

*Western Breast Services Alliance
Breast Services Enhancement Program*

Young Women's Project

Community Consultation - Report May 2003

Contents



<i>Acknowledgements</i>	2
<i>Executive Summary</i>	3
<i>1: Introduction</i>	8
1.1 Project overview	8
1.2 Literature review	8
1.3 Study objectives	9
1.4 Methodology	10
1.5 Response	12
1.6 Participant details	12
<i>2: Results</i>	13
2.1 Theme One ~ Diagnostic and treatment experiences	13
2.2 Theme Two ~ The hormonal impact of breast cancer	16
2.3 Theme Three ~ The Emotional impact on women and their families	18
2.4 Theme Four ~ Social networks and informal support systems	24
2.5 Theme Five ~ Professional support and information	28
2.6 The Women's Priorities	31
<i>3: Discussion & Conclusion</i>	32
<i>4. Recommendations</i>	36
<i>References</i>	37
<i>Appendices</i>	39
1. Focus Group Interview Schedule	
2. Participant Information and Consent Form	
3. Participant Demographic Information Form	
4. Strategies for Service Improvement. Participants' Priority Areas by Category	

Acknowledgements



The Young Women's Project Team would like to thank the following individuals and organisations.

- The women who so generously gave of their time to participate in this study or agreed to their images to be used in the production of this report.
- Members of the Young Women's Working Group who informed and supported this project in many ways.
- All clinicians, Medical Records staff, secretarial staff and other stakeholders who helped in the identification of eligible participants and assisted in inviting these women to take part in the project.
- Women's Health West and Brimbank City Council who provided facilities for the focus groups.
- Breast Cancer Network Australia who kindly enabled us to access photographic images of women to illustrate this report.

This report was written by Mary Bartlett, Bronwyn Flanagan and Sheila Hirst with assistance of the Western Breast Services Alliance Steering Committee.

Special Tribute Mary Bartlett 1955 ~ 2003

The Western Breast Services Alliance pays tribute to the work of Mary Bartlett, the Young Women's Project Officer 2001 – 2003. Mary died from breast cancer in October 2003.

Mary's commitment to improving services for young women with breast cancer will live on.

This project was undertaken as part of the Western Breast Services Alliance, Breast Service Enhancement Program. The Western Breast Service Alliance brings together Western Health, Melbourne Health and the Royal Women's Hospital in collaboration with associated health services in the Western metropolitan region of Melbourne.

The program is funded through BreastCare Victoria, an initiative of the Department of Human Services.





Executive Summary

Background

The Young Women's Project is a major initiative of the Western Breast Services Alliance (WBSA) Breast Service Enhancement Program (BSEP). The project aims to improve outcomes for younger women (aged 45 years or less) with breast cancer by providing consistent, quality care in key areas of identified need.

Breast cancer primarily affects women over 50 years of age, however significant numbers of younger women are diagnosed with the disease. For example, within the WBSA in 2000 alone, 28 women under 40 years of age and an estimated 45 women aged between 40 and 45 years were diagnosed with breast cancer.

While breast cancer and its treatment are stressful experiences for women of all ages and can significantly impact on self-esteem, young women with breast cancer have been found to experience some unique problems due to their earlier life stage. Both the physical and psychological burdens of breast cancer and its treatment are often magnified in this group, and often underestimated and overlooked.

Previous research had established two interconnected areas of special need for young women—artificially-induced menopause and its associated infertility, and psychosocial issues.

While a literature review informed the first phase of the WBSA Young Women's Project, the purpose of the community consultation was to identify and prioritise the local issues and service gaps based on the experiences and priorities of women treated by the WBSA.

In summary, the purpose of the community consultation (phase one) of the Young Women's Project undertaken in November 2002 was to:

- identify and clarify the critical and particular needs of younger women with breast cancer
- identify strategies that women found helpful to cope with these issues
- identify gaps in services and ways in which service providers assisted or could better assist women
- prioritise issues to be addressed.

Methodology

Participants were women diagnosed with breast cancer within the past five years who were either treated by a WBSA breast service or lived in the catchment area. Women under 40 years of age at diagnosis were our primary target group. Women aged 40-45 years at diagnosis were invited to participate to allow identification of any differences between the two age groups.

Of the 145 eligible women invited to participate, 71 responded. Forty five women consented to participate in a focus group discussion, of whom 37 actually participated.

Demographics

Seventeen of the participants were under 35 years of age at the time of diagnosis, with a further eight being aged 35-39 years. Twenty-nine women were married or partnered.

Twenty-eight women had a total of 59 children, of whom 39 were aged under 15 years.

While most women had early breast cancer, at least four women had had either a local or systemic recurrence.

Key Findings

The qualitative data was analysed under five key areas:

- diagnostic and treatment experiences
- the hormonal impact of breast cancer
- the emotional impact on women and their families
- social networks and informal support systems
- professional support and information.

Following is a brief outline of key issues emerging from the focus group discussions, in each of the five identified key areas.

Diagnostic and treatment experiences

-
- *The women had concerns about the effectiveness of diagnostic mammography and delays in diagnosis, the lack of access to BreastScreen for younger women, and that BreastScreen's message for older women might provide false reassurance for younger women.*
-
- Delays in diagnosis, the speed of surgical treatment, limited time for decision-making and the way their diagnosis was communicated, including clinicians' negative responses to alternative/complementary therapies, were also a source of anxiety and distress.
 - The physical environment of health services and hospital systems—crowded waiting areas, long waits in clinics and seeing other very sick people in the Day Chemotherapy Unit—added to distress.

The hormonal impact of breast cancer

- The potential or actual loss of fertility was a significant issue for many participants.
 - There was considerable confusion and ambivalence about the need for contraception.
 - For breast-feeding women, little advice was given to assist with weaning.
-
- *Menopausal symptoms ranged from mild to very severe, however it was the psychological impact of these symptoms that many women rated as more significant than the physical.*
-
- Limited information, inconsistent management practices, and the lack of acknowledgement of women's symptoms all compounded women's distress.

The emotional impact on women and their families

- The emotional impact of breast cancer was far-reaching, impacting not only on the participants but also on their partners, children, other family members and the women's wider support networks.
- While psychosocial issues are not unique to younger women, they were magnified by the women's age and life-stage, the hormonal influences of treatment, the additional and differing needs of young or adolescent children and the women's role within their immediate and wider family.
- Ongoing tiredness and depression persisted after treatment for at least some women. It appeared to be difficult for both the women themselves and their service providers to recognize and manage this depression.

Identity was a crucial issue. Women's sense of identity was enhanced or threatened by workforce experiences, their role as mothers, body image issues and the loss of libido and interest in sex.

- The impact of breast cancer on participant's sex lives was felt keenly by both women and their partners, yet most women found that sexuality issues were not addressed as part of their treatment. Discussion group facilitators also noted that it felt uncomfortable to discuss emotionally sensitive sexuality issues with the women.
- Women's anxiety and distress was increased by uncertainty, physical reminders of body changes, new symptoms and follow-up appointments and tests.

