Sexual Wellbeing and Breast Cancer in Australia:

Experiences of people with breast cancer and health professionals

Executive summary May 2011

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Acknowledgments

We wish to thank all the women who participated in this survey, especially your candour and honesty in sharing your experiences with what is a deeply personal issue. In participating in this project you have helped to bring this important issue to light, and contributed to improving outcomes for many women.

We also wish to thank all the health professionals who participated. We appreciate your willingness to sharing your strategies and reflections on supporting women.

Suggested citation
Introduction

A diagnosis and treatment for breast cancer can have a significant negative impact on women’s sexual wellbeing. This is an issue that is too often ignored, and many women feel isolated and alone as a result.

In 2009, BCNA surveyed around 200 women with breast cancer about sexual wellbeing, and found a significant unmet need for information and support with this issue. As a result we added a new section on sexual wellbeing issues in the second edition of the My Journey Kit, and produced an edition of The Beacon specifically on this topic.

As BCNA wanted to better understand the extent of the issues experienced by women, and for the health professionals who support them, in late 2010 we commissioned Professor Jane Ussher and her team from the University of Western Sydney (UWS), to conduct research in this area, on our behalf.

The purpose was to better understand the issues for individuals with breast cancer and health professionals, and to identify practical solutions for women to help manage sexual wellbeing issues.

This executive summary report outlines the results of this research. Part One details the results of a survey completed by 2210 people with breast cancer, which was supplemented by interview and focus group accounts with a further 6 women with breast cancer.

Part two focuses on the results of a separate survey completed by 159 health professionals, supplemented by interview accounts from a further 11 health professionals. The majority of health professionals (84.4%) who completed the survey were primary health care professionals with breast care nurses comprising the largest proportion (62.5%). Health professionals working in allied health comprised 15.5% of the total number of health professional participants.

Please note that the tables and figures outlined throughout this summary, provide the percentage and count for each response. Percentages may not total 100, as participants could choose more than one response and/or not all participants provided a response.
Part One: Experiences of people with breast cancer

General profile of participants

The survey was attempted by 2210 participants, with 1965 responding to all questions representing an 88.9% completion rate. The average age for participants was 54 years ranging from 18 through to 84 years; participants were predominately female (99.8%), self-identified as Anglo-Australian (89.1%), had further tertiary education and/or training (60.7%), and represented all Australian States and Territories, with 45.6% from regional, rural and remote geographical zones. The general profile of participants is outlined in more detail, in table 1 below.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Count (N) / Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>54 years (18 – 84 years)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>98.8% (2185)</td>
</tr>
<tr>
<td>Male</td>
<td>0.2% (5)</td>
</tr>
<tr>
<td>Cultural Background</td>
<td></td>
</tr>
<tr>
<td>Anglo Australian</td>
<td>89.1% (1910)</td>
</tr>
<tr>
<td>European</td>
<td>8.8% (188)</td>
</tr>
<tr>
<td>Aboriginal/Torres Strait Islander</td>
<td>0.3% (8)</td>
</tr>
<tr>
<td>Asian</td>
<td>1.5% (32)</td>
</tr>
<tr>
<td>Middle Eastern</td>
<td>0.1% (4)</td>
</tr>
<tr>
<td>African</td>
<td>0.1% (2)</td>
</tr>
<tr>
<td>Geographical location</td>
<td></td>
</tr>
<tr>
<td>Metropolitan</td>
<td>54.4% (1191)</td>
</tr>
<tr>
<td>Regional</td>
<td>27.5% (601)</td>
</tr>
<tr>
<td>Rural</td>
<td>16.7% (365)</td>
</tr>
<tr>
<td>Remote</td>
<td>1.5% (32)</td>
</tr>
<tr>
<td>State/Territory</td>
<td></td>
</tr>
<tr>
<td>Australian Capital Territory (ACT)</td>
<td>2.7% (58)</td>
</tr>
<tr>
<td>New South Wales</td>
<td>26.5% (580)</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>0.7% (16)</td>
</tr>
<tr>
<td>South Australia</td>
<td>8.8% (192)</td>
</tr>
<tr>
<td>Tasmania</td>
<td>3.2% (69)</td>
</tr>
<tr>
<td>Queensland</td>
<td>21.8% (478)</td>
</tr>
<tr>
<td>Victoria</td>
<td>25.4% (555)</td>
</tr>
<tr>
<td>Western Australia</td>
<td>11.0% (240)</td>
</tr>
</tbody>
</table>

Table 1: General profile of participants
Relationship profile of participants

The relationship profile of participants is outlined in table 2 below.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Count (N) / Average</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationship status</strong></td>
<td></td>
</tr>
<tr>
<td>Partnered – Living together</td>
<td>80.1% (1747)</td>
</tr>
<tr>
<td>Partnered – Not living together</td>
<td>5.2% (113)</td>
</tr>
<tr>
<td>Not in a relationship</td>
<td>14.7% (321)</td>
</tr>
<tr>
<td><strong>Period of time</strong></td>
<td></td>
</tr>
<tr>
<td>Partnered - length of relationship</td>
<td>24.5 years (2 months – 59 years)</td>
</tr>
<tr>
<td>Not partnered - time since last relationship</td>
<td>7.2 years (2 months – 49 years)</td>
</tr>
<tr>
<td><strong>Gender of Partner</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>98.0% (1994)</td>
</tr>
<tr>
<td>Female</td>
<td>2.0% (41)</td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>84.2% (1830)</td>
</tr>
<tr>
<td>No</td>
<td>15.8% (343)</td>
</tr>
<tr>
<td><strong>Relationship end since onset of breast cancer</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7.4% (158)</td>
</tr>
<tr>
<td>No</td>
<td>92.6% (1970)</td>
</tr>
<tr>
<td><strong>Current sexual relationship</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>77.2% (1662)</td>
</tr>
<tr>
<td>No</td>
<td>22.8% (491)</td>
</tr>
</tbody>
</table>

