

## Research paper

# Exploring lesbians' health behaviours and risk perceptions

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### ABSTRACT

Little is known about lesbians' healthcare behaviour in the UK or about the ways it may differ from that of heterosexual women. The UK Lesbians and Health Care Survey examines lesbians' health behaviours, specifically their participation in breast and cervical screening, their risk perceptions of cancer and their experiences of healthcare. The survey utilised a combined research instrument which collected both quantitative and qualitative data. The sample was socially diverse and included participation from 1066 lesbians living throughout the UK. Descriptive statistics are presented for health behaviours, alongside qualitative explanations for them. Lesbians were somewhat more likely to have never had a smear test and attended less regularly for cervical screening. They were less likely to practise breast

self-examination regularly, but equally as likely to have had mammograms as heterosexual women. Content analysis of the qualitative data was used to identify key categories. Pain and distress and appropriate attitudes and behaviour were the most commonly cited adverse and positive experiences for both breast and cervical screening. Lesbians were much less likely to believe they were at risk of cervical cancer than heterosexual women. These data contribute to our understanding of lesbians' patterns of health-seeking behaviours, and may help to inform the provision of culturally competent healthcare.

**Keywords:** culturally competent healthcare, healthcare experiences, risk, screening

## Introduction

It is only comparatively recently that systematic research has been undertaken in lesbians' healthcare behaviour and health risks. One of the reasons for this oversight is the belief that lesbians form only a very small proportion of the population. However, a national survey carried out in 1990 and repeated in 2000 found that the proportion of lesbians in the UK population had more than doubled (to 4.9%) in the intervening decade (Johnson *et al*, 2001). While some may argue that such figures still represent an undercount of the lesbian population (Plumb, 2001), they suggest that lesbians form a significant minority group.

Since the pioneering study conducted by Bradford and Ryan in 1988, subsequent research in the USA has investigated lesbians' participation in screening, for example by Diamant *et al*, 2000; their sexual health (Morrow and Allsworth, 2000) and their experiences of healthcare (Saulnier, 1999). It has been assumed

that lesbians have the same health risks and behaviours as heterosexual women. Yet, lesbians may be at higher risk for cardiovascular disease (Roberts *et al*, 2003) and polycystic ovary syndrome (Agrawal *et al*, 2004) and have different patterns of healthcare behaviour.

Previous US research has found that lesbians do not attend regularly for cervical screening (see for example Marrazzo *et al*, 2001). Lesbians were the least likely, of any group of women, to have had a smear test in the past five years (Price *et al*, 1996). Of even greater concern are findings that between 5% and 10% of lesbians have never been screened for cervical cancer at all (e.g. Roberts and Sorensen, 1999).

Less is known about lesbians' breast screening behaviour; one US study (Ellingson and Yarber, 1997) found that slightly more than twice the number of heterosexual women regularly practised breast self-examination (BSE) than did lesbians (45% vs 21%

$n = 166$  vs  $77$ ). Their findings suggested that being lesbian was a stronger predictor for not practising BSE than the commonly accepted factor of increasing age. In relation to mammography, lesbians attend at similar rates to heterosexual women. Researchers have attributed this higher than expected uptake to awareness of the potentially higher risk of breast cancer among lesbians (Lauver *et al*, 1999).

Perceptions of risk are widely believed to motivate women to participate in screening (Umeh and Rogan-Gibson, 2001). In relation to cervical cancer, lesbians are often described as being at lower risk than heterosexual women because of the disease's association with heterosexual sex. Lesbians who have previously had sex with men may be at some risk, as well as lesbians whose female sexual partners have had previous heterosexual sex (Carroll *et al*, 1997). Furthermore, there is growing evidence to suggest that lesbians who have only had sex with women and who have never smoked have still developed cervical abnormalities which might place them at risk of cervical cancer (Bailey *et al*, 2000). Price *et al* (1996) suggest that lesbians are only one-third as likely as heterosexual women to be told they are at risk of cervical cancer. Other studies have indicated that lesbians are explicitly told by healthcare workers that they do not need to be tested (see for example Marrazzo *et al*, 2001).

