Understanding lesbians’ healthcare behaviour: the case of breast self-examination

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Abstract

Lesbians’ risk of breast cancer is a much-debated issue in health research because lesbians are believed to be at higher risk of the disease than are heterosexual women. This belief is based upon particular risk factors for breast cancer, which are said to be more prevalent in lesbians; and upon differences in preventive health behaviours: in particular, lesbians are said to be less likely to practise breast self-examination (BSE). This paper presents data collected as part of the UK Lesbians and Healthcare Survey ($n=1066$) focusing on lesbians who report never practising BSE ($n=218$; 20%) and the explanations they offer for their healthcare behaviours. It identifies six types of explanation for not practising BSE: (i) “I don’t know what I’m looking for”; (ii) “I’ve never got into the habit”; (iii) “I’m frightened in case I find something”; (iv) “I don’t think I’m at much risk”; (v) “I’m uncomfortable with my body”; and (vi) “My partner does it for me”. These findings are important for increasing understanding of lesbians’ healthcare behaviour and for developing health promotion materials relevant to their needs. \textcopyright 2002 Elsevier Science Ltd. All rights reserved.

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Introduction

Although deaths from breast cancer in Britain have fallen slightly in the past decade (Kmietowicz, 2000) it remains the most common type of non-preventable cancer in women. There are some well recognised risk factors for the disease which include: getting older, having a close female relative with breast cancer; having no children, or delaying childbirth after the age of 30; not breast feeding; being overweight; drinking alcohol; and environmental factors (Arditti & Schreiber, 1994; Hulka & Stark, 1995; Wunsch, 1997). The overwhelming majority of women, however, have none of the risk factors for breast cancer except for age (Batt, 1994). The complex inter-connection of these risk factors (and other known and unknown factors) means that prevention is not possible (Heyderman, 1996), and so medical attention has turned to breast self-examination (BSE), particularly for women who are below the age for the UK national breast screening programme. Currently, despite controversy about the efficacy of BSE (see the recent review in Brabow & Kline, 2000), biomedical sources continue to advise women to practise (e.g. Forrest, 1986; Taylor, 1991; Austoker, 1994). The available knowledge suggests that BSE can encourage women to find breast lumps through regular and systematic checking of their breasts, looking for changes (rather than by chance). As many as 90\% of breast lumps are found by women themselves (Durham, 1991; Barnett, 1997).

Lesbians’ risk of breast cancer

Lesbians’ risk of breast cancer is a much-debated issue in health research because lesbians are believed to be at higher risk of the disease than are heterosexual women (Bybee, 1991; Lucas, 1993; O’Hanlan, 1995; Rankow, 1995). This belief is based upon risk factors for breast cancer, which are said to be more prevalent in lesbians.
These are: that lesbians are less likely to have children (Rankow & Tessaro, 1998; Roberts, Dibble, Scanlon, Steven, & Davids, 1998); are more likely to delay childbirth beyond the age of 30 (Bybee, 1991); that older lesbians are more likely to drink alcohol (Bradford & Ryan, 1988; Roberts & Sorensen, 1999) and are more likely to be overweight than heterosexual women (Deevey, 1990). Haynes’ (1992) epidemiological overview of these risk factors was widely reported in the media, with the press extrapolating—somewhat wildly—from it to make such claims as: ‘one in three lesbians risks death from breast cancer’ (Selvin, 1993) and ‘early indications are that breast cancer may cut as wide a swathe through the female and lesbian populations as HIV has through the world of gay males’ (Gessen, 1993). The findings are controversial. Firstly, given that so little is known about lesbians’ health, it is difficult to ascribe such socially undesirable characteristics as obesity and heavy drinking to lesbians as a group; secondly, these risk factors confuse behaviour (e.g. having children) and identity (being lesbian) (Yadlon, 1997). However, Haynes’ suggestion of lesbians’ increased risk for breast cancer was not previously unheard of within the small literature of lesbian health. The possibility of lesbians’ greater susceptibility to breast cancer appears first to have been raised by O’Donnell, Pollock, Leoffler, and Saunders (1979) in relation to childless lesbians, and such a suggestion was reported by others (Johnson, Guenther, Laube, & Keetel, 1981; Hepburn & Gutierrez, 1988, Burns, 1992) prior to Haynes’ paper. Whether or not lesbians are at higher risk of breast cancer than are heterosexual women (and we simply do not know, because the research has not been done), there is a common perception, at least in the USA, among lesbians themselves that they are (Solarz, 1999).