Table 2: Relationship profile of participants
Breast cancer and treatment profile

The breast cancer and treatment status profile for participants is presented in table 3 below.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Count (N) / Average</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Years since first diagnosis</td>
<td>4 years</td>
</tr>
<tr>
<td></td>
<td>(&lt; 1 year – 32 years)</td>
</tr>
<tr>
<td><strong>Stage at diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Early breast cancer</td>
<td>74.6% (1602)</td>
</tr>
<tr>
<td>Locally advanced breast cancer</td>
<td>19.9% (428)</td>
</tr>
<tr>
<td>Secondary breast cancer (spread to other parts)</td>
<td>4.2% (91)</td>
</tr>
<tr>
<td>Don’t know / unsure</td>
<td>1.3% (27)</td>
</tr>
<tr>
<td><strong>Current treatment status</strong></td>
<td></td>
</tr>
<tr>
<td>Completed treatment</td>
<td>45.6% (974)</td>
</tr>
<tr>
<td>Currently receiving treatment</td>
<td>45.5% (971)</td>
</tr>
<tr>
<td>Between rounds of treatment</td>
<td>1.2% (26)</td>
</tr>
<tr>
<td>Subsequent diagnosis of breast cancer</td>
<td>6.8% (145)</td>
</tr>
<tr>
<td>Subsequent diagnosis of a different cancer</td>
<td>0.8% (18)</td>
</tr>
<tr>
<td><strong>Menopausal status</strong></td>
<td></td>
</tr>
<tr>
<td>Post-menopausal</td>
<td>77.8% (1697)</td>
</tr>
<tr>
<td>Peri-menopausal</td>
<td>13.4% (292)</td>
</tr>
<tr>
<td>Pre-menopausal</td>
<td>8.8% (192)</td>
</tr>
</tbody>
</table>

Table 3: Breast cancer and treatment profile
The Impact of Breast Cancer on Sexual Wellbeing

1956 participants reported changes in sexual wellbeing, described as decreases in: feeling desirable (73%, 1385), intimacy (60%, 1090), frequency of sex (78%, 1427), sexual arousal (74%, 1344), sexual pleasure (64%, 1151), satisfaction with sex (62%, 1096), energy for sex (76%, 1379), and interest in sex (71%, 1308).

I feel as if an integral part of my life is no longer well within my reach.

Although I am getting older and therefore might be expected to lose interest in sex to a certain degree, sex has been an important component of my life until I started receiving treatment for breast cancer. I worry about my loss of interest in sex and I miss the sexual aspect of my life (65 year old woman, early breast cancer, diagnosed 2008)

Very upsetting. I love my husband very much and our relationship is very good. My physical body does not arouse or respond like it used to (51 year old woman, early breast cancer, diagnosed 2008)

1259 participants provided further information about the impact of these changes. The most common responses were emotional consequences (38%, 439), physical changes (22%, 249), changes to self and femininity (19%, 212), and reconciliation of self to changes (11%, 123).

It's very upsetting but I have no interest in sex at all, couldn't care if I never have sex again!!! (49 year old woman, early breast cancer diagnosed 2009)

Main problem is lack of interest and vaginal dryness. Husband VERY supportive but doesn't initiate sex as often because he doesn't want to be pushy as he knows I just can't be bothered a lot of the time (50 year old women, early breast cancer, diagnosed 2008).

Sex is the last thing on your mind when your chest hurts, you lose all your hair, you are tired and feel very unattractive - you just want to survive and get through (35 year old woman, secondary breast cancer, diagnosed 2009).

When does breast cancer first impact upon sexual wellbeing?

Of 1728 participants who responded, the majority (52.7%, 911) said at the point of treatment; 27.3% (472) said it was at diagnosis; 20% (345) said it was after treatment had finished.

How important is sex for people with breast cancer?

91.5% (1848) reported that sex had been a very or somewhat important part of their life before breast cancer, compared to 63.3% (1281) identifying sex as important in their lives now. The proportion of participants who report that sex was not an important part of their lives increased from 8.4% to 36.7% after the onset of breast cancer.

Which aspects of breast cancer or breast cancer treatment affect sexual wellbeing?

Of 1954 participants, the most frequently reported causative factors were: tiredness (71% n=1387), vaginal dryness (63%, 1237), hot flushes (51%, 1000), feeling unattractive (51%, 993), weight gain (49%, 953), difficulty being aroused (46%, 894), feeling uncomfortable exposing my body (44%, n=860), medication side effects (39%, 762), loss of confidence in myself (38%, 751), depression/anxiety (38%, 738), difficulty reaching orgasm (36%, 701), loss of sensation (36%, 700), reduced nipple sensation (35%, 692), pain during intercourse (33%, 653).
Conclusion

These findings support and extend previous research that reports significant changes in sexual wellbeing after diagnosis and treatment for breast cancer, which can take place at the point of diagnosis, treatment, or after treatment has been completed. This is an important issue for individuals with breast cancer, described by many as the most difficult aspect of their breast cancer experience (see also Thomas-MacLean, 2005; Bertero & Wilmoth, 2007).