Social networks and informal support systems

- The need for support was a prominent issue for women and for their families, with partners, children, parents and other family members, as well as friends and colleagues, all being potential sources of support – although their actual experience of support received varied widely, from positive to difficult.
- While caring for their children kept many women going, they needed practical support with this, particularly with younger children. Handling the emotional needs of adolescents was also highlighted as a particular challenge.
- Some of the women found it particularly difficult to respond to their mothers' and sisters' emotional responses to their situations, and needed to develop specific strategies to deal with this.

It was clearly evident that the women wanted to talk with other women with similar experiences, with women indicating they would prefer to be approached to take part in individual or peer support programs rather than having to seek them out.

- Partners were not always well supported, and a lack of concern for partners' needs, and availability of services for them, was highlighted.

Professional support and information

- Women found support both informally and formally within the health care system and were very appreciative of those offering this support, including clinicians, local GPs, breast care nurses, social workers and counsellors.
 - Women were particularly sensitive to the communication style of service providers, with off-hand comments triggering intensely emotional and long-lasting responses.
 - Overall women indicated that they received good information about their diagnosis and treatment options, although some indicated they got too much and others too little.
-
- *Identified gaps in information included information on fertility, menopause management, other treatment side-effects, lymphoedema, costs and how to navigate the health system.*
-
- Strategies that assisted in information recall included an additional appointment prior to treatment, taping of consultations, having more time with service providers and a checklist of questions to ask along the pathway.
 - *'Not knowing what to ask'* was a barrier to gaining information. However, information alone did not prepare women for the actual experience. The value of peer support or of attending a cancer education program, combining information with experience, was again highlighted.

Differences between older and younger participants

While many issues were similar for all women, there were some significant differences between young women under 40 years at diagnosis and those aged between 40 and 45 years. These differences reflected women's age and life stage.

The younger women under 40 were more concerned with:

- issues of fertility and contraception
- the challenges of new relationships
- the impact of menopause on libido and sexuality
- longer term effects of menopause, such as osteoporosis
- issues of managing a young family.

Younger women aged 40-45 were more concerned with:

- more significant hot flushes
- the loss of libido and its effect on their marital and family relationships
- managing adolescent and young adult children.

Women's Priorities

Women's key priorities for service improvement were:

- improved psychosocial care
- improved access to practical support eg childcare
- more access to information, particularly about the hormonal impact.

Almost two-thirds of participants identified emotional support as one of their key priorities.

Recommendations

From the community consultation stage of the Young Women's Project, WBSA has identified three critical areas for service enhancement in 2003.

1. The development and implementation of pathways or protocols for improved referral and management of young women regarding hormonal issues, including fertility protection, contraception, breast-feeding and menopause management.
2. The development and implementation of structured approaches to psychosocial assessment and referral.
3. Development of a patient pathway/checklist for young women, to enhance their ability to make informed decisions about their care.



1. Introduction

The Western Breast Services Alliance (WBSA) is a group of public and private service providers who have joined together to implement the Breast Service Enhancement Program (BSEP). This program is one of nine Victorian demonstration projects aimed at improving breast care services for women across Victoria, as part of the Department of Human Services Breast Disease Service Redevelopment Strategy 1999 - 2003.

The key stakeholders in the WBSA BSEP are Melbourne Health, Western Health, The Women's and Children's Health Service (Royal Women's Hospital), in association with the Freemasons Hospital, Melbourne Private Hospital, Frances Perry House and Western Private Hospital.

A key initiative of the WBSA BSEP Service Plan 2002–2003 is to develop and implement a Young Women's Project. Younger women with breast cancer have been found to have some unique problems, which may be overlooked. Both the physical and psychological burdens of breast cancer and its treatment are magnified in this group, and are often underestimated.

1.1 Project overview

The overall goal of the Young Women's Project is to improve outcomes for younger women (women under 45 years of age) with breast cancer by providing consistent, quality care in key areas of identified need. These areas of need have been clarified in the project's first phase through focus group consultation with young women with breast cancer.

The results of this study, outlined in this report, will inform the second phase of the project to improve services for young women.

1.2 Literature review

A breast cancer diagnosis and treatment imposes a significant psychological burden on women (Sammarco, 2001; Ganz et al., 1996; Ganz et al., 1998). While breast cancer primarily affects women over 50 years of age, significant numbers of younger women are diagnosed with the disease (NBCC, 1999). Within the WBSA in 2000, 28 women under 40 years of age and an estimated 45 women aged between 40-45 years were diagnosed with breast cancer (Victorian Cancer Registry, 2002).

Two interconnected areas of need for young women have been identified in the literature—artificially induced menopause and its associated infertility, and psychosocial issues.

Artificially Induced Menopause and Associated Infertility

Unlike the gradual loss of oestrogen in women experiencing a natural menopause, young women with breast cancer may experience premature menopause within a few weeks to months of their treatment with chemotherapy, hormone suppression or oophorectomy (Davis, 2002). The more abrupt onset of menopausal symptoms such as hot flushes, mood swings, disrupted sleep, vaginal dryness and loss of libido can affect the woman's quality of life. The impact on sexual functioning may be significant in these younger women with breast cancer (Ganz et al., 1998). The loss of childbearing potential is also of greater concern to younger women than for those undergoing natural menopause, who have usually completed their families (Bachmann, 1994).

Early menopause is known to be a strong predictor of osteoporosis for all women; chemotherapy-induced ovarian failure causes rapid bone loss in pre-menopausal patients (Saarto et al., 1997; Shapiro et al., 2001). Similarly premature menopause increases the risk of cardiovascular disease and breast cancer survivors may be at higher risk (Davis, 2002).

There is a strong inter-relationship between artificially induced menopause and women's psychosocial adjustment. Women's experience of menopausal symptoms can be influenced by anxiety, depression and stress (Davis, 2002). Conversely menopausal symptoms may impact on women's emotional response to breast cancer and its treatment (Ganz et al, 1998).

Psychosocial Issues

Breast cancer and its treatment are stressful experiences for women of all ages and may significantly impact on a woman's self-esteem (NHMRC, 2001). However the impact can be more psychologically demanding for younger women, due to their earlier life stage (Wang et al., 1999; Lerman et al., 1994; Schover, 1994; Northouse, 1994). Issues such as fertility and childbearing, treatment-induced menopause, raising young children, achieving career goals, body image, sexuality and relationship concerns may compound their distress (NBCC, 1999; NHMRC, 2000).

Younger women have reported significantly more distress at the time of hospitalisation and have experienced more depression whilst undergoing treatment than their older counterparts (Northouse, 1994; Mor et al., 1994). Single or separated younger women may be more vulnerable to anxiety and depression (NHMRC, 2001) as may women who have already experienced considerable life stress (Maunsell et al., 1992).

The financial impact of breast cancer on young women and their families may be greater, and everyday activities such as work, sports, sexual relationships, housework and child care can be substantially affected (NHMRC, 2001).

Breast cancer impacts on family members and their reactions play a key role in women's ability to cope. Lack of support from family and friends may be associated with poorer emotional adjustment. Young single women and those who do not live in a traditional unit may be particularly vulnerable (NHMRC, 2001; Arora et al, 2001).

