

Lesbian and bisexual women and breast cancer

A policy briefing



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Cover photo. Among this group of friends – some heterosexual, some lesbian or bisexual – is a woman who has secondary breast cancer. She gratefully acknowledges solid support from her ‘family of friends’, including on this trip to a music festival. There is a lack of formal psychosocial services specifically designed for lesbian and bisexual women and their partners. Studies suggest this means women either use their own social support circles or may struggle to find ongoing support (see page 6).

This briefing was prepared by Kiran Dhami, Policy Officer, Breast Cancer Care.
Email: kiran.dhami@breastcancercare.org.uk

Introduction

Purpose of this briefing

Lesbian and bisexual women with breast cancer have been relatively hidden in discussions about standards of treatment and care for breast cancer in the UK. Yet research indicates distinct issues that deserve to be highlighted and discussed. Breast Cancer Care has an ongoing commitment to understanding and tackling equalities issues in breast cancer. This policy briefing is part of that work.

The information presented draws on published research and other work examining the experiences of lesbian and bisexual women and breast cancer. UK research on this issue has tended to be small-scale, but there are clear, consistent themes across studies. These echo issues in the larger body of research from the USA and Canada.

We hope our briefing will be useful to:

- policymakers concerned with ensuring health and social care is responsive to all, regardless of sexuality (or other differences)
- healthcare professionals working to provide the best possible care for their patients
- cancer charities and other groups providing services to women affected by breast cancer, including those who are lesbian and bisexual.

Our recommendations (page 3) are aimed at improving services. We hope they will be useful to all groups wanting to take action on this issue.

Why this is important

Some research suggests that disclosing sexual orientation is a key factor in raising patients' overall levels of emotional wellbeing and helping to lower anxiety (Boehmer et al, 2005). However, many lesbian and bisexual women choose not to disclose their sexual orientation to healthcare workers (Hunt et al, 2008a), perhaps because they feel it is not relevant (Hunt et al, 2006b) or have concerns about how the disclosure will be received (Hunt et al, 2008b).

Evidence suggests there is a lack of experience and training about lesbian and bisexual experience within the healthcare system (Hunt et al, 2008a; Hunt et al 2008b; Stonewall Scotland, 2010; Hunt et al, 2007; Stonewall, 2010; British Medical Association, 2004; Fish, 2010; King et al, 2003; Hunt et al, 2006a). This has the potential to affect a lesbian or bisexual woman's experience of support during a breast cancer diagnosis, and her subsequent treatment and wellbeing.

While discrimination on the grounds of sexual orientation in the provision of goods, facilities and services (including healthcare) in the public and private sectors was prohibited in law in April 2007 (Equality Act [Sexual Orientation Regulations], 2007) and was consolidated in the Equality Act 2010, this is a relatively recent development. Historically, lesbian and bisexual women have been 'invisible' in service provision because of an assumed heterosexuality that places the onus on individuals to disclose their sexuality – an unlikely scenario when social and state attitudes were more overtly hostile than they are now. Recent changes in legislation promoting equal rights, together with a better understanding of the impact of homophobia in society and evidence of the distinct needs and experiences of lesbian and bisexual women, provide a positive backdrop for policymakers and professionals to build on good practice and ensure that cancer services are responsive, respectful and appropriately delivered to this group of women.

Key points

- Some evidence suggests lesbians are at higher risk of adopting lifestyle behaviours that increase the risk of developing breast cancer, such as consuming alcohol, obesity and a reduced likelihood of having children and breastfeeding.
- Half of 6,000 lesbian and bisexual women in one UK survey (Hunt et al, 2008) had negative experiences in the health service in 2007 despite the illegality of discrimination based on sexual orientation. The comprehensive 2010 Cancer Patient Experience Survey (Department of Health, 2010) also highlighted less positive experiences of lesbian and bisexual cancer patients compared to heterosexual patients, particularly around communication with healthcare professionals and in relation to the respect and dignity with which they were treated.
- The relatively small numbers of lesbian and bisexual women in research studies and the lack of health-related data collected for this group mean that statistically significant and widely meaningful results can be difficult to obtain.
- There is no evidence of any clinical differences among women of different sexual orientations diagnosed with breast cancer. However, research suggests it is beneficial when healthcare professionals and others delivering cancer services are sensitive to the needs and experiences of lesbian and bisexual women, do not assume a patient is heterosexual, and use images and language inclusive of lesbian and bisexual women.
- Healthcare professionals may believe that lesbian and bisexual women do not have different needs to heterosexual women. However, there are indications from these communities that people would like to receive more information relevant to their sexual orientation (National Cancer Equality Initiative, 2010).
- There is poor provision of specialist services for lesbian and bisexual women with breast cancer, despite evidence of the need for this among some women and poor signposting of women to/from lesbian and bisexual community groups by health/charity services.