These findings also confirm the conclusion that there are multiple factors associated with changes to sexual wellbeing after breast cancer, including the tangible effects of cancer and cancer treatment; physical changes in the body; emotional changes; and relational factors. A uni-dimensional approach which only focuses on one aspect of experience is therefore inappropriate and a multi-factorial approach is needed.
Impact of Breast Cancer on Sexual Relationships

The majority of 1999 respondents reported that breast cancer had affected their sexual relationship, with 24% (469), saying it was affected “dramatically”, 26% (n= 520) “considerably”, 32% (647), “somewhat” and only 15% (294), “not at all”.

The effect of cancer treatment has been devastating to our sexual relationship, to my self-esteem and to my partner’s sexual self-esteem (53 year old woman, early breast cancer, diagnosed 2008).

It is very frustrating for my partner, my interest in sex has declined, therefore creating tension in the marriage (42 year old woman, early breast cancer, diagnosed 2003).

I broke up with my husband of over 10 years at the same time as diagnosis. I had to emerge from treatment alone and single and felt old, undesirable and unsupported in this area. Must be even worse for younger women who have not had many relationships at all. (45 year old woman, secondary breast cancer, diagnosed 2007).

The majority reported relationship difficulty or breakdown, which was attributed to the participant’s disinterest in sex; partner rejection or absence of support; partner fear or inability to cope; partner’s taking on the role of carer; or existing relationship difficulties.

The feelings of exhaustion and pain have meant a whole change in my relationship - my partner is now my carer - and I think it is this fact which has altered our sexual relationship. I feel guilty about being a burden to my partner and even though I want more intimacy I am then too tired to really follow through. (57 year old woman, locally advanced breast cancer, diagnosed 1987).

I went from a high libido to no libido or interest at all; my husband replaced me in less than 2 months. For me there is simply no point in looking for information as I really no longer care if it returns or not because I now also have to deal with trust issues. I just don’t see myself being that gullible again. (52 year old woman, locally advanced breast cancer, diagnosed 2010).

I went into shut down mode where I only had emotional energy for myself. Therefore I found it hard to have energy for mustering an interest in sex. This in turn caused my husband to become frustrated and impatient. This made it worse because I felt pressure, but anger because I didn’t think I should feel pressure given the circumstances! (42 year old woman, early breast cancer, diagnosed 2010).

A smaller proportion reported relationship improvement, manifested as feeling closer or experiencing greater intimacy with their partner since the diagnosis of breast cancer. This was attributed to breast cancer offering an opportunity to renegotiate intimacy; better communication since diagnosis; the fact of having a secure relationship before breast cancer; or the development of a new relationship since breast cancer.

We stopped taking our sex life for granted and made an effort to maintain intimacy and our sex life, even when it was difficult at times. (58 year old woman, early breast cancer, diagnosed 2009).
I feel my love for my partner is even stronger if that is possible and I know he feels the same (38 year old woman, early breast cancer, diagnosed 2009).

Impact of breast cancer or changes to sexual wellbeing on partner

1348 participants reported that their partner had experienced negative consequences as a result of their breast cancer, including fear of hurting her during sex (52%, 708), lack of interest in sex (37%, 498), difficulties in communication (34%, 459), tiredness (28%, 375), and change in role (seeing me as a patient) (20%, 269).

He just looks at my problems as one of those things that just happens and we just have to learn how to deal with it. (51 year old women, early breast cancer, diagnosed 2008)

Impact of breast cancer upon single women and new relationships

413 participants described the impact of cancer upon their ability to enter into a new relationship, with 57% (236) indicating that changes to their sexual wellbeing since the onset of cancer had affected their ability to enter into a new relationship.

Very disappointing, I feel like a different person. I have no desire to get involved again whereas I really enjoyed the thrill of the chase before (66 year old woman, early breast cancer, diagnosed 2006).

I feel less confident and avoid relationships (40 year old woman, locally advanced breast cancer, diagnosed 2003).

The most frequently identified issues were related to feelings around appearance and the perceptions of others with ‘body image/attractiveness concerns’ noted by 77% (196); ‘lack of confidence’ (66.5%, 169); ‘not feeling desirable’ (65%, 165); and ‘fear of rejection’ (46.5%, 118). The most common physical effects reported were ‘fatigue’ (46.5%, 118), ‘vaginal dryness’ (42.9%, 109) and ‘upper body or other pain’ (22.8%, 58).

My husband died after months of lung cancer and 1 month prior to my 2nd breast cancer. I do not have the confidence to form another relationship as I have had a bilateral TRAM FLAP reconstruction and am scared of rejection (woman (age not supplied), locally advanced breast cancer, diagnosed 1995).

My libido is non-existent and I fear a relationship because I think that they will get sick of my lack of desire for sex and look elsewhere or end the relationship. I think that is why I'm afraid of having a relationship (45 year old woman, secondary breast cancer, diagnosed 2004).

As I'm not in a relationship, I feel a need for intimacy on an emotional level but would be concerned that this would come with an expectation for sexual intimacy so have avoided getting into a relationship to meet my emotional needs to avoid having to deal with sexual issues (45 year old woman, early breast cancer, diagnosed 2005).

Conclusion

These accounts of relationship change after breast cancer confirm previous research reports that the diagnosis of cancer can change the relational dynamics between people with cancer and their family members, in particular their life partners, which can have an impact on their ability to cope. Equally, whilst the experiences of partners are often neglected in research on sexuality and
intimacy post-cancer, there is growing acknowledgement of their unmet needs in this area. Reported disruptions include decreases in their own sex drive; fear of initiating sex with their partner; difficulty regaining a level of ‘normality’ within the sexual relationship; and feeling unwanted and unattractive because of cessation of sex. Many of these findings have been confirmed and extended by the findings of the present study.