Lesbians are sometimes described as being at higher risk of breast cancer than heterosexual women. Haynes (cited in Yadlon, 1997) suggested there were five 'lifestyle' reasons for lesbians' higher risk. These are: lesbians are less likely to seek regular gynaecological care; they are less likely to have children; they are more likely to delay childbirth beyond the age of 30 years; they are more likely to be overweight and more likely to drink alcohol than heterosexual women. Subsequent research has suggested that there are differences in some of the risks. Lesbians have been found to report more breast biopsies, to have a higher body mass index and to be less likely to have had children than heterosexual women (Roberts *et al*, 1998). While assumptions about lesbians' increased risk for breast cancer remain controversial (Yadlon, 1997), a recent population study found that lesbians and bisexual women reported higher prevalence rates of breast cancer than did heterosexual women (Valanis *et al*, 2000). No previous study has asked about lesbians' perceptions of their breast cancer risk in relation to their perceptions of heterosexual women's risk.

Studies of lesbians' healthcare experiences have revealed barriers that lesbians face in accessing appropriate and effective healthcare. Healthcare providers have sometimes been found to be uncomfortable with providing care to lesbian patients, and to have difficulties in establishing effective communication (Hinchliff *et al*, 2005). The findings contrast with reports provided by heterosexual women, who do

not commonly cite poor relationships with healthcare providers as barriers to their attendance for screening (Conroy *et al*, 2002). The literature about lesbians' good experiences of healthcare is comparatively small; the inclusion of their partner (or significant other) in care-giving (Saulnier, 1999) has been found to be important.

In the USA, research has led to a national agenda for lesbian health (Solarz, 1999), recommendations for the healthcare needs of lesbians (Council on Scientific Affairs, 1996), and on the inclusion of lesbians in population-based surveys funded by government (Dean *et al*, 2000). By contrast, the Lesbians and Health Care Survey (LHCS) is the first large-scale survey of lesbian healthcare behaviour and risk perceptions in the UK. This paper presents qualitative explanations about lesbians' healthcare behaviours, together with descriptive statistics about frequencies. Quantitative data have been presented elsewhere (Fish and Anthony, 2005). In the absence of other national data, the LHCS is well placed to both make a contribution to understanding the distinctiveness of lesbians' healthcare behaviour, and influence culturally competent healthcare.

## Conduct of the study

### Survey development and design

The UK LHCS was partly modelled on a much-cited national survey of lesbian healthcare in the USA (Bradford and Ryan, 1988). It was divided into four broad sections: cervical screening, BSE, breast screening (mammography), and demographic information. The survey asked respondents to take part if they were able to self-define as lesbians. Self-definition was important, so that respondents were able to articulate their experiences, as lesbians, of health services.

The design of the questionnaire was informed by a series of preliminary focus groups with lesbians talking about their healthcare, which helped to ensure that the design was sensitive to the language and concepts of the proposed participants (Wilkinson, 1998). The survey conformed to the ethical guidelines of the British Sociological Association, and it was approved by a health research ethics committee. The research instrument collected both quantitative and qualitative data, so that patterns of screening could be mapped alongside more detailed explanations for lesbians' health behaviour. The qualitative data were analysed using content analysis (Lindzey and Aronson, 1968) in which key categories of response were identified, and all responses coded into these categories. Each response was subdivided into discrete units of data, for example, different reasons for non-participation in

screening. Response categories were constructed by a process that consisted of bringing together the units of data that are related to the same content, and then testing the usefulness of tentative categories by referring back to the literature.

## Sample

No census-based sampling frame is available to define a population of lesbians, and so lesbian health researchers generally use non-probability methods, typically employing multiple sampling methods (Solarz, 1999). The LHCS included sampling from over 300 social, political and health groups over a 12-month period in 1997–1998, in order to achieve a socially and geographically diverse sample. A total of 3627 questionnaires were distributed and 1066 were returned: a return rate of 29%, which is comparable to those of similar studies (Morris and Rothblum, 1999). The study has one of the largest samples ( $n = 1066$ ) of any single study conducted among lesbians in the UK to date. This paper presents an overview of the qualitative data using five themes identified from the data:

- participation in cervical screening
- practice of BSE
- participation in mammography screening
- experiences of breast screening
- perceptions of risk.

Each is discussed in the following section.

## Findings

### Demographic profile of the survey sample

The sample in the LHCS includes a broad age range from under 20 to over 70 years; 61% of the participants were between 30 and 50 years old, while 8% were aged 51 years and above. Overall, 90% of the sample indicated they belonged to the 'White' ethnic group, while 4.4% nominated an ethnic group other than 'White'. In addition, 4% said they belonged within the category 'Other'. Although the highest proportion of the sample lived in urban settings, the geographic distribution of the survey included lesbians living throughout the UK from Cornwall to the Outer Hebrides. Fifty-seven percent of participants were employed full-time, and 16% were employed part-time. In addition, 11% stated they were students, and 9.5% were unemployed. Eight percent of the sample reported that they had a disability. Thirty-four percent were educated to degree level, and 19% were educated up to 'A' level standard.