Limitations of the data

The majority of research on breast cancer and lesbian and bisexual women has been conducted in the USA. Because of differences in demography, as well as social, political and economic structures, caution is needed when extrapolating data to a UK context.

The academic and medical research into lesbian and bisexual women and breast cancer is usually small-scale and qualitative because lesbian and bisexual women make up a relatively small proportion of the female population. This means it is unlikely that research samples will be big enough to be statistically significant or definitive. It also reflects the niche status of the subject matter, the relative lack of historical and current data that is collected on sexual orientation in healthcare compared to other equalities areas, such as ethnicity and age, and the subsequently poorer status it is afforded in projects, initiatives and service delivery (National Cancer Equality Initiative, 2008).* There is even less known about the experiences of black, Asian and minority ethnic (BAME) lesbian and bisexual women living with breast cancer as well as those with disabilities.

*The National Cancer Equalities Initiative (2008) audit of cancer services found that only one initiative out of 77 was targeted to sexual orientation and cancer.

Recommendations

For healthcare professionals and commissioners of healthcare

- In staff training and updates, include information about, and understanding of, the experiences of lesbian and bisexual women.
- Encourage feedback from lesbian and bisexual patients on their experiences of services.
- Encourage clinical staff not to make assumptions about patients' sexuality and/or their attitudes to treatment options.
- Encourage neutral language that does not assume heterosexuality when addressing and questioning patients. For example, 'first name' instead of 'Mrs X' and 'partner' instead of 'boyfriend' or 'husband'.
- Create safe and welcoming environments, including ensuring the visibility of lesbian women of different ethnicities in literature and waiting room items.
- Ensure any information on local lesbian and bisexual women's breast cancer support groups is available and offered to patients.

For cancer charities

- Ensure services welcome, and are relevant to, lesbian and bisexual women of different ethnicities. For example: relevant images in marketing materials; providing a specific space for lesbian and bisexual women to talk to each other on online forums; ensuring support groups are facilitated as safe spaces to 'come out' and issues raised are competently discussed; having links to information specifically for lesbian and bisexual women accessible on a charity's website and through the search engine function.
- Run user involvement audits to check an organisation is responsive to the needs of lesbian and bisexual women.
- Build links with lesbian and bisexual women's community organisations, including BAME groups, and use their expertise to inform work or support existing networks and encourage referrals.
- Encourage the collection of data on lesbian and bisexual women and cancer whenever research or audits are carried out internally or by external groups.
- Encourage use of data to improve access to, and quality of, services.
- Consider targeted initiatives for lesbian and bisexual women if there is evidence of demand for this.

For policymakers

- Ensure that the National Cancer Equalities Initiative (NCEI) addresses the specific needs of lesbian and bisexual women and is resourced to have impact on this issue.
- Ensure that health department research/surveys include a question on sexual orientation.
- Ensure that GP commissioning consortia assess the impact of their commissioning decisions on lesbian and bisexual patients.
- Encourage local data collection (by PCTs and forthcoming GP consortia) that includes lesbian and bisexual women. If specific health-related data do not exist in terms of sexual orientation, existing and relevant demographic data can be used when gathering information for commissioning purposes, for example from London Councils.
- Clarify how the statutory duty for the NHS Commissioning Board and GP consortia to address health inequalities will be monitored and used to drive improvements for different groups of patients with cancer.
- If unsure about what appropriate terms to use in policy, refer to specialist organisations such as Stonewall, the Lesbian and Gay Foundation or Women's Health Matters.