There is also a growing literature examining psychological distress in partners, who have been found to exhibit depression and anxiety, sleep problems and fatigue, and appetite disturbance. The reporting of high rates of depression or anxiety, anger, guilt, and fear, as well as tiredness, in the present study, confirms these findings.

Finally, the accounts of women who are not in a relationship highlights the importance of sexual wellbeing for women who are currently single, and the need for single women to receive support, if they ask for it, to alleviate fears or concerns about entering a new relationship. Sexual wellbeing is not only a relational issue; changes in sexual wellbeing, and in sexual desire and arousal, can also have an impact on those who are not in a relationship.
Fertility and Breast Cancer

24.7% (452) of the 1830 participants who answered the question ‘has breast cancer had an effect on your fertility?’ reported that it had, had an effect, with 53.9% (987) reporting that it had not, and 24.4% (391) reporting that they did not know. Many women reported that they had not been informed about infertility prior to treatment, and did not know about interventions to preserve fertility.

My dream to have children was NEVER discussed, I was placed into early menopause and suffer side-effects from that, recent tests show I have hardly any eggs and will probably never have my own child (44 year old woman, early stage breast cancer, diagnosed in 2007).

Can’t have children because they had to bring on menopause. Very angry. (45 year old woman, secondary breast cancer diagnosed in 2004).

The causes of infertility post-cancer were attributed to: Chemotherapy (213); Oophorectomy (41), Menopause, (34). The majority of women described infertility as a devastating experience; however, for some older women, and those who had finished having children, menopause was welcomed.

This is a very, very, important issue as breast cancer survivors are constantly reminded of their fight with the cancer in their daily life due to the impact it has on the sexual relationship with your partner. The cancer changes everything anyway but this impact lasts the longest and is a constant in the relationship and is a very important part of trying to return to a "normal" life after treatment and the disappointments that infertility as a result of the cancer has left in the relationship. (49 year old woman, early breast cancer, diagnosed 1996).

I was oestrogen positive so I can’t have any more children which I desperately wanted, it’s too much risk, also my ovaries stopped producing eggs on my 4th round of chemotherapy (39 year old woman, locally advanced breast cancer, diagnosed in 2010).

Conclusion

These findings support and extend previous research which reports that fertility is a matter of major concern for people with cancer. Indeed, since 2006, psychosocial guidelines for the care of people with cancer include recognition of the need for support in relation to fertility post-cancer (Lee et al., 2006), as a central objective. However, current guidelines do not provide practical strategies for the application of such support in clinical practice, and fertility is still rarely addressed by health professionals (Quinn et al, 2009; King et al, 2008; Crawshaw et al, 2008).
Pathways to Addressing the Impact of Sexuality and Breast Cancer

Speaking about changes to sexual wellbeing or sexual relationships

1999 participants responded to the question “since the onset of your breast cancer, have you spoken to anyone about changes to your sexual wellbeing or sexual relationships?” 65% (1292) said “no”, and 35% (704) said “yes”.

I tried talking to a counsellor straight after the surgery but they didn't know what to say (59 year old woman, early breast cancer, diagnosed 2000)

The person most commonly spoken to was: partner/husband (n=515), with 48% reporting being satisfied with the discussion; GP (332), 38% satisfied; friend/relative (32), 48% satisfied; oncologist (265), 33% satisfied; breast care nurse (139), 60% satisfied; psychologist (123), 52% satisfied; counsellor (83), 44% satisfied; support group (75), 63% satisfied.

There is a doctor and nurse in the room at the time of consultations and I never felt comfortable opening up in front of two people, plus they never asked. It looked as though I was coping very well so I suppose they never thought to ask either. (50 year old woman, locally advanced breast cancer, diagnosed 2010).

Talking about sexual wellbeing to partners

Of 1902 participants, a greater number said that they never talk to their partner about sexual wellbeing or intimacy since the diagnosis of breast cancer (19%, 343), compared to those who said they never talked to their partner before breast cancer (9%, 173). There was no difference between the number of participants who talk to their partner sometimes before breast cancer (65%, 1233) compared to after breast cancer (63%, 1121). However, a fewer number of participants reported always talking to their partner after breast cancer (17%, 311), than before breast cancer (26%, 496).

Reasons for not speaking to anyone about changes to sexual wellbeing

1323 participants described why they had chosen not to speak to anyone about the changes to their sexual wellbeing. The most common responses were: I talk to my partner 38% (503); embarrassment 36% (473); I can cope on my own, 32% (428); I don’t know how anyone can help 32% (420); sex is a private matter 23% (303); the changes are not significant 20% (268); and I don’t know who to talk to 19% (263).

Because I am not in a relationship I would find it hard to discuss my feelings of sexuality, or lack thereof (67 year old woman, early breast cancer, diagnosed 2009)

My medical oncologist did ask me about sexuality and I did say, “Ooh it’s a little bit sore at the moment.” Um, and I was very embarrassed because he was a male and he was embarrassed. So we were both kind of a little bit embarrassed about it like, I felt like he wasn’t really comfortable. Um, he suggested that I see the breast care nurse, um, and she was really good and you know, she made a joke of it and gave me some Sylk and a goodie bag, she said, “I’ve got a goodie bag for you, you take that home and you’ll be fine.” Then she rang me up to see if that was fine, I said, “No it didn’t work.” And she goes, “Oh damn.” Anyway - - - (age and diagnosis details not available)
180 participants provided more information about why they did not discuss sexual wellbeing in response to an open-ended question. The responses were: Sex is not a priority (22%, 40); Waiting until after treatment to see if things improve (19%, 34); Not in a relationship (17%; 31); Health Professional difficulties (9% 15); Age issues (7%, 13); I'm a health care provider myself (3); Rural issues (2).

