



**NATIONAL BREAST  
CANCER CENTRE**

INCORPORATING THE  
OVARIAN CANCER PROGRAM

Psychosocial impact  
in the areas of body image  
and sexuality for women  
with breast cancer

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April 2004

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# I EXECUTIVE SUMMARY

It is estimated that breast cancer will affect one in eleven women during their lifetime.<sup>1</sup> The potential for the diagnosis and treatment of breast cancer to impact on a woman's sexuality and body image is well recognised and there has also been an increasing awareness of the psychosocial distress associated with breast cancer, which has put a new emphasis on quality of life.<sup>2</sup> Sexuality is an important quality of life issue to breast cancer survivors, particularly as more women are living longer and have increased concerns with the quality of all aspects of their lives.<sup>3</sup>

The aim of this report is to present an overview of published research about the psychosocial impact of breast cancer on women's body image and sexuality. It also considers the supportive care issues for women and their partners, as illustrated through a series of focus group interviews. This report details the nature and frequency of occurrence of body image and sexual difficulties in women with breast cancer, with a particular emphasis on the past decade. It also identifies the impact of premature menopause on younger women, the impact of treatment regimens, and finally, the impact of each of these on the psychological functioning of women in their relationships, family, and community.

The key findings of the literature review and focus group interviews are summarised below and suggestions for the direction of future work are also considered.

It is recognised that body image and sexuality are issues that require sensitive exploration with women who have been diagnosed with breast cancer. As survivorship becomes more common, appropriate consideration of these aspects of quality of life is increasingly important and health professionals caring for women diagnosed with breast cancer should consider these issues throughout the woman's treatment and into survivorship.

## **Key findings**

Traditionally, the management of breast cancer has focussed on survival with psychosocial and quality of life issues only more recently being afforded appropriate status. The management of breast cancer significantly influences both body image and sexuality, but neither issue has received sufficient attention historically, particularly in the process of gaining women's informed consent before treatment has commenced. Although limited research exists about body image and sexuality and appropriate interventions, a number of conclusions can be drawn.

1 Psychosocial impact in the areas of body image and sexuality for women with breast cancer

**Breast cancer and its treatment can have a significant physical and emotional impact on body image.**

The impact of breast cancer on body image varies greatly among women, with both the diagnosis and treatment having a significant impact on this aspect of well being.<sup>2-5</sup> The impact may include: altered sexual function;<sup>6-21</sup> poor self-image;<sup>6-10,21</sup> loss of libido,<sup>6-10,19</sup> and relationship problems;<sup>6,18,21,22</sup> Although body image is often perceived as relating to physical appearance alone, women describe it as involving a sense of wholeness and functionality.<sup>22,23</sup> Evidence suggests that women who consider body image to be a major part of their sense of self-worth, attractiveness or wholeness may be at an increased risk of poor psychosocial adjustment following treatment for breast cancer.<sup>23</sup>

**The psychological sequelae of surgery for breast cancer can potentially have a significant negative impact on a woman and her relationships.**

The psychological sequelae of surgical treatment for breast cancer on body image and sexuality include: embarrassment in exposing one's body;<sup>13,24</sup> discomfort showing scars, overall body change;<sup>13,21,25</sup> lack of sexual interest;<sup>6,21,25</sup> problems with sexual relations and resumption of sexual activity;<sup>7</sup> general sexual dysfunction;<sup>6,16,17,21,25</sup> sexual satisfaction and concern about frequency;<sup>9-17,25</sup> and difficulties with becoming sexually aroused.<sup>24,25</sup>

**Breast conserving surgery is associated with better overall psychological adjustment, including improved body image.**

Many women are offered a choice between breast conserving surgery and mastectomy without compromising their chances of survival. While initial research provided conflicting results about the psychosexual outcomes of mastectomy compared with breast conserving surgery, more recent analyses has concluded that breast conservation leads to improved psychosexual outcomes.<sup>19,21,26</sup> Differences in overall psychosexual outcomes between mastectomy and breast conserving surgery include that women with breast conserving surgery have better preserved body image, earlier resumption of sexual activity<sup>26</sup> and maintained breast caressing during sexual activity.<sup>24</sup>

**The impact of body image and sexuality following surgical treatment should be carefully discussed with all women, particularly younger women, who appear to experience more concerns about body image and greater emotional distress.**

Further studies add more weight to the impact of surgical treatments on body image and sexuality, particularly for younger women with breast cancer.<sup>23,27,28</sup> This does not imply that older women are not significantly concerned about body image and sexuality. However, women of younger ages are more likely to choose breast conserving surgery over mastectomy.<sup>14</sup> Clinicians should ask a woman about any body image and sexuality concerns that she may have when surgery is discussed.

**Chemotherapy has both direct and indirect effects on sexual functioning in women with breast cancer.**

Chemotherapy can have a significant impact on a woman's physical and emotional state, which in turn may affect quality of life.<sup>21,28-30</sup> Chemotherapy has been associated with long term impairments in sexual functioning.<sup>2,3,21,25,31,32</sup> The influence of chemotherapy on sexuality is direct, through gonadal and hormonal effects, and indirect, by producing feelings of fatigue, apathy, nausea, vomiting and malaise and causing sleep or appetite disturbances that interfere with libido.<sup>28</sup> Commonly used adjuvant chemotherapeutic agents and combination regimens of drugs can have prominent effects on a woman's body image and sexual confidence.<sup>29-35</sup>

Recent studies that evaluate the impact of adjuvant chemotherapy on quality of life have indicated significant effects on sexual dysfunction.<sup>2,3,21,25,28-35</sup> These include pain or difficulty with intercourse, problems with vaginal dryness, impaired sexual activity, and decreased sexual drive.<sup>29,30,32,33</sup> The severity of sexual dysfunction following chemotherapy can be high; studies reporting between 50-60% of women treated for early breast cancer experience sexual dysfunction beyond 12 months post treatment.<sup>30,36</sup> Increase in sexual dysfunction among women who receive high doses of chemotherapy over conventional doses has been also been reported.<sup>21,29</sup>

Change in sexual functioning following chemotherapy is more evident in women who become menopausal following chemotherapy.<sup>2,32,36</sup> The role of induced ovarian failure, with reduction in both oestrogen and testosterone, is receiving more attention. Induction of premature menopause due to adjuvant therapies, discontinuation of hormone replacement therapy, psychological reactions to cancer and hormonal based cancer therapies can further contribute to changed sexual functioning. Initial data<sup>28</sup> have indicated that ovarian hormonal blood levels highlight not only deficiencies of oestrogen but also androgen in producing sexual dysfunction.<sup>28</sup> Further research in this area is required.

## **Radiotherapy and hormonal treatments for breast cancer appear to have a lower impact on body image and sexuality.**

Radiation therapy as the primary adjuvant treatment has significantly less impact on sexual function than adjuvant chemotherapy.<sup>7-9,15,24,33,37-42</sup> No studies were found that reported extensive increases in psychosexual problems following radiotherapy. Adjuvant radiotherapy to the breast may have short-term side effects, including breast tenderness and skin redness, but there is no evidence of significant impact on sexual functioning. A study that compared sexual outcomes before and after radiation treatment found that the quality of sexual activity for 75% of women was unchanged or better, where primary radiation therapy was chosen by women prior to surgery.<sup>40</sup>

Lymphoedema is a well recognised side effect of axillary radiotherapy, particularly when used in combination with axillary dissection. However, the impact of lymphoedema on sexuality has not been well documented.

The impact of the various hormone or endocrine therapies on body image or sexuality have been less extensively studied. Many such therapies appear to provide symptomatic relief and survival advantage to women with breast cancer, while causing relatively few side effects.<sup>43-45</sup> The most frequent of side effects include hot flushes, weight gain, nausea, lethargy and vaginal bleeding, discharge or irritation.<sup>45</sup> Tamoxifen has been the main subject of studies. Hot flushes occur in two thirds of women taking tamoxifen, one third of whom report severe flushes.<sup>46</sup> Anecdotal reports describe tamoxifen both increasing and decreasing libido; these appear to be very rare events.<sup>47,48</sup> It is clear that while tamoxifen increases hot flushes and vaginal discharge, evidence suggests that it does not significantly increase depression.<sup>5,49</sup>

## **Premature onset of menopause as a result of breast cancer treatment may significantly influence a woman's sexual functioning, body image and self-esteem.**

Menopause will occur as a result of surgical removal of the ovaries or may be the consequence of chemotherapy, which can ablate ovarian function, causing the cessation of ovulation and loss of fertility. Those women who do not become menopausal after treatment for breast cancer have reported more satisfactory sexual functioning, including the presence of normal sexual desire, sexual gratification and better marital adjustment, compared with women who do become menopausal.<sup>50</sup>

Research about adjuvant therapies has been primarily focussed on extending survival with insufficient attention to quality of life issues such as body image and sexuality. One recent review

of the research from 1966 to 1996 explored menopausal status in the setting of adjuvant chemotherapy and chemotherapy related amenorrhea.<sup>51</sup> These authors concluded that ovarian damage was the most significant factor affecting body image and sexual adjustment following adjuvant chemotherapy. In another descriptive study, premature menopause was the key association between chemotherapy and sexual dysfunction.<sup>52</sup>

A specific study of sexual functioning following treatment with adjuvant chemotherapy, which controlled for endocrine therapy, showed that chemotherapy was associated with significant sexual dysfunction and menopausal symptoms.<sup>32</sup> These women were more likely to report weight change, hot flushes, mood swings, vaginal dryness, decreased libido, dyspareunia, and difficulties in achieving orgasm.

**Adjustment to the changes in body image and sexual functioning will occur over time, though this will vary considerably for individual women.**

Longitudinal studies have highlighted that women's adjustment to changes in body image and sexuality changes over time. While most women do adjust, some will experience long term morbidity with regard to body image and sexuality.<sup>2,3,13,25</sup> Although the impact on sexual functioning one year post surgery is reported as limited, problems with body image, sexual interest and functioning had emerged in follow up studies conducted two to three years later.<sup>13,25</sup> This delayed onset has important implications for being able to offer women timely assessment and intervention. Early studies (1953-1981) have also recognised that the quality of a woman's sexual relationship prior to surgery will influence post-operative sexual adjustment.<sup>53</sup> Thus, spouses who indicated lower pre-mastectomy sexual functioning report decreased sexual functioning post-operatively.<sup>53</sup> However, many women were observed to seek greater intimacy within their relationship following the cancer diagnosis than they did previously.<sup>53</sup>

## **Implications of the findings – summary statements**

### **General clinical implications**

- A woman and her partner should be encouraged by health professionals to discuss their concerns about body image and sexuality at any stage along the illness/health pathway.
- Any disabilities or chronic physical discomfort that a woman may have should be assessed by a member of the health care team as this will have an impact on body image and

sexuality. Disabilities or chronic physical discomfort may include pain and side effects of treatments such as restricted arm movements or lymphoedema.

- A woman's concerns about her body image and sexuality and that of her partner should be assessed over time by a member of the health care team, such as a specialist breast nurse. Issues that may be of concern include:
  - how comfortable a woman and her partner are about looking at any scars
  - a woman's ease of self-observation before a mirror
  - how a woman feels about undressing and exposure her body in front of her partner
  - comfort in intimacy or sexual interactions
  - impact of cancer on the relationship
  - occurrence of menopausal symptoms, including hot flushes
  - any changes in libido, arousal (including vaginal lubrication), intercourse and orgasm, discomfort or pain during intercourse
- A woman's adjustment to altered body image and sexual functioning from diagnosis and continuing into survivorship should be regularly reviewed by an appropriate member of the health care team, such as the woman's general practitioner.