The facts

At present there is little statistical information relating to cancer by sexual orientation, in part due to the fact that the NHS does not routinely collect and record data* on sexual orientation. Additionally, many lesbian and bisexual patients choose not to disclose their sexuality to health professionals. This could be because of perceived (Hunt et al, 2008b) and actual homophobia (Hunt et al, 2008a; Hunt et al 2008b; Stonewall Scotland, 2010; Hunt et al, 2007; Stonewall, 2010; British Medical Association, 2004; Fish, 2010; King et al, 2003; Hunt et al, 2006a) within the health service or because patients feel that disclosing one's sexuality is irrelevant in a healthcare setting (Hunt et al, 2006b). There is no recorded information about how many women with breast cancer are lesbian or bisexual.

Some studies and reports, including a 2009 report by the All Party Parliamentary Group on Cancer (APPG, 2009), have concluded that lesbians may be at a slightly increased risk of breast cancer as compared to non-lesbians (Hunt et al 2008a; Kavanaugh-Lynch et al, 2002). When compared using the Gail Risk Model**, lesbians had a significantly higher five-year and lifetime risk for developing breast cancer (Dibble et al, 2004).

Some research has highlighted that lesbians as a group may have a greater propensity for adverse breast cancer risk factors related to lifestyle including: nulliparity (having no children) (Zaritsky et al, 2010; Valanis et al, 2000; Case et al, 2004), obesity (Boehmer et al, 2007a; Case et al, 2004) and drinking more alcohol than the recommended amount (Creith, 1994; Fish, 2007; Gruskin, 2001; Ettorre, 2005; Valanis et al, 2000; Brandenburg et al, 2007; King et al, 2003). However, it is important to note that being a woman is the strongest risk factor for breast cancer and that being a lesbian in itself is not a risk factor for breast cancer. The emphasis is on certain behaviours that may be risk-inducing and could be more prevalent in (but not exclusive to) lesbian communities (Fish, 2003; Breast Cancer Care, 2007).

There is no evidence to suggest that mortality and survival rates differ according to sexual orientation, although the absence of routine recording of sexual orientation in the NHS makes this hard to verify (National Cancer Equality Initiative, 2010).

* The Office of National Statistics (2007) announced that six UK public sector surveys will include questions on sexual orientation. However, none of them collect data relating to health. Neither does the Health Protection Agency collect data on lesbian and bisexual women.

** The Breast Cancer Risk Assessment Tool is based on a statistical model known as the Gail model, which uses a woman's own personal medical history, her reproductive history and the history of breast cancer among her first-degree relatives to estimate her risk of developing invasive breast cancer over specific periods of time. For more information see: www.cancer.gov/bcrisktool/about-tool.aspx#gail

The issues

Visibility and targeting in breast awareness messaging

Despite some evidence of higher risk behaviours (linked to an increased risk of breast cancer) by lesbian and bisexual women, they have not been the specific focus in any breast cancer awareness campaigns in the UK (Fish, 2007). However there have been some local breast awareness initiatives. For example, a leaflet, *Lesbians and Cancer*, with a very small section on breast cancer (Barking and Dagenham Primary Care Trust, 2007). The Lesbian and Gay Foundation (a national voluntary sector organisation) also publishes some materials about breast cancer on its website (Lesbian and Gay Foundation, www.lgf.org.uk).

Many breast health awareness messages are delivered to women when they attend surgeries and clinics for contraceptive advice or smear tests. Because lesbians are less likely to attend these, they may be less aware of them (Fish, 2006).

Perceptions of risk

The cancer awareness measure has been used to ascertain whether there are differences in awareness levels according to sexual orientation. A survey (Gunstone, 2010) of 600 lesbian and bisexual women was conducted in 2010 using the cancer awareness measure, which found that among younger women, lesbians had the highest awareness of breast cancer being the most common cancer for women (80 per cent) compared to bisexual and heterosexual women. However, this does not necessarily correlate to the perceptions of their own potentially slightly elevated risk as 73 per cent of women in a survey of 1,000 lesbians in the UK believed their risk of developing breast cancer was the same as that of heterosexual women. Nineteen per cent thought it was higher and three per cent said it was lower (Fish, 2005). In the older age group, heterosexual women were most likely (80 per cent) to know that breast cancer was the commonest cancer for women (Gunstone, 2010).