### Participation in cervical screening

Participants were asked: 'Have you ever had a cervical smear test?'. In subsequent questions, lesbians were asked for the reasons for their attendance and non-attendance for cervical smears. Eighty-five percent of participants reported receipt of a smear test, and 15% ( $n = 165$ , of 1066) had never attended for a smear (3% were ineligible). The remaining 132 lesbians (12%) were eligible (by age) to attend for screening, but had never been screened. A further 15% ( $n = 159$ ) of those who had ever attended for a test reported that they no longer did so. There were 566 different explanations given for regular screening falling into four broad categories: 'early detection' (40%,  $n = 227$ , of 566); 'prompted by the service' (22%,  $n = 123$ , of 566); 'sexual experiences' (17%,  $n = 95$ , of 566); 'experiences of an abnormal smear' (10%,  $n = 57$ , of 566) (see Fish and Wilkinson, 2000a for an analysis of these findings).

In total there were 125 different explanations for non-attendance, falling into three broad categories. The most frequent explanation given by lesbians for never having had a smear test was 'because I don't need one' (41%,  $n = 51$ , of 125); followed by 'because of negative aspects of the procedure' (39%,  $n = 49$ , of 125) and 'because I'm too busy' (20%,  $n = 25$ , of 125) (see Fish and Wilkinson, 2000b).

### Practice of BSE

The survey asked participants 'Have you ever practised BSE?' and a follow-up question, 'Do you currently practise BSE on a regular basis?'. In subsequent questions, lesbians were asked for the reasons for their practice and non-practice of BSE. Eighty percent of lesbians in the sample said they had practised BSE at least once, while 20% ( $n = 218$ ) said they had *never* practised BSE. In the sample as a whole 13% ( $n = 137$ ) reported regular monthly practice, while 7% ( $n = 76$ ) said they do not currently practise at all. Lesbians gave 122 different explanations for their practice of BSE, coded into four categories: 'experiences of problems' (25%,  $n = 31$ , of 122); 'awareness of particular risks' (25%,  $n = 30$ , of 122); 'established routine' (24%,  $n = 29$ , of 122); 'knowledge about BSE' (14%,  $n = 17$ , of 122) (see Fish and Wilkinson, 2003a). They gave 229 different explanations for not practising BSE. These were coded into six categories, namely: 'I don't know what I'm looking for' (34%,  $n = 79$ , of 229); 'I've never got into the habit' (21%,  $n = 48$ , of 229); 'I'm frightened in case I find something' (12%,  $n = 28$ , of 229); 'I don't think I'm at much risk' (11%,  $n = 26$ , of 229); 'I'm embarrassed or uncomfortable with my body' (7%,  $n = 15$ , of 229); 'my partner does it for me' (7%,  $n = 15$ , of 229) (see Fish and Wilkinson, 2003b).

## Participation in mammography screening

The survey asked participants 'Have you ever had a breast screening test (mammogram)?'. Those who answered 'yes' were asked the follow-up question: 'How many mammograms have you had?'. In subsequent questions, lesbians were asked for the reasons for their attendance and non-attendance for mammograms. Of the 86 lesbians who were eligible for a screening test by virtue of being aged over 50 years, 80% had had a mammogram. Thirty-seven percent ( $n = 32$ ) said they had mammograms on a regular basis. Seventeen percent ( $n = 15$ ) said they had received several in the past, but no longer attended for mammography. There were 851 different explanations for not having had a mammogram falling into four categories: 'I have never been called' (53%,  $n = 452$ , of 851); 'I don't think I'm at much risk' (21%,  $n = 177$ , of 851); 'because of negative aspects of the procedure' (15%,  $n = 128$ , of 851); 'don't know about it' (7%,  $n = 57$ , of 851). There were 201 different explanations for having had a mammogram, and these were coded into four categories: 'I have experiences of problems' (31%,  $n = 63$ , of 201); 'I am prompted by the service' (28%,  $n = 56$ , of 201); 'I am aware of particular risks' (16%,  $n = 32$ , of 201); 'I am reassured by mammography' (11%,  $n = 21$ , of 201).

## Experiences of cervical screening

Participants who had had cervical screening were asked: 'Have you personally had any bad experiences of cervical smear tests?' and 'Have you personally had any good experiences of cervical smear tests?'. Under half of those who had attended for at least one smear, 44% ( $n = 394$ ), reported that they had had *bad* experiences of smears, while 46% reported *good* experiences of smear tests ( $n = 418$ ). There were 787 different explanations for bad experiences, which were coded into three categories: 'experiences of pain and distress' (39%,  $n = 308$ , of 787); 'negative aspects of the procedure' (31%,  $n = 245$ , of 787); 'inappropriate attitudes and behaviour' (25%,  $n = 194$ , of 787).