Lesbians’ practice of breast self-examination (BSE)

Key differences in breast health care between lesbians and heterosexual women appear to be that lesbians are less likely to practise breast self-examination (Bradford & Ryan, 1988; Rankow, 1995; Burnett, Steakley, Slack, Roth, & Lerman, 1999) and that lesbians delay in seeking treatment for breast problems (Trippet & Bain, 1993; White & Dull, 1997). It may be then, that there is a higher mortality risk among lesbians because their malignant lumps are not detected sufficiently early (Love, 1995). In a study which compared breast self-examination practice in a sample of 303 heterosexual and lesbian women, Ellingson and Yarber (1997) found that slightly more than twice the number of heterosexual women regularly practised BSE than did lesbian women (44.9% vs. 21%). One-third of women in both groups never, or rarely, practised BSE. They found a stronger association between being lesbian and not practising BSE than between increasing age and not practising BSE (c.f. Phillips & Brennan, 1976; Payne, 1991). The women in their (USA) study were reminded by their annual gynaecological examination to perform BSE and it was more likely that heterosexual women attended such regular check-ups than did lesbians. In the UK, there is no equivalent practice; however, heterosexual women may be more likely to have attended a family planning clinic for contraception and to have found that BSE was promoted there.

This paper reports on the findings of a national survey on Lesbians and Health Care in the UK. It focuses on those lesbians who do not practise BSE and its aim is to explore the range of explanations that they give for never having done so. Although, as noted, previous studies have found that lesbians are less likely to practise BSE, few have focused on the reasons that lesbians give for their healthcare behaviour. The findings are important because lesbians are an overlooked population in the healthcare system and breast health has been a largely neglected area within the small body of literature in lesbian health care (Zeidenstein, 1990) (with some notable exceptions: Dykenosis, 1995; Lesbian Avengers, 1996; Wilton 1997). Understanding why lesbians do not practise BSE may help in the development of appropriate health promotion materials for the group.

Method

The UK Lesbians and Healthcare Survey is partly modelled on a much-cited national survey of lesbian health care in the USA (e.g. Bradford & Ryan, 1988). It involves a self-administered questionnaire, which includes questions about lesbians’ perceptions and experiences of breast self-examination. It has the largest sample (n = 1066) of any single study conducted among lesbians in the UK to date. Because no census-based sampling frame is available to define and randomly sample lesbians for study (O’Connell-Davidson & Layder, 1994), lesbian health researchers commonly use non-probability methods, that go beyond convenience sampling, by employing multiple sampling methods (Solarz, 1999). The Lesbians and Healthcare Survey entailed the use of such a sampling frame in order to achieve a socially and geographically diverse sample, (see Fish, 1999, 2000; for an extended discussion of sampling in lesbian communities).

Although mostly quantitative, the design of the questionnaire included qualitative text boxes in which respondents could give more detailed reasons for their behaviour. The qualitative data were analysed using content analysis (Lindzey & Aronson, 1968)—in which key categories of response were identified and all responses were then coded into these categories. Each
qualitative response was sub-divided into discrete units of data (e.g. different explanations for practising BSE). We then constructed response categories by a process that consisted of bringing together the units of data that are related to the same content, testing the usefulness of tentative categories by referring back to the literature, and then modifying them in the light of the data. Both authors were involved in coding—the level of agreement was high, and any disagreements were resolved by discussion. In our analysis, we aimed both to map the diversity of healthcare behaviours and the explanations given for them and to ‘preserve’ the ‘flavour’ of individual responses within the data set as a whole (c.f. Silverman, 1993). The content analysis is summarised by means of descriptive statistics (e.g. number and percentages of responses for each category) and data extracts are used to illustrate the kinds of explanations lesbians gave. The categories provided an organisational schema for the empirical findings, which can then be related to existing literature in the area of lesbian health and used to develop more comprehensive explanations of lesbians’ healthcare behaviour.

The questionnaire asked respondents: “Have you ever practised breast self-examination?” Those who answered ‘no’ were asked the follow-up question: “Many lesbians don’t practise breast self-examination. Why is this the case for you?” The explanations that lesbians gave for never practising BSE are the focus of the following section. Lesbians themselves made the assessment that they had never practised BSE, although in some responses it would appear that respondents had attempted, but had not continued the practice.