In terms of awareness of specific risk factors, few respondents in one UK survey of 900 lesbian women mentioned obesity as a risk factor in developing breast cancer (three per cent) (Fish, 2006). Half thought family history was the main risk factor in developing breast cancer (when actually it only accounts for between 5–10 per cent of cases) (Love, 1995). The main risk factors are being female and increasing age.

Breast screening

The survey of more than 6,000 lesbian women in Britain found that four in five lesbians over the age of 50 have had one breast screening test, which is similar to women in general (Hunt et al, 2008a). However, an earlier survey of 1,000 lesbian women in the UK found that lesbians were much less likely to say that appropriate attitudes and behaviour of health professionals contributed to a good experience of breast screening than heterosexual women (37 per cent versus 69 per cent) (Fish, 2005).

Time of presentation or diagnosis

The cancer awareness measure survey mentioned above also examined what lesbian women said they would do in relation to presentation with possible cancer signs or symptoms. This data needs to be regarded with caution because it reports on what lesbian women say they would do, rather than what they actually do. The survey found that among younger women in Britain (16–39), lesbians and bisexual women were very slightly less likely than heterosexual women to say that they would present within a week of finding a lump. Bisexual women had similar results to heterosexual women (around 65 per cent). Among older women (40-plus) the difference was greater, with heterosexual women more likely to present to a doctor within a week of finding a lump (80 per cent) than older lesbians (75 per cent) or bisexual women (68 per cent) (Gunstone, 2010).

Access to treatments

There is no robust evidence to suggest differences in treatments offered or taken up based on sexuality (National Cancer Equality Initiative, 2010).

There is no clear evidence to show differing attitudes towards reconstruction depending on sexual orientation. One small US study (Boehmer et al, 2007b), suggesting that sexual minority women may be more inclined to reject reconstruction, is dismissed by another report (Rubin, 2009) whose similarly small number of lesbian and bisexual participants rejected stereotypes that posited lesbians were less invested in breast reconstruction than heterosexual women. The overall message was that assumptions should not be made about treatment preferences based on someone's sexuality. However, there were some specific issues raised by lesbian and bisexual women during the breast reconstruction decision-making process suggesting differing values held about plastic surgery, physical appearance and functioning, and the impact of cancer/mastectomy/reconstruction on their romantic relationships. Healthcare professionals therefore need to be open to the possibility of some different attitudes among lesbian and bisexual women to these issues.

Access to information

While lesbian and bisexual women have many of the same information needs as heterosexual women, research indicates that some would like to receive more information relevant to their sexuality (Fish, 2010; Hunt et al, 2008a). Some lesbian, gay and bisexual (LGB) organisations have information about breast cancer and lesbian and bisexual women on their websites (Stonewall, www.stonewall.org.uk; Lesbian and Gay Foundation, www.lgf.org.uk). However evidence of signposting from these groups to cancer services/charities and vice versa is limited. While much of the breast cancer information written for women with breast cancer is likely to be relevant to lesbian and bisexual women (particularly if the language and images used demonstrate it is inclusive), there is little evidence that information providers are being proactive in reassuring lesbian and bisexual women that information and services include them. For example, 'searches' for 'lesbian,' 'bisexual,' or 'sexual orientation' in some of the key cancer information websites do not yield any immediate results. There is a risk that this gives lesbian and bisexual women the message that they are not visible in an organisation and that their needs would not be met.

Access to emotional support

There is research evidence suggesting lesbian and bisexual women are more likely than heterosexual women to experience mental health problems (King, 2003; Skegg et al, 2003). Some research links this to the discrimination they face (Mays et al, 2001; Meyer, 2003; Warner et al, 2004).

However, there are few, if any, psychosocial services specifically designed for/by lesbian and bisexual women with breast cancer and their partners. Existing support groups often require long journeys for those needing them (Fish, 2010).

Formal support groups are often focused on the needs of heterosexual women (Matthews et al, 2002; Fish, 2010). One small US study reported that whereas lesbian and bisexual women were just as likely to attend breast cancer support groups when diagnosed, they were much less likely to report ongoing involvement. They also reported higher stress associated with their diagnosis than the heterosexual women in the study, lower satisfaction with care received from medical staff, and a trend toward lower satisfaction with the emotional support that was available (Matthews, 2002). This last point seems to be reflected to some extent in the UK, where one study of in-depth interviews with 17 lesbian women revealed discomfort at the assumed heterosexuality of the attendees at support groups. One woman who felt emotionally supported through the group did not have her sexual orientation acknowledged (Fish, 2010). There is a danger that services designed to bolster self-esteem at a difficult time could reinforce the message that being lesbian and bisexual is unacceptable.