While the literature has informed the WBSA Young Women's Project, the purpose of the community consultation was to identify and prioritise the local issues and service gaps based on the experiences and priorities of women treated by the WBSA.

1.3 Study objectives

The objectives of the community consultation were to:

- Identify and clarify the critical and particular needs of younger women with breast cancer;
- Identify strategies women found helpful to cope with these issues;
- Identify gaps in current services and ways in which service providers assisted or could better assist women;
- Prioritise issues to be addressed in the next project phase.

1.4 Methodology

The project proposal was submitted to and approved by the Institutional Ethics Committees at four major breast service providers within the WBSA.

Participant population

Participants were women diagnosed with breast cancer within the past five years who were either treated by a WBSA breast service or lived within the WBSA geographical area. The women were divided into two sub-groups:

- women who were aged under 40 at time of diagnosis
- women who were aged 40-45 years at time of diagnosis.

Given their smaller numbers and an understanding that key issues may be magnified in younger age groups, women under 40 years of age were our priority group. The purpose of the older age group was to allow identification of any differences between the two age groups (Krueger and Casey 2000).

Our original older sub-group was to be women aged between 40-49 years at time of diagnosis. Given the relatively large numbers in this age group, we reduced the age range to 40-45 years.

Design

The consultation was undertaken primarily through focus group discussion. Up to five focus groups were planned, four to be held for women aged under 40 and one group for women aged 40-45 years at diagnosis. Because of timing issues, only four focus groups were held. Two groups were held for younger women, one group for older women and one was of mixed ages.

For the convenience of the participants, the focus groups were conducted in three local community settings and one hospital. The groups were held on four consecutive days, at different times of day. Each group was conducted by a facilitator and a note-taker, with a breast care nurse in attendance to provide additional support to the women as required.

Our aim was to facilitate discussion about the specific issues, concerns and coping strategies of younger women diagnosed with breast cancer. This discussion was guided by a predetermined interview schedule (*Appendix One*). With the women's permission all groups were audio-taped and additional written notes were made.

A range of written information on services, support groups, websites of interest, etc was available to the women at the end of each session.

Individual interviews were also offered to participants who did not wish to participate in a focus group or who were key informants for community groups under-represented in the focus groups due to language, cultural or sexuality issues.

Recruitment

Women were identified through health information listings in four major hospitals, supplemented by the private practice listings of associated service providers. In addition women were recruited through community promotion.

Women identified as ineligible to participate for clinical or other reasons were excluded from the project.

All eligible women received a letter of invitation signed by their treating clinician or the WBSA Clinical Coordinator, outlining the project's purpose and confidentiality issues. A detailed Participant Information and Consent Form (*Appendix Two*) and a reply paid envelope were included. Contact details of project staff were given so that any questions women had about the project could be answered promptly.

Those women who did not respond to the introductory letter within two weeks were sent a follow-up letter seeking their participation. No further contact was made with women who indicated their refusal to participate or chose not to reply to the letter.

Women who consented to participate were contacted by phone to arrange a convenient focus group session. In line with the current practice of the National Centre for Consumer Participation in Health participants were offered \$40 to reimburse transport or other expenses.

Informed Consent and Confidentiality

All women were asked to sign the consent form prior to attendance at a focus group, including permission to tape the discussion.

To ensure confidentiality, non-clinical project team members facilitated the focus groups. All identifying data was secured in accordance with Ethics Committee requirements. All data collected from participants was de-identified and collated. Clinical members of the project team only had access to de-identified data.

Before each group, women were again informed about the strategies to maintain privacy and were asked to respect the privacy of other focus group participants themselves.

Data collection and measurement

De-identified demographic information (*Appendix Three*) was collected from each participant and collated as group data.

In order not to influence the issues that women discussed, the interview schedule commenced with broad questions. These early questions focused on how breast cancer had impacted on women's and their family's lives at diagnosis, during treatment and on completion of treatment. Women were asked to identify helpful strategies and service gaps. Questions about early menopause, fertility and/or psychosocial issues were asked if not initially raised by the group (*Appendix One*).

At the end of each focus group, the women were asked to write down their top three priorities for improving services for other young women. These lists were collated separately.

Analysis

The audio-tapes were transcribed verbatim and qualitative thematic content analysis conducted. This involved two of the research team independently reading the entire transcript and each generating a list of common themes. The two researchers then reviewed the themes together and allocated the data under the key themes. The common themes were then further summarised under five key areas of interest.

All data on the transcripts which could identify either the women or individual service providers was removed.

1.5 Response

150 women were invited to take part in the project. Of these, 139 were identified through hospital or service provider listings and 11 through community promotion. Eighty-nine (59%) were aged under 40 years at time of diagnosis and 61 (41%) were aged 40-45 years. Three letters were returned as undeliverable and two families indicated that the woman had died. The letters did not generate any negative reactions from women or family members.

Of the 145 eligible women, 71 (49%) responded to the invitation. Fifty-four women agreed to participate, with 45 consenting to participate in a focus group and/or interview and nine women to an individual interview only. Seventeen women declined to participate.

Of the 45 women consenting to attend a focus group, 37 (82%) were able to attend at one of the designated times.

Because of unexpected resource issues during the study period, individual interviews were not undertaken.

1.6 Participant details

All 37 women who agreed to attend a specific focus group did so. The participants' demographic profile is summarised in Table One.

Table One: Demographic profile of focus group participants

		<i>Number</i>
<i>Age at diagnosis</i>	< 35 years	17
	35-39 years	8
	40-45 years	12
<i>Highest educational level</i>	Completed secondary	15
	TAFE/Apprenticeship	12
	Graduate/post-graduate	10
<i>Marital status</i>	Married/partnered	29
	Divorced	3
	Single	5
<i>Ethnic background</i>	Australian / English speaking	29
	Non-English speaking background	8
<i>Children</i>	Have children	28
	No children	9

Of the eight women who were from non-English speaking backgrounds, only two spoke a language other than English at home. The participants had a total of 59 children, of whom 39 (65%) were aged under 15 years.

Although we did not formally ask women about their disease status, it was evident through the focus group data that at least four women had had either a local or systemic breast cancer recurrence.



2. Results

For many of the women, participating in the focus group was the first time that they had met another young woman with breast cancer. The data reflects the diverse views and the breadth of their experiences. Many women spoke in powerful and evocative language, which is reflected in the quotes used throughout this report.

The collated data was analysed under five key areas:

- diagnostic and treatment experiences
- the hormonal impact of breast cancer
- the emotional impact of breast cancer and its treatment
- social networks and informal support systems
- professional support and information.

The first three areas deal with the women's experiences with the system and the impact of breast cancer on themselves and their families, while the last two areas reflect approaches that facilitated or hindered the women's capacity to manage.

There was significant interplay in the data between the different areas. For instance, issues related to the treatment system impacted on women's emotional responses. Similarly menopausal symptoms had both a physical and emotional component.