Findings and discussion

One-fifth (20%) of the total sample (n = 218, of 1066) report never having practised BSE. In total lesbians gave 229 different explanations for not practising BSE (some respondents gave more than one explanation). These explanations were coded into six key categories: (i) “I don’t know what I’m looking for”; (ii) “I’ve never got into the habit”; (iii) “I’m frightened in case I find something”; (iv) “I don’t think I’m at much risk”; (v) “I’m embarrassed or uncomfortable with my body”; and (vi) “My partner does it for me”. All but 19 of the explanations were accounted for by these categories. We will consider each of these categories in turn.

(i) “I don’t know how to do it”. The most frequent explanation given by lesbians for never having practised breast self-examination is that they do not know what they are looking for. Some 34% (n = 79, of 229) of explanations fell into this category. In these explanations, lesbians expressed doubts about their ability to detect abnormalities. This category includes three types of explanations: “I don’t know how to do it”, ‘I’ve never been shown how to do it’ and ‘I don’t know what I’m looking for’.

In the first type of explanation, lesbians talked about being unfamiliar with the technique for breast self-examination: “I wouldn’t know what to do” (R187); “I don’t really know how to do it properly” (R146); “I wouldn’t know how to start” (R902). They indicated that “not knowing how to” (R036) is what prevents them from doing BSE. These explanations can be broadly characterised as concerns about their ability to perform BSE.

Second, lesbians said that there is “no information on how to” (R962a) and that healthcare workers do not promote breast self-examination: “I have never been properly informed about when one should begin doing it” (R685a), or told “in what circumstances it may be important” (R500a). In their explanations, lesbians said that it is not clear where to go for advice about BSE: “but I don’t know who to ask” (R627b); “I’ve never actually been shown how to do it, therefore don’t but given the advice & help I [sic] probably do it” (R264); “My ‘well women’ at the local doctors is supposed to include breast examination. I have not yet been asked if one could be done or if I know what to do” (R466). ‘Being shown’ featured quite strongly in their responses although being told once is not sufficient to establish the practice: “I keep being told or reading & just keep forgetting the right procedure” (R243).

Third, some lesbians explained that they did not practise BSE because they were uncertain ‘what to look for’: “I’m not quite sure what I’m looking for anyway” (R217b); “I’ve never really known what it is I’m supposed to be looking for” (R691); “apart from a big lump” (R798b). Others specified that they did not know how to distinguish a lump from lumpiness: “I’ve tried but my breasts change all the time and how do you tell? (whether you should go to the doctor or not)” (R807); “I would have no idea what constitutes a lump as opposed to lumpiness” (R535a); “Apparently I have naturally lumpy breasts which make self-exam problematic” (R1058). Some expressed uncertainty about what to look for because of the lumpy nature of breast tissue and because they were not sure about their technique: “Don’t know how. Always feel lumps. But I think this is normal” (R158); “Don’t really know how to my breast(s) seem lumpy anyway—I don’t know if I could tell the difference” (R829). In these explanations, the concern is whether they can differentiate between ‘normal’ lumpiness and a lump that needs to be investigated.

In the BSE literature, these three factors (i.e. knowing how to do BSE, being shown how to do it, and knowing what one is looking for) are said to make it less likely
that women will examine their breasts on a regular basis. First, research is said to indicate that women differ in their confidence in terms of their ability to do self-examination correctly (Stillman, 1977; Miller, Hurley, & Shoda, 1996; Savage & Clarke, 1996; Champion & Scott, 1997) and a number of studies have evaluated strategies designed to improve women's technique (Turner et al., 1984; Brailey, 1986; Agars & McMurray, 1993). In the 'popular' literature also, explanations of the procedure, sometimes accompanied by photographs or diagrams, endeavour to ensure that women improve the efficacy of their performance—for example through patterns of palpation (Boston & Louw, 1987; Faulder, 1989; Cirket, 1992; McConville, 1994; Stoppard, 1996). These concerns about ability or technique were articulated in lesbians' accounts here, in that they expressed concerns that they did not know how to do BSE.

Second, the literature suggests that having received personal instruction from a nurse or doctor increases the frequency of practice, particularly when a woman has been shown how to do BSE by one-to-one example (Emmanuel, Potts, Thomson, & Twomey, 1989; Lashley, 1987; Lauver, 1987; Faulder, 1982; Nettles-Carlson, 1995). In Stillman's study one of the reasons women gave for not practising BSE was that they had never been shown how to do it (1977; 125); and only 87 respondents (of her sample of 142) said that they had learned about BSE from a doctor or a nurse. George (2000) found that the strongest influence for initiating BSE was physician advice. Here too, lesbians said that they have never been shown how to do BSE, or that they would like to be shown how to do it.

