Breast Cancer Network Australia

Partners Survey 2008
Introduction

Breast Cancer Network Australia (BCNA) aims to empower, inform, represent and link together women with breast cancer. With these goals in mind, we recently conducted a survey into the effects of breast cancer on women’s partners and on their relationships.

We had a number of goals in mind when we stared this research. Firstly, we wanted to find out about whether changes occurred within the relationship at different stages in the breast cancer journey. Secondly, we wanted to find out about how partners provided support – what helped and what didn’t. Lastly, we wanted to get more information about how partners were supported.

Survey design and sample

One hundred women were randomly selected from BCNA’s ‘Review and Survey Group’ which comprised of women who have registered to respond to surveys. Sixty-four responses were received in total, giving us a response rate of 64 percent.

An online survey was emailed to women. The survey comprised of 15 questions, including open ended and multiple choice questions. All survey questions were optional.

Throughout the survey, we asked women about the effects of breast cancer on their relationship with their partner at specific stages of their journey. For the purposes of the survey we identified four specific stages, or key times within the breast cancer journey, based on research conducted in this area by Lethborg. These are: the time of diagnosis, the time of active treatment, the time approximately 12 months after active treatment, and the time approximately two years after active treatment. We asked about what changes occurred at each stage.

Survey Results

Information about participants

The graph below shows the number of women who participated from each age group.

Ages of survey participants

![Ages of survey participants graph]

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The majority of survey participants live in New South Wales (40.6 per cent), followed by Victoria (28.1 per cent), Queensland (14 per cent) and Tasmania (6.2 per cent). Three participants (4.6 per cent) live in South Australia and three in Western Australia and one (1.6 per cent) lives in the Northern Territory.

All survey participants indicated that they had experienced early breast cancer, with diagnosis dates ranging from 1988 to 2008. Four participants indicated that they had secondary breast cancer.

The majority of women who completed the survey were married (76 per cent) followed by those in a defacto relationship (10.9 per cent). A small number of women indicated that they did not live with their partner but were in a relationship (4.7 per cent) and the remaining ticked the ‘other’ category (7.8 per cent).

The majority of participants had a male partner (95 per cent), three participants (4 per cent) had a female partner and four did not answer this question.

**Changes within the partnership**

Some women felt that their partners did not understand their situation or were at a different stage to them. Others felt their partners were very supportive, with a number of participants noting that breast cancer strengthened their relationship.

**Closeness, communication and intimacy**

Some participants said they felt closer to their partner during their breast cancer journey, with 40 out of 48 indicating this occurred around the time of diagnosis.

> ‘I was 29 when diagnosed...It was nine months after we had been living together that I found out. I think we have made it through the tough times and our relationship is getting stronger again.’

> ‘Our whole relationship has been better since.’

However, others said they felt more distant from their partner during their breast cancer journey, with many stating this occurred approximately 12 months after the end of active treatment.

> ‘My partner did not understand my fear about checkups.’

> ‘I feel that my husband didn’t understand the impact this has had on my life.’

> ‘My husband seemed to ignore the fact I had cancer.’

For many women, communication with their partner was effected. Forty participants said their communication improved, while 23 said their communication deteriorated. Of those who said their communication improved, 24 out of 40 women said this occurred at the time of diagnosis. Of those who said their communication deteriorated, 10 out of 23 women reported that this occurred approximately 12 months after the end of active treatment.

> ‘Our communication has improved since the diagnosis of breast cancer.’
In terms of **intimacy**, thirty-seven participants indicated that there was less intimacy in their relationship during their breast cancer journey; however nineteen participants noted that their intimacy increased overall.

**Practical changes, stress and separation**

Thirty-six participants felt the **practical aspects of their partnership changed**, with the majority (26 out of 36) indicating that this occurred at the time of active treatment.

>  "Probably fielding phone calls was the most important thing."

>  "He shopped…and cooked - very supportive during every stage."

Twenty out of 41 women reported feeling that their relationships was under the most stress during their active treatment. Fourteen stated the most stress was felt at the time of diagnosis.

Interestingly, only four participants chose to comment about their **relationship ending**. This was an optional question.

**Support and assistance at different stages in the journey**

Most women (87.5 per cent) reported that their partners were most supportive either at the time of diagnosis or right throughout the breast cancer journey. Women commented on what kind of support they received from their partner and how they felt about it.

>  "During my chemo he was wonderful at making sure I took all the meds I had to, if he hadn’t I know I would have forgotten which tablets and when."

>  "I felt my partner supported me through all through my cancer journey and continues to do so."

>  "He was always supportive, but when it came to discussing the possibility of not surviving it, he didn’t want to discuss it…"

>  "During the whole journey, but she was most concerned when I was feeling the effects of the radiation and tried to make me comfortable."

Not all women felt their partners were supportive all of the time. Some women told us their partner were least supportive during their active treatment, while others felt a lack of support after active treatment.