## **Referral**

- If a woman or her partner have any concerns at any time before, during or after active treatment has finished, a referral to a sexual health counsellor, psychologist or psychiatrist should be considered by members of the health care team.

## **Surgical management**

### **Exploring attitudes and feelings**

- The attitudes and feelings of the woman and her partner should be explored before, during and after treatment with the surgeon and other members of the health care team.

Attention should be paid to:

- body image, including sense of self, femininity and significance of the breast
  - sensory changes of the chest wall and upper arm and pain
  - post-surgical tiredness
  - access to a range of prostheses and access to prostheses fitters
  - access to appropriate styles of clothing (swimwear, line of cleavage)
  - the supportive role of intimacy with a partner
  - the impact of treatment on sexual function, including desire, arousal, sexual intercourse and orgasm
  - any fertility issues of relevance to the couple
  - consequences and fears related to the cessation of hormone replacement therapy
  - expectations and concerns regarding adjuvant therapies
- If a woman has a mastectomy, a member of the health care team such as a specialist breast nurse should be present for removal of dressings. The team member or nurse should encourage the woman's partner to be present, if this is desired by the woman. A temporary prosthesis should be offered as soon as possible following surgery.

### **Partner involvement**

- If desired by the woman, her partner should be present during the surgeon's discussion of surgical management options.

### **Decision making about surgical treatment**

- In discussions about the choice between breast conserving surgery and mastectomy, women should be informed that body image is better preserved with conserving surgery. The latter facilitates a better fit of clothing, reduces the need for a prosthesis, avoids potential discomfort with nudity and assists in maintaining sexual relationships.

- Women should be informed that where there is a choice between breast conservation surgery or mastectomy, body image and sexuality, including arousal with caressing the breast, is better preserved with conservation surgery.
- When mastectomy is selected as the preferred form of primary surgical treatment, the surgeon should discuss the option of early reconstruction irrespective of the woman's age.

### **Adjuvant treatments**

- Women should be fully informed of the short and long term effects of cytotoxic and endocrine therapy on body image and sexuality. Specific discussion should address both the physical and emotional impact of side effects, including:
  - fatigue, nausea and vomiting, diarrhoea, hair loss and treatments for these side effects
  - infertility, premature menopause, hot flushes, weight gain and mood change
  - sexual dysfunction, such as decreased libido, vaginal dryness, dyspareunia and anorgasmia
- Quality of life changes relating to body image and sexuality should be discussed at the time when women are offered the choice between chemotherapy regimens that offer differences in absolute survival, such as anthracycline, CMF, or, less commonly, high dose chemotherapy with bone marrow rescue.

### **Radiation therapy**

- While radiation therapy does not have a strong psychosocial sequelae often detected with women undergoing other treatments, the timing of adjuvant radiotherapy may correspond most closely with a woman's increasing recognition of changes in her body image and sexuality. A member of the treatment team should explore and support the woman's adjustment at this time.

## **Breast reconstruction**

- If breast reconstruction is relevant, a woman and the appropriate members of the health care team, such as a surgeon, plastic surgeon and specialist breast nurse should explore each of the following issues:
  - types of reconstruction, including advantages and disadvantages.
  - possibility of “adjustment” surgery to the other breast.
  - a woman’s and her partner’s expectations of the reconstruction.
  - the impact of each method of reconstruction on body image and sexuality, including both positive and negative aspects, such as:
    - maintenance of body shape when clothed
    - improved self image and confidence
    - lifestyle benefits
    - loss of sensory arousal from nipple, areola and breast
    - differences in texture between reconstructed (implants, flaps) and normal breast
    - need for nipple reconstruction and tattooing
    - potential long term variations in the shape of the reconstructed breast

## **Sexual functioning**

- If a woman and the health care team consider hormone replacement therapy, the woman should be provided with detailed information to assist with making an informed choice, as there is likely to be complexity of issues to consider.
- In the case where a woman is severely distressed about her body image or sexuality, a comprehensive appraisal is warranted. This appraisal should include a discussion about a woman’s concerns in current and or past relationships, the nature of any changes, physical examination and appropriate hormone assays. A multidisciplinary team approach including a gynaecologist, general practitioner, psychologist or psychiatrist, specialist breast nurse and oncologist should be considered.

## **Directions for future work**

Further study is required in many areas. The unmet needs of women in the domains of body image and sexuality, particularly for psychosocial support and information were strongly reflected in both the research review and the focus group interviews that form part of this report. The results indicate the need to make the health care team aware of these concerns and to ensure sensitivity when communicating with women and their partners.

One area of notable deficit is an understanding of cultural issues. In exploring body image and sexuality, care should be taken to be culturally sensitive at all times, including awareness of the customs of specific religious groups. It is the responsibility of all members of the health care team to be informed regarding the specific cultural sensitivities for the women in their care.

Data from interviews also highlighted the impact lymphoedema has on both body image and sexual function. While the impact of lymphoedema as a side effect of treatment is well recognised, its impact on sexuality has not been thoroughly explored.

The role of high dose chemotherapy with stem cell rescue continues to be explored in research and the consequences for women are yet to be fully examined. The development of premature menopause and the impact of ovarian failure on a woman's sexual functioning also requires further study. Although hormonal treatments for breast cancer appear to have a less impact on body image and sexuality, the role of hormone replacement therapy in the management of sexual functioning has not been thoroughly examined.

Despite research about body image and sexuality issues, identification of strategies to respond to women with such concerns are yet to be explored. Further research is needed to ensure the needs of women in this area are met during their treatment, follow-up and into survivorship.

Similarly, support needs related to body image and sexuality have received limited attention in published literature even though in this study most women acknowledged that they needed support to cope with alterations in body and sexuality following treatment for breast cancer.

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## **2 INTRODUCTION**

It is estimated that breast cancer will affect one in eleven women during their lifetime.<sup>1</sup> The potential for the diagnosis and treatment of breast cancer to impact on a woman's sexuality and body image is well recognised. In 1952, a report by Rennecker and Cutler<sup>2</sup> about the psychological problems of adjustment to breast cancer highlighted that the loss of a breast was a traumatic event that could profoundly affect women's sexuality and femininity. Increasing awareness of the psychosocial distress associated with breast cancer has put a new emphasis on quality of life.<sup>3</sup> Sexuality is a multi factorial dimension of quality of life that, in addition to its physical expression, encompasses emotional, intellectual, and social aspects. These enhance personality, relationships, communication and love. Sexuality is an important quality of life issues' to breast cancer survivors, particularly as more women are living longer and have increased concerns with the quality of all aspects of their lives.<sup>4</sup>

### **Aim**

The aim of this report is to present an overview of published research about the psychosocial impact of breast cancer on women's body image and sexuality. It also considers the supportive care issues for women and their partners, as illustrated through a series of focus group interviews.

This report details the nature and frequency of occurrence of body image and sexual difficulties in women with breast cancer, with a particular emphasis on the past decade. It also identifies the impact of premature menopause on younger women, the impact of treatment regimens, and finally, the impact of each of these on the psychological functioning of women in their relationships, family, and community.

## **3 METHODOLOGY**

### **3.1 Research Review**

A computerised CD-ROM search of Australian and international publications between 1966 and 2001 was conducted in order to identify relevant studies examining psychosocial support in the areas of sexuality and body image for women with breast cancer. Searches were initially conducted in MEDLINE and Psychlit databases, and subsequently supplemented with further

searches in additional databases, namely, the Cochrane database, Embase Psychiatry, Clinpsych and Cinahl databases. Further, this was complemented with hard copy searches of all relevant current content editions of articles published and the International Index Medicus. Hand searches of government documents or reports and personal communications with relevant authors working in the field were also included. Letters via e-mail addresses were sent to the main cancer organisations and societies around the world in countries including: Australia, New Zealand, United States, United Kingdom, The Netherlands, France, Italy, Spain, Denmark, Sweden, Germany, Norway, and Japan. A request was made to provide information about any unpublished or ongoing research addressing the role of psychosocial support in the areas of sexuality and body image for women with breast cancer, and to provide information about resources available to assist women with sexuality and body image difficulties. The review of resources was conducted to identify if there was a need to develop additional resources, and if so, in what areas the resources should focus.

As a result, evidence-based statements for health professionals were developed to increase awareness, to assist health professionals to inquire about, and appropriately respond to, body image and sexuality issues in women with breast cancer. These evidence-based statements are provided in the executive summary.

Overlap with recent broad reviews about psychosocial issues in breast cancer and breast reconstruction was avoided. A review summarising the literature between 1986 and 1996 about psychosocial issues dealing with breast cancer<sup>5</sup> is available from the National Breast Cancer Centre. A review about breast reconstruction, which includes information about patient and professional resources is also available from the Centre.<sup>6</sup>

Key words used in primary database searches included *body image, sexuality, premature menopause, hormonal use, high dose chemotherapy, younger women, family relationships, radiotherapy, surgery, and sexual disorders including vaginismus, dyspareunia, sexual desire, arousal, orgasm and treatment of sexual dysfunction*. One hundred and twenty citations were retrieved of which 35 articles met the criteria of being specific observational or treatment studies about body image difficulties, sexual dysfunction, and predictors of risk. Articles that included sexuality as part of a general descriptive report about breast cancer (but no more detailed consideration of the issues) were abstracted but not included in the list of eligible studies. Many articles made only brief reference to sexuality.

Articles were independently appraised by two readers using standard criteria. These data included: disease stage; time since diagnosis; patient numbers; outcome measures; methodology; instrument scales used; results; and a quality of evidence rating. Descriptive, qualitative studies and case reports were given equal weighting to intervention studies. The latter were reviewed in terms of treatment settings, treatments, time since treatment, the consistency of intervention applications, independence of assessors of outcome and proposed achievements of treatments. Although we sought to examine all studies, homogenous patient selection (breast cancer patients were highly considered) was important, with the bulk of the emphasis falling on those study designs that used consecutive samples entered into randomised controlled trials.

## **3.2 Focus group interviews**

### **Research design**

An explorative, descriptive, qualitative research design was undertaken using focus groups to explore the experience of women and their partners of breast cancer and its treatment on body image and sexuality.

### **Participants**

Women who had been diagnosed with breast cancer and who had completed treatment, and their partners were invited to participate in this study. In total 27 women and six male partners and four female partners participated in the interviews. They were from Sydney, Melbourne, Brisbane and two large rural centres, Lismore and Alice Springs.

### **Recruitment**

In Lismore, a visiting medical oncologist recruited women and their partners. In Sydney, leaflets were distributed to breast cancer support groups asking women and their partners to volunteer for the project. In Alice Springs, lesbian women and their partners were recruited through snowball sampling and advertising in a lesbian magazine.

## **Data collection**

Tape-recorded focus group interviews were held in Sydney and Lismore to collect data. Three focus group interviews were held at each site for heterosexual women: women who were pre-menopausal at diagnosis, women who were postmenopausal at the time of diagnosis, and partners. Two focus group interviews were held for lesbian women in Sydney. Women and partners were interviewed separately. Telephone interviews were also conducted with lesbian women and partners from interstate on a one-to-one basis at a time that was convenient to women.