Third, there is the suggestion, in the BSE literature, that health promotion campaigns tell women to look for a change in their breasts but do not explain what the precise changes are (Stoppard, 1996). Such campaigns appear to ignore the fact that normal changes such as the pre-menstrual lumpiness of the breasts are common. These changes in the breast can provoke uncertainty of what to look for (Savage & Clarke, 1996; Stillman, 1977)—and this uncertainty is not limited to women themselves: some doctors can also be confused (Elliott, 1994; Love, 1995; Reid, 1994; Stoppard, 1996). These uncertainties featured in lesbians' accounts here, in that they expressed concerns that they did not know exactly what they are looking for.

In sum, then, many lesbians who do not examine their breasts said that this was because they were concerned that they did not know the correct procedure; that they had never been shown how to do BSE; and that they did not know what they were looking for. There are obvious implications for health education and health promotion here—and we will return to these.

(ii) “I've never got into the habit”. In 21% of explanations (n = 48, of 229), lesbians said that they had never got into the habit of doing BSE. In these responses, lesbians said that they knew about BSE, but they had not developed a routine: “it's something I have thought about but never got into the habit” (R017). Many lesbians said they postponed the activity: “I always think about it but always leave it for next month” (R224a). In part their explanations for not doing BSE are attributed to a “busy life” (R1019). Specific pressures are sometimes identified: “Always put it off for another week. Too many other hassles—kids, work, coming out etc” (R967). In other responses, BSE was seen as an additional burden in their lives “...feel I have enough to remember as it is, without adding to it” (R1015a).

In the literature, there is support for the difficulty some women find in establishing a routine. Because BSE is such a conscious and infrequent behaviour it can never become a 'habit' in the sense of automatic behaviour (Grady, 1988). In addition, the onset of a menstrual period (sometimes suggested as a 'prompt') serves as only a distant reminder, since (ideally) BSE should be done a week later—and is obviously of no value to the post-menopausal woman. Habits are also said to need to provide some reinforcement so that they can be maintained: the best outcome from BSE is that nothing is found. Because normal breasts are often lumpy, however, a woman who practises BSE may find a change in her breasts and have to make a judgement about it. Not only may the practice of BSE lack reinforcement, but it may also increase anxiety (Hailey, Lalar, Byrne, & Starling, 1992; Owens, Daly, Heron, & Leinster, 1987). There is no agreed-upon age at which women should be encouraged to begin performing BSE, for example, Boston and Louw (1987, p. 111) argue that the habit should be developed early, as teenagers, so that by the time a woman enters the 'danger' years self-examination is already established as a routine.

In the light of these considerations of 'routine' in the literature, the data may suggest that lesbians do not perform BSE due to difficulties inherent in the procedure itself. Lesbians here said that they never get round to it, they have never really thought about it or that they forget to do it. Self-examination has not become an automatic behaviour for them, despite the fact that some said that they know about BSE or that they thought it was a good idea. Others said that they cannot be bothered to do BSE and it may be that they do not see any immediate rewards for practising self-examination. Because there is not an agreed upon age (unlike the age of 50 for mammograms) when BSE should begin, they can postpone the ‘habit’ for another month or until they are older.

In short, many lesbians said that they had never practised BSE because they had never got into the habit; they had never really thought about it; or that they could not be bothered doing it. This could well be due to the nature of the procedure and it is an issue that has
been partly addressed in recent ‘breast awareness’ health promotion campaigns.

(iii) “I’m frightened in case I find something”. Being frightened or worried in case they found something was another important reason given by lesbians for not practising BSE: some 12% (n = 28, of 229) of the responses fell into this category. Their worries ranged from a general and unspecified fear, through the fear of finding a lump, to the fear, not only of the possibility that a lump might be cancer, but also of possible medical interventions. Some lesbians expressed fear about BSE without clarifying what they were frightened about: “Medical nightmare” (R936). Sometimes their fear appeared to overwhelm their recognition of the benefits of self-examination: “I’m very frightened of doing so I think I need to but I’m scared” (P534) and there were those who use avoidance strategies: “and have a ‘bury my hand in the sand’ thing” (R416b). Other lesbians said that they do not self-examine because they were frightened by the possibility of finding a lump: “I’m too scared I will find a lump in my breast so I don’t bother” (R193); “Too frightened in case I find something” (R218); “I think I’m too scared in case I found a lump” (R579). Still others expressed a fear of cancer: “Probably don’t want to think about cancer!” (R978), or apprehension about possible treatment for cancer: “A friend died of breast cancer (straight)—I don’t want to be put through all that” (R716).

