



Executive Summary

Accessing information and support from the NHS and voluntary sector: Experiences of Asian and African Caribbean women with breast cancer

Reducing inequalities in cancer care has been a key health policy issue for a number of years, yet disparities in incidence and outcomes continue. The recent Cancer Reform Strategy (2007) aims to reduce inequalities in cancer incidence and outcomes, and enhance quality and experience of care (Department of Health, 2007). Fundamental to this is the equitable provision, and uptake, of information and support. The voluntary sector plays a key role in providing information and support to people affected by cancer (DoH, 2007). However, little is known about how voluntary organisations can best provide information and support to help reduce inequalities across the cancer population generally, and Black and minority ethnic (BME) groups specifically. The purpose of this study was to explore the suitability and accessibility of information and support provided to women with breast cancer from Asian and African Caribbean communities.

Aims of the research

- Describe the information and support needs of Asian and African Caribbean women diagnosed with breast cancer
- Identify the sources of information Asian and African Caribbean women access, and prefer to use
- Detail the factors influencing uptake of services provided by voluntary organisations

Sample

Twenty Asian and African Caribbean women diagnosed with breast cancer took part in one of four focus groups held in London and Birmingham. These locations reflected areas of the UK with the highest ethnic diversity.

Summary of Research Findings

Delayed diagnosis

- Younger Asian and African Caribbean women reported that their diagnoses were delayed, often as a result of their breast health concerns being dismissed by healthcare professionals.

Problems obtaining culturally relevant information

- Women felt they had to be proactive and ask questions that related to specific cultural concerns they had, as appropriate information was often not offered by healthcare professionals.
- Some women wanted consultations in their own language to ensure they could express themselves accurately, and understand information being given.

Inadequate time spent with breast care nurses

- Breast care nurses were seen as a key source of information and support. However, many women felt breast care nurses did not have the time to 'make a connection' i.e. get to know them, assess their needs and provide information and support as appropriate.
- Women felt information distributed at diagnosis was overwhelming. They suggested the breast care nurse should sit with patients and go through leaflets, selecting information relevant to that patient.

Lack of culturally appropriate practical support services

- Women reported inequitable access to culturally appropriate practical support services including colour prostheses, wig-fitting services and lymphodema sleeves.
- Asian and African Caribbean women had specific concerns regarding skin and hair care, diet, prostheses, and lymphodema sleeves.

Importance of peer support

- Being able to speak to someone who had been through the cancer experience was deemed very important - both as a source of emotional support but also as a source of information/practical tips.
- Some women preferred speaking to someone from a similar cultural background. Whereas others felt that an experience of cancer was more important.
- Younger Asian and African Caribbean women felt particularly isolated when first diagnosed. They were more concerned with meeting women of a similar age than cultural background.

Impact of diagnosis on self

- Many women felt positive about the future.
- However, some described the negative impact of breast cancer on body image and femininity (partly a result of surgery, but also due to inappropriate wigs/prostheses/lymphoedema sleeves).

Cultural and familial barriers to support

- Women in the African Caribbean groups suggested family and friends had been supportive but lacked understanding of what they were going through.
- Women discussed society's perception of BME communities 'looking after their own' but highlighted that not everyone has strong support networks. They felt that, regardless of support available from family and friends, relevant services should be highlighted, and accessible to all.
- African Caribbean women were less likely to talk about their 'private business' with people they did not know, although younger women were more willing to share their experiences and concerns.
- Some Asian women mentioned requesting female doctors as they felt uncomfortable undressing in front of male doctors.

Lack of BME representation

- Women highlighted a lack of BME representation across staff (in both the statutory and voluntary sectors), in information materials and services.
- There were varying views as to whether publications and services should be BME-specific or, at least, inclusive of all cultures.
- Women felt the media portrayed breast cancer as a 'white woman's disease.'

Barriers to accessing voluntary services

- Lack of BME representation in staff, publications and services.
- Lack of appropriate practical support services and signposting to relevant services.
- Confusion over which voluntary organisation offers what.
- Services are not accessible at appropriate times e.g. the Helpline should be open after work and at weekends.
- Women want locally-based services, in settings they trust and feel comfortable in.

Recommendations

1. Better signposting and services marketing strategies for women from BME groups to statutory and voluntary support services.
2. Statutory and voluntary sector service providers should promote, and develop, more inclusive services portfolios for BME women
3. Statutory and voluntary sector service providers should consult with women from BME groups regarding future service developments
4. Health care professional communication training should include cultural awareness skills and diversity issues

Conclusions

Women from Asian and African Caribbean communities have similar information and support needs to the wider population with breast cancer. However, they do have unique information needs that should be addressed, particularly regarding skin healing after treatment and practical support concerns.

Improved BME representation and imagery across staff, information materials and support services is necessary to ensure that statutory and voluntary sector organisations are seen as accessible and culturally relevant organisation to women from Asian and African Caribbean communities.

Access and signposting to culturally appropriate practical support services, including prostheses, hair loss services and lymphodema sleeves, varies across the UK. The statutory and voluntary sectors should work together to improve the BME cancer experience, providing culturally appropriate services and signposting accordingly.

For a copy of the full report, please contact Emma Blows, Research Officer:

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