The word sex hasn't come up once in the whole of my treatment, not with gynaecologists, not with oncologists or radiotherapists or nurses, nothing, no word. Doesn't even – it's almost as if we're talking breast cancer, we're not talking sex, you know. It's not come up once in my experience. (Age and diagnosis details not available)

Who would individuals with breast cancer like to speak with about changes to sexual wellbeing or sexual relationships?

1325 reported on who they would like to speak to about changes to sexual wellbeing or their sexual relationship. The most common responses were: partner/husband (69%, 907); GP (26%, 346); breast care nurse (22% 300); counsellor (20% 267); psychologist (18%, 249); oncologist (17%, 231); sex therapist (16%, 217). These findings suggest that couple communication is the most desired form of communication, desired by nearly two thirds of the sample, with less than a quarter wanting to discuss sexual wellbeing with a health professional.

Do women want information about changes to sexual wellbeing after breast cancer?

Of the 1901 who responded to the question “would you like to receive information about breast cancer and sexual wellbeing?”, two thirds of the sample (68%, 1287), said yes.

Has information been obtained about breast cancer and sexual wellbeing?

Of 1907 participants who responded to the question, “have you obtained information about breast cancer and sexual wellbeing?” over half of the sample (59%, 1117), said no. This suggests that a substantial proportion of individuals desire to have information, but have not been able to access it.

Of those who said that they had obtained information, 791 provided details about the type of information that was obtained, and satisfaction with this information. The most common reports were information about: effects of cancer treatments on sexual wellbeing (470, 53% satisfied); changes to my body (447; 57% satisfied); breast reconstruction (363; 61% satisfied); body image and appearance (303; 51%); sexual functioning (273; 50% satisfied); information about partners (204; 47% satisfied); where to go for support (164; 54% satisfied).

What type of information about breast cancer and sexual wellbeing is wanted?

1350 participants gave information about the type of information they would like to receive about breast cancer and sexual wellbeing. The following were rated as very important by a substantial number of participants: vaginal dryness (680); Relationship changes (597); difficulties in being aroused (549); hot flushes (529); information for partners (524); loss of sensation (520); pain during intercourse (498); body image and appearance (469); depression/anxiety (436); how to talk about sexuality and intimacy (411); anxiety about sex (386); relationship communication (377); loss of identity (344); sexual wellbeing across stages of cancer (311); breast reconstruction (308); lymphoedema (269); sex aids and products (123).

Of 1456 respondents, the majority wanted to receive information through: booklet/leaflets (62%; 905); newsletters (60%, 865); or websites (57%; 821). A minority of participants wanted to receive information through group information sessions (18%; 261), or telephone help-lines (10%, 141).

66 respondents provided information about other forms of receiving information. The main responses were: email (n18); one to one session with a professional (n17); support group (n8).
Difficulties in accessing information about breast cancer and sexual wellbeing

1632 participants responded to the question “have you experienced difficulty in sourcing information about the effects of breast cancer on sexual wellbeing? 74% (1210) said “no”; 26% (422) said “yes”.

Further information about difficulties in sourcing information was provided by 363 participants. The main responses were: I have not tried to look for information (121); Information does not meet my needs (116); I do not know where to look (92); Health professionals reluctant to discuss sexual issues (28).

*It is quite difficult to talk about sex even to a health professional and sometimes the information were given at great speed and it’s overwhelming at times since I have to overcome the embarrassment first, then I can't receive the information, advice and where to go for support as I would like to have. Don't know where to go for support - to talk about it is a major obstacle for me. (38 year old woman, early breast cancer, diagnosed 2008).*

Acknowledging the needs of marginalised women

A number of women gave accounts of feeling that their needs and concerns were marginalised, and their sexuality ignored, because they were seen as too young, too old, were in a same sex relationship, or because they were not in a relationship.

*Whenever I seek information about my sexual wellbeing (or lack of it), the issue of my age bracket gets 'in the way'. Evidently, I am not supposed to have an active and satisfying sex life at my age anyway. However, I don’t believe this to be correct, and I was enjoying sex, got relatively easily aroused and would often masturbate right up to early 2008. I was 61 then and don't believe that I was effectively much younger or very different from the individual I am now. But the breast cancer has happened in the meantime, and I believe it is the cause of my changed response to sex. I would very much like to resolve the problem(s) in regard to my sexual wellbeing, as I firmly believe I should be able to continue to enjoy sex till the day I die. I miss it now. (Age and diagnosis details not available)*

What has been tried to deal with changes to sexual wellbeing or sexual relationships

1598 participants provided information on what they had tried to deal with changes to their sexual wellbeing after the onset of breast cancer. The most common responses were: talking to partner husband (61%, 969); lubricant (57%, 915), exercise (45%, 716), reading information booklets/leaflets (31%, 500), talking to a health professional (26%, 411), anti-depressants (20%; 316), psychotherapy/counselling (16%, 260), sex aids (14%, 220), medications (11%, 180), books (11%, 169). All other responses were reported by less than 10% of the sample. Many respondents tried more than one means of dealing with changes to sexual wellbeing.