In these explanations there is also a suggestion that lesbians did not want to be responsible for their own diagnosis: “I don’t want to take responsibility for discovering a lump” (R810); “I wouldn’t necessarily trust my own judgement as I would probably panic very easily” (R1045b). Sometimes the fear was whether their symptoms would be taken seriously: “the fact of having something” (R456).

In the literature, breast cancer is said to be the disease that women fear the most (Read, 1995). It has received steadily increasing media coverage in recent years and its profile is higher than that of all other common cancers (Saywell, Beattie, & Henderson, 2000). Not surprisingly then, women are said to be frightened of what they may find because breast lumps are frequently associated with breast cancer (Fallowfield & Clark, 1991). In the face of such fears and anxieties, most writers seek to allay women’s concerns by advising the regular practice of BSE to promote early detection (Stopard, 1996). Yet in order to encourage women to perform breast self-examination the message from health promotion campaigns aims to raise ‘anxiety’ about the seriousness of breast cancer without inducing ‘paralysing fear’ or the ‘obsessional examination’ of the breasts (Fallowfield & Clark, 1991, p. 33). In raising awareness of breast cancer, it has often been deemed necessary to talk about the disease in strong terms. This is evident in both populist writings (Carter, 1996) and in medical texts (McPherson, 1994). Breast cancer more than any other cancer is said to be a ‘particularly cruel cancer’ (Franklin, 1996) which ‘is extremely rampant and very, very scary’ (Cappellino, 1996). The statistics are said to be ‘devastating’ (Wakeley, 1996), it is a disease which seems to be inescapable: ‘with … 30,000 cases each year in England alone it’s easy to see the odds are against you’ (Yashar, 1996). This loss of life is equivalent to a ‘jumbo jet crashing every week of the year’ (Read, 1995).

In the light of such accounts, it is not surprising that women are scared of breast cancer, and what is described, in the literature, as the ‘ostrich position’ (McConville, 1994, p. 182) could be a reasonable response to this disease. However, the findings of this study do not support the suggestion in the literature that fear is the most commonly given reason for not performing BSE on a regular basis (Baum, Saunders, & Meredith, 1994; Boston & Louw, 1987; Faulder, 1989). By contrast with these studies only 12% of respondents’ explanations in the Lesbians and Health-care Survey suggested that fear was the reason for not practising BSE.

Lesbians did cite fear, then, as an explanation for not practising BSE, but it was not the most common explanation provided in this study. Their fear was most often expressed in terms of fear about finding a lump and fear that the lump might turn out to be breast cancer.

(iv) “I don’t think I’m at much risk”. The fourth category of explanations for not practising BSE included lesbians’ beliefs that they were not at risk for breast cancer. Such beliefs featured in 11% (n = 26, of 229) of explanations given for not practising BSE. This was mostly because the younger lesbians in the sample perceived themselves to be too young to develop the disease: “I’m only 17! I don’t think I’m at much risk” (R164); “I was under the impression breast cancer does not affect women of a younger age group much (the risks are not as high)” (R272); “When breast cancer is mentioned I always think of old ladies” (R299); “Probably because I’m quite young (20s) and have the impression that there’s not much risk of breast cancer till I reach my late 40s/early 50s” (R435). But occasionally it was because they thought that they were too old: “I’m in my late 70s and don’t think I’m likely to develop breast cancer” (R826) and “have never given it a thought, now much too old to worry” (R827).

Other less frequent reasons that lesbians gave for not believing themselves to be at much risk included the association of breast cancer with family history: “I believe that it is hereditary to some degree so I feel fairly safe” (R381); “I have no history of breast cancer within the family so I suppose I don’t see the immediate danger”
Lesbians’ own explanations mirror the literature on risks of developing breast cancer which suggests that almost 80% of breast cancers occur in women over 50 (Heyderman, 1996) and that a woman’s age is one of the most significant risk factors (Faulder, 1989). Before the age of 30, a woman is highly unlikely to develop breast cancer (Faulder, 1989). Most of the images of women with breast cancer, however, give the impression that it is a disease of young women. Susan Love (1995, p. 184) suggests that many older women under-estimate their risk because they are not getting the message that this disease becomes more common in older women.