Two members of the research team conducted the interviews. In Sydney the interviews were conducted at the New South Wales Cancer Council or Australian Catholic University (North Sydney), in Lismore at the private rooms of the visiting oncologist. Each interview lasted between 1.5 and 2 hours. Telephone interviews lasted between 1.0 and 1.5 hours.

A semi structured interview schedule was used to canvas several issues. Firstly the effect of treatment for breast cancer on body image and sexuality on women as perceived by women and their partners. Secondly, the interviews explored how the health care team met the needs of women and their partners, particularly in relation to their support and information needs. Finally, the support needed by women was discussed, together with the impact of treatment for breast cancer on relationships. While the interview schedule was used as a guide, groups and individuals were facilitated to allow participants to explore other issues related to body image and sexuality.

## **Data analysis**

Interviews were transcribed verbatim, and entered into the software package QSR NUD\*IST version 4.0. The program assisted in the tallying and sorting of codes and categories, and the sorting and extraction of selected text segments after manual coding had been completed.

Transcripts were read and coded to capture the meaning of the data. All the transcripts were coded independently by two members of the research team and the codes compared and any differences resolved. The codes were sorted and categories and subcategories identified by the researchers. The categories and subcategories were used to write a description of the women and their partner's experience.

## **Ethical considerations**

Several strategies were implemented to ensure the protection of the rights of the participants involved in this study. The Research and Ethics Committee of Australian Catholic University granted ethical approval for the conduct of this study.

Participants were fully informed of the nature of the study by the researcher and written information provided before written consent was obtained. Participation in the study was strictly voluntary and did not attract financial remuneration.

Due to the sensitive nature of the subject being explored it was acknowledged that there might be some risk of psychological distress to the participants as they discussed their body image and sexuality. In order to minimise this, all participants were informed that they were free to refuse to answer any questions, stop the interview and/or withdraw from the study at any time without negative consequences. Participants were given a list of local services that could provide counselling about the issues of body image and sexuality.

Audiotapes were numbered and coded and not identified by name. No references to name or identifying features were used during analysis and report writing.

Data were available only to the research team. All data including audiotapes, computer disks and computer print outs were stored in a locked filing cabinet in the researcher's office during the project. All data will be kept for at least five years after completion of the project.

## **Limitations of the method**

The purpose of the study was to undertake an in depth exploration of the experiences of the women and men interviewed in the study rather than a broad perspective of a larger sample. Care should be taken in generalising the results to the broader community. All the participants were volunteers suggesting that they had views that they wanted to express.

There are many areas that this research was unable to address. It must be recognised that this research has not explored the impact of body image and sexuality for women diagnosed with breast cancer from different cultural backgrounds.

## 4 RESULTS

The psychosocial impact of breast cancer on women was examined from a number of different perspectives. These included the impact of diagnosis and treatment on body image and sexuality, information and support needs related to body image and sexuality, and the role of the health care team. The following were examined: treatment effects related to breast cancer including surgery, high and standard dose chemotherapy regimens and hormonal therapies; the impact of premature menopause, family relationships; and risk factors associated with predictive outcomes of sexuality problems.

Throughout this document exemplars from the interviews with women and their partners are shown in italics to illustrate the results of the systematic analysis and provide context or insight into areas not covered in published research such as the experience of lesbian women. This in no way implies that the data from the focus group interviews should be given equal weight as the systematic analysis, or any greater weight than research of this type would normally be given. A full report of the focus group interviews is available from the authors.

### 4.1 The women's experience: an introduction

Body image and sexuality is one aspect of the total experience of breast cancer.<sup>7,8</sup> An exploration of the experiences of women diagnosed with breast cancer is required to understand women's needs in relation to body image and sexuality. While research has focused on evaluating the impact of a specific treatment on body image or sexual function, there is limited exploration of the total experience of breast cancer from the women's perspective. The impact of breast cancer on this global aspect of psychosocial health can vary considerably, as was highlighted by the women in our interviews. Women expressed concern that, in focusing on the impact of breast cancer on sexuality and body image, they do not become medicalised, but their whole person is recognised as paramount to the experience, and they require sensitive assessment and support, as with other areas of the breast cancer experience. This does not ignore that for some women, more active interventions may be required to facilitate adjustment to the physical and emotional impact of breast cancer and subsequent treatments.

*And you know ... there's a real danger always with these things, when you recognise people need support or whatever, then it becomes over medicalised. You have a big problem, this is the solution for it and that's where the pendulum swings the other way. Because obviously that's going to frighten people away too. Frighten men away.*

*[Premenopausal woman]*

There is limited agreement within the health care literature about the definition of ‘body image’ and ‘sexuality’. The authors of most studies fail to define the terms or to explain the different approaches used to measure the impact of the disease on body image and sexuality. It is important to understand how these terms are operationalised by women and their partners when reviewing the available research. Women who participated in the interviews completed for this report found it relatively easy to define or describe body image, but the term sexuality was unable to be defined by most participants. It was generally agreed that body image was a societal construct and sexuality a more personal construct. Generally body image was defined as:

*I suppose how you perceive yourself and also how others perceive you.*

*[Postmenopausal woman]*

Women view their bodies not only socially and sensually, but also in an existential sense, where the wholeness of body is needed to be truly present in the world.<sup>9</sup> There is a complexity of meaning to ‘body’ for a woman with breast cancer, requiring differing levels of clinical intervention in response to this varied meaning. Thus, a social support program such as “*Look Good, Feel Better*” responds to the body as a social symbol.

Understanding the significance of the breast for women with breast cancer, and within society at large, assists in comprehending the impact of breast cancer on women and their partners.<sup>10</sup> Given the nature of the disease, the women and men interviewed focused primarily on the personal and societal significance of breasts, although the impact of breast cancer and its treatment on other anatomical areas were also discussed. The women expressed a range of positive feelings for their breasts prior to surgery, and linked their breasts with their womanhood:

*... I didn't develop breasts until I was about 42-43, so I've only had breasts for a very short period of time. I was a joke because I was so flat-chested, all of a sudden I managed to grow them and I was so proud of them, ... I had them for a few years and then all of sudden one's been cut from me ... - I loved them so much when I grew them and I thought, these are wonderful, I'm going to cherish these and nurture these breasts*

*[Premenopausal woman]*

A woman’s response to her breasts is strongly influenced by the portrayal of women in society. Women in the focus group interviews identified that after surgery they became even more aware of the media’s portrayal of women and breasts:

*I mean society raise up breasts. ... I'll go to the movies and I'm watching film stars, or I'm watching television ads and I'm so aware of what the media do with women's bodies and breasts are just at the forefront at the whole time.*

*[Premenopausal woman]*

Sexuality moves beyond the physical dimension of the body to consideration of the complexity of human sexual behaviour, which includes aspects such as attraction, gratification of desires, fantasy, lovemaking and sexual intercourse. The term 'sexual functioning' which is ascribed in the clinical setting is predominantly expressed using behavioural terms and identifying problems that are described in terms of sexual dysfunction. Health professionals must take care to relate to the whole person, the woman, rather than assuming body image and sexuality equate with sexual dysfunction.

## **4.2 Impact of Breast Cancer and Treatment on Body Image**

The impact of breast cancer on body image and sexuality varies greatly between women, with both diagnosis and treatment having a significant impact on well being.<sup>3,4,11,12</sup> The impact can include altered sexual function,<sup>11,13-27</sup> poor self-image,<sup>13-17,27</sup> loss of libido,<sup>13-17,26</sup> and relationship difficulties.<sup>9,13,25,27</sup> The results of these studies were supported by the focus group interviews, in which women described the physical impact of hair loss, weight gain, lymphoedema, fatigue, a feeling of disassociation and a lack of alignment in the arm, chronic wound infection, pain, limited range of movement in the shoulder, changed skin sensation in the area of surgery and arm and dry skin due to stopping hormone replacement therapy or radiotherapy. The impact was no less or greater depending on menopausal state, though specific symptoms may vary (such as chemically induced menopause). Some women did not consider the changes in body image and sexuality due to treatment for breast cancer to be significant.

The partners interviewed indicated that they noticed the changes had a marked impact on the women's perception of body image and sexuality, including sexual functioning. This impact resulted not only from breast surgery, but also chemotherapy and to a lesser extent radiotherapy. Partners also noticed the changes identified by women, and also commented on vaginal dryness and decreased libido.

*I guess it was the chemo induced menopause and she has a few physical problems from there. ... And then there's some dryness there that we have to cope with. It's taken some of the spontaneity away, but(sic) she misses that.*

*[Male partner]*

## **Physical and emotional impact**

While body image is often thought of in terms of physical appearance, sense of wholeness and functionality are also important.<sup>9,28</sup> Evidence suggests that women with breast cancer who have invested significantly in body image as a source of their sense of self-worth adjust poorly following treatment.<sup>28</sup> Women with heightened perceptions of body image pertaining to either attractiveness or wholeness are at an increased risk of poor psychosocial adjustment following treatment for breast cancer.<sup>28</sup>

*Well, I had a very powerful perception of myself as being an attractive person, just essentially reasonably attractive beforehand and I know I went through a great grief and mourning period where I simply didn't feel that. ... not saying that I feel that now, but in essence I felt very shrouded by what had happened.*

*[Premenopausal woman]*

The psychological sequelae of surgery for breast cancer on body image and sexuality include: embarrassment in exposing body;<sup>18, 24</sup> discomfort showing scars and with overall body changes;<sup>20,29</sup> lack of sexual interest;<sup>13,29</sup> problems with sexual relations and resumption of sexual activity;<sup>14</sup> general sexual dysfunction;<sup>15,23,24,29</sup> sexual satisfaction and concern about frequency;<sup>16-24,29</sup> and difficulties with becoming sexually aroused.<sup>29,30</sup> All have the potential to have a significant negative impact on all aspects on the woman's life and her relationships. This was highlighted in the focus group interviews.

*I could cope without any sort of sexual relationship at all. Sexual attention. To be honest, I don't have any energy for that and so somehow it turns into a real focus. Because it takes a lot of energy just to think of the other person.*

*[Premenopausal woman]*

Outcomes related to body image have been examined as clinical evidence has demonstrated no advantage of mastectomy over breast conservation in breast cancer survival.<sup>31</sup> Initial research in this area provided conflicting results. More recently a meta-analysis of these studies concluded that breast conservation leads to improved psychosexual outcomes.<sup>32</sup> Differences in overall

psychosexual outcomes between mastectomy and breast conserving surgery include women with breast conserving surgery having better preserved body image and earlier resumption of sexual activity<sup>32</sup> and maintained breast caressing during sexual activity.<sup>30</sup> More recent evidence suggests that the variation in outcome due to surgery type may only become apparent over time.<sup>32</sup> The possible long-term effects of diagnosis and treatment on sexual functioning include problems ranging from “not feeling sexually attractive”, to “no interest in having sex”, to “feelings of not being attractive to their partner”.<sup>29</sup>

*Well ... I do have [a reconstruction], but funnily enough, since then I never enjoy my husband touching my breasts now. Not my reconstructed one or my own breast.*

*[Postmenopausal woman]*

Body image problems experienced by women following surgery include embarrassment in exposing their bodies, discomfort showing scars and with overall body changes.<sup>20,29</sup> A focus on the breast or lack thereof, rather than on the whole person, occurs for some women in this situation where grief over their loss may dominate.