>  "While I was in hospital to have the tumour removed, he would rush in each night for 20 minutes, tell me how busy he was, how tough it was to be working and running the house, doing the shopping, washing and feeding two cats and how tired he was- then he was gone!"

>  "I am nearing the end of my treatment/surgeries but have never felt more alone and in need of affection. I am currently not getting any of the support or understanding I did in the earlier days around the time of diagnosis and initial surgery."

>  "[Partner was not supportive] once treatment ended."

**What was most helpful for women?**
Many women said practical and emotional support was most helpful to them, for example, when their partners did the shopping, household chores, cooking meals and fielding calls. From the comments made by women, the practical support seemed to be most helpful at the time of diagnosis and at the time of active treatment. Comments from women included:

‘He did whatever was required to make my life easier - from providing small appetising meals to ensuring I always had clean pyjamas.’

Others said it was most helpful when their partners attended appointments and treatment sessions, helped with childcare and took time off work to take care of things.

‘He spent many boring hours in the hospital waiting for me.’

‘He ran me soothing baths.’

‘Listen and talk with me about treatments, decisions, statistics, my feelings and fears. Offer lots of cuddles, support and reassurance both emotionally and physically. Accompany me to all medical appointments.’

‘My partner moved in with me to help care for me and my two teenagers.’

Emotional support was also very important for many women. Some women said that it was helpful for them when their partners listened and showed understanding about different therapies and treatments for breast cancer. Others found it helpful when their partners talked with them about the diagnosis and treatment.

‘Talked about my diagnosis and looked at breast cancer research with me.’

Women also commented that it was beneficial to talk about their feelings and fears with their partner.

‘[He] let me cry,’

‘He was just there for me without being overly protective.’

‘Just held me and didn’t try to fix anything.’

‘Leaving me be when I was undergoing chemo. I didn’t have the added pressure of him and I was able to get over it on my own and deal with it how I wanted to.’

What was least helpful for women?

Women identified a number of ways in which their partners were unsupportive in emotional and practical ways. For example, some women said that their partners were not supportive during treatment or when test results arrived. Others said their partners were unavailable emotionally.

‘He switched off sometimes, probably through fear.’

‘Seemed to close down once treatment finished.’

Some women told us that their partners didn’t always look after the household or practical matters. Others noted that their partners tried to help too much or were overprotective.

‘He was distraught because he couldn’t fix the breast cancer.’
Support for partners of women with breast cancer

Forty-three women told us their partners received support from external sources. Twenty-nine women said their partner received the most support from friends, 25 said their partner was supported by family and 13 said their partner sought support from printed information. Women were able to select more than one answer to this question.

Forty-four participants said that their partner was encouraged by their doctor to be involved with their treatment, while 11 indicated that their partner was not encouraged.

‘My partner was included in the original planning and treatment and came to follow up appointments…when possible.’

‘My first doctor would only speak to my husband and not me! Needless to say I rapidly changed to a doctor that could relate to us both!’

Discussion

This survey provided an interesting insight into the significant impact of breast cancer on women’s relationships with their partner. In particular we found that the effect on women’s relationships was different at different stages of the breast cancer journey, with many women reporting that they felt their relationship had strengthened as a result of the breast cancer journey.

Overall couples seemed to become closer at the time of diagnosis, with many women reporting that their partnership was strengthened at this time. At the time of diagnosis, communication and feelings of closeness often improved. Women noted that practical support from partners, such as running the household and doing the chores was very helpful at this stage.

Stress increased for many during the period of active treatment, and practical and emotional support from partners seemed to be most important at this stage. Lack of practical support, such as not looking after the household, was consistently noted as a negative during this time. Emotional support was considered to be vital by many women who completed the survey. Women said it was very helpful when their partners listened to them, took an interest in research about breast cancer, supported them emotionally and didn’t try and ‘fix’ things.

Interestingly, the end of active treatment and up to two years after, was the point at which some women felt a lack of support from their partner. There was often pressure to feel ‘normal’ by partners and others, or to be ‘over it’. While women noted that the most stress was felt at the time of active treatment, nearly 40 per cent commented throughout the survey about lack of support after active treatment or their partner not being at the same ‘stage’ as them. Some women noted that their partners avoided talking about death or cancer recurrence. This was particularly apparent for women approximately 12 months to two years after the end of active treatment.

Not surprisingly, participants reported when their partners were stressed this affected their ability to provide support. Women reported that their partners found the most support from family and friends, followed by printed information, then their breast care nurse.

Of course, individual circumstances always play a role in how women and their partners work through a breast cancer diagnosis and the subsequent journey. For example, some
women told us their partners were also facing illnesses and treatments, which added stress to their relationship. For others, supporting and caring for children had its challenges during the breast cancer journey.

However, the common theme that emerged from our survey was that, for many couples, the breast cancer journey was significant, and that the journey doesn’t end with the end of active treatment, but in fact this marks a new stage in their relationship.