Family history of breast cancer is particularly emotive, because although it only accounts for a small proportion of cases, it is a common cause of breast cancer at a young age (Read, 1995). The representations of breast cancer in the literature overwhelmingly link the disease to hereditary factors (Stoppard, 1996). Because of these representations of risk, some women believe that they are not vulnerable to breast cancer because they have no family history (Salazar & Carter, 1994).

Widely held beliefs, then, about increasing age as the most important risk factor for breast cancer featured here in lesbians’ explanations for not perceiving themselves to be at risk. Lack of family history and lack of symptomology were also given as reasons for not practising BSE.

(v) “I’m uncomfortable with my body”. Feelings of embarrassment and discomfort are articulated in some of the explanations (7%, n = 15 of 229) that lesbians gave for not practising BSE: “uncomfortable with my body” (R151), “embarrassment” (R1038). Although recognising that breast self-examination is a good idea, some lesbians felt unable to self-examine: “I know I should but it feels awkward to check my own breasts” (R217) and “I believe strongly in the importance of self-examination but I think my relationship to/with my breasts stops me” (R745). For some lesbians, the discomfort was about the body in general: “am used to little interaction with my body” (R860); “I Don’t [sic] like touching my own body” (R579). For others it was specifically the breasts: “I don’t like the feel of my own breasts” (R726) and “I do no [sic] like my body fumbled with except by my partner. & self-examination smacks too much of masturbation” (R576). Sometimes strong feelings were evoked by the prospect of BSE: “It makes me nauseus” [sic] (R865).

A few respondents also spoke of negative feelings about themselves and their bodies overall: “I’m sure there are deep seated psychological reasons why I don’t do them—a sort of recklessness & self destruct part of myself when it comes to looking after myself totally” (R448d); “I don’t do it because it would involve viewing my body—femininity & sexuality positively. I suppose, in some ways—especially in relation to health, I live ‘outside’ of my body” (R542). Or suggested that their lack of practice of BSE was linked to other preventive health measures that they did not engage in also: “I have a very poor attitude towards my health and don’t go for any sort of health checks, teeth, eyes, gynaecological [sic] etc....This is not good I know” (R416).

These explanations of feeling uncomfortable or embarrassed can also be found in the literature on BSE. However, it appears to be a less common explanation among lesbians than in studies of (presumed) heterosexual women which found that 18–23% cited embarrassment as a reason for not practising BSE (Stillman, 1977; Brailey, 1986). Women have often been taught to find shame in, and feel alienation from, their bodies and the prospect of practising BSE is an uncomfortable one for some women (Boston & Louw, 1987; Love, 1995). Embarrassment sometimes appears to be strong enough to detract from practising BSE: e.g. for 18% of women in Stillman’s (1977, p. 126) study. Similarly, 23% of Brailey’s (1986, p. 227) respondents agreed with the statement ‘Even though it’s a good idea, I find examining/having to examine my breasts an embarrassing thing to do’. Elsewhere in the literature, Fallowfield and Clark (1991) suggest that it is older women who find BSE embarrassing. The practice of BSE is linked to positive attitudes to the body and participation in other preventive health measures (Calnan, 1984a), women who do not practise BSE are also less likely to attend for dental check-ups or cervical smear tests.

To summarise, a number of lesbians suggested that they do not practise BSE because they felt uncomfortable and embarrassed about their bodies.

(vi) “My partner does it for me”. The final type of reason given for not practising BSE was that ‘my partner does it for me’ and 7% (n = 15, of 229) of the responses fell into this category. Some of the responses emphasised the pleasurable aspects of this: “It’s much more enjoyable when your partner does it” (R287); “shes [sic] always playing with my tits if there was anything wrong I would know” (R354); “Much more pleasurable” (R455). Other explanations highlighted finding problems early: “I’m quite sure my partner would let me know if she felt anything” (R466); “my partner would notice lump/bumps” (R715); “when I am intimate with my partner I think she would notice” (R862). Sometimes it is only an expressed hope that a partner will notice changes: “I dont no [sic] how + I hope my partner will notice if anything [sic] not right” (R787) whereas others suggested that their partners were more proficient: “My partner...knows a lot about the ways breasts feel + how they change” (R055); “She’s a nurse” (R233) and “As you can
see...she has far more knowledge of what she should be looking for” (R442).