*... and then when I got home, I still didn't really want anybody to look at me, because I didn't have a breast form at that stage, I wore big shirts and things so that I could cover it up and it wasn't obvious.*

*[Premenopausal woman]*

*I wore a camisole for ages after I came out of hospital, even though I had an implant. It took a long time before I could show [partner's name] my breasts and he wasn't worried. I mean it was me ... in my head and I mean even though he said he wasn't worried and I know that he wasn't, but he said: You're more than breast and all that sort of stuff and I know he really believed it, but I didn't. It took me a long time to feel comfortable.*

*[Premenopausal woman]*

Additional studies about the outcome of surgical treatments add further weight to the impact on body image and sexuality.<sup>22,33-55</sup> This is especially the case for younger women with breast cancer,<sup>28,41,50</sup> which is not intended to imply that older women are not significantly concerned about body image and sexuality. Evidence suggests that women of younger ages are more likely to choose breast conserving surgery over mastectomy<sup>32</sup> when the option is made available, indicating that concerns about body image and sexuality are important considerations, particularly in younger women, when considering choice of surgical technique.<sup>56-58</sup>

Concern with body image and sexuality may impact on a woman's behaviour. Women in the interviews reported difficulty adapting to the physical changes and the resulting physical limitations

from surgery and treatment. This had an impact on women's relationships with partners, making them hesitant to initiate physical contact, and changed behaviour in relation to exposing their body to partners and family. Several women described the approaches they took to cloaking and concealing their chest from their partners. For example:

*... my husband said, you seem to walk away from me when you take your clothes off, but I wasn't ever aware of that.*

*[Premenopausal woman]*

All women in the interviews who experienced hair loss commented that this was very traumatic, with some reporting it as more traumatic than the loss of a breast as it couldn't be hidden from others.

*I think having lost my hair, that was the major thing. That was very traumatic, to look in the mirror in the evening before going to bed, no breast, no hair, ... Oh my God, look at me! ... And I was so conscious when it was growing back, it was so super short, everyone's looking at me... and it took a while to get over that.*

*[Postmenopausal woman]*

Weight gain also had a significant impact on women's body image. Some women commented about fatigue leading to loss of libido following breast cancer treatments. Tiredness was significant enough to cause a change in lifestyle and to force the women to curtail their activities. Some women also reported being surprised by the amount of pain, the limited range of movement in the shoulder and the general discomfort experienced after surgery; effects which were present to different degrees many years after initial surgery. These effects also had an impact on sexual function, including libido and positioning during intercourse.

*... nobody told me about what was going to happen after. That I was going to have a brick in my chest and my arm was going to be like wood and the [feeling of] disassociation, ... My body just wasn't me ... [a] lack of wholeness ...*

*[Postmenopausal woman]*

Complications following surgery, such as wound breakdown and development of seromas, added to the distress experienced. In terms of lifestyle changes other women and their partners talked more about changes to the type of clothing<sup>32</sup> including swimming costumes that they could wear post surgery and the restrictions on some activities like sports, household activities and sunbathing.

## **Overall comment about body image**

Descriptive studies show that body image concerns expressed by women with breast cancer are directly related to treatment outcomes. Breast conserving surgery is associated with better psychosocial adjustment, including improved body image.<sup>32</sup> Concern about body image outcome when treatment options are being considered is a potential predictor of poor psychosocial adjustment. Existential life sequelae follow choice of surgical treatment. Body image outcomes are reported to be intimately associated with sexuality.

### **4.3 Impact on Sexual Functioning**

The diagnosis and treatment of breast cancer can have a direct impact on sexual function. The aetiology of sexual dysfunction in breast cancer has not been well studied. There are multiple predisposing factors, including pre-existing sexual problems and normal age-related changes in sexual functioning.<sup>5</sup> Significant deterioration in sexual and marital functioning as well as quality of life are long term consequences of breast cancer treatment.<sup>32</sup> One study reported that, at three years post surgery, 47% of women reported being not interested in sex, 48% had difficulty becoming aroused, 64% had lubrication difficulties and 52% had difficulty reaching orgasm.<sup>29</sup> In the focus group interviews, both women and their partners acknowledged changes made in their lovemaking as a result of physical changes, but did not suggest that the changes necessarily decreased their enjoyment of sex. Women and their partners highlighted the need for good communication, time and a willingness to experiment to maintain a healthy sexual relationship.

Sexual dysfunction can be prominent for women after treatment and presents in various forms. The most frequently identified problems include: absence of or reduction in sexual desire, followed by anorgasmia, vaginal lubrication difficulties, dyspareunia, inhibited orgasmic satisfaction, lack of interest in partner, brevity of intercourse, and vaginismus.<sup>59</sup> Sexual history prior to the diagnosis and treatment for breast cancer is an important consideration when exploring sexual dysfunction, as poor functioning prior to diagnosis can be aggravated by breast cancer treatments.<sup>59</sup> Sexual dysfunction is noted to be more predominant following chemotherapy, but has also been reported after surgery and radiotherapy.<sup>59</sup>

Research in this area has focused on specific treatments for breast cancer. The impact on sexual function will be described following the treatment modalities of surgery, chemotherapy, radiotherapy and hormone therapy.

Survival is a primary consideration for many women and their partners when choosing treatment for breast cancer. In the interviews conducted, body image and sexuality were secondary considerations at the initial stage of treatment. For a small number of women, body image and sexuality were primary considerations in treatment choice; this was particularly so with adjuvant treatment such as chemotherapy. Women commented that body image and sexuality should be discussed along with treatment choices.

*Well I think it's whatever stage you're at. When you're diagnosed, that's all consuming and you hear the word "cancer" you think you're going to be dead by the end of the year. Well I did. And you know losing a breast didn't worry me at that stage. It was just when I first saw it after it was done and then I started to think about all the other issues, how my husband would feel about it.*

*[Postmenopausal woman]*

Some women felt confident to evaluate the information themselves and make a decision, while others wanted doctors to recommend treatment for them. They pointed out that choosing surgical treatment was important and that to be satisfied with the decision in the future they needed to have all the available information. As discussed previously, many women and their partners sought information from a variety of sources in order to make an informed and rational choice.

Despite the evidence about survival following different treatments, women commented that they faced pressure from some members of the health care team, family or friends to have a mastectomy to increase their chances of survival. Other women said that they did not expect to have a mastectomy, as the general information they had received indicated that most women do not have mastectomy any more. Women discussed how information obtained from different sources was inconsistent and sometimes confusing, which lead to frustrating and feeling uncertain about to decide what was correct.

*because these people, who I see as my family, were so overcome by my diagnosis and second diagnosis. They were as fearful as me that I might die and so they were trying in their own way to convince me to have a double mastectomy, because they wanted me to be here, because that's what it boiled down to.*

*[Lesbian woman]*

## **Impact of Surgery on Sexual Function**

Surgical treatment for breast cancer has an impact on sexual function.<sup>27,32</sup> The physical changes that results from surgery can have an effect on a woman's body image, which in turn can lead to sexual dysfunction.<sup>60</sup> Research comparing mastectomy, breast conservation and early and delayed

reconstruction revealed improved outcomes for women who had undergone conservative surgery.<sup>27,60</sup>

Breast conservation has been shown to be more advantageous than breast reconstruction in terms of maintaining pleasure and frequency of breast caressing during sexual activity.<sup>30</sup>

A meta-analytic review (1980-1995) summarised the findings of 40 studies addressing the psychosocial outcomes of breast conserving surgery versus mastectomy.<sup>32</sup> This review showed modest, but significant, advantages for breast conserving surgery in improving adjustment in the domains of body/self image, psychological, marital/sexual and social adjustment, and cancer-related fears and concerns.<sup>32</sup> Improvement in adjustment was observed in the latter three domains at assessments made 12 months or longer post treatment. The study notes that some of the advantages of breast conserving surgery that are relevant to body image and sexuality include better fit of clothing, avoiding the need for a prosthesis, avoidance of potential discomfort with nudity and assistance in maintaining sexual relationships.

Methodological limitations of the review include a high use of self-report measures in the majority of the studies. Bias may be introduced by reluctance on the part of respondents to report any negative outcomes associated with breast conserving surgery. Other confounding variables are that some studies include patients who had breast reconstruction, self report assessments were conducted at the time of chemotherapy and radiotherapy treatments, patients with knowledge of poorer prognostic features were studied and choice of surgery in relationship to the age of the patient was not clarified.

Despite these limitations, the review emphasises that the extent of difference between the outcomes between mastectomy and breast conserving surgery is not significant, however, the benefits of conservation clearly extend beyond body image when long-term follow up assessments are considered. Strategies should be adopted that encourage women to take an active role in decision-making and to express her preferences of choice of surgical treatment.<sup>32</sup>

Interview participants highlighted the impact of surgery on sexuality, with both women and their partners describing the physical problems and the impact this had on sensuality and sexual relationships. These included altered skin sensation on the chest wall following mastectomy, some loss of sensitivity of areola and nipple following conservation surgery, loss of range of movement in the shoulder, pain in shoulder and axilla, lymphoedema, and pain in chest wall. These changes were long term and women reported that they had not been forewarned or told how physical changes might affect their sexual function. The physical changes reported by these women affected

spontaneity and changed their experience of sex, with some reporting an inability to move as comfortably during sexual intercourse as they could prior to surgery:

*It has taken us quite a bit of experimenting to get into positions that she finds comfortable. ... I guess we've explored what were all the possibilities beforehand anyway and it's still taken us a while to get into this - it would be silly to say a habit, but routine and I just wonder if other people have got the imagination to try lots of stuff, different positions.*

*[Male partner]*

Both men and women who were interviewed commented on the change in sensitivity (sometimes numbness, sometimes hypersensitivity) to the skin on the side affected by surgery, and their surprise at the impact this had on sexual function, particularly in relation to foreplay. Some women reported a lack of desire or discomfort when their breasts were touched.

Some women also reported a decreased libido following treatment for breast cancer. This was more prevalent in women whose body image was severely affected by surgery. Male partners reported that women's loss of libido and difficulty reaching orgasm complicated the process of initiating sex. Some men expressed concerns about initiating sexual activities, particularly not wanting to force themselves on their partners, but also being aware that the woman may feel uncertain about their attractiveness if sex was not initiated by the male partner.

*Well not to initiate, I mean sex is always a problem in relationships, lets face it and there's always a problem, who wants more sex and who wants less sex and so on and about who's going initiate it and who's not going to initiate it and so on ... And after this, what you feel is you've got to let the woman initiate because obviously you're not going to impose your [pause] desires you know because obviously you don't die from it, but that of course puts strains on the relationship as well. Because you're not initiating it, [she thinks] "He doesn't love me any more".*

*[Male partner]*

## **Impact of Radiotherapy on Sexual Function**

Radiation therapy for breast conserving treatment of breast cancer does not have the strong psychosexual sequelae often detected with women undergoing adjuvant chemotherapy. No studies were documented that reported extensive increases in psychosexual problems following radiotherapy. Radiotherapy as the primary adjuvant treatment has significantly less impact on sexual function.<sup>14-16,22,30,45,46,59,61-64</sup> Studies have reported the incidence of sexual dysfunction following radiotherapy to be as low as 6%.<sup>59</sup> A study that compared sexual outcomes before and

after radiation treatment found that the quality of sexual activity for 75% of women was unchanged or better, where primary radiation therapy was chosen by women prior to surgery.<sup>62</sup>

A report from the same group of researchers compared mastectomy with breast conserving surgery and radiotherapy, where chemotherapy was administered equally to both arms of the study,<sup>45</sup> Women who had a mastectomy felt less attractive, less sexually desirable, and more ashamed of their body; they enjoyed sexual relationships less than they did before treatment. The women who had radiation therapy were followed up for three years post treatment and experienced no change in any of these areas.<sup>45</sup>

A descriptive study comparing breast conservation with immediate breast reconstruction after mastectomy also confirmed no association between radiation therapy and the psychosexual outcomes of body image and sexual dysfunction.<sup>30</sup> Sexual variables including desire, physiological arousal, coital satisfaction, a dry vagina, and dyspareunia were not associated with previous treatment with radiotherapy.