There were 814 different explanations for good experiences, which were coded into three categories: 'appropriate attitudes and behaviour' (38%,  $n = 311$ , of 814); 'positive aspects of the procedure' (36%,  $n = 291$ , of 814); 'no pain or embarrassment' (16%,  $n = 128$ , of 814).

## Experiences of breast screening

The questionnaire asked participants who have had breast screening 'Have you personally had any bad experiences of mammograms?' and 'Have you

personally had any good experiences of mammograms?'. Over one-quarter (26%,  $n = 51$ ) of participants reported *bad* experiences of breast screening, while over one-third (35%,  $n = 70$ ) reported good experiences. There were 113 different explanations for bad experiences falling into three categories: 'experiences of pain and distress' (53%,  $n = 61$ , of 114); 'inappropriate attitudes and behaviour' (23%,  $n = 25$ , of 114); 'aspects of the procedure' (15%,  $n = 17$ , of 114). There were 123 different explanations for good experiences, and they were grouped into three categories: 'appropriate attitudes and behaviour' (37%,  $n = 46$ , of 123); 'aspects of the procedure' (24%,  $n = 30$ , of 123); 'no pain' (16%,  $n = 20$ , of 123).

## Perceptions of risk

Participants were asked: 'How do you see lesbians' risk of developing cervical cancer (relative to that of straight women)?' and 'How do you see lesbians' risk of developing breast cancer (relative to that of straight women)?'. Fifty-one percent of survey participants said that lesbians' risk of cervical cancer is lower than that of heterosexual women, and 43% said the risk is the same, while only 2% said lesbians' risk is higher than heterosexual women's risk. The most common explanations for lesbians' perceptions of cervical cancer risk were, lower: 'no sex with men' 37% ( $n = 26$ , of 707); the same: 'sexual behaviour' 38% ( $n = 201$ , of 526); and higher: 'lesbians are less likely to have smears' 41% ( $n = 14$ , of 34). Only 3% said lesbians' risk of breast cancer is lower than that of heterosexual women, 76% said their risk is the same, and 19% stated their risk is higher. The most common explanations for lesbians' perceptions of breast cancer risk were, lower: 'lesbians are unlikely to take the contraceptive pill' 50% ( $n = 14$ , of 27); the same: 'being lesbian is not a risk factor for breast cancer' 38% ( $n = 237$ , of 628); and higher: 'because fewer lesbians have children' 56% ( $n = 141$ , of 252).

## Discussion

In comparison with the general population of women in the UK (Matheson and Babb, 2002), lesbians in the sample were younger, had a higher level of educational achievement, had better jobs and were more likely to hold a full-time job. There were similar proportions of lesbians from ethnic minorities as there were in the UK population at the time the study was conducted. Moreover, black-African, black-Caribbean and black-Other lesbians were better represented in the survey than their proportions in the population (3.6% vs 1.6%). However, while the LHCS sample was

demographically diverse, at least as much as in other non-probability studies, it is not likely to be fully representative of lesbians living in the UK. This is because lesbians form a hidden population that is both geographically dispersed and relatively small. Some lesbians fear that their identities may be revealed even in anonymous surveys (e.g. by postcode or other demographic data); population-based studies have found high refusal rates to items on sexual identity (Valanis *et al*, 2000). It is, however, a better *distributed* sample than that obtained by the only other UK survey of lesbians to include a criterion for geographic distribution. In that study by Henderson *et al* (2002), the 11 regional health authorities were used. In comparison, the LHCS achieved returns from 117 out of 122 postal areas.

### Participation in screening

Twelve percent of the sample had never attended for a cervical smear test, and a further 15% reported that they no longer attended. In comparison, 15% of all women in the UK do not attend regularly for smear tests (Department of Health, 1999). Furthermore, lesbians' attendance was less regular than found in US studies of lesbians (Roberts and Sorensen, 1999). The most common explanation for not attending for cervical screening, cited in 41% of explanations, was the perception they were not at risk for cervical cancer. In comparison, heterosexual women most commonly reported fear and embarrassment as reasons for non-attendance (McKie, 1993). Thirteen percent of lesbians in the LHCS regularly practised BSE, in comparison to 41% of all women (Umeh and Rogan-Gibson, 2001). In addition, they appeared to be less likely to practise BSE on a regular basis than US lesbians (13%, LHCS vs 21%, Ellingson and Yarber, 1997). Thirty-four percent of those who had never practised BSE explained that they did not know what they are looking for. Although these reasons are similar to those found in other studies, presumed heterosexual women appeared to be more likely to say that starting a new habit was the greatest barrier (Umeh and Rogan-Gibson, 2001). Of those participants who were aged 50 years and above, 80% had had a mammogram. These data about ever having attended for mammography are similar to those of presumed heterosexual women (75%); however, 22% of them failed to re-attend, in comparison to 10% of heterosexual women (Marshall, 1994).