Surprisingly, this category does not appear widely in the literature to explain why women do not practise BSE. However, in the small body of work that specifically considers lesbians' breast health, O'Donnell et al. (1979) and James (1993) suggest that some lesbians do not examine their breasts because their partners do it for them. This is not to suggest that this practice is unique to lesbian relationships, for the possibility that a partner may find a lump during sexual activity has been discussed by heterosexual women (Ayolah & Weinstock, 1979; Colbourn, 1996). However, Masters, Johnson & Kolodny (1986) note that lesbian couples usually spend much more time and care on breast play during sex than do heterosexual couples, so perhaps lesbian partners are more likely to monitor each other's breasts for changes or to notice changes on an ad hoc basis.

A number of lesbians explained not practising BSE by indicating that partners did it for them (or, at least, were particularly aware of their breasts).

(vii) “Other explanations”. Finally, there were a small number of explanations given (8%, n = 19, of 229) which did not fit into the six categories above. These included doubts about the efficacy of BSE as a tool for early detection: “By the time you feel a lump it's too late anyhow—this getting it early is rot” (R388b); having a doctor who performed breast examinations: “and my doctor does this for me 3 times a year” (R348); and general awareness of own body: “I think I would probably notice if anything was wrong” (R332). These findings are also represented in the literature. Women in Salazar and Carter’s (1994) study felt that breast examination made no difference to the outcome if the disease should occur and that it was unnecessary because they participated in other early detection techniques. Women in Calnan’s (1984b) study said that they did not practise BSE because they were confident they would know if something was wrong without doing BSE.

Conclusion: implications for understanding healthcare behaviour and developing health promotion

Twenty per cent of the respondents (n = 218, of 1066) in the Lesbians and Healthcare Survey reported that they have never practised breast self-examination. This figure is higher than that reported in Bradford and Ryan’s US study (1988): 14% of the lesbians in their sample said they had never practised BSE. This discrepancy is interesting in the light of the literature (reviewed earlier) proposing that lesbians are at higher risk of breast cancer than heterosexuals, and suggesting that lesbians in the US, at least, believe this to be so (Solarz, 1999). Data from the present survey (yet to be reported) suggest that lesbians in the UK do not commonly share this perception. The discrepancy may also, of course, be due to a stronger emphasis on BSE in US preventative healthcare and/or better-targeted health promotion literature.

How do the explanations given by lesbians in this survey contribute to our understandings of why a fifth of them have never practised BSE? And how might respondents’ explanations inform the development of health promotion materials relevant to lesbians’ needs as well as to the concerns of women more generally? The most common explanation given by respondents in the Lesbians and Healthcare Survey was that they did not know how to perform BSE or what they were looking for in doing it. Concerns about technique such as those expressed here by lesbians have been acknowledged, to some extent, elsewhere. It is suggested that the best and simplest way to “be breast aware” is to feel the breasts with a ‘soapy hand’ (rather than a flannel) while washing (Baum et al., 1994, p. 158). These suggestions may be usefully incorporated into health promotion campaigns. Despite the importance of personal instruction, many lesbians said they that they had not been shown how to do BSE. These explanations appear to confirm Burns’ (1992) suggestion that lesbians may be less likely than heterosexual women to be taught BSE. Lesbians also said that they did not know what they were looking for. The ability to distinguish lumps from lumpiness has been a feature of health promotion campaigns, for example, in the Department of Health’s campaign, women are urged to ‘know what is normal for you’, and ‘know what to look and feel for’ (DoH, 1995).

Many lesbians, however, said that they did not know what was ‘normal’ and Stoppard (1996) has suggested that health promotion materials do not explicitly address the differences between lumps and lumpiness. This distinction could usefully be incorporated into the health promotion literature. For example, data, yet to be reported, suggest that health promotion materials currently address the issue about whether a lump is potentially cancer as a comparative decision (with the way a woman’s breast felt in previous months) rather than as a definitive one (i.e. specifying what the lump will feel like). Lesbians suggested that they needed to be able to relate lumps to everyday objects in making the decision. Love (1995) suggests that lumps are likely to be about the size of a grape, but smaller than a walnut.

In this survey, many lesbians also said that they had never got into the habit of practising BSE on a regular basis. Medical opinion has now moved away from the rigid and ritualised timetable of monthly BSE—reflected in these concerns expressed by survey respondents. Instead, women are advised to take convenient opportunities to observe and feel their breasts, while washing or dressing (Austoker, 1994). Again, this could be more...
widely—and explicitly—adopted in health promotion campaigns.

