

# The Human Touch

**An exploration of the psychosexual and relationship needs of lesbian and bisexual women affected by cancer and its treatments**

Implications and recommendations for healthcare professionals



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# Introduction

It is known that in the UK that cancer represents a considerable challenge to women's health, with 182,000 new cases every year<sup>1</sup>. However, it is unclear how many of the women affected identify as lesbian, gay or bisexual (LGB) as information about sexual orientation is not routinely collected in the patient record.<sup>2,3</sup> If we consider NHS surveys, it has been shown that an average of 3.4% of women across all ages completing the 2022 GP Patient Survey identified as 'LGB or other'. If we look at the younger cohorts responding to this survey, this percentage increases to 6.4%.

There is an evolving body of research, evidence and clinical literature that sheds light on the sexuality, psychosexual health and relationship sequelae of these cancers (especially breast cancer) and treatments, and interventions which may aid adaptation and recovery in heterosexual women and their partners.<sup>4,5,6,7</sup>

Although the general health care needs of individuals from sexual minority groups (i.e. not heterosexual) have begun to be recognised and addressed by practitioners,<sup>8,9,10</sup> there remains a lack of psychosexual and relationship specific literature to help guide practice and practitioners in this area.

This resource presents the findings from a doctoral thesis<sup>11</sup> which explored the psychosexual and relationship needs of cisgender lesbian and bisexual women affected by cancer and its treatments, together with some implications and recommendations for practitioners.

The study took place between 2016 - 2017, and adopted a phenomenological approach. It consisted of interviews and online questionnaires with 22 cisgender lesbian and bisexual women from across the UK.

# Experiences of LGB women living with cancer

As with their heterosexual peers, LGB women experience an impact on their psychosexual and relationship health in a number of ways.

## Importance of sexuality during treatment and survivorship

Almost unanimously, LGB women said that at the time of their diagnosis and throughout the treatment of their cancer, sexuality (including sexual orientation and sexual intimacy) was the last thing on their mind. The overriding priority for the women and their partners at that time was survival, anything else was secondary. In some cases, the needs or concerns of their partners were also too much for the women to consider. At the time of diagnosis many of the women expressed their shock and disbelief, but this was quickly followed by all-consuming treatment regimens with what felt like endless rounds of hospital appointments, treatment and scans/tests. This became their 'new reality' with all of its related difficulties and fears.

**"... you know our relationship or sexuality and all that was not the thing uppermost in our minds it was the worry about this bloody cancer..." (Interview participant 3)**

**"During treatment all real sex was off the agenda - neither me or my girlfriend felt like it. We were both just getting on with me getting better." (Questionnaire participant 11)**

The women told of how they had no interest in being sexual or intimate with their partners as they felt too tired, nauseous or sick, in pain, and stressed to be concerned with or engage in intimacy with their partners. Whilst patients are made aware of these side effects and a wealth of supporting information was available to them, most people either undergoing or caring for those undergoing treatment did not really have a full understanding of the reality until the treatment regimens began. People often underestimated the levels of fatigue that the treatments can cause, and the possible impact this can have on their lives. It is hardly surprising given both the enormity and life altering impact of the diagnosis, together with the effects of treatment that the women did not feel able to be intimate with their partners.

**"Didn't feel like having sex for a long time, with the chemo mainly. Felt sick and tired, really tired. Didn't feel sexy anymore because of the state the operation left - I had lumpectomy but the scar was bad and my breast looked odd." (Questionnaire participant 7)**

**"When they told me I had breast cancer the sexual side of our relationship took the back burner. During the chemo I felt crap, sick, tired, and washed out. All I could think about was getting through the drug cycles and for it all to be over." (Interview participant 4)**

Several of the women spoke about pushing their partners away if they believed that their partner was wanting to be intimate with them. It was not uncommon for people to misinterpret their partner's behaviour, often projecting onto them their own anxieties. This, in turn, led to further misinterpretation by the partners who felt rejected and hurt, as sexual intimacy was not on their minds whilst the person they loved was experiencing such a dreadful time.

It is well known within psychosexual and relationship literature (especially within object relations theory) that some people often find it difficult to express their intimate and loving feelings towards a partner in any other way than through being fully sexual with them.<sup>12</sup> It is, therefore, not surprising that both the women and their partners experienced difficulties in this area during their cancer experiences, as the 'patient' would feel 'pressured' by their partner whilst the partner would feel hurt and vulnerable when they were 'rejected'.