A summary of the findings in each of these areas is outlined, with gaps in service and potential strategies to address these identified. Quotes (in italics) from the participants illustrate and reinforce the data, and allow the voices of the women to be heard.

Key points and suggested strategies highlighted in the text come from both suggestions by participants and by the project facilitators, based upon a combination of the focus group findings and our own knowledge and experience.

Following the data from the five key areas, the results showing the **women's individual priorities for service improvement** are summarised on page 31.

2.1 Theme One - *Diagnostic and treatment experiences*

The data highlighted a number of issues around the women's diagnostic and treatment experiences and reflected particularly on hospital/health care systems and processes. These included issues at key stress points in the diagnostic and treatment pathway as well as issues related to hospital facilities.

The diagnostic process

There was considerable confusion and some anger about the role of the BreastScreen program for younger women and the effectiveness of mammography in this age group. Many participants were concerned that the BreastScreen message for older women provided false reassurance for younger women.

Two women had specifically contacted BreastScreen for investigation of their breast symptom and were frustrated by their inability to attend. These women felt that BreastScreen should offer both a screening and diagnostic service.

Within diagnostic services, several young women reported difficulty in having their breast lumps fully investigated and were concerned that had they not pushed for further tests, the diagnostic delay may have jeopardised their prognosis.

Being told their diagnosis

Most women indicated that they were told their diagnosis face-to-face, with a number of women commenting positively on the time spent with them and the sensitivity of the clinician.

Two women were told of their diagnosis over the phone. While they were shocked, or 'gobsmacked' as one participant put it, they had a sense that this avoided a long wait for their results and expedited their early treatment. The women also indicated that a request to attend for an unexpected appointment would have been tantamount to being told their diagnosis. Several other participants felt strongly that women should not be told their diagnosis over the telephone.

Suggestion

Every effort should be made to ensure that young women receive their diagnosis in a face-to-face consultation and arrangements for this to happen agreed upon at the initial consultation.

Treatment issues

The women had mixed views about the value of time between the diagnosis and treatment, with women mostly agreeing to the treatment schedule proposed by the service provider.

For some women the time between diagnosis and surgical treatment, or between surgery and chemotherapy, was too rushed, while others appreciated the quick turnaround. A few women were given the choice of timing while others sought extra time and additional appointments to enhance decision-making. One woman found the extra time gained through an unexpected delay invaluable in helping her prepare for treatment.

Key Point

Many younger women prefer active involvement in treatment decision-making, and may require more time to consider their options.

Suggestion

Strong consideration should be given to providing an additional pre-operative consultation in which treatment options can be clarified further and information revisited.

Women's anxiety and distress in the early treatment pathway were exacerbated at times by the hospital facilities including crowded waiting areas and long waiting times in varying clinics. The Chemotherapy Unit was very confronting for some women and family members.

I mean I was 31 years of age and the chemo room was full of lots of very, very sick people. It was very confronting. Maybe there just needs to be different facilities for the younger people. Or at least different rooms.

Key Point

Young women and their families are often unfamiliar with serious illness and with the health care system.

Suggestions

Young women need to be better prepared for their first experience of the different service areas within the healthcare setting. Strategies need to be explored to minimise clinic waiting times and thus decrease anxiety and distress.

Alternative/Complementary Therapies

Many of the women talked about their use of a wide range of alternative or complementary therapies in addition to conventional therapy. For some women there was a strong need to 'leave no stone unturned'. Several participants would have appreciated more support from clinicians about alternative/complementary therapies and found the clinicians' dismissive attitudes to these therapies very negative ~ 'taking away hope'.

Suggestion

Clinicians should be actively encouraged to discuss the options of using complementary and alternative therapies with young women in an open and non-judgemental way, with due regard for current evidence.

Treatment Completion

As for other women with breast cancer, the end of treatment was a time of significant stress. The women highlighted that there was a strong sense of isolation and abandonment. For at least two women, having a specific goal at the end of treatment, such as a holiday, was a useful strategy to manage this period.

Key Point

The end of treatment is a time of significant stress and uncertainty.

Suggestions

Mechanisms should be in place to support the woman at the end of her treatment. These should include encouraging links with services in her local community, and developing realistic goals and coping strategies.

Consideration should be given to a routine 'end-of-treatment' appointment with a breast care nurse, social worker or other provider of psychosocial support and the offer of an ongoing link with service providers.

2.2 Theme Two - The hormonal impact of breast cancer

The hormonal impact of breast cancer treatment raised particular issues for young women who had to deal with both the physical and the psychosocial impact of artificially induced menopause. Women's different responses highlighted the confusion, ambivalence and at times, somewhat paradoxical nature of their experiences.

The inconsistency in management practice, the limited evidence available and the lack of acknowledgement of women's symptoms compounded the perceived problems.

Fertility and Contraception

The potential or actual loss of fertility was an issue for many of the participants, including those older younger women who had completed their families.

So I've stopped menstruating now. I must say you would think that I would be relieved ... but somehow I just feel that it's a loss of another bit of me..... I wasn't ready really ... not that I was thinking of more children But it was a loss.

Of the nine participants who had not had children, three (single and younger) were pro-actively offered treatment to protect ovarian tissue and/or referral to the Royal Women's Hospital for ovarian tissue/egg preservation. Others found out almost by chance.

I found out on the morning of my first chemo – they said 'Have you had your eggs frozen?' – I said 'What!' No one mentioned it before.

These women had realistic expectations about the limited potential benefit of ovarian/egg preservation but felt these offered 'hope' and 'peace-of-mind'. One participant indicated how difficult she found the decision-making in this area and how she would have valued more time to decide, as well as the opportunity to talk with another woman who had been through a similar experience.

Another woman, a member of a young women's support group, highlighted that fertility information was very variable amongst this group's members. Some wanted more children in the future but were oblivious to possible fertility issues.

Key Point

There are currently no consistent guidelines to assist clinicians and women in making decisions about the management of fertility related issues resulting from breast cancer treatment.

Suggestions

Clinicians should openly discuss fertility with all young women after a breast cancer diagnosis and offer them referral to a fertility treatment specialist before treatment begins.

A follow up appointment with a fertility specialist at the end of treatment should be encouraged.

Contrasting with some women's sense of loss about their fertility, others experienced confusion and ambivalence about the return of menstruation after chemotherapy and the need for contraception.

I had a period last month but I have been told I'm still in menopause. But my biggest fear is pregnancy. I am still only 38 and so if my ovaries are still working, although I am told that they are not, then why have a period if they are not. I'm a bit confused.

While some women welcomed the return of their periods, it came with an uncertainty about whether an accompanying rise in oestrogen levels placed them at greater risk of breast cancer recurrence.

Contraceptive advice was varied, with women being uncertain whether they needed to continue contraception and in what form. The experience of one woman who became pregnant between surgery and chemotherapy poignantly highlighted the need for appropriate contraceptive advice.

While most women indicated they were given little contraceptive advice, one woman (single and aged 34) questioned the need to be continually asked about contraception.

Key Point

Young women should be advised to avoid becoming pregnant while undergoing treatment. (NHMRC, 2001 p.37) — and the reasons why this is necessary should be clearly explained to them.

