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## **Breast cancer, sexuality and intimacy: Addressing the unmet need**

To the Editor:

Breast cancer is the most commonly diagnosed female cancer with more than 1.7 million new cases in 2012 [1]. Sexuality and intimacy problems caused by breast cancer diagnosis and treatment affect large proportions of women [2]. Sexual problems can occur at any time of the disease trajectory. Some problems are expected to resolve after treatment [3] whilst others last for many years [4, 5]. Sexual activity may not be a priority for all women, particularly during treatment [6] but sexuality and intimacy are still regarded as an important element of quality of life [7]. Despite recognition of the importance of sexual issues to patients, there is a lack of effective support services and interventions [8] and sexual issues are rarely discussed in the oncology setting [9]. The aim of this qualitative study was to: explore the extent of sexual problems in terms of their severity for individuals; examine coping mechanisms and existing support services and determine how patients' experiences might be improved. Leeds West NHS Research Ethics Committee provided ethical approval.

Eleven breast cancer patients who identified themselves as currently or previously experiencing a problem with sexuality as a result of breast cancer or treatment were recruited. Recruitment was limited to the number of women who responded to advertising and volunteered to participate over a 6 month period. Age of participants ranged from 33-56, the majority (n=6) were married. In line with Horden's [10] definition we included single women and women in relationships as both groups may have experienced sexuality and intimacy problems. All participants had received surgery (2 mastectomy, 3 mastectomy with reconstruction, 6 wide local excision). The majority of participants (n=9) had also received at least one other form of treatment. The majority of participants (n=8) had early breast cancer. A researcher (ST) conducted semi-structured interviews (19-39 minutes, median 33 minutes) examining: medical background and diagnosis; relationship and family background; impact of cancer diagnosis and treatment; impact on sexuality and intimacy; and access to support. Interviews were audio-recorded and transcribed verbatim. Thematic analysis of the interviews identified four main themes.

1) Sexuality and intimacy problems. Women experienced five main types of sexuality and intimacy problems. Body image concerns were prevalent regardless of the type of

surgery women had received. *'I wasn't sure if I could deal with what I'm now left with which is sort of a lumpy breast and loads of scars'* but for women with advanced disease body image seemed to be less important *'How I look doesn't bother me as much as how I feel'*. Loss of breast sensation was a common problem and often made sexual activity less enjoyable. Only the women who had received endocrine therapy experienced problems with vaginal dryness. For some women, this meant sexual intercourse was extremely painful but for others it was impossible. An added complication for some women was the inability to orgasm or reduced libido.

2) The impact on emotions and relationships. Women mentioned feelings of anger and sadness in relation to their changed body and the effect breast cancer had on their sexual function *'I just feel that the way I wanted to do it is no longer possible and I'm pi\*\*ed off [participant cries], I'm not pi\*\*ed off I'm very sad'*. For some women, their experiences were so severe and had such a profound impact on their lives; they were considering treatment changes as a result. One woman had considered the use of potentially 'risky' oestrogen treatments to try and improve her sexual function. Many participants experienced a relationship breakdown or were currently considering ending a relationship. The breast cancer diagnosis was not usually the main cause of the breakup or the relationship difficulties but it acted as a 'catalyst' to speed it up. Women expressed a need to focus on survival or felt they were 'protecting' themselves from the pain of not being sexually active.

3) Coping mechanisms. Participants used a variety of different approaches to help them to cope with the problems they had experienced with sexuality and intimacy. Some women felt the most effective coping mechanisms were to deal with the issue themselves or with their partner. Some women sought medical advice from GPs, oncologists or specialist nurses for problems relating to sexual activity and occasionally, women were referred to more specialist services. *'Well I've been very proactive about it and I talk to my oncologist...and he admitted that he really... didn't know what to offer to help so he referred me to the menopause clinic'*. The majority of the women had accessed services such as counselling, holistic treatments and therapies. These services were helpful but they did not tend to focus specifically on sexuality issues. Less typically, women had accessed psychologists or psychotherapists. Again, these services focused on emotional experiences without focusing specifically on sex or intimacy.

4) How can experiences be improved? Participants felt their experiences could be improved in three ways: more information; increased availability of support services and a designated contact within the clinical team to speak to about sexuality and intimacy concerns.

This research has highlighted the importance of sexuality in women's lives and given an indicator of the devastating effect breast cancer and treatment can have. One striking finding evident in this study is that some women balanced decisions about ways to improve their sexual functioning with fears surrounding the potential negative impact this may have on their prognosis. The women interviewed reported a lack of information provision. The findings suggest that information provision regarding sexuality and intimacy issues should be paced and tailored according to stage of disease and treatment regime. Women with primary disease need more information about body image at the time of surgery, whereas women with advanced disease need more information about sexual function. Women receiving endocrine therapy need information about the specific physical problems they may experience, how these problems can be overcome and to what extent they will resolve after treatment. Although not evident in this small sample, information provision may also need to be targeted by age as younger women may have greater sexuality information needs [11]. Participants commented on the lack of support services dealing specifically with sexual problems. Many of the women interviewed felt their situation could be improved by having someone to talk to. It has been reported previously that there is an unmet need amongst breast cancer patients for effective and accessible treatments that address sexual problems [12, 13]. Oncology nurses may be the best people to deal with sexuality issues with patients but they would need specific training to do this [14].

The interviews gave an insight into sexuality and intimacy issues experienced by breast cancer patients and highlight the complexity of the problem. Addressing sexual problems amongst breast cancer patients requires a multifaceted approach that focuses on the complex nature of the problem not just the physical aspects of sex and provides patients with regular access to specialist support both during cancer treatment and in survivorship [15]. Clear referral pathways to effective and targeted support services are identified as being key areas for service improvement.

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