Adjuvant radiotherapy to the breast may have short-term side effects, including breast tenderness and skin redness, but there is no evidence of significant impact on sexuality. The impact of lymphoedema secondary to axillary radiotherapy is well recognised as a side effect, but the impact of this on sexuality has not been thoroughly explored. Data from our interviews, however, highlighted the impact lymphoedema has on both body image and sexual function.

*.. nobody told me about what was going to happen after. That I was going to have a brick in my chest and my arm was going to be like wood and the disassociation, ... My body just wasn't me and still has moments when it's – an objective part of it, this part here [pointing to chest wall and arm] is an object. ..*

*[Postmenopausal woman]*

## **The Impact of Hormone Therapy on Sexual Function**

A variety of endocrine therapies are now available, providing considerable symptomatic relief and survival advantage to women with breast cancer, while causing relatively few side-effects,<sup>65-67</sup> The most frequent of these include hot flushes, weight gain, nausea, lethargy, and vaginal bleeding, discharge or irritation, while tamoxifen has 1% rate of thromboembolic events and a risk of endometrial cancer of 2 cases per 1000 patients per year.<sup>67</sup> Any impact on body image or sexuality appears small.

Specific hormonal therapies are classed as nonsteroidal antiestrogens (e.g. tamoxifen, toremifene, droloxifene and raloxifene), steroidal antiestrogens (e.g. faslodex), luteinizing hormone-releasing

hormone agonists (e.g. goserelin), selective aromatase inhibitors (e.g. anastrozole, letrozole, vorozole, formestane and fadrozole), progestins (e.g. medroxyprogesterone acetate) and androgens/antiandrogens.<sup>67</sup>

Tamoxifen has been the main subject of studies. Hot flushes occur in two thirds of women taking tamoxifen, one third of whom report severe flushes.<sup>68</sup> Anecdotal reports describe tamoxifen both increasing and decreasing libido; these appear to be very rare events.<sup>69,70</sup> The report of the National Surgical Adjuvant Breast study is clear that while tamoxifen increases hot flushes and vaginal discharge, it does not significantly increase depression.<sup>12,71</sup> This is a noteworthy finding given the folklore about mood changes with tamoxifen. A meta-analysis comparing tamoxifen with other hormonal therapies showed comparable response rates for metastatic disease, but different toxicities, with other therapies globally showing more fatigue and weight gain but less flushing than tamoxifen.<sup>72</sup>

In the recent large NCI survey of sexual functioning of American breast cancer survivors was studied an average of three years post diagnosis.<sup>3</sup> Almost half the sample were currently taking tamoxifen (ranging from 31% of women less than 50 years of age, to 57% of women 60 years and older). Tamoxifen did not make a significant contribution to sexual dysfunction. A limitation of this study was that it only appraised the 65% of women who indicated that they were sexually active, and lack of interest in sexuality was a common reason for being sexually inactive. However, the finding was similar to that reported by Schover *et al.*<sup>30</sup>

In one study, only 3% of women were noted to discontinue tamoxifen because of side-effects,<sup>50</sup> and a minority report some degree of sexual dysfunction. Anecdotally in case reports, women complained about soreness, dryness, and shrinkage of the vagina as a consequence of tamoxifen. It has been hypothesised that tamoxifen may increase sex hormone binding globulins, reducing the bio-availability of testosterone.<sup>50</sup>

Selective aromatase inhibitors have replaced the non-selective aminoglutethimide and achieve profound suppression of plasma oestrogen. They may cause less weight gain than megestrol acetate.<sup>73</sup> Studies have reported rates of vaginal dryness at <2%; hot flushes <13%.<sup>74</sup> Trials comparing anastrozole with tamoxifen are currently being conducted. Preliminary results suggest that anastrozole was of equal efficiency with tamoxifen in first line treatment of post-menopausal women with advanced breast cancer and had somewhat fewer side effects, including vaginal bleeding.<sup>75</sup>

Letrozole is another selective aromatase inhibitor with greater potency than aminoglutethimide and good tolerability.<sup>76</sup> Hot flushes have been reported at rates between 5-20%.<sup>77-79</sup>

Luteinizing hormone-releasing hormone (LHRH) analogues such as goserelin act through the hypothalamic-pituitary axis to suppress ovarian function and generate side effects such as vasomotor instability, vaginal dryness and headaches.<sup>80</sup> There are reports of mood disorders associated with such therapy.<sup>81,82</sup> In one small trial involving 149 premenopausal women who had not received chemotherapy, treatment with goserelin was associated with the experience of more intense menopausal symptoms that appeared more quickly, compared with tamoxifen.<sup>83</sup> With the exception of hot flushes and sweating, the side effects of goserelin were less severe when taken in combination with tamoxifen.<sup>83</sup> An adverse effect of goserelin on sexual functioning and sexual frequency in younger women has also been documented in a recent prospective study, although this effect did appear to be reversible following cessation of treatment.<sup>84</sup>

Hormone replacement therapy is a controversial issue in breast cancer care. Currently the HABITS (*hormone replacement therapy after breast cancer: is it safe?*) trial is asking that important question about whether oestrogen replacement therapy can be safely given to women who have been treated for breast cancer.<sup>85</sup>

While not described in the literature review, our interviews highlighted problems experienced by postmenopausal women on hormone replacement therapy (HRT) at diagnosis. Several postmenopausal women were taking HRT prior to the diagnosis of breast cancer. Following diagnosis, and sudden withdrawal of HRT, women reported rapid onset of menopausal symptoms such as severe hot flushes, vaginal dryness and skin changes, all identified as very distressing.

*Well I actually found the hot flushes were terribly distressing for me.*

*[Postmenopausal woman]*

In summary, hormonal treatments for breast cancer are currently associated with a number of side effects, but provide a significant survival advantage and considerable symptomatic relief. Their role has been strongly established, but further studies are required to fully examine the role of hormone replacement therapy in the sexual dysfunction of women with breast cancer.

## **Impact of Chemotherapy on Sexual Function**

Chemotherapy can have a significant impact on a woman's physical, emotional and cognitive state, which in turn may affect quality of life.<sup>27,50,86,87</sup> Chemotherapy has been associated with long term impairments in sexual function.<sup>3,4,27,29,88,89</sup> The influence of chemotherapy on sexuality is direct, through gonadal and hormonal effects, and indirect, by producing feelings of fatigue, apathy, nausea, vomiting, malaise and causing sleep or appetite disturbances that interfere with libido.<sup>50</sup>

Commonly used adjuvant chemotherapeutic agents and combination regimens of drugs can have prominent effects on a woman's body image and sexual confidence; these include cyclophosphamide, methotrexate, 5-fluorouracil, adriamycin, epirubicin, mitoxantrone, etoposide, vincristine, cisplatin, carboplatin, thiotepa, ifosfamide and paclitaxel.<sup>61,86-91</sup>

Recent studies evaluating the impact of adjuvant chemotherapy on quality of life have indicated significant effects on sexual dysfunction,<sup>3,4,29,50,61,86-91</sup> including pain or difficulty with intercourse, problems with vaginal dryness, impaired sexual activity, and decreased sexual drive.<sup>61,86,87,89</sup> The severity of sexual dysfunction following chemotherapy can be high, with studies reporting between 50-60% of women treated for early breast cancer having sexual dysfunction beyond 12 months post treatment.<sup>49,87</sup> Increase in sexual dysfunction among patients subjected to high doses of chemotherapy over conventional doses has also been reported.<sup>86</sup>

The impact of chemotherapy on body image was also evident in the qualitative data gathered. For many of the women interviewed, the physical impact of chemotherapy on body image, such as weight gain and hair loss had a significant impact on their sexual function:

*I just found that at the time I was very fit ... And then I had chemotherapy in May. I just ballooned and then recently decided, no, I can't look at myself, I look gross. And I also had as much hair as I've got now I really felt quite revolted, it really put me off sex, too.*

*[Premenopausal woman]*

*Well it's about identifying yourself as female or male. ... That's how I felt, having no hair and I'm about to go through that yet again for the second time. My feeling is – I felt androgynous, my breasts and my hair were attributes of my femininity and I had extremely long hair, I never had it cut in my life, so it was quite a big shock.*

*[Premenopausal woman]*

Change in sexual functioning following chemotherapy was more evident in women who became menopausal following chemotherapy than for other breast cancer treatments.<sup>3,49,89</sup> The role of induced ovarian failure, with reduction in both oestrogen and testosterone, is receiving more attention. Induction of premature menopause due to adjuvant therapies, discontinuation of hormone replacement therapy, psychological reactions to cancer and hormonal based cancer therapies can further contribute to changed sexual functioning.<sup>89</sup> The need to provide women with appropriate information about the possibility of chemotherapy induced menopause was noted by several authors.

The effects of premature menopause identified in the interviews included vaginal dryness, decreased sex drive and an affect on the sexual spontaneity. Men reported that both they and their partners missed this

spontaneity and the normal vaginal secretions produced during intercourse, not only because of the loss of spontaneity, but also because of the role they played in male arousal.

*I mean it's no big deal, but I mean I'm just saying the smell and the moistness [of vaginal secretions] and so on is quite nice, a turn on and so on. If it's not there, it's not there, but...*

*[Male partner]*

Preliminary data have indicated that ovarian hormonal blood levels highlight not only deficiencies of oestrogen but also androgen in producing sexual dysfunction.<sup>50</sup> In one study, 10 patients with breast cancer post adjuvant chemotherapy had testosterone levels indicative of androgen deficiency syndrome. Currently there are no data identifying the frequency of this outcome and whether it is more likely following adriamycin/cyclophosphamide compared with cyclophosphamide/methotrexate/fluoruracil, or other regimens. Unpublished data from the Australian pilot (n99, Basser, personal communication) and the International Breast Cancer Study Group (IBCSG) Trial 15 will shortly generate findings about the impact of high dose chemotherapy regimens such as epirubicin and cyclophosphamide on sexual functioning.

## **Impact of Autologous Bone Marrow Transplantation and High Dose Chemotherapy on Sexual Functioning**

In Australia in 1996, breast cancer accounted for 18.2% of autologous transplants. However in recent years, treatment with high dose chemotherapy with autologous bone marrow transplantation for the treatment of breast disease has declined after studies showed no benefit for high dose chemotherapy over conventional therapy.<sup>92</sup>

Few studies have examined the effect of high dose chemotherapy on specific psychosexual outcomes of women with breast cancer.<sup>93,94</sup> One review of studies of high dose chemotherapy concentrated on acute non-mortal side effects and survival; long term outcomes have not been the research focus.<sup>93</sup>

A descriptive study of women with breast cancer (mostly stage III & IV) assessed pre and post treatment with high dose chemotherapy [cyclophosphamide/ thiotepa/ carboplatin] and autologous bone marrow transplantation showed that 33% and 34% of the patients reported concerns with intimate relations and appearance respectively.<sup>94</sup> This raised concern about the need for follow-up of sexual issues by health professionals.