Because images of breast self-examination in the literature frequently portray younger women, some older women are said to under-estimate their risk of breast cancer (Love, 1995). In comparison, although women with family history form a small minority of breast cancer sufferers (Yalom, 1997) their stories form a substantial sub-genre in media portrayals of breast cancer (Suywell et al., 2000). Women may believe, then, that hereditary factors account for a greater proportion of cases than they (in fact) do and they may also believe that the risk of breast cancer decreases with age: both beliefs may lead some women to under-estimate their risk. The health promotion literature could usefully emphasise that it is older women who are most at risk and it could also downplay the role of hereditary factors in breast cancer.

Lesbians in this survey also said that they were frightened of what they might find and that they were uncomfortable with their bodies. These explanations echo Love’s (1995, p. 25) observations that BSE is a destructive way to define breasts, which alienates women from their bodies by setting up a ‘search and destroy’ mission in which the breast is the enemy. Health promotion appears to draw heavily upon this narrative of breast health and breast pathology.

This survey suggests some alternative narratives. For example, some lesbians, despite reporting that they had never practised BSE, had their breasts examined by a partner. These kinds of explanations appear to be less talked about in the context of breast health (and ‘my partner does it for me’ has not featured in the literature as an alternative to BSE). Yet lesbians’ explanations suggest that they derive pleasure from the experience and that the responsibility and/or anxiety is potentially shared with a partner. These (very different) narratives—of ‘pleasure’ and ‘shared care’—might offer alternative ways of accounting for and promoting breast health. Such narratives draw upon views of the body as a source of pleasure, rather than of pathology. Health promotion campaigns based upon them might help to establish a relationship between a woman and her body that is not based upon notions of shame and guilt, replacing these conceptions with knowledge and acceptance. Whether or not a woman has a partner, and whether this partner is female or male, her breasts can be seen as a potential source of pleasure. One of the outcomes intended in Haynes’ study (1992) of lesbians’ risk of breast cancer was to encourage lesbian partners to conduct breast examinations on each other (Coward, 1992). Although the practice described in the section: “my partner does it for me” is evidently not the formal procedure of BSE, recent developments in breast health care promote “breast awareness” and advocate its integration into everyday life. This could be a valuable way of ‘becoming familiar’ (Solowij, 1996, p. 12) with a partner’s breasts. Health promotion for lesbians might include reference to a partner in breast health care, so that lesbians may be encouraged to practise BSE together. This is supported by a suggestion in the literature that lesbians want their partner to be included in discussion and decision-making about their health (Lee, 1998). This suggestion might also be extended to health promotion literature for heterosexual women.

More generally, in encouraging women to practise, BSE is often presented as a simple procedure (e.g. Brailey, 1986; Hailey et al., 1992). Yet the data presented here suggest that there are a number of uncertainties inherent in BSE that health promotion campaigns have failed to address. For example, there are uncertainties about the normal changes in the breast over time; knowing the difference between abnormal and normal lumpiness; whether a woman can trust her own judgement or be taken seriously by her GP; confusion amongst medical experts (c.f. Elliott, 1994) and doubts about the efficacy of BSE in reducing breast cancer mortality. These uncertainties are not necessarily best dealt with by informational and educational messages which primarily aim to reduce uncertainty (c.f. Brabow & Kline, 2000). Indeed, women who are particularly concerned with these latter issues may not only be unmoved by informational or educational efforts designed to increase their ‘how to’ knowledge—they may actually be discouraged from BSE practice if their concerns are ignored or delegitimised by traditional educational efforts that fail to respond to uncertainties that cannot be reduced. Brabow and Kline (2000) propose an alternative understanding of BSE which, rather than attempting to reduce women’s uncertainty, instead acknowledges the different forms of uncertainties and makes suggestions for coping with them.

Health promotion around BSE, in summary, might usefully address issues, shared among lesbian and heterosexual women alike, of being able to distinguish between a lump and lumpiness; of moving the focus of BSE from technique to habit; of promoting the breasts as a source of pleasure rather than fear and acknowledging the complexities and uncertainties in the practice. In addition, a campaign might incorporate some of the particular features of lesbians’ health behaviour—they may be more likely to practise BSE with a partner and less likely to engage in other preventative health behaviours (for example, cervical screening), or to attend for family planning services, (where BSE may be promoted). It is also likely that specific measures will need to be taken to ensure that lesbians have access to health promotion literature, and that such literature is appropriate to their needs and concerns.
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