Some studies have shown that lesbians have alternative social support circles that include former partners, friends and supportive family members (Heaphy et al, 2003; Fish, 2010). A UK study has shown that higher proportions of lesbian women live alone, which may mean finding ongoing support at this time is difficult (Heaphy et al, 2003; Fish, 2010). Living alone, and the alternative support relationships lesbians may have to negotiate, can have implications for the type of day-to-day support required and care in times of crises (Heaphy et al, 2003).

Carers/partners

More than 250 gay and lesbian participants aged over 50 in one UK report (Heaphy et al, 2003) reported an overwhelming emphasis on partners as the most likely carers in times of chronic illness, as well as healthcare professionals in the case of older age. Few of the participants expected family members to take on this caring role. They also expressed limited expectations of community support to recognise and respect their sexuality.

'My partner had breast cancer and although the care she received generally was good, our relationship was never acknowledged and at best I was treated as her "friend", which at times we found difficult and stressful. We didn't like to say anything critical to staff about this because the important thing was that they behaved well to my partner and her care was good.'

Olivia, London (Hunt et al, 2008a).

Patient experience of contact with healthcare professionals

Some research suggests that disclosing one's sexual orientation is a key factor in raising patients' overall levels of emotional wellbeing and that it helps to lower anxiety (Boehmer et al, 2005).

Disclosing one's sexuality to a healthcare professional has health benefits that include:

- being able to communicate more freely with doctors, which may in turn raise satisfaction with the level of care received
- not being subject to inappropriate questioning
- avoiding feelings of anxiety about inadvertently revealing ones sexuality (Fish, 2010).

Findings in the USA and the UK have indicated that women's perceptions of the discrimination they may face from providers if they disclose their sexuality influences the amount and type of discussion they have with professionals (Dehart, 2008; Fish, 2010; Hunt et al, 2008a). One small US study found that women's perceptions of homophobia by healthcare professionals significantly contributed to how often they engaged with healthcare providers (Dehart, 2008).

However, 'coming out' can be difficult if a fear of homophobia restricts a person's ability to disclose their sexual orientation to their healthcare professional team (for example, only half of the 6,000 lesbian and bisexual women surveyed in the UK were 'out' to their GP) (Hunt et al, 2008a). It is not always overt and direct homophobia that is at play but sometimes there are subtle ways in which people feel reaction to their sexual orientation may be negative. Lesbian women are often adept at reading subtle cues through body language, for example to ascertain whether they are in a 'safe' environment to come out (Fish, 2010). These issues may be compounded for BAME lesbian and bisexual cancer patients because of intersecting forms of discrimination. The Cancer Patient Experience Survey 2010 (Department of Health, 2010) found that cancer patients from ethnic minorities experienced worse levels of care, although this is not just specific to cancer services but replicated across the NHS more widely.

Hunt's survey found that just three in 10 lesbian and bisexual women said healthcare workers did not make inappropriate comments when they came out. Just one in 10 lesbian and bisexual women in the same survey felt their partner was welcome during a consultation (Hunt et al, 2008a).

The National Cancer Patient Experience Survey (Department of Health, 2010) highlighted significantly less positive experiences of lesbian and gay patients, compared to heterosexual respondents, particularly on quality of communication with healthcare professionals, and the respect and dignity with which they were treated.

Some of the main issues lesbians raised about coming out to healthcare professionals in one small but in-depth UK-wide sample included: concerns that disclosure would result in a poorer service and/or discrimination; the difficulty of having to keep 'coming out' to different healthcare professionals where there was no continuity of service; being subject to inappropriate questioning from medical staff; concerns about confidentiality; and lack of relevant and targeted information and support groups for carers of lesbian cancer patients (Fish 2010).

'I don't believe I have equal access to appropriate healthcare services as my heterosexual counterparts – partly due to the lack of understanding of specific lesbian health needs and, at times of illness, not always feeling emotionally confident or sufficiently resilient to frequently have to cope with outing myself each visit, facing a barrage of heterosexist and inappropriate questioning from GPs and other health workers. Most of which results in me not bothering to seek medical intervention or preventive healthcare advice until it's virtually not a choice. I will self help and self treat as far as possible. The healthcare sector is alienating, unsafe and does not meet my needs.'