Suggestions

Women should be counselled about the need for contraception during treatment, the preferred method(s) of contraception, and how to proceed after treatment.

Referral to a primary health care provider or specialist service may be required.

In the area of lactation, the two women who were breast-feeding at the time of diagnosis were given limited advice about weaning their babies and about medication for drying up their milk. The problem of weaning a young baby was further compounded by the speed with which women were hospitalised for surgical treatment. For one woman still receiving early treatment, discussing these issues evoked significant emotional distress.

Key Point

Breast feeding a young baby and subsequent 'fast-track' weaning, compounds the traumatic experience of breast cancer for young women.

Suggestion

The woman should be given adequate time to make alternative arrangements for feeding prior to surgery, and encouraged to seek advice from a lactation consultant, maternal and child health nurse or obstetrician where appropriate.

Menopausal Symptoms

Most of the participants who had chemotherapy and/or hormonal manipulation had experienced some menopausal symptoms. Some experienced relatively mild symptoms while for others they were quite severe. The younger participants tended to be more affected by the psychological rather than the physical impact.

And even things like sexuality... I just felt that I had been ripped off and I'd become a middle-aged post-menopausal woman.

Menopausal symptoms included hot flushes, weight gain, loss of memory and loss of libido. Some women found that gradually increasing their Tamoxifen dosage helped them manage some of these physical symptoms. Younger women in particular were concerned about the long-term impact of menopause on osteoporosis.

Menopausal symptoms tended to compound the emotional impact of breast cancer on women and on their family relationships. For several women, particularly those in the older age group or with teenage children, the menopausal symptoms significantly impacted on their marital and family relationships.

It (menopause) was dreadful, absolutely dreadful. I was 41 when I went on tamoxifen and I've had hot flushes since. They are dreadful, constant. That causes a lot of other problems. It's ruined my sexual appetite for sure. And I find that very distressing...

A few women gained information about adjusting their medication, symptom relief and/or reassurance that their experiences were menopause-related. Overall women found that they were in need of additional support and information.

No, I haven't found anyone to talk about that. It would be good thing to do for women who have to go through menopause. I think more counselling along those lines would be really helpful.

I think what would be a good idea would be a well-women's clinic where you could touch base on things – not just about breast cancer but maybe osteoporosis, menopause and just have a nucleus of people you could link with.

Key Point

There are currently no consistent guidelines to assist clinicians and women in making decisions about the management of menopause related issues resulting from breast cancer treatment.

Suggestions

A consistent approach is needed for the assessment and management of both short and long- term menopausal symptoms, with adequate referral mechanisms in place.

Information on the implications of early menopause in women who have had breast cancer should be readily accessible to all young women.

Discussion of conventional and alternative therapies for relief of menopausal symptoms needs to take place.

Linkages to community support services and peer support are desirable.

2.3 Theme Three - The emotional impact on women and their families

The emotional impact of breast cancer was very significant for many of the young women who took part in the focus groups. It caused anxiety and depression, significantly challenged their sense of identity and impacted on their relationships with partners, children and other family members. Some women adopted strategies to maintain control over their lives in spite of the uncertainty. For others the diagnosis enabled them to re-prioritise their lives.

The breast cancer experience also directly impacted on partners, children and other family members, affecting the complex dynamics of family relationships. The capacity of partners and other family members to support women was influenced by their own responses and coping mechanisms. As a result, some women had to deal with the additional burden of others' emotional responses. These issues are addressed under *Social Networks and Peer Support*.

While psychosocial issues are not unique to younger women, they were magnified by the women's age and life-stage, the hormonal influences of treatment, the additional and differing needs of either young or adolescent children and their role within their immediate and wider family.

Anxiety and Distress

Women experienced anxiety, distress and fearfulness for themselves and their families. Key times in the clinical pathway were at diagnosis, completion of treatment, follow-up and diagnosis of recurrence. These feelings were increased by uncertainty, physical reminders of body changes, new symptoms, follow-up appointments, tests or the lack of tests, coping with children and the real and perceived reactions of family and friends.

You don't think about it every day. I don't sit there and consciously say 'I had breast cancer'. But everyday I am reminded of it in some way – feeling tired, by putting on a shirt that I used to fill out quite nicely... so you don't think about it consciously, you're just reminded of it – and every morning when you get dressed, you kind of know.

The fear of recurrence was always present and follow-up appointments were both reassuring and anxiety producing. Some women sought more frequent follow-up appointments to manage their anxiety.

While participants were anxious about follow-up tests, they valued the 'certainty' that the tests brought yet found the reliance on clinical assessment and judgement disconcerting.

... So I come (for the follow-up) and they have a bit of a feel and say 'You look great and everything's excellent. See you in nine months' and I say 'How do you actually know that?' How do you know?

While living with the uncertainty, several women maintained their work and other commitments to maximise control over their lives. Many women sought to reprioritise their lives as part of their coping strategy. For one woman this meant walking away from an unsatisfactory marriage, while for others it meant learning new skills or simply not letting 'the small things in life become mountains'.

Key Point

The ongoing uncertainty with which these young women live their lives needs to be acknowledged.

Suggestion

A realistic understanding and expectation of follow-up investigations should be fostered. Young women need to be clearly informed that intensive follow-up neither improves their survival nor quality of life (Loprinzi et al, 2000).

Tiredness and Depression

Tiredness during treatment was compounded by travel, work and family responsibilities. For some women there was a sense of underlying depression.

The tiredness was the hardest thing because at the time of the treatment I was looking after two toddlers.

For some women maintaining normal home and work commitments during treatment was important to keep some sense of control. This took its toll in terms of excessive tiredness both during and after treatment.

I'm always, always tired. I just can't get over it. Sleep doesn't help. I'm just tired. I just don't do as much as I used to do.

Ongoing tiredness and depression clearly persisted after treatment for at least five participants who, on reflection, appeared to have known risk factors for depression. Other life stressors that compounded women's tiredness and depression included family deaths, social isolation and fractured relationships. While the young women talked about excessive tiredness, they had difficulty naming or recognising this as a symptom of possible depression. If service providers in the acute and primary health sector did recognise the woman's depression it appeared to be not well managed.

Key Point

Ongoing tiredness may be a symptom of depression (NHMRC 1999) and should not be overlooked.

Suggestions

Women need to be given information on strategies to help manage their tiredness both during and after completion of treatment.

A structured psychosocial assessment must be incorporated at key points in the woman's management, including her long term follow up.

All young women should be routinely offered referral to a social worker for practical as well as psychosocial support at the commencement of treatment. Further follow-up will be dependent on the individual woman's needs.

Identity

The issue of identity was raised by a number of women. Maintaining their identity was an important coping strategy for some women, and a means of maintaining control at a time of significant stress. For others there was a sense of being 'camouflaged', that their identity was changing. They wanted this new identity to be accepted and not hidden from view.

People look at you and think you are the same person, which you are, but...

Factors influencing women's sense of identity included:

- paid work
- unpaid work, ie their parenting role
- body image issues.