At present the use of high dose chemotherapy is only recommended within the confines of a clinical trial. However if high dose chemotherapy is prescribed in this setting the number of younger women experiencing ovarian failure will increase. The result will be loss of both oestrogenic and androgenic hormone production. Physiologically, both oestrogen and testosterone are needed for the female sexual response. Oestrogen influences the vagina's response to sexual stimulation, while testosterone influences desire and orgasm. The ovaries generally produce 95% of a woman's oestrogen, but only 25% of her testosterone. However testosterone production from the ovaries would generally continue for some ten years post menopause.<sup>65</sup> Hence ovarian ablation from high dose chemotherapy may produce a different sequence to normal aging if it results in a female androgen deficiency syndrome as well as the expected oestrogen deficiency syndrome.

Studies that identify sexual dysfunction with associated hormone deficiency status as a long-term consequence of high dose chemotherapy are required.

#### **4.4 Premature Menopause**

By and large, research has been focussed on extending survival without careful examination of quality of life issues such as body image and sexuality. For example, menopause naturally requires adaptation to a range of bodily changes, and its premature onset as a result of treatment of breast cancer may significantly influence sexual functioning, body image and self-esteem in pre-menopausal women. Bilateral oophorectomy as surgical management of advanced breast cancer precipitates menopause. It is also clear that chemotherapy brings a substantial risk of premature menopause and altered quality of life. Chemotherapy can ablate ovarian function causing the cessation of ovulation with loss of fertility and premature menopause.

One recent review of the literature from 1966 to 1996 explored menopausal status in the setting of adjuvant chemotherapy and chemotherapy related amenorrhea.<sup>80</sup> These authors concluded that ovarian damage was the most significant long-term sequelae of adjuvant chemotherapy. In another descriptive study, premature menopause was the key association between chemotherapy and sexual dysfunction.<sup>81</sup> A specific study of sexual functioning following treatment with adjuvant chemotherapy, which controlled for endocrine therapy, showed that chemotherapy was associated with significant sexual dysfunction and menopausal symptoms.<sup>89</sup> These women were much more likely to report weight change, hot flushes, mood swings, vaginal dryness, decreased libido, dyspareunia, and difficulties in achieving orgasm. Premature menopause in these patients causes oestrogen loss, followed by vaginal atrophy; androgen reduction is also relevant in decreasing sexual desire and orgasm. One study evaluated factors that influenced the sexual life of women affected by breast cancer and compared women who still had regular menses with those who were

menopausal.<sup>82</sup> The regular menstruating women reported significantly more satisfactory sexuality, including the presence of normal sexual desire, sexual gratification and better marital adjustment than those who were menopausal.

The key issue that arises for women in this predicament is hormone replacement therapy. In Kaplan's sexual therapy clinic, ten patients were identified with decreased levels of serum testosterone following adjuvant chemotherapy for breast cancer. All women had been satisfied with their sexual relationships prior to treatment; however after treatment the women reported loss of libido, difficulty with sexual satisfaction, and diminished enjoyment of clitoral stimulation. It seems likely that chemotherapy induces unwanted hormonal changes in a proportion of women, particularly in those who experience premature menopause. Testosterone has previously been used as fourth line hormonal therapy for advanced breast cancer. However, if today concern exists about the metabolism of testosterone into oestrogens, associated treatment with selective aromatase inhibitors that block this metabolic pathway may be warranted. Trials in this area are needed to clarify this treatment regime.

Studies examining the menopausal effect of chemotherapeutic regimens on women treated for breast cancer are few. As studies of different chemotherapy regimens strive to improve survival, concurrent examination of their impact on sexuality as a dimension of quality of life is called for. High dose chemotherapy with bone marrow rescue could be expected to induce premature menopause with consequent sexual problems. Furthermore, the choice made by several women to accept hormone replacement therapy in the setting of breast cancer points to the urgent need for studies that explore the safety of this approach.

#### **4.5 Adjusting to Changes in Body Image and Sexuality**

Adjustment to the changes in body image and sexual functioning occurs over time, though this can vary considerably. This was highlighted in our interviews with women from all groups reporting differing periods of adjustment. Some women seemed to adjust relatively easily to the loss of a breast, whereas others struggled.

However, time can lead to healing and adjustment, or as highlighted in longitudinal studies,<sup>3,4,20,29</sup> a worsening of problems. These studies revealed that while there was limited impact on sexual functioning one-year post surgery, it worsened over the subsequent years of follow-up. By the second and third years of follow-up, there were problems regarding body image, sexual interest and

functioning.<sup>20,29</sup> This lack of immediate onset has implications for the health care team in determining timing of assessment and intervention.

To overcome the physical and psychological barriers created by a diagnosis of cancer requires commitment and resourcefulness. In the interviews from both partners and the women it was evident that sexual adjustment was dependent on several factors: the impact on body image, the unique dynamics of any relationship including its nature prior to diagnosis, the emotional make-up of the individuals, and their psychological adjustment to the illness. The pre diagnosis relationship has been highlighted as a significant factor in assisting with adjustment to changes in body image.

*I mean if you've got a good relationship, then it's probably going to be fine as long as, you know you probably have to talk more and listen more and if you've got a bad relationship, it's probably going to be a bad time and you know there's no good saying to some man that you've got to listen more if he's not interested in doing it.*

*[Male partner]*

Early studies (1953-1981) recognised that the pre-operative relationship influenced post-operative sexual adjustment.<sup>85</sup> Thus, spouses who indicated lower pre-mastectomy sexual functioning reported decreased sexual functioning post-operatively.<sup>85</sup> However, in contrast with desire for sexual intercourse, many patients were observed to seek greater intimacy within their relationship following this cancer diagnosis.<sup>85</sup>

*On some levels, having had a mastectomy has only made us closer and there's much, much more to our relationship than what a breast can affect.*

*[Premenopausal woman]*

One study of survivors of breast cancer showed that worry about intimacy was greatest in single women who were dating.<sup>29</sup> This was confirmed in our focus group interviews. Women without a partner at the time of diagnosis found adjustment to the changes difficult and remained concerned about how to begin a new relationship, when to share news about the mastectomy and what impact this would have on the subsequent relationship.

*but I want to talk to somebody who's been through it, who's single, who can say, well is there a life after this? Can I meet a man, What do I say to that man, I've got no breast? And will he accept me without my breast?*

*[Premenopausal]*

The initial viewing of the scar after surgery was a major hurdle or watershed point for both the woman and her partner as noted in the interviews. For the latter, it was the time to face any fears that they would not be able to deal with the sight of the wound and the lack of a breast. For some

women, the initial viewing of the scar was very traumatic; for others, it was the first time that they really considered the impact of the surgery on their body. Some were unable to reveal their chest to their partner for some time after surgery, needing time to adjust to the changes to their body. How this was handled by the health care team is considered important by the woman as it can possibly impact on her ultimate adjustment.

*I was lucky when I first saw my scar, they realised the day before that I hadn't looked, ... and the Social Worker was with me and said: "Well you really should look before you go home" ... So the two of them stayed with me when I actually saw it. Actually they gave me a little hand mirror first and then they moved over the dressing table and I did cry when I saw it. ... but you see this one big one and then there's nothing there, you're like a boy. And all the staples, it's very visible and all your scarring is raised and red, it was just awful.*

*[Postmenopausal woman]*

Some women interviewed commented about the fact that although our society emphasises body image and that treatment for breast cancer does impact on this, they were able to get on with life. They recognised that they needed to put the experience into perspective and move forward.

*... But you know these are all part of the treatment and so you get on with it and it's often not until later on that you have a chance to reflect on these things that you realise how hard it is. But you do, get on with it, you buy a wig and so forth, but as you go, you are conscious of the fact that there are changes.*

*[Premenopausal woman]*

Other issues that were raised by women in our interviews included that they had difficulty adjusting following surgery and treatment for breast cancer and finding it difficult to explain why they were different. Some of these women also experienced feelings of shock, panic attacks, distress at unemployment, loss of confidence and periods of despair. Some women described feeling resentful towards those with breast cancer who were doing well.

*What's wrong with me? Why am I taking so long [to recover and adjust]? Everybody's [other women with breast cancer] out there doing great things and yet I'm flat out surviving.*

*[Postmenopausal woman]*

To some extent, women judged their adjustment by how they felt exposing their bodies or viewing them in the mirror. Some used a variety of approaches to celebrate their new body. Other women felt that reconstruction completed their adjustment.

*I mean in the very beginning I talked to the surgeon about the work that he was doing and because I was thinking from very early on I had in my mind about body art and that I was going to put this tattoo on.*

*[Lesbian woman]*

Some women reported very positive outcomes from cancer. They were able to develop a new outlook on life. This included an appreciation of the events of each day and a sense of valuing themselves as a person. For some women, the experience of breast cancer was a stimulus for major change in their life.

*Well I've always suffered from depression and I do see a psychiatrist, but funnily enough breast cancer was such a positive thing in my life that I suffer far less from depression now. ... when I got the cancer diagnosis ... since then, I'm just doing so many voluntary things, like I work with the [name of organisation] outreach program at a refuge that's been set up for domestic violence victims ...*

*[Postmenopausal woman]*

## **4.6 Actively Maintaining Body Image**

Several studies have highlighted that maintenance of confidence in one's body is an important dimension in limiting deleterious impact of breast cancer on body image and sexual function.<sup>32</sup> Research contrasting breast conservation with mastectomy revealed significantly better preserved body image, fewer problems in connection with nakedness, earlier resumption of sexual function and a strong feeling of preserved sexual attractiveness for women who have breast conservation surgery.<sup>32</sup> As reported earlier, younger women are more likely to select breast conserving surgery over mastectomy,<sup>28,32,41,50</sup> when the option is made available, suggesting that concern for body image and sexuality are important issues when considering choice of surgical technique.<sup>56-58</sup> Moreover, it is noteworthy that despite considerable research on body image and sexuality, there is little research that addresses how to respond to women with such difficulties, particularly those previously who have mastectomy. Data from our focus groups are used to further explore this area.

Women and their partners interviewed described in great detail how they responded to this predicament of altered body image. They were very concerned to maintain the way they presented themselves to others. To this end, clothing, prostheses and breast reconstruction were important. Although the prosthesis was clearly considered important, it was often described in negative terms, such as expensive, hot and uncomfortable. It could also be difficult to get a prosthesis that was the right size, particularly for postmenopausal women or those with larger breasts. The discomfort experienced when wearing a prosthesis was not recognised by many, as they declared expectations

that it should be worn at all times. However, the prosthesis gave others an important sense of normal body form that increased their self-confidence, as described by this woman:

*... The moment I had that prosthesis in my bra and they told me to put a T Shirt on and I looked in the mirror and I was so happy. I almost physically hugged the professional fitter, because you sort of perceive yourself as a woman with two breasts, suddenly you've got one breast, you're not quite exactly the same..*

*[Premenopausal woman]*

The type of clothing previously worn was often inappropriate after surgery. This included dresses with straps, swimming costumes and certain types of underwear. For larger breasted women, finding a bra that was supportive and comfortable was more problematic following surgery. The changes that women had to make in selecting clothing following surgery had an impact on their sense of self and the image they wished to present to the outside world. Premenopausal women raised this point more frequently. For some, concealment was paramount; for others, it was unnecessary, as they wanted to use their experience to educate others.