**“For a while we stopped having any intimate (sexual contact) - whilst all the treatment was happening - I really didn’t feel I had the energy or the desire to. I was too busy with trying to get better, to get through the dreadful treatment (I was sore from the operation and felt so sick with the chemo. I just couldn’t have cared less about making love with my partner - I would freeze if I even thought she was wanting to be intimate. I pushed her away a lot - we were normally tactile (even if we didn’t have sex), but I just didn’t want to be touched at all. I guess it was hurtful for her, but I didn’t care really (I felt so awful).” (Questionnaire participant 10)**

## **Returning to sexual intimacy following treatment**

Sexual intimacy was very much ‘off the agenda’ for the women during their treatment phase. For most, it was something which they and their partners found to be more important again once the treatment(s) had finished. For these women, the sexual side of their relationship was something which returned gradually as they began to feel stronger and more ‘normal’ again. As would be expected, the resumption of sexual contact was something which took time and was taken slowly, often with a degree of hesitancy, allowing both women in the relationship to re-find their role within the relationship. Moving away from the ‘cared for’ and ‘carer’ dynamic back to a more adult, equal relationship.

**“... and then it sort of gradually came back after. A big step actually.....I think there was some hesitations and taking it slowly really ...just being close being intimate you know not always going for orgasms and stuff.” (Interview participant 3)**

A number of the women experienced a huge alteration in their sexual relationship with their partners. Some found that they had to ‘renegotiate’ the nature of the sexual relationship, finding that they needed to be in control of any sexual intimacy with their partners. It appeared that most of these women were struggling with a reduction or loss of sexual desire possibly as a result from their continued treatment with Tamoxifen (an anti-oestrogen hormone therapy for breast cancer). For others, changes related to their altered body image and feelings of ‘self’. Some women said that they had never been able to resume their pre-cancer sexual or intimate relationship with their partners, leaving them feeling angry and frustrated. Fortunately, most of these women reported that their relationships were strong enough to adapt to these changes, but this wasn’t always the case.

## **Body image, feelings of attractiveness, and femininity**

Similar to the experiences of heterosexual women, the women in this study identified the importance of their partner’s response to their altered body image. Those women whose partners were positive and supportive experienced better psychological adjustment than those whose partners were less positive or supportive. In addition, some of the women said that they felt dirty and unattractive and couldn’t understand how their partners would want to be sexually intimate with them. This was especially experienced by the women who had undergone stoma surgery:

**“After the operation I was, felt really disgusted by the stoma and the bag – it felt like being a child again but worse as I had even less control of what and when the poo came out. I felt dirty - couldn’t see how my partner would want to touch me again or even be in the same room. We did talk about this and lots of other things and were able to work through it together.” (Questionnaire participant 8)**

Some of the women expressed surprise that their body image was an issue for them as they had assumed LGB women would be less affected by this. Several of the women identified the impact of their cancer on their self and sexual identity, with their previous views of themselves as strong ‘Amazonian women’ being severely challenged. Furthermore, several identified changes in the way in which they viewed their place in the world (either transiently or permanently), which had an impact on their overall adaptation to being a cancer survivor.

## Effects of a treatment induced menopause

The women in this study reported experiencing vaginal dryness and dyspareunia (painful intercourse). This was coupled with altered body sensations and sexual feelings, leading to difficulties with sexual arousal. These changes had led the women and their partners to explore 'new ways' of being sexual together, in some instances widening their sexual repertoire and improving their sexual intimacy. When these 'new ways' were achieved, this was seen as a positive consequence of their cancer experience.

## Surgical impact on sexual function

The direct impact of surgery was expressed by one of the women (who had surgery for bladder cancer) in the following way, highlighting the strength of the distress which she stated was overlooked by her healthcare team.