Paid Work

A number of women were able to take time off work, while for others there was no choice but to keep working throughout treatment. Some women saw work as a 'saviour', giving them a sense of control. For others, a perception that 'they were strong' set up a false expectation that was hard to live up to.

All my friends, colleagues and family were saying 'be strong, keep going, don't let this alter your life – you have to be the same person – be strong'. So you keep doing everything you used to do – work, keeping the house, etc and ... you never let your body recover – And you're always tired.

The Parenting Role

For many women, whether they were working or not, their role and identity as 'mother' was a critical one, from which they could not take time off.

I found the hardest thing was having four kids to look after and we didn't really have a lot of family support and people thought that I could cope. But they weren't there when I was throwing up or when I was crying because my babies needed me ... it was really hard. I couldn't take time off work.

Some women's role as mother was significantly threatened by the cancer diagnosis.

Look, we (mother and daughter) are very close but I can't do that sort of stuff (support her when she was upset) because I just end up crying and I'm the matriarch of the family. You know I am the strong one – so for them to see the Queen go down, I can't do it.

For one woman, the threat to her maternal role was so strong that she had an imaginary fight with cancer in her living room.

I haven't finished my work here. I want to see my son grow up, get married. I'd like to be a grandmum and grow old... And I thought 'You (the cancer) ... bastard, you're taking it away from me. So I have a stand up fight in my living room. I... Just swore and screamed and yelled... afterwards I felt like 'I can cope now'. I can continue and get on with it.

Body Image Issues

The body image changes that influenced women's sense of identity were weight gain, weight loss, breast changes and hair loss. Both weight gain and weight loss were significant challenges and altered the way women felt about themselves.

Several women indicated that others did not recognise them as a result of weight and other body changes and this caused some confusion for them about their own identity. For one woman with advanced disease (and for others) her relatively 'well' look was misleading.

I have put on weight and sometimes when I was seeing former work friends they'd say 'Wow, you look fantastic – you look great' and I felt like saying 'Yeah, but I feel like shit'.

Key Point

The negative effects of weight changes need to be acknowledged.

Suggestion

Women should be advised of the value of regular exercise, offered referral to a dietician where necessary, and made aware of appropriate community exercise programs.

Overall the participants did not indicate that physical changes in their breast(s) had a significant impact on their body image. This may well reflect that many women had breast conserving surgery. There was a strong sense that women would rather 'keep their breast than their hair'. However women did identify that they had to make adjustments to their dressing, not being able to wear low-cut tops or strapless dresses like other women of their age.

One young woman had great difficulty coming to terms with her mastectomy which also impacted on her marital relationship.

My husband found it really difficult to cope – not so much that I had cancer... But that the body changed, the body shape and the fact that it is not there anymore – I had trouble coping with this too. It took me quite a number of days for me to look in the mirror ‘Oh God, it’s disgusting’. And I kept saying ‘Oh it’s horrible, it’s not me. It isn’t me’ ... Eventually, of course you come to accept that it is you, no matter what, but my husband could never and he... Well we are separated now but he never touched me or looked at me.

For many of the young women, hair loss was the overt manifestation of their breast cancer, particularly to the outside world. It presented them with significant challenges.

It annoys me how maybe people judge me... I know that certain people are just going straight to the bald head. And I have been to hell and back and I don’t want people saying: ‘Where’s your hair?’

Hair loss dominated the discussion related to body image. While in no way diminishing its impact, perhaps the considerable discussion on hair loss may have concealed other more covert or taboo areas of body image changes.

The women had varying reactions to their hair loss, with some only experiencing thinning and others full hair loss. For some women, the hair loss had limited impact and one woman regarded it very positively. For others the hair loss was devastating: *‘Shocking, absolutely shocking’*.

In spite of being warned about hair loss, some women still felt unprepared for its impact. Again this was an area where women would have appreciated talking with another woman who had experienced this.

Strategies that women used included having their hair cut short prior to chemotherapy, shaving their head once hair loss commenced and wearing wigs or bandanas. For several women tangible support came from the males in their lives, - family members, friends and /or colleagues – who shaved their heads as well.

My middle son said to me ‘Mum if you’re worried about having no hair, I’ll just take mine off.’ So the three of them (sons) did. Imagine that, it was wonderful. We had a big unveiling in front of my mother and sisters. And in the end I thought, ‘I can’t stand the wig – it’s so hot.’ I took it off and we were all dancing around the room. It was just the best day.

In dealing with hair loss and other body changes, women expressed different views on the role of wigs and of their experiences of the *Look Good, Feel Better* Program (LGFB), a program which provides women undergoing cancer treatment with information and skills in the use of make-up, wigs and scarves to help deal with any hair loss. Some women felt that they could indeed maintain their identity and self-esteem through the use of wigs and make-up.

... what I saw in the mirror (with no hair or with a blonde wig) was not me – Then as soon as I had a wig on that was my own style and everything, then I thought ‘Right! I am going to get one of them’ ... it helped me to remember who I was.

Other women found the positive feedback from others very affirming following their participation in the LGFB.

While looking good may have helped many women and helped others around them to feel better, for others it had a downside. The same strategies made it harder for some women to gain sympathy from others, along with a feeling that they were not able to allow their real identity to emerge.

And I found the worst thing –lather on the make-up, wear the wig to hide this, hide that and look like nothing has happened to you. And then someone would say ‘Well, what’s wrong with you? – you look perfectly fine’. And I’d think, ‘If only you were on the inside looking out, you’d understand’.

I bought two wigs in anticipation, took them home and put them on when my hair fell out. But I hated it because it wasn’t me. Like I was in disguise.

Key Point

Breast cancer significantly challenges the identity of young women. Service providers need to be aware of and acknowledge this in consultations/discussions with the women.

Suggestions

Young women need to be given practical information regarding hair loss and the value and women’s differing experiences of the use of wigs and programs such as Look Good, Feel Better.

Contact with and support from peers should be actively encouraged.

Sexuality and changing intimate relationships

For some of the participants in established relationships, a breast cancer diagnosis did not significantly change this relationship, and was a source of strength for them. Other relationships were more significantly challenged with at least two long-term relationships breaking down (one initiated by the woman and another by the partner).

For single women there were changes in the dynamics of some relationships, particularly at the time of diagnosis. For one young woman, a newly establishing intimate relationship transitioned to a supportive friendship. A number of single women found benefits in transient relationships or rekindled old relationships especially during treatment. These relationships enhanced their self-esteem.

Women’s confidence and self-esteem influenced their capacity to successfully establish new relationships; once established, a new relationship boosted confidence. However some single women felt particularly vulnerable about telling potential new partners about their breast cancer. At least one young woman clearly retreated from opportunities to establish new relationships.

Within relationships, ongoing tiredness, loss of libido and body changes impacted more directly on women’s sexuality than on their partners’. For many women it was they who noticed the body changes and that their body ‘*didn’t do what it used to do*’. Other women noticed more subtle changes in their sexual relationships.

My husband had a vasectomy and I felt that was a huge vote of confidence that I was going to be around for a long time. But he didn’t cope well with the surgery. It was suddenly sex with our pyjama tops on.