*I did fill in a questionnaire at hospital regarding what counselling I felt I needed but never heard any more from them. Since I did get help with physio and lymphoedema etc. it did make me feel that I shouldn't be pushing that issue. (52 year old woman, locally advanced breast cancer, diagnosed 2009).*
I tried to get some counselling through the hospital but they were not interested, at times I have felt extremely desperate, after the diagnosis my partner and I achieved a new closeness but he ruled out sex. I now masturbate regularly, and have considered purchasing a vibrator but find it a bit confronting. Have also considered reconstruction but realised it would not be good enough as far as my husband is concerned, for him sexually I will always be damaged goods. I have considered separating but over time we have reached an accommodation where we have a fond but non sexual relationship. (58 year old woman, early breast cancer, diagnosed 2003).

Conclusion

In previous research conducted in Australia by members of the current project team, successful re-negotiation of intimacy post-cancer was associated with good couple communication and positive relationship context (Hawkins et al., 2009, Gilbert et al., 2009). This suggests that the most common coping response in the present study, “talking to partner/husband”, is an important and appropriate strategy.

The finding that only 25% of participants in the present study had discussed sexual wellbeing with a health professional, despite the high levels of distress reported, is a matter of concern. This appears to confirm previous findings that few health professionals engage in discussions of sexual wellbeing with people with cancer, even in areas where it might be expected, such as breast cancer. There are a range of reasons for not speaking about sexual wellbeing after breast cancer, which suggests that health professionals should respect the choice of individuals to not discuss sexual wellbeing, and at the same time, be aware that individuals with breast cancer may be too embarrassed to raise the issue, or not know what help is available.

Whilst the majority of the respondents wanted to receive information about sexual wellbeing, nearly two thirds had not actually received any. This suggests that information needs are not being met. A range of information is required, on topics ranging from physical, to psychological, to relational issues, which the majority of participants prefer to access through reading material.
Part Two: Sexual Wellbeing and Breast Cancer: Health Professionals Perspectives

This section of the executive summary outlines the results of a survey completed by 159 health professionals, supplemented by interview accounts of a further 11 health professionals. The sample comprised health professionals across a range of professions and geographical locations. The majority of the sample (84.4%, 114) were primary health professionals, with breast care nurses comprising the largest proportion (55.2%, 88), and health professionals working in allied health making up 15.5% (21) of the sample.
Sexual Wellbeing in the Management of Breast Cancer

Do health professionals consider sexual wellbeing to be an important issue for women with breast cancer?

Of 145 health professionals, the majority reported that sexual wellbeing is a ‘very important’ (89%) issue. Nursing (90.2%) and allied health professionals (94.4%) were more likely to endorse the view that the issue of sexual wellbeing was “very important” when compared to doctors (57.1%).

Which aspects of sexual wellbeing do health professionals consider are important for women with breast cancer?

Of 144 health professionals, ‘body image and physical attractiveness’ was endorsed by the majority (98.6%, 142) as the most important change to sexual wellbeing after breast cancer. Physical changes, menopausal symptoms, relationship issues, and sexual desire/changes in libido were also endorsed by over 90% of the health professionals.

Do health professionals currently raise the issue of sexual wellbeing as part of their consultations with women?

Only 33.8% (49) of 145 health professionals reported that they ‘always’ address the issue of sexual wellbeing with women with breast cancer. The majority (57.9%) reported that they ‘sometimes’ addressed this issue, and 8.3% ‘rarely’ address this issue with women.

When do health professionals raise the issue of sexual wellbeing?

Of 142 health professionals, the majority (58.5%, 83) reported that it was ‘part of my standard practice’, 57.7% reported that the ‘woman or her partner raises the issue’, and 51.4% reported that they are prompted to raise the issue because they ‘identify it as a particular concern for the woman or her partner’. Doctors were more likely to address sexual wellbeing when it is raised by the woman or her partner (85.7%), and were less likely raise the issue as part of their standard practice (28.6%). In contrast, nursing (61%) and allied health professionals (55.6%) indicated that they raise the issue of sexual wellbeing as part of their standard practice.

I think when they come to see a medical oncologist; they talk to them about the possibilities of chemotherapy or hormone therapy. I think, once they’ve had that consult, it’s a good time to for the Breast Care Nurse to try and meet with them, and then just gently explain what your role is and perhaps put that aspect out there to think about. I mean, of course, it’s different for every woman, because if you’ve got a very young lady who’s newly diagnosed and is going to be treated quite aggressively, then, ah, fertility and sexuality are very much at – at the forefront. Because if she’s planning – hasn’t had a family and is planning on having one, then you need to talk to her about, you know, fertility and perhaps going to see somebody about, banking eggs and – and freezing them and things like that. So, that becomes a question upfront straight away. But if you’re looking after an older woman, yeah, you just need to probably raise it and then say that things may be different but there are things that you can do.

I think a good time to follow-up with it, - you know, addressing sexual wellbeing issues, is actually when they go onto actual treatment - like, if they’re having chemotherapy and stuff like that (Breast Care Nurse/Cancer Care Co-ordinator, 6-10 years experience in cancer field, rural area)
Post mastectomy or surgery. If they’ve had a mastectomy I think it needs to be bought up, sort of, fairly quickly. Um, and if not, just in the first, sort of, months or so, I think. You know, when they’re just having general chemo or radiotherapy (Oncology Nurse, 3-4 years’ experience in cancer field, rural area).

How do health professionals raise the issue of sexuality and what approaches are used?

