than 30% of BME women said having more choice of where to have the test would encourage them to attend, compared to 22% of white women
• Only 28% of BME women said they would be comfortable talking to a male GP about cervical screening, compared to 45% of white women
• 30% of BME women stated that more knowledge about the test and why its important would encourage them to attend the test, compared with only 15% of white women

The National Screening programme supported a Pilot Patient Navigation programme to improve the uptake of breast screening in women from the African Caribbean community. The Navigation Pilot identified women who had been invited for breast cancer screening but who had not attended their appointment. The pilot engaged with these women and successfully made appointments for 250 of the 637 women (Betterdays and Black Cancer Care, 2011).

Impact in BME Communities

The impact of both lower breast awareness levels and lower levels of take up for screening services by BME communities is leading to both more advanced disease and poorer survival levels. A 2010 NCIN report identified women from Black and Minority Ethnic groups are more likely to present with more advanced breast cancers and have poorer survival than White women. Similarly the All Breast Cancer Report 2009 showed that patients known to be black were diagnosed with breast cancers with a worse prognosis than those in other ethnic groups: their breast tumours were significantly larger, of higher grade, more likely to be node positive and had a worse Nottingham Prognostic Index (NPI) score.

In 2010 the NCIN carried out a systematic review of literature that found that non-white ethnic origin is associated with longer delays in presentation for urological and breast cancers, but with shorter delays for stomach cancer.

Patient Experience

To date two national cancer patient experience surveys have been carried out. The first took place in 2000, 2% of the sample described themselves from BME groups (this figure excludes the Irish who were included with the white British population). In 2004 the National Audit Office carried out an interim survey of which 2.8% of all respondents were of BME origin (excluding Irish) and the most recent survey carried out in 2010 where over 67,000 cancer patients took part 4% (excluding Irish) who were of BME origin.

In all three surveys there were significant variations in the experience of white cancer patients compared to BME cancer patients. BME cancer patients consistently reported a poorer experience of NHS cancer services than white cancer patients. Out of the 67 questions BME patients reported a statistically lower experience across 22 of the questions, which are listed below:

• Saw GP once or twice only before being told needed to go to hospital (Q1)
• Patient felt they were seen as soon as necessary (Q3)
• Health stayed about the same whilst waiting for appointment with hospital doctor (Q5)
• Staff explained completely what would be done during test procedure (Q8)
• Given easy to understand written information about tests (Q9)
• Results of tests explained in a way that the patient could understand (Q10)
• Completely understood the explanation of what was wrong with them (Q14)
• Definitely involved as much as they wanted to be in decisions about which treatment to have (Q14)
• Got understandable answers all/most of the time to questions posed to doctor (Q34)
• Doctors talked in front of the patients as if they were not there (Q37)
• Patient received answers from a ward nurse that were understandable all or most of the time (Q39)
• Had confidence and trust in all ward nurses (Q40)
• Ward nurses talked in front of the patient as if there were not there (Q41)
• Always/nearly always enough nurses on duty to care for patients (Q42)
• Patient often thought doctors/nurses were deliberately not telling them certain things (Q43)
• Give enough care and help from health and social services after discharge (Q52)
• Hospital stall definitely did everything they could to control side effects of Chemotherapy (Q56)
• Patient definitely given enough emotional support from hospital staff when an outpatient or day case patient (Q58)
• At last outpatient appointment with a cancer doctor, seen within 30 minutes (Q60)
• GPs and Nurses at the practice definitely did everything they could to support patient whilst they were having cancer treatment (Q64)
• GPs/other staff worked well together to give the best possible care (Q65)
• Patient did not feel that they were being treated as a set of cancer symptoms (Q67) rather than as a whole person

The National Cancer Action Team developed the National BME cancer voice to help provide a greater understanding into the experience of BME cancer patients and their families. The BME voice will work to highlight areas for improvement.

Conclusion
Recently published data and information on ethnicity and cancer is helping to frame some of the questions around ethnicity and cancer, and the issues associated with ethnicity. The NCIN and the National Cancer Equality Initiative are working towards improving the current data sources available. However, a more systematic approach to the inclusion of ethnicity would help to bring both a deeper understanding about the progression of the disease amongst BME groups, and also allow greater measurement of the impact of interventions.

The current evidence and data identifies higher incidence rates amongst some BME groups, more advances breast disease, and poorer outcomes. These factors when coupled with a poorer experience of NHS cancer services highlight the need for a more targeted approach.

The National Cancer Action Team and the National Cancer Equality Initiative is working with partners and stakeholders, through a number of projects to ensure there is:

• A more coordinated approach to data analysis and dissemination of data
• A targeted approach to improving cancer awareness amongst people from BME communities
• A National BME cancer voice
• A greater understanding of delivering culturally sensitive cancer services

References
Betterdays Cancer Care and Black Cancer Care (2011): Patient Navigator Pilot report.

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