Women, particularly in the older age group, were acutely aware of the impact of the loss of intimacy on their relationship.

You don’t feel the same you don’t feel interested, that’s for sure. It’s very sad because my husband still is, but I am not – it is very hard. It is part of your marriage and your marriage starts going down the hill if you can’t, you know, have a good relationship.

Women indicated that there was very limited opportunity to discuss sexuality or relationships issues with their clinicians or other service providers and some women were given misinformation. Two participants who attended a *Living with Cancer* course or sexuality seminar had found this very helpful for themselves and their partners. Overall the participants supported the need for greater information and counselling in this area.

Key Point

Significant disturbance in sexual functioning has been reported in women, especially young women, with early breast cancer (NHMRC, 2000; Arora et al, 2001).

Suggestions

A brief psychosexual assessment should be part of the formal, ongoing assessment of each woman, with established avenues for referral of women with significant relationship issues.

Women should be encouraged to attend education and information sessions addressing intimate relationships.

*Health services should facilitate access for women and their partners to relevant educational programs, such as *Living With Cancer* and specific sexuality programs.*

2.4 Theme Four ~ Social networks and informal support systems

The need for psychosocial support was a prominent issue for women and for their families. Family relationships were very important, with partners, children, parents and other family members, as well as friends and colleagues, being potential sources of support. Sometimes this support was not forthcoming in the way that women wished. In some instances women had to protect or offer support themselves to family members or friends, placing an additional burden on them. In this situation some women became estranged from particular family members or friends.

Women identified that additional support was also needed for their partners, children and parents.

Husbands / partners

Overall women in marital or significant relationships found that they gained much support from their husbands/partners. However the women spoke of the challenges that breast cancer had presented for their partners, many of whom were young themselves.

When I got my results... my husband turned green... He was so shocked. I really think that when you're talking about young women, you have to remember you're also talking about young men...

In addition to supporting and caring for their partners and their children, husbands/partners had to continue to work, be a linkage for other family and friends and at times protect their partners from others.

The partners were not always well supported. Being young, they may have had little to do with the health system and sickness previously. Often it was only after treatment had been completed, and sometimes by chance, that women gained insight into the difficulties and sense of powerlessness that their partners had experienced. One partner felt excluded from information by service providers, and that partners' distress was sometimes invisible and/or unacknowledged.

Over time, some women found that they had to protect their husbands and provide them with the reassurance they needed and sometimes they *'didn't tell him more about things than I need to'*.

While women were aware of the lack of support for their partners, they were uncertain if and with whom their partners talked, and were aware that their partners were reluctant to seek help. One woman found a support group very helpful for them both.

We are part of a support group – the first day we went my husband heard things he didn't want to hear and said, 'We shouldn't be doing this'. But now he has made himself a whole new bunch of buddies... But I think it is still hard for him to go to work and pour his guts out.

Key Point

The distress of husbands and partners is sometimes overlooked in the treatment of young women with breast cancer.

Suggestions

Health professionals should include partners in their discussions with women, if the woman is happy for this, and ascertain how they are coping.

Information on support groups for partners should be provided.

Referral of partners for advice on and access to practical support services should be encouraged. This may be to a social worker, other health professional with counselling skills or a peer.

Children

In every focus group there was discussion about coping with children. One group in particular had a long talk about sons' reactions. On reflection there was limited discussion about the impact of a breast cancer diagnosis on daughters.

The presence of children helped some women to cope and keep things in perspective: *'because you have just got to get on with it'*.

Maintaining a sense of normality for younger children in particular was a significant priority. Women could not take time off from their role as *'Mum'* although for some, their husbands took on greater responsibility for the children. Some women got significant help with their children from family and friends, while others did not. One woman only found out by chance about the possibility of Council help for her three young children. Significant additional practical assistance was needed with children in this age group.

The women found that coping with their children's diverse reactions and finding the right level of information and support was a challenge. For younger children, there was a need for reassurance and to know that *'Mum would be OK'*. Some women were surprised at how much information their young children had absorbed from overheard conversations and how that translated into anxieties about their mother dying.

My little one who was only six at the time, walked into his classroom and said, 'My mum's got a lump in her boob and she's gunna die'.

It was more difficult to gauge the level of needs of individual adolescents and some women misjudged these needs.

I didn't know he (my son) was really distressed... And one day he said 'Look Mum, I really need to know what's going on'. And I felt so sorry for him. Here I am trying to be as natural as possible, not to make him feel insecure ... and in actual fact, I think I made it worse.

The capacity to manage adolescents was influenced by women's menopausal symptoms, their disease status and the individual child.

I think that the worst thing about treatment was menopause. It causes so much disruption in your family. I have teenage kids and you tear your hair out normally. And they were very distant, they weren't coping with it, I wasn't coping with it, I completely lost touch with my kids and so did my husband.

Some adolescents became more estranged or distressed, and some wanted to know only the basics. Others were very involved and went with their mothers to treatment. One woman with advanced disease relied on her former husband to support their daughter.

I couldn't face my daughter. I just couldn't look at her because I would start crying and I couldn't deal with her and with the cancer. If something happens, she goes, 'What's wrong, what's wrong?' I go, 'Nothing, I am alright'. And I tell her Dad to tell her.

Suggestions

All women with young and adolescent children should be offered guidance about what to tell the children about their diagnosis and how to do this, as well as how and where to find practical help.

Consideration should be given to routine referral of all women with young and adolescent children to a social worker or other health professional to assist with this.

Other Family and Friends' Reactions

The impact of a breast cancer diagnosis on an adult child or sibling can present a significant threat to parents and other siblings, especially mothers and sisters. While some young women had substantial support from their parents, others rejected that support. Still others wanted more support from their mothers and siblings. Women experienced difficulty in coping with older parents, going back to a parent/child relationship and challenging in-laws.

As daughters and sisters, some of the women found it particularly difficult to respond to their mothers' and sisters' emotional responses. In some instances, women were fearful of and had to develop strategies to cope with actual or anticipated emotional responses.

There was recognition that it was hard to deal with distress you had 'caused' and that it was hard for a parent to see her child with a life-threatening illness.

But when I rang my Mum, she just cried and cried on the phone. I just felt 'Oh, no'. I almost felt that I'd let her down... You don't want to see your mother upset.

The issue I have is with my mother. So the second time (second breast cancer diagnosis) I said 'Just don't cry this time' ... It's that thing of a parent doesn't want to see a child maybe die before they do.

The level of support from family members varied from very good to very poor. In some situations, the family had the same expectations of the woman as before (eg doing Christmas dinner while on chemotherapy). While some relationships became closer, others became estranged.

Friends and colleagues provided great help for some women, offering practical and emotional support. This help included practical assistance with childcare, help with meals and supporting a woman at medical consultations. Women really valued this help, and were especially grateful when it came from unexpected sources.

...and even the local alcoholic would bring in fish'n chips every week –that's still one of the biggest things anyone could have done.

Women were reluctant to ask for help, so that an offer of specific help was more appreciated than a general offer of help. As with family members, some friends fell away, with others needing support for themselves rather than being able to offer help.