*I guess the other thing is, in terms of functionality, is whether it places any limitations or changes in terms of how you functioned previously. And for me it felt it did in terms of the clothes that I could wear, that changed almost overnight and interestingly, sort of contemporaneously, the fashion changed in terms of all dresses are suddenly strappy and of course the bras and stuff that you buy for a prosthesis are huge, I mean, they're nothing like the underwear that I used to wear in the past. So I have a whole wardrobe full of dresses that I can't wear and, all the underwear that I couldn't wear...*

*[Premenopausal woman]*

*For 3 years, she just wouldn't look at herself at all and for those couple of years that I knew her as a friend, there was no body [shown], it was just all baggy clothes, even though she had the prosthesis and looked normal, she had a bad image problem.*

*[Female partner]*

Only a minority of women in the focus groups had breast reconstructions. Others were considering this option, and there was considerable interest in the experience and outcome of those who had had reconstructions, including modelling their results. However, still others expressed no interest in reconstruction. For women who had had a reconstruction, their body image was the driving force for this surgery.

*I had a reconstruction, but it wasn't for my husband, it was for me. Oh it was just my whole body image, because I love clothes and I've never felt old and it was important to me.*

*[Postmenopausal woman]*

Not all women had been offered reconstruction, and for those that were not, there remained a sense of rejection of being considered unworthy. Women questioned who was offered reconstruction and expressed the opinion that it might be more likely if the woman has a male partner.

*Something I thought of was, well, I don't look glamorous ... But I just sort of felt, what is it about me that they think I don't care what I look like? Yet I'd got to a stage where I was ready to have a companion or something.*

*[Postmenopausal woman]*

While there is limited research about the psychosocial benefits of breast reconstruction (see the National Breast Cancer Centre's commissioned report *Breast reconstruction: a review of the research and patient and professional resources*),<sup>95</sup> the loss of sensation following breast reconstruction has been emphasised as a relevant matter for informed consent when outlining this treatment.<sup>61</sup>

Both male and female partners interviewed recognised that maintaining body image was important to their partners. Where possible, they would support this, to emphasise that their partner remained a sexually attractive woman,<sup>96</sup> as described by one of the men:

*[name] has always seemed to respond well to presents of lingerie and things like that. I've made a point of still doing that. Buying whatever you call them, camisoles?*

*[male partner]*

## **4.7 Impact on Relationships**

Sexuality is one means of developing greater intimacy in a relationship. Overcoming any physical and psychological barriers created by cancer requires commitment and resourcefulness. As has been described, sexual adjustment is dependent on several factors, not the least being the nature and quality of the pre-existing relationship. Our discussion is necessarily focussed on sexuality and does not attempt to deal with broader family issues that are the focus of other reviews.

Any study of sexual functioning that ignores the quality of the dyadic relationship is limited. Early studies (1953-1981) did recognise that the pre-operative sexual relationship influenced later adjustment.<sup>85</sup> These studies focused on heterosexual relationships, and to date there has

only been one study by Fobair et al that compared lesbian and heterosexual women's response to breast cancer.<sup>97</sup> Fobair et al report that lesbian women suffer fewer problems with body image however predictions regarding sexual functioning were not confirmed. Some noteworthy observations from studies of heterosexual relationships include that of Wellisch and colleagues, who showed that when men were more involved in the decision-making regarding their wife's treatment, they rated more highly their level of sexual satisfaction both before and after treatment.<sup>98</sup> Furthermore, men's failure to see their partners naked was often of their own choosing. Other researchers found that one quarter of male partners reported a decreased desire for sexual intercourse post illness.<sup>99</sup> Another common response was described as a protective role that the partner can assume, sometimes at the expense of open communication between the couple.<sup>96</sup> Clearly the nature of the dyadic relationship is critical to sexual functioning for any and every couple.

In the interviews, both women and their partners noted that the strength of the relationship prior to the diagnosis was important and the nature of the relationship determined how well partners could support the women throughout treatment of breast cancer.

*Well I guess that all revolves around all the relationship you have with your partner. I doubt that anybody could have equipped me any more than I have been. [wife's name] and I have a really open relationship and so this was just another issue that we dealt with ..*

*[Male partner]*

Women acknowledged not only the importance of their partners' participation in the process following diagnosis of breast cancer, including decision making, but the critical role partners played in helping them adjust to changes in body image and sexuality through support and reassurance. Women described that when their partners could not cope with the loss of their breast, it made it harder for them to cope.

*He made that statement, he said, "I can't cope with this". That's what he said to me. "I'm sorry, I can't cope with this". So where does that leave me?*

*[Premenopausal woman]*

*..... my husband's completely accepting of me and made a point of not allowing the lack of the breast to interfere with our sex life. We didn't stop, well since I've got better, we wanted to get straight back into it, so it couldn't become an issue I suppose. Of course it's never going to be the same, life's never going to be exactly the same and sex is never going to be exactly the same. Not worse. It's just different. [laughs].*

*[Premenopausal woman]*

In a more recent studies comparing mastectomy and breast conserving surgery in which sexuality was studied, all of the negative changes in sexual behaviour toward the partner were more prominent in the mastectomy group.<sup>52</sup> These consisted of avoidance of undressing in front of their partner, having sexual intercourse in the dark, and avoidance of being touched by their partner. In a further mastectomy versus breast reconstruction study, marital happiness was not significantly associated with treatment outcome.<sup>30</sup> Factors predictive of greater psychological distress in their family relationships included a troubled marriage, poor body image, sexual dissatisfaction, and treatment with chemotherapy.

Some women in the interviews reported finding it difficult to believe partner's reassurances that the loss of a breast did not worry them, but acknowledged that it was probably more to do with themselves than their partner.

*He said, "I don't care what you look like", but then we have all heard that before. And then they probably mean it, but I care what I look like, you might not, but I do.*

*[Premenopausal woman]*

In one quality of life study,<sup>3</sup> younger women experienced greater difficulties in relationships. Older survivors had the least difficulty communicating with their partners, but no age related differences were reported for affection across all of the ages examined. In our interviews, some women reported talking about body image and sexuality to their partners, though not necessarily immediately after surgery, needing time to adjust themselves. Other women found it hard to talk to their partners, and consequently found other women who had been through the experience more of a support.

Women and their partners who participated in the interviews identified that the diagnosis and treatment of breast cancer changed the dynamics within the relationship. When one partner experiences decreased libido and other alterations in sexual functioning, initiation of sex is fraught with misunderstanding. Furthermore, within the relationship, the woman can receive more attention and support due to her illness. Spending more time in each other's company during treatment and recovery also put strain on the relationship. Women noted that they felt pressured,

not necessarily by their partners but by themselves, to resume sexual activity and household duties. Strain can develop when the partner has to take over extra duties, as well as provide support. These were seen especially when young children were involved.

*so I suppose there's that feeling of great responsibility and keeping the balance wherever I can between these 3 [herself, partner and child] stressed people...*

*[Female partner]*

One could easily assume that any outcome of sexual functioning, as a consequence of cancer, would occur within the primary couple.

#### **4.8 Information Needs About Body Image and Sexuality**

Within our literature review, no systematic work was found assembling the information needs of women and their partners related to the impact of breast cancer on body image and sexuality. This was surprising given the evidence that supports breast conservation and highlights the significant impact of treatment on body image and sexuality. Data from our interviews will therefore be used to further explore this area.

Both partners and the women in our focus group interviews described feeling ill prepared for the impact of surgery and the follow-up treatments on sexuality and body image. They were given very little, if any, information on this effect of treatment by members of the health care team. Consequently, they accessed information from as many sources as possible over the course of time. Women sought reassurance, practical tips and personal experience from other woman who had breast cancer, as described by this woman:

*Support of other women who are going through it at the same time. I mean people who are going through it now.*

*[Premenopausal woman]*

Women also read books containing womens stories about breast cancer to understand other's feelings and reactions. Women used our focus groups to share practical information about managing prostheses, reconstruction and clothes (particularly swimming costumes).

Both the women and their partners in the focus groups stated that the only information they received prior to surgery about changes in body image and sexuality were photographs of women post mastectomy and the physical effects of chemotherapy on sexual function in some cases.

This information was considered to be of limited benefit because of its poor quality, lack of detail and because it didn't cover the emotional impact of these and other effects of treatment for breast cancer. Furthermore, women noted that much of the educational material was written for other audiences, for example, information about menopause was aimed at older women. Lesbian women commented that it was more difficult for them to obtain any information about body image and sexuality that specifically addressed their needs.

*I think pictures are good, but they're not a living woman. Pictures are pictures and they can look pretty stark. pictures for me depict medical books, it would have to be done with sensitivity, to get away from medical imagery, do you know what I mean ?*

*[Lesbian woman]*

How to address the impact of treatment on sexual function, both in the short and long term, was a significant issue for women and their partners. Both identified several issues about which they needed information, but didn't receive anything. These included: the effects of stopping hormone replacement therapy, with consequent management of re-emerging symptoms; the effects of premature menopause; the impact of chronic pain or sensory change in chest wall and arm, limited range of movement in the shoulder and lymphoedema; loss of libido; improving poor self image; the physical impacts on sexual functioning; and maintaining sexual health. Participants stressed that the minimal information they did receive did not deal with the emotional impact of these physical effects. Sometimes women who did not receive information about early menopause (induced by chemotherapy) or the effects of stopping hormone replacement therapy sought help from complementary medicine practitioners. This highlights an area of unmet need for patients in our current service system.

*I think the literature that's around tends to cope with how to physically deal with for example hair loss, rather than talk about what that might mean emotionally for people. ... There's very little support material that goes beyond the basics.*

*[Lesbian woman]*

Women varied as to when they would like to receive information about body image and sexuality. Suggestions ranged from receiving information at the time of diagnosis, to at the time of viewing the scar, four days after the mastectomy, at the first check-up or before leaving hospital. This range indicates the skill and sensitivity required by the health care team to assess the needs of different women. It was suggested that, as a simple first step for changing practice in this area, women receive information that they could read when ready.

One of the frequently mentioned sources of information in the interviews was the Internet. A search was conducted to determine available resources in the area of body image. Currently there are a range of resources available providing extensive information for women with breast cancer about many diverse issues, including prevention, treatment and therapies, as well as psychosocial issues that involve sexuality and breast cancer support.

#### **4.9 Support Needs Related to Body Image and Sexuality**

During the focus group interviews, most women acknowledged that they needed support to cope with the alterations in body image and sexuality following diagnosis and treatment for breast cancer. Apart from partners, women sought support from friends, family and support groups. Women commented that frequently they found the support from these sources didn't meet their needs. In some cases, women's distress was such that they sought professional support from counsellors.

*I would encourage women to go where ever they could get some support and some help. There's no right or wrong place to go. ... Women [need] to know that what they're feeling at the moment, at the time, during their treatment, during their diagnosis and the following months, is normal. This is the big thing, I can't emphasise that enough.*

*[Lesbian woman]*

The most important source of support for some women was other women, who had been through the experience of surgery and treatment for breast cancer, as they felt that these were the only women who could understand how they were feeling and respond in appropriate ways.

*the Breast Cancer Support Service, they can feel comfortable, ... talking to somebody else. They say things to you that they wouldn't normally say to their family or other people, because – silly things, embarrassing things that will happen to you, that they will feel comfortable saying to you [BCSS volunteer] because you've already been there.*

*[Premenopausal woman]*

However other women found the support offered through the BCSS to be of little personal benefit. Some women cited that the BCSS was unable to offer volunteers who were of a similar age, in similar circumstances or of the same sexuality. Several women reported a negative experience with volunteers whom they perceived to be lacking in skills to address their areas of concern.