Madeleine, London (Hunt et al, 2008a).

End-of-life care

There has been little work done on end-of-life care in relation to sexual orientation, although several recent projects have sought to explore the issues. The General Medical Council has recently consulted with lesbian, gay and bisexual communities in order to include their concerns and experiences in the Department of Health's End of Life Care Strategy (National Cancer Equality Initiative, 2010). A project by the National Council for Palliative Care in conjunction with the Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organisations, involving in-depth interviews and a larger scale survey, found that many lesbian, gay, bisexual and transgendered people perceived that services at the end of life were not fully open to them, or that they would be reluctant to approach them. On the other hand, end-of-life care providers, such as hospices, largely reported that they felt they were meeting the needs of this group (National Council for Palliative Care and the Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organisations, 2010).

Acknowledging someone's sexual orientation in hospice and palliative care settings can be difficult, with many healthcare professionals given little direction as to how to approach this subject within this setting (Cagle et al, 2009).

While many of the end-of-life issues are similar for all individuals, older lesbian and bisexual women may have some issues specifically related to their sexual orientation, such as discrimination, poor care services that fail to take issues of sexual orientation into account, or anxieties that palliative and end-of-life care services that come into their home might 'out' them or involve negative judgements (Price, 2005).

Legally, lesbian, gay, bisexual and transgendered people have the right to involve their partner in decisions about their care at the end of life, and this isn't limited to those who are in a civil partnership.* The legislation makes it clear that the commonly held belief that 'next of kin', spouses or blood relatives have the exclusive or main right to be consulted is erroneous. However, in practice, it has sometimes been documented that spouses or blood relatives can be prioritised over same-sex partners (Rayner, 2002).

How Breast Cancer Care can help

We provide information and support for anyone affected by breast cancer, at every stage. Our free, confidential Helpline is here for anyone who has questions about breast cancer or breast health. For contact details, see the outside cover.

Breast Cancer Care's website provides online support through its Discussion Forums, where people with breast cancer can exchange tips on coping with the side effects of treatment, ask questions and talk through concerns. With dedicated areas for specific topics and groups, including one for lesbian and bisexual women, these online spaces offer a safe and secure way for people to gain support and reassurance from others in a similar situation. **www.breastcancercare.org.uk/forum**

For information about our policy work or this briefing please contact the Policy and Campaign team at policy@breastcancercare.org.uk

* Under the Mental Capacity Act 2005, everybody engaged in making a decision about a person who has lost capacity, including professionals, is legally obliged to take account of the views of the person's partner about the person's best interests. People can strengthen that by nominating their partner as somebody to be consulted about their best interests, or by giving their partner proxy decision-making authority, using a Lasting Power of Attorney.

References

All Party Parliamentary Group on Cancer (2009). *Report of the All Party Parliamentary Group on Cancer's Inquiry into Inequalities in Cancer*. APPGC and Macmillan

Barking and Dagenham Primary Care Trust (2007). *Lesbians and Cancer*
www.healthwithpride.nhs.uk/upload/files/172.Lesbians_Cancer_Leaflet.pdf

Boehmer, U., Bowen, D.J. & Bauer, G.R. (2007a). 'Overweight and obesity in sexual-minority women: evidence from population-based data' in *American Journal of Public Health*, June, 97(6), pp. 1134–1140

Boehmer U., Linde, R. & Freund, K.M. (2007b). 'Breast reconstruction following mastectomy for breast cancer: the decisions of sexual minority women' in *Plastic and Reconstructive Surgery*, February, 119(2), pp. 464–472

Boehmer, U., Freund, K. M. & Linde, R. (2005). 'Support providers of sexual minority women with breast cancer: who they are and how they impact the breast cancer experience' in *Journal of Psychosomatic Research*, 59(5), pp. 307–314

Brandenburg, D.L., Matthews, A.K., Johnson, T.P. et al. (2007). 'Breast cancer risk and screening: a comparison of lesbian and heterosexual women' in *Women & Health*, 45, pp 109–130