**“My operation removed part of my vaginal wall and there was a real possibility of damage to clitoral sensitivity. When you talk about sex problems after bladder removal, everyone assumes you mean penetrative sex (which may or may not be possible afterwards). The loss of feeling to the clitoris is not considered important – it was WAY more important to me than penetration (and I'd imagine lots of other women!)” (Questionnaire participant 5)**

## Impact on relationship dynamics

Despite potential differences in relationship dynamics within same-sex female relationships, most of the experiences reported in this study reflected those previously identified in the heterosexual population. Cancer diagnosis and treatments had led to the usual roles within the relationship being thrown into disarray, with the partner and friends taking on additional roles and responsibilities. The women felt distressed by the changes and increased dependence on others, impacting negatively on their self-esteem and self-image. More frequent relationship talk led to less relationship distress and better relationship and general adjustment over time. Couples who were able to talk together about their concerns and feelings were better placed to come through the cancer experience with a strong, or stronger, relationship. This was seen as a positive effect of cancer.

Several studies have previously identified that how a couple deals with cancer is partly influenced by their coping styles and roles within the relationship prior to the diagnosis.<sup>13,14</sup> These studies also found that established relationships are less vulnerable to distress and breakdown than less stable or newer relationships. This was true for the relationships of the women in this study. In keeping with previous studies,<sup>15</sup> the experiences of having cancer exacerbated existing problems and unsatisfactory relationships. This led some women to end their relationships. In other cases, it was the partner who chose to end the relationship after the stress of dealing with cancer and treatments became too much.

Where the women were not in a relationship, they identified their fears and reluctance to either seek or enter into a new relationship. As with heterosexual women, these women found they were unwilling to expose themselves to potential rejection when they were already feeling emotionally vulnerable.<sup>7</sup> The women often wished to explore their worries, especially in terms of when to tell a future partner that they have had cancer and how to 'protect themselves emotionally' from any rejection and hurt.

# Experiences of the partners

## Importance of sexuality and sexual intimacy during treatment

As with their heterosexual peers, the partners of the women in this study found thoughts of being sexual unimportant and frivolous, especially at the time of diagnosis and during the treatment phase. They also identified being frightened to touch their partner as they were worried they might hurt them through inappropriate touch. The partners were also far more worried that their partner could die, leaving them by themselves, than thinking about being sexually intimate.

**“I came close to losing the person I love, they are so important to me. This took priority over everything else. It made me re-evaluate what was important.” (Interview partner 1)**

**“I don’t want to think about life without her!” (Questionnaire participant 3, had been with partner for over 45 years)**

## Altered relationship dynamics

Alterations in communication styles led to increased couple conflict and avoidance of having difficult conversations. Changes in the relationship dynamic prevented them from being able to mutually discuss their feelings about grief, loss, potential recurrence and potential death. This led to both partners feeling left alone with their fears. As with the partners in De Vocht’s work<sup>7</sup>, some of the partners in this study reported the experience that ‘things were never the same again’ and that somewhere along the path from diagnosis through treatment they had ‘lost their soulmate’ and sexual partner.

The partners had identified and reported that there were continued alterations in the communication in their relationship post treatment. As a consequence, they chose to ‘protect’ their partner by avoiding conflict over minor issues. Unfortunately, as they had not explained why they had changed their approach and way of communicating, this led to the couple having more substantial arguments as both parties ‘bottled up’ their feelings.

## A loss of self and adopting the carer role

Some of the women said that they had also suffered a sense of a loss of identity through becoming ‘just the partner and carer’. This was accompanied by a sense of loneliness and some women reported mixed thoughts and emotions about the validity of their feelings.

**“Just became the carer - doing everything for her and little time for me. Felt guilty if I thought about my needs as hers so much more.....With everyone, including the hospital staff I felt I was her partner - I lost my own identity. At times I felt angry about this - who was there for my needs? Of course, I would then feel guilty for thinking and feeling like that (I’m always good at beating myself up).” (Questionnaire participant 1)**



## Fear of homophobia and assumed heterosexuality

One of the main concerns the all of the women expressed about their dealings with healthcare professionals was their fear of a homophobic response from the staff. A particular concern was the involvement of the partners in consultations, decision making and care. They reported experiencing some hesitation about 'outing' themselves (disclosing their sexual orientation) to staff, which given the age of the women and the history of homosexuality in the UK, is hardly surprising.

There were some women who, perhaps due to their previous encounters with health care professionals, did not feel comfortable disclosing their relationship to the patient and were distrustful of healthcare professionals. Some of these women reported having experienced problems in adjusting to the impact of cancer on their lives and would perhaps have benefited from some focused interventions if they were given indicators that it was safe to disclose and seek support.