Young, single women stated that they needed to talk to other young single women for support. This need related to a concern expressed throughout the interviews with dating and telling new partners that they had a mastectomy.

Some lesbian women were part of support groups but always felt slightly alienated from the group, as their sexuality was never acknowledged.

*Everything's geared to heterosexual people and even in our breast groups where you can try and get some answers, the whole conversation goes around what their men folk want and that kind of stuff. I never at any time felt comfortable discussing my lesbian feelings and how it might affect me at any time.*

*[Lesbian woman]*

Women who were involved in support groups found them very worthwhile, but acknowledged that they didn't often address body image and sexuality, unless conditions are created that encourage them to address these issues.

Women identified that issues related to body image and sexuality were difficult to broach with family and friends and when they did, the support they needed was often not there. Similarly, gestures that were intended to be supportive often seem to devalue the woman's experience. Women commented that they needed someone to listen to them, whereas often the support of friends was unhelpful, because it was aimed at cheering them and being positive, consequently appearing to dismiss their concerns, as expressed by this woman:

*They make comments to me the whole time that they think they're saying the right things. ... , like, but you're hair's going to grow back. They just make statements that say, "well it's not all that bad, it's not as if your hair's gone forever [name], it's going to come back". They don't really know what I'm feeling and the fact that I haven't got any hair right now. And I mean my breast is not going to grow back.*

*[Premenopausal woman]*

Many women in the focus group interviews highlighted that body image and sexuality remain taboo topics, stating that they had never really discussed honestly how they feel about their body image and sexuality. Humour was used to help them deal with the changes in body image and sexuality and to relate to friends and family. Others developed a positive approach and only wanted positive people around them.

*I've been happy with my body image, I mean I can laugh at the fact that I've lost my boob. I played in an orchestra and I went to the pub with friends afterwards one night and the Leader of this orchestra said, "well what does this prosthesis look like anyway?" And I turned around and there was hardly anyone around and I just got it out and threw it at him. I mean that's my way of coping and I've got a black humour anyway.*

*[Premenopausal woman]*

Because women found difficulty finding support for issues related to body image and sexuality, they often talked about it to an impartial counsellor or communicated with friends at a distance rather than face-to-face.

*Well I guess for me, now, I've sought some therapy, and it's been very good for me and I probably would have ended up having some totally emotional crash if I hadn't sought out somebody. But I think it would have helped me out of a year of agony if I'd had been able to have that help beforehand and directly after the mastectomy especially. I just was in a terrible state.*

*[Lesbian woman]*

Both male and female partners acknowledged that there were times when they needed assistance in how best to support women in relation to body image and sexuality, and some didn't know where to turn for help.

*Yeah, for me it may have been helpful at the time if I'd read say someone's biography I suppose of what they'd been through. And I suppose in a sense that's why I started my log. I suppose with the idea of allowing others to be able to read it ...*

*[Male partner]*

Partners acknowledged the value of speaking to someone who had also gone through the experience. Both men and women agreed though that frequently others ignore partner's support needs, as friends and family concentrate on supporting the women.

*The biggest relief for me, this is two and a half years after the final treatment, was to find a guy that I knew briefly years ago, that I'd run into at work. ... his wife had breast cancer and they moved back here and we found we had something in common and it was probably a 20-minute conversation. But to know that he and she had been through similar sorts of fears and experiences was a great relief for me, because I really hadn't talked it through with anyone other than [partner's name]. And you don't say: "Shit, I was scared" to [partner's name].*

*[Male partner]*

*I mean even hearing your experiences, has been really good, because I haven't talked to anybody, so I think that is great, being able to share experiences and hearing that somebody else fell apart, you know. I don't feel such an idiot! It's probably a normal reaction.*

*[Female partner]*

Female partners commented on how isolated they felt and were more open about the possibility of joining a group than male partners, who were ambivalent about joining men's groups, citing fears that other men would not have accurate information or would not be open emotionally.

#### **4.10 Support from Health Care Professionals**

In our focus group interviews, women and their partners reported generally finding little support from health care professionals in the areas of body image and sexuality. The only clinicians that were identified as consistently offering support in this area were general practitioners, and in some cases nurses. The overall feeling was that the health care professionals were too busy with 'medical things', and that, in their experience, the team did not appear to treat body image and sexuality as an important issue. They were perceived to be unwilling to deal with such issues, even if they could see the woman's need.

*Look I honestly don't think that was the issue for them [doctors]. I think they are more focussed on the clinical issues ...[they would] deal with body image and sexuality issues if you raised them, but they definitely didn't have a protocol no matter how subtle, that worked you through some of those issues.*

*[Lesbian woman]*

Many stated that they would not feel comfortable bringing up the issue of body image and sexuality with most members of the health care team. Several reasons were cited. Firstly, there was a lack of time and privacy during consultations – both women and their partners felt rushed during consultations or visits to clinics. Secondly, women commented that the members of the health care team were often young, and did not appear to have the skills and knowledge to be able to offer effective help in this area. Thirdly, most women did not try to raise the issue because they interpreted from the doctor's behaviour or attitude that he or she would feel uncomfortable or consider the issue irrelevant and outside the scope of their speciality.

*But they're also pressed for time. That's my feeling. I mean....You get this hurry, hurry feeling, particularly in the clinics.*

*[Postmenopausal woman]*

*My surgeon was ... a very practical middle aged gentleman and I can't imagine that, if I would have come up with questions like that, I think he would have felt that was irrelevant. Not so much irrelevant, but a different area in a way. Not his area is what I think. I think he might have felt uncomfortable with that.*

*[Postmenopausal woman]*

Lesbian women reported that their interaction with professionals was complicated by their sexuality and past experiences of the healthcare system. These women said they would not have discussed body image and sexuality with these professionals because of prior discomfort in attempting to discuss sexuality with them.

*I think if I was to raise an issue of sexuality with anyone, oncologist, nurse or whatever, they'd probably freak. I mean they might cope with a heterosexual person raising the issues, but they really wouldn't cope with me raising the issues.*

*[Lesbian woman]*

Several women commented that when they did raise these issues, they were rebuffed or their concerns were dismissed. This reinforced their perception that the health care professionals were not willing or able to help with problems related to body image and sexuality.

*But I tried to talk to the resident about that [sexuality and sexual function]. You know she was so young ... You don't want to embarrass them either. I mean the resident that I tried to talk ... couldn't understand it [woman's problem], well I certainly wouldn't have tried with anybody else after that.*

*[Postmenopausal woman]*

Women felt disappointed when the issue of body image and sexuality was not raised when they needed it, or when they could not find a suitable member of the health care team with whom they could discuss these issues. It was noted that body image and sexuality may not have been addressed directly. Women appreciated surgeon's considering body image when discussing treatment options with them.

Women report that their relationships with the health care team was aggravated or damaged by unsupportive comments about body image and sexuality. Women felt that this was due to health professional's feeling uncomfortable or lacking the necessary skills in dealing with people.

*My GP ... said to me, " well look, you're over the hill anyway. ... you're past your use by date anyway" ... I thought he could have said something nicer... because you know we look at 20 year olds and we think of them as being in their prime and anyone that's a long way from that is you know considered differently.*

*[Postmenopausal woman]*

*If they could have been a little bit more interested in the human level, the whole experience would have been a plus. I'm not saying that what they did was wrong technically.*

*[Male partner]*

Following their experience of breast cancer, some women took on a role of educating health care professionals in the area of body image and sexuality in order to improve the experience for other women later diagnosed with breast cancer.<sup>100</sup>

## **Perceived Role for Health Professionals**

Women had difficulty in defining a role for the members of the health care team to deal with issues of body image and sexuality.<sup>101</sup> Women expressed the view that the surgeon could only play a small part in these issues and only after certain rapport had developed over time. Prior to surgery, he or she needed to acknowledge that both the surgery and subsequent treatment will impact on body image and sexuality<sup>24</sup> and perhaps refer women to others more qualified for counselling if necessary.

The women stressed that the manner in which these issues were raised and the timing of this was important. All participants concurred that body image and sexuality needed to be raised as part of routine care. Some were concerned that issues could become medicalised and therefore a set or cookbook style 'treatment' developed for all. It was noted that these issues are very personal and sensitive and each woman and her partner need to be treated individually. Women agreed that if a member of the health care team opened up discussion about body image and sexuality, then the women felt it gave them permission to discuss these issues.

*I think it's incredibly important. I mean I think it wouldn't be that hard to do. All they'd have to say is if ever you want to talk about how you feel about your body image and sexuality, feel free to do so. That's all they have to say.*

*[Lesbian woman]*

*it would have to be part of a routine. ... because people [healthcare team] are very busy and you don't want to impose on them. You know I was conscious when I was in having the mastectomy all you're concerned about is just trying to deal with the pain and doing the exercises and all of that. The last thing you require is someone saying "let's have a body image conversation"*

*[Premenopausal woman]*

The women suggested that the health care team member primarily responsible for talking about these issues needs to be highly skilled, have developed rapport with the woman, preferably be female, and have 'life experience'. It was recognised that this professional needs to have a caring and open attitude so as to be able to relate to women from different backgrounds and with different sexual orientation, responses and needs. Some lesbian women expressed a desire that they be able to access another gay woman to discuss body image and sexuality.

*They would have to be a very accepting, understanding sort of a person, because everyone is so very different in how they handle that sort of thing. They have to be very accepting of women right across the board, because they are going to have women from different cultural ethnic sexual situations for a start and everyone handles their sexuality differently. So they're going to have to be very well versed in the differences of women.*

*[Lesbian woman]*

Women identified that a well-trained specialist breast nurse could be an appropriate team member to fulfil this role. Some men and women thought that their GP could discuss body image and sexuality; again preference was expressed for a female GP. Other women considered nurses to be more appropriate due to their gender and training, but recognised that they would require even more training. Others still preferred referral to a psychologist/counsellor or therapist outside the health care system. Women suggested sex therapists, social workers, psychologists or psychiatrists as sources of help, but again suggested that such referral needs to be individually based.

*And I think I guess the next best thing from having the BCSS and people who have actually had the experience would be a specially trained nurse. And I'm not just talking about the regular nurses on the wards, someone who's actually trained, whose sole focus and interest would be women who have been through that sort of experience.*

*[Premenopausal woman]*

Women identified that extensive discussion about body image and sexuality issues should be conducted in a quiet place where women cannot be overheard or interrupted and preferably not in a busy clinic.

## 5 CONCLUSION

The voices of women with breast cancer and their partners have reinforced an emerging literature that highlights the importance of body image and sexuality as a significant component of overall quality of life. Cancer treatment does potentially alter both perception of body image and sexual functioning. Information provision about these concerns becomes an important dimension of informed consent. Furthermore, clinicians are challenged to sensitively communicate openness to inquiry about these issues and a willingness to help when concerns do develop.

Implications of the findings of this report and the need to provide women with psychosocial support for body image and sexuality issues have been outlined in the executive summary and should be considered for enhancing clinical care and improving the ultimate outcome for both women with breast cancer and their partners.

Finally, there are a number of issues detailed in this report that also warrant further study. These studies should be encouraged to investigate the unmet needs of women in the domains of body image and sexuality and to improve the overall care of women with breast cancer.

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