The majority (74.5%, 102) of 137 health professionals reported that they ‘mention sexual wellbeing as part of a general discussion of breast cancer and breast cancer treatments’. 51.1% raise the issue by ‘offering women written information on sexual wellbeing and breast cancer’, 43.1% ‘raise the issue indirectly by asking about physical health concerns’, and 40.1% of health professionals ‘directly ask women whether they have any concerns about sexual wellbeing’. Doctors were more likely than other health professionals to raise sexual wellbeing indirectly by asking about physical health concerns (85.7%) compared to nursing staff (38.5%) and allied health professionals (44.4%). Only 22.6% reported engaging ‘in a full discussion of sexual concerns and suggest strategies to help’.

I try to make a bit of humour out it, and I often say look um - they ask breast care nurses to talk about sexuality um - following breast cancer; and then I try to make them laugh, and I say, “Look, I’m not a sex expert, ask my husband.” Which usually gives them a laugh and it kind of relaxes it a bit (Breast Care Nurse, 3-5 years’ experience in cancer field, metropolitan area).

It’s just the more you talk about it the more you normalise it. You normalise it that it’s just another part of life and it’s another part of your body. It’s like your range of movement for your arm, that’s an important part of your life and these intimacy areas are important as well. So it’s normalising it I think (Lymphoedema practitioner, 5 years’ experience in cancer field, metropolitan area).

With any conversation about sexuality, but particularly when people are really vulnerable after they’ve had chemo or radiotherapy for breast cancer, and their body image is so hugely changed after they’ve had breast cancer, so having that conversation about what is normal and how that can shift when you have surgery, and coming into that space of self-acceptance is really important, too (Women’s Health Nurse, 16 years’ experience in cancer field, rural area).

What aspects of sexual wellbeing do health professionals convey to women with breast cancer?

Of 108 respondents, the two aspects of sexual wellbeing that health professionals were most likely to address were ‘Physical changes’ (87%) and ‘Body image and physical attractiveness’ (87%). The second and third most common aspects to be addressed included ‘Menopausal symptoms’ (84.1%) and ‘Relationship issues’ (74.6%). Allied health professionals were most likely to address relationship issues (88.9%) and body image and physical attractiveness issues (83.3%). Nursing professionals most commonly addressed menopausal symptoms (91.7%), body image and physical attractiveness (89.6%), and physical changes (e.g. vaginal dryness, lymphoedema, vaginal discharge) (88.5%). Doctors most commonly addressed physical changes (100%), and menopausal symptoms (100%). No differences were found between health professionals.
according to region or sector. ‘Discussion of sex aids to assist with sexual functioning’ (15.9%) was the aspect of sexual wellbeing that was least likely to be addressed.

If a woman has had a mastectomy, body image can be an issue so I recommend pretty camisoles which can make them feel better about things (Breast Care Nurse3-5 years’ experience in cancer field, metropolitan area).

But you know just think of the feelings that you had when you first met your partner or that and the holding hands and intimacy doesn't necessarily mean intercourse. Intimacy can just be closeness, and so with these big changes to your body, that - start with that closeness. It is very important that you can start talking to people and partners again. Um, what I find sometimes is that it’s sort of like the elephant in the room that the woman is feeling like this and their partner is feeling like that and they don’t want to talk because there is that fear that she feels that her partner will think her body is so changed and unattractive. And yet the partner will think oh I’d better not touch because I’m going to hurt her. So that’s one of the main things I think that I find is important. Just that re-establishment of intimacy. (Lymphoedema practitioner, 5 years’ experience in cancer field, metropolitan area).

21 participants provided further information, as did the interviewees. In their discussion with women, health professionals worked to normalise sexuality and changes to the body post-breast cancer, provided women with information about alternative forms of intimacy, discussed practical strategies and help with lubrication, and also informed women that they can ‘always come and talk’.

What referral strategies and resources do health professionals draw upon and provide to women with breast cancer?

Of 138 health professionals, the majority (80.4%) reported referring women to an ‘appropriate professional’; 67.4% provided women with a ‘booklet or information sheet’; 4.3% reported providing women with ‘audio-visual material’.

The interview accounts revealed that not all health professionals felt they had adequate access to a referral network. This was particularly the case for health professionals working in rural and regional areas of Australia, who provided many accounts of not knowing where to refer women to, or not having access to an appropriate professional within the area. Some of the health professionals working in rural and regional areas also expressed concern about the costs women with breast cancer may incur if they saw an appropriate professional, as well as the considerable travel time and associated fatigue involved in getting to an appointment.

I have been working without a social worker for three months, you know, I hope to get a new one in January. There’s certainly no sexual counselling available in the area that I’m aware of and it - it would mean, you know, trying to seek somebody out in [state], or something like this, but you know, these people have already travelled huge amounts and they’re really kind of, broke. I mean, it sounds like a bit of an excuse, but yeah, it’s not (Breast Care Nurse/Cancer Care Co-ordinator, 6-10 years’ experience in cancer field, rural area).