Breast Cancer Care (2007). *Breast Cancer Risk: What it Means to You*. Breast Cancer Care

British Medical Association Equal Opportunities Committee (2004). *Barriers in Medicine: Doctors' Experiences*. BMA

Cagle, J.G. & Bolte, S. (2009). 'Sexuality and life-threatening illness: implications for social work and palliative care' in *Health & Social Work*, August, 34(3), pp. 223–33

Campbell, D. (2005). '3.6m people in Britain are gay – official'. Archived on the *Guardian* website, accessed December 2010, www.guardian.co.uk/uk/2005/dec/11/gayrights.immigrationpolicy

Case, P., Austin, S.B., Hunter D.J. et al. (2004). 'Sexual orientation, health risk factors, and physical functioning in the Nurses' Health Study II' in *Journal of Women's Health (Larchmt)*, November, 13(9), pp. 1033–1047

Creith, E. (1994). Unpublished survey cited in www.lesbianinformationservice.org/bias.htm and <http://kc.csip.org.uk/upload/ALCOHOL2.doc>. Accessed December 2010

Dehart D.D. (2008). 'Breast health behavior among lesbians: the role of health beliefs, heterosexism, and homophobia' in *Women & Health*, 48(4), pp. 409–427

Department of Health (2010). *National Cancer Patient Experience Survey Programme 2010 National Survey Report*. Department of Health

Dibble S.L., Roberts, S.A. & Nussey, B. (2004). 'Comparing breast cancer risk between lesbians and their heterosexual sisters'. *Women's Health Issues*, 14, pp. 60–68

Ettorre, E. (2005). *Making Lesbians Visible in the Substance Abuse Field*. Haworth Press

Fish, J. (2010). *Coming Out About Breast Cancer: Lesbian and Bisexual Women's Experiences Of Breast Cancer*. National Cancer Action Team and De Montford University

- Fish, J. (2007). *Lesbian Health: Briefing 5*. Department of Health
- Fish, J. (2006). *Heterosexism in Health and Social Care*. Palgrave
- Fish, J. & Anthony, D. (2005). 'UK national lesbians and health care survey'. *Women & Health*, 41(3), pp. 27–45
- Fish, J. & Wilkinson, S. (2003). 'Understanding lesbians' healthcare behaviour: the case of breast self-examination'. *Social Science and Medicine*, 56(2), pp 235–245
- Gruskin, E.P., Hart, S., Gordon, N. et al, (2001). 'Patterns of cigarette smoking and alcohol use among lesbians and bisexual women enrolled in a large health maintenance organization' in *American Journal of Public Health*, 91(6), pp. 976–979
- Gunstone, B. (2010). *Cancer Awareness: the Impact of Sexual Orientation*. YouGov
- Heaphy, B., Yip, A. & Thompson, D. (2003). *Lesbian, Gay and Bisexual Lives over 50: A Report on the Project 'The Social and Policy Implications of Non-Heterosexual Ageing'*. Nottingham Trent University: York House Publications
- Hunt, R. & Fish J. (2008a). *Prescription for Change, Lesbian and Bisexual Women's Health Check 2008*. Stonewall and De Montford University
- Hunt, R. & Dick, S. (2008b). *Serves You Right: Lesbian and Gay People's Expectations of Discrimination*. Stonewall
- Hunt, R. Cowan, K. & Chamberlain, B. (2007). *Being the Gay One: Experiences of Lesbian, Gay and Bisexual People Working in the Health and Social Care Sector*. Stonewall
- Hunt, R. & Cowan, K. (2006a). *Harassment and Sexual Orientation in the Health Sector*. Stonewall
- Hunt, R. & Cowan, K. (2006b). *Monitoring Sexual Orientation in the Health Sector*. Stonewall
- Kavanaugh-Lynch, M.H.E., White, E., Daling, J.R. & Bowen, D.J. (2002). 'Correlates of lesbian sexual orientation and the risk of breast cancer'. *Journal of the Gay and Lesbian Medical Association*, 6, pp. 3–4
- King, M. & McKeown, E. (2003). *Mental Health and Social Wellbeing of Gay Men, Lesbians and Bisexuals in England and Wales*. University College London and MIND
- Lesbian and Gay Foundation website breast cancer materials, accessed November 2010, www.lgf.org.uk/breast-cancer
- Love, S. (1995). *Dr Susan Love's Breast Book*. Addison-Wesley Publishing Company
- Matthews, A., Peterman, A., Delaney, P. et al (2002). 'A qualitative exploration of the experiences of lesbian and heterosexual patients with Breast Cancer' in *Oncology Nursing Forum*, 29(10), pp. 1455–1462
- Mays, V.M. & Cochran, S.D. (2001). 'Mental health correlates of perceived discrimination among lesbian, gay, and bisexual adults in the United States' in *American Journal of Public Health*, 91(11), pp. 1869–1876
- Meyer, I.H. (2003). 'Prejudice, social stress and mental health in lesbian, gay and bisexual populations: conceptual issues and research evidence'. *Psychological Bulletin*, 129, pp. 674–697