### Experiences of screening

Forty-four percent of survey participants reported bad experiences of cervical screening, with 46% reporting good experiences. By contrast, (presumed) heterosexual

women were much more likely to report good experiences of smear tests than bad ones (74% and 12% respectively) (Summers and Fullard, 1995). Cervical screening appears to be a more painful and distressing procedure for lesbians than for heterosexual women. It is the most frequent explanation given for a bad experience, reported by 39% of those citing bad experiences. By contrast, heterosexual women appeared to be more likely to find the test uncomfortable, and they commonly reported embarrassment (McKie, 1993); embarrassment rarely featured in lesbians' explanations.

In the breast screening data, 26% reported bad experiences, and 35% reported good ones. Few studies have collected quantitative data about women's experiences; a US comparative study of lesbian and heterosexual women found that lesbians were less satisfied with their care (Fobair *et al*, 2001). Heterosexual women appear to be much more likely to say that appropriate attitudes and behaviour of staff contributed to a good experience of breast screening (Smith *et al*, 1991) than were lesbians in the present study (69% vs 37%).

### Perceptions of risk

The LHCS asked lesbians about perceptions of their risk of cervical and breast cancer *vis-à-vis* heterosexual women. Two other studies have investigated how lesbians perceive their risk of cervical cancer. The first (US) study found that the majority (60%) of the lesbian participants perceived that lesbians, bisexual and heterosexual women were equally likely to develop cervical cancer (Price *et al*, 1996). In the second study, 75% of British lesbians who were attending for smear tests perceived their need for cervical screening to be equivalent to that of heterosexual women (Bailey *et al*, 2000). In the present study, substantially fewer lesbians, 43%, perceived that they were equally likely to be at risk as heterosexual women. These data suggest that lesbians in the LHCS who were not already participants in the screening programme were less likely to believe their risks of developing cervical cancer are the same as heterosexual women's risk. These findings may explain why British lesbians in this study were less likely than UK heterosexual women and US lesbians to attend for smear tests.

The LHCS found that 19% of lesbians believed their risk of breast cancer to be higher than that of heterosexual women, while three-quarters (76%) believed that their risk was the *same* as that of heterosexual women. This is an unexpected finding, in view of the commonly held assumption in the USA that lesbians are at higher risk for the disease (Solarz, 1999). One possible explanation may be that lesbians' increased risk for breast cancer has been more widely reported in

the US media than in the UK (Selvin, 1993), and consequently British lesbians may be less familiar with the debate. Alternatively, UK lesbians may be sceptical about the purported risk factors for breast cancer, which are common lifestyle correlates among lesbians rather than a lesbian identity *per se*.

In conclusion, lesbians in the study were less likely to participate in routine health screening such as smear tests and BSE, and less likely to re-attend for mammography. They were more likely to report bad experiences of screening than were heterosexual women in similar studies; experiences of pain were the most common explanation given for both breast and cervical screening. The research also highlighted that they were less likely to believe they were at the same risk of cervical cancer as heterosexual women. These findings have implications for the development of culturally competent care. McGee and Johnson (2004), in their discussion of the concept, have drawn attention to the need for practitioners to understand how culture may mediate experiences of health. Cultural competence can also be usefully applied to lesbians' healthcare; it implies understanding of why lesbians might be reluctant to attend for screening, the effect of heterosexism on their health and health behaviour, and awareness of their health risks. The findings also contribute to the limited literature on lesbians' good experiences of screening: appropriate attitudes and behaviour of health professionals were the most commonly cited reasons. These data may inform the development of relevant healthcare for lesbians. The introduction of the Equality Act 2006 makes this timely; the legislation included proposals to prohibit discrimination on the grounds of sexual orientation in the provision of goods and services, including health (Women and Equality Unit, 2006). By providing culturally competent practice, healthcare may begin to offer services which indeed offer *Fairness for All*.

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#### CONFLICTS OF INTEREST

None.

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