We live in a smaller community, not tiny, but I’m from one of the regional sites originally. So, you know, certainly, if we have clients out there, it can become quite difficult to talk about sexuality with people you’ve known, you know, for 10 years, or you know the family or they know yours. So, I think
I’d be wary of that. And I mean we’re wary of that in general because, you know, we certainly have clients who say, “Oh, look, I know that person, I know that nurse” you know, perhaps me, or, you know, my colleague, “would rather not see them because we know them so well.” So, I guess that’s another barrier and that would be somewhat unique to our area (Oncology Nurse, 1-2 years’ experience in cancer field, rural area).
Assisting Health Professionals in Addressing Sexual Wellbeing for People with Breast Cancer

Barriers to raising sexual wellbeing with women with breast cancer

Of 117 health professionals 52.1%, (61) reported that a 'lack of privacy/inappropriate setting' accounted for why sexuality was not addressed. ‘Sensitivity to a woman’s culture or religion’ was reported by 51.3%; 35.9% reported ‘time constraints and pressures’; and 30.8% felt that ‘the woman would be uncomfortable’; 4.3% (5) reported that there are ‘more important things to discuss’; 0.9% (1) said ‘is not a medical concern’; and 1.7% (2) reported ‘sex is a low priority for the woman’. The open ended survey responses and interview accounts revealed other barriers, including a lack of perceived skills and training, and difficulty broaching the issue of sexual wellbeing with older women who are assumed to be sexually inactive.

You know, there’s a room full of people, but two metres apart, or a metre apart from each other - you know, you can't really say, “Well, how is your sex life going?” (Breast Care Nurse/Cancer Care Co-ordinator, 6-10 years' experience in cancer field, metropolitan area).

An older woman (early 80's) was quite offended that I had brought up sexuality issues and assertively stated that she was not interested and that I was "silly" to think she would have concerns about sexuality given her age!!" (Breast care nurse, 6-10 years' experience in cancer field, rural area).

What do health professionals think is needed to assist them in raising sexual wellbeing with women with breast cancer?

When health professionals were asked what would assist them in raising the issue of sexual wellbeing with women with breast cancer, ‘a list of appropriate referral sources’ (81.5%, 110) and ‘fact sheets’ (81.5%, 110) were most commonly identified, followed by ‘information booklets’ (72%, 104), and ‘a sexual wellbeing consultation checklist’ (61.5%, 83).

Would health professionals like further professional development or training on the sexual wellbeing needs of women with breast cancer?

An overwhelming majority of health professional (87.1%, 122) reported that they would like further professional development and training on the sexual wellbeing needs of women with breast cancer. In addition, the majority of health professionals (67.7%, 84) would prefer to receive this training and development via ‘written information and resources’. The second two most common preferences reported by health professionals for training were: ‘online self-directed training/modules’ (61.3%, 76); and ‘workshops’ (61.3%, 76).

I suppose workshops with role playing - just to be able to talk about those things out loud gets over, gets you over the being tongue tied. And also listening to how other people handle those sorts of questions (Lymphoedema practitioner, 5 years' experience in cancer field, metropolitan area).

I would love to be able to turn up to a two-day workshop and have someone say to me, “Right. In these circumstances, this is exactly what you say, and here are some fabulous free resources for you to utilise, and here’s a number to call anytime you get stuck, and here’s some free supervision, ongoing.” (Psychologist, 3 years' experience in cancer field, rural area).
Conclusion

The findings from the survey and the interviews reveal that the majority of health professionals consider sexual wellbeing to be an important issue for women with breast cancer. However, less than a third of health professionals reported ‘always’ addressing this issue with women, with most health professionals only ‘sometimes’ address sexual wellbeing with women. The finding that overall 57.7% of health professionals in this sample are prompted to raise the issue after ‘the woman or her partner raises the issue’ may be problematic in the light of recent research which has shown that people with cancer believe that the onus should be on health professionals to raise this issue with them.

Some of the perceived barriers preventing health professionals from addressing sexual wellbeing included: a lack of privacy in a clinical setting; a lack of time – especially during the first consultation; difficulty negotiating cultural and religious sensitivities; a lack of perceived skills and training; and difficulty broaching the issue with older women who are assumed to be sexually inactive. On this last point, given that more than two in three (69%) breast cancers in women are diagnosed in those aged 40 to 69 years, (Australian Institute of Health and Welfare & National Breast and Ovarian Cancer Centre, 2009), it is important that health professionals address sexuality for women irrespective of age, so that the majority of women with breast cancer are not excluded from such discussions.

The most common aspects of sexual wellbeing that health professionals conveyed to women post-cancer related to physical changes, and body image/physical attractiveness. However, in the interviews many health professionals reported offering practical strategies to assist women with lubrication, as well as conveying to women the idea that sexuality is a normal and important part of a person’s quality of life. In addition, many health professionals also provided detailed accounts about having discussed alternative sexual practices with women and information about how to redefine intimacy if penetrative sex was no longer possible or desirable. It is promising that many of these health professionals are discussing a range of intimate and sexual practices that fall outside the coital imperative. As research has shown, those who engage in alternative practices report being *as satisfied or more satisfied* with their post-cancer sexual relationship (Gilbert et al., 2010a).

Almost all of the health professionals reported that they would like further information and training about sexual wellbeing in the context of cancer, and in particular, how to raise the issue of sexuality with women. This finding is consistent with other research which shows there is a need for health professionals to be skilled specifically in how to raise and discuss sexual issues with patients (Woodhouse et al., 2008). This information and training would be best delivered via a written resource, through engagement with an online learning resource or via a workshop providing written resources.
Next steps for BCNA

BCNA will use the results of this research to identify strategies and to develop information and resources for women with breast cancer, and the health professionals that assist them, to better support women to effectively manage the impact of breast cancer on their sexual wellbeing. Further updates will be provided through our website www.bcna.org.au and our quarterly *Beacon* magazine.

For further information about this research contact Michelle Marven, Policy Manager, Breast Cancer Network Australia on 1800 500 258, or by email policy@bcna.org.au