National Cancer Equality Initiative (2010). *Cancer Inequality Report: Evidence, Progress and Making It Happen*. Department of Health

National Cancer Equality Initiative (2008). *Review of Cancer Inequalities Good Practice Matrix: Papers Presented to the NCEI meeting 16 December 2008*. Department of Health

National Council for Palliative Care and the Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organisations (2010). *Meeting the Needs of LGBT People at the End of Life*. In press

NHS Breast Screening Programme (2009). *All Breast Cancer Report*. West Midlands Cancer Intelligence Unit

Office of National Statistics (2007). *Report from the Review of Equality Data*. Office of National Statistics

Price, E. (2005). 'All but invisible: older gay men and lesbians'. *Nursing Older People*, 17(4), pp. 16–18

Rayner, C. (2002). 'Healthcare, older lesbians and gay men'. *Working with Older People*, 6(4), pp. 26–28

Rubin, L. R. (2009). Decision-making about postmastectomy breast reconstruction among lesbian and bisexual women. Paper presented at the annual meeting of The Association for Women in Psychology Annual Conference 2010.

Skegg, K., Nada-Raja, S., Dickson, N. et al. (2003). Sexual orientation and self-harm in men and women, *American Journal of Psychiatry*, 160(3), pp. 541–546

Stonewall (2010). *Stonewall's Top 100 Employers 2010*. Stonewall

Stonewall Scotland (2010). 'Facts and figures' accessed November 2010, www.stonewall.org.uk/scotland/at_home/2798.asp#Attitudes_in_Scotland

Stonewall website, accessed November 2010
www.stonewall.org.uk/what_we_do/research_and_policy/health_and_healthcare/3473.asp

Valanis, B. G., Bowen, D. J., Bassford, T. et al (2000). 'Sexual orientation and health: comparisons in the WHI sample'. *Archives of Family Medicine*, 9 (9), pp. 843–853

Warner, J., McKeown, E., Griffin, M. et al (2004). 'Rates and predictors of mental illness in gay men, lesbians and bisexual men and women: results from a survey based in England and Wales'. *British Journal of Psychiatry*, 185(6), pp. 479–485

Zaritsky, E. & Dibble, S.L. (2010). 'Risk factors for reproductive and breast cancers among older lesbians'. *Journal of Women's Health*, January 2010, 19(1), pp. 125–131

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Perlita Harris (right) of the Coming Out About Breast Cancer steering group, with her family. Dr Harris has had a diagnosis of breast cancer and is one of Breast Cancer Care's Voices user involvement group. These are volunteers affected by breast cancer who share their experiences, and provide views and opinions on many aspects of Breast Cancer Care's work.

About Breast Cancer Care

Breast Cancer Care is here for anyone affected by breast cancer. We bring people together, provide information and support, and campaign for improved standards of care. We use our understanding of people's experience of breast cancer and our clinical expertise in everything we do.

For information and support on any aspect of breast cancer or breast health contact our free and confidential Helpline, staffed by experienced nurses and specially trained workers with a personal or professional experience of breast cancer. Interpreters are available in any language. Calls may be monitored for training purposes. Confidentiality is maintained between callers and Breast Cancer Care.

Call **0808 800 6000** (Text relay 18001)

Or visit **www.breastcancercare.org.uk**

Central Office
Breast Cancer Care
5-13 Great Suffolk Street
London SE1 0NS

Telephone **0845 092 0800**

Fax **0845 092 0820**

Email **info@breastcancercare.org.uk**