**“No way - we grew up in a time when being a dyke wasn't accepted. My partner has a long history of mental health problems (severe depression) as a result of her parents sending her to a mental institution to get 'corrected'. So neither of us really trust health professionals.”**  
*(Questionnaire participant 9)*

Some of the women described how they had experienced the issue of assumed heterosexuality (also known as heteronormative assumptions) in their care journey. This was most often in relation to the pre-chemotherapy assessment and the 'tick list' approach in regard to fertility section. Some felt discussions regarding their future wishes for children were bypassed when the women said they were in a same-sex relationship.

**“... there were assumptions made about egg collection, when I said I was gay it was like OK onto the next question.”** *(Interview participant 4)*

For this participant in particular, this had felt dismissive. She reports that her sexuality felt not worthy of discussion, and this in turn was a rejection and negation of her and her partner as women. At a time of great vulnerability, such as discussions about fertility, it is important that all patients feel secure and supported. Experiences of cancer care that appear to dismiss the patient or their partner's identity are troublesome not only in the immediate context, but also for their potential effect to discourage the sharing of personal and intimate concerns.

## Support groups and helplines

The women in this study identified that cancer support groups and helplines were very heterosexually focussed. In their experience, the groups they had attended had not been 'gay friendly' and were not found to be 'safe places' to be open and fully discuss their concerns and worries.

**“... it is where I really noticed the invisibility of being gay and that's where some of that stuff. There were all grannies, they were all absolutely heterosexual and married and grand and families and I just thought I felt I stuck out like a sore thumb ... it just felt like we are a mile apart ....it's incredibly heterosexual it's for, yeah know, it's all very feminised it's all about makeup, it's all about particular type of what you wear and whatever.”** *(Interview participant 2)*

This lack of LGBT inclusion was also found in the information they received and the support agencies they accessed.

**“I'm the type of person who needs to get information and understanding of a situation to feel able to control and cope with difficulties. So, for me it would have been useful if, when I contacted the [XXX] helpline, they had been able to recognise and have knowledge about LGBT relationships. They didn't**

so I was left feeling let down and frustrated, I felt so vulnerable at the time and they really didn't help." (Interview partner 1)

## The therapeutic relationship

Issues regarding the women's experiences with health care practitioners were also highlighted. The partners reported the need for the practitioners to have both a better understanding of the diversity of the patients they are caring for, and better communication and interpersonal skills. Both the patients and partners found that the staff were technically and clinically competent, but often lacked the human skills needed to make them feel comfortable and part of the care partnership.

**"Technically I couldn't fault them, they were excellent. But I/we were made to feel like a little cog in a big wheel, a bit like being on a conveyor belt. Most of the nurses were pleasant enough, but they lacked the gentle, human touch that I know myself and [XXX] needed – especially when things got tough." (Interview partner 2)**

### Implications for practice

For many people, including lesbians and bisexual women, sexuality and its expression are seen as important factors in a person's quality of life. It has been suggested that this is especially important for patients with cancer and their partners. Cancer and many of its treatments can severely compromise a person's sexuality and their ability to express themselves sexually.

Closeness, intimacy, and sharing (along with other elements of sexual expression) may be avoided or neglected by patients and their partners at a time when they could be beneficial for the individual's wellbeing. During difficult episodes such as diagnosis and treatment, the closeness and comfort an intimate partner can provide can be crucial, however complications in communication can cause issues with the ability to provide support.

Healthcare professionals have an important part to play in helping to prevent this metaphorical barrier coming between the patient and their partner. By being able to support LGB couples, these relationships would be better equipped to overcome the actual or perceived barriers to appropriate health care these women can often face. By challenging the heteronormative view of relationships and support we find in healthcare, we can help patients feel less invisible and under-supported.

The relationships of lesbians and bisexual women are no less real than those of their heterosexual counterparts. Healthcare professionals need to create an environment in which LGB women and their partners feel 'safe' to disclose the nature of their relationship. Furthermore, healthcare professionals need to feel confident in their knowledge and skills in offering brief counselling to these women and their partners. Excellent advice on how to cultivate an appropriate, safe environment is given in the 'Provider Pack: Breaking down barriers to LGBTIQ+ inclusive cancer care', produced by Live Through This, available in the resources for professionals section of the website.

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