Suggestions

Young women need to be encouraged to ask for specific, practical help from family, friends and others.

The Breast Cancer Network of Australia's brochure on advice for friends and colleagues should be available to all women.

Coping strategies to deal with the reactions of other people need to be discussed with each young woman.

Peer Support

From the data, it was clearly evident that the women wanted to talk with other women in similar circumstances. For many of them, participation in the focus group was the first time that they had met someone like themselves. Following the groups, women spent time talking informally with each other.

Women had different experiences of individual or group peer support. Some women were reluctant to link in with a support group as they perceived themselves of '*having had cancer, but no longer having cancer*'. A small number of women had been to a support group, but it was difficult for them to identify with groups for older women or older people with different needs to theirs.

Two women spoke positively about their experiences of different support programs, even though they were initially very challenging. For one woman, attending a *Living with Cancer* program was very valuable for both herself and her husband. For another very young woman, her attendance at a support group brought her into contact with several people who later died. This was very '*scary*' but as she reflected:

... maybe I had to go through the scary bit to reach this... 'at peace'.

For a few women, individual support came informally as friendships formed while they went through treatment. One woman had a very positive contact with a woman through the Cancer Council of Victoria's volunteer program, while for another no suitable match could be found.

Some women found it difficult to make initial contact with a support group and would have preferred to have someone contact them.

Key Point

Young women would benefit from contact with other young women with breast cancer.

Suggestions

Women need to be made aware of the role of peer support and have its value acknowledged by health care providers.

Health care providers need to facilitate the referral of young women to appropriate, accessible peer supports.

Strategies to facilitate both formal and informal peer support within health services should be encouraged.

2.5 Theme Five - Professional support and information

Women found support both informally and formally within the health care system and were very appreciative of those offering this support, including clinicians, local GPs, breast care nurses, social workers and counsellors.

A few women gained really valuable practical support through a social worker, while three made particular mention of their general practitioners. These GPs had offered additional support, out-of-hours contact and simplification of medical jargon.

My GP was good, he was great. I'd say, 'Explain that to me' because they (the specialists) would use all these terms that I thought, 'What does that mean?' And I was a bit embarrassed in front of the specialists to ask. So he'd explain everything because I didn't understand the doctor's lingo. And now I do.

The women identified a number of areas of difficulty.

Improved support

The notion of support was not just about formal support mechanisms but was also reflected in the way in which service providers communicated with women. At the time of diagnosis and early treatment, women were particularly sensitive to their service providers' communication style. An off-hand comment or negative response triggered a very strong emotional response and stayed with the woman over time.

After my first treatment I rang the oncologist because I had to make a decision about whether I was going back to work. And I was so scared about the whole work thing and he said, 'Why can't you work?' I've never cried so much before, I cried and cried. I didn't want to go back to see him. And my surgeon couldn't understand why I was so upset.

Women's experience of counselling was mixed and its timeliness was crucial. One woman had a very positive experience of a nurse counsellor in the BreastScreen assessment process, but found the lack of someone to support her at the treatment planning stage devastating. Another woman found it very distressing to be interviewed by the counsellor prior to a confirmed diagnosis of breast cancer.

A few women identified that seeing the same doctor at review consultations was optimal for continuity and sensitive care. Women found it very disconcerting when the clinician did not know their history and then appeared to make very cursory or off-hand remarks.

Key Point

Service providers need to be sensitive to younger women's vulnerability in times of great stress and the ease with which information or an attitude can be misinterpreted.

Suggestions

Routine psychosocial assessment should be built into the care of all women and form part of the multi-disciplinary discussion.

Access to psychosocial care needs to be improved for young women. Service providers need to be made aware of the range of psychosocial services available.

Links with GPs must be strengthened to ensure better access to local community support services.

Ongoing communication skills training should be encouraged for all health care professionals, including junior medical staff.

Wherever possible, the continuity of care of a young woman should be ensured by her seeing the same service provider.

Meeting women's information needs

Gaining access to accurate and timely information is a key component of informed decision-making. Information, in verbal or written form, was provided to women by clinicians and other health providers and was supplemented by the plethora of breast cancer information available in the community and on the Internet. Some women got too much, some got too little, and accessing appropriate information at the right time remained a challenge for others.

In general women found that their service providers provided them with good information about their diagnosis and treatment options, although some indicated that they wanted better understanding about treatment and its effects. The value of good quality written information to supplement clinician information was clearly identified.

There was a book I was given. It was called 'A Guide to Early Breast Cancer'. I did read it through straightaway but some of it just didn't click. As you went along different stages, you sort of read up in those chapters – it was like a bible. Obviously you couldn't digest it all at once but we keep referring back to it.

One woman in particular shopped around to find the right surgeon for her. She was seeking information about reconstruction options. She found it difficult to find someone who would discuss all the options upfront, as each individual provider tended to put forward their preferred approach only.

Women recognised the difficulty in giving them information at a time of high stress and that it was hard for them to absorb all of it at initial diagnosis. Women who were given the opportunity for a second appointment to discuss treatment options further found this very helpful. Other women indicated that they would have appreciated this opportunity to clarify any information given.

I was really emotional at the time (of diagnosis) so even if they gave me the information and there was some written information I was given, I must say it just didn't sink in. I went out and bought lots of books and read and read. And I tried to identify where I fitted into all this. The doctors were fantastic but in some ways they gave me basic information and then they left me to it.

One woman found taping critical consultations very useful, including consultations about results and adjuvant management. She listened to the tapes several times to aid her understanding. No other participants had been offered or initiated taping of consultations.

While overall women received good information about diagnosis and treatment options, some gaps were identified. These included specific issues such as fertility, menopause management, drug side-effects (especially Tamoxifen) and lymphoedema. A few women felt they needed a better understanding of how to navigate the health care system and the costs involved in care within the private sector. Women also wanted information about practical issues such as child care, as well as information on how to manage relationship and sexuality issues arising out of or compounded by breast cancer treatment.

The limitations of information were identified and there was recognition that information alone did not prepare women for the experience.

I had an experimental treatment and it was really high doses and I didn't know what to expect. And they gave you all this information, they've written it all down and they say, 'You'll be really sick'. But to go through it, it's completely different.

The value of programs such as *Living with Cancer*, combining information with shared experiences, was highlighted by one woman.

I was given a lot of information and also this course we did (Living with Cancer) – that's also given us contact with other people who are going through the same thing and I found that one of the most helpful things.

There was general agreement that 'not knowing what to ask' was a barrier to seeking the information that women needed. The need for an information checklist was highlighted by several women and was endorsed in the women's individual priorities.

I like the idea of having a check-list of questions to ask because you are taking in so much information and you tend to remember stuff that you need to know at the time. And stuff like fertility might not have actually entered your head until you see the questions written down.

In summary, some strategies which the women found helpful, or would have liked, included:

- an explanation of the health system and how best to use it
- more time to be talked through the information given to them
- a follow up appointment after diagnosis and before surgery to discuss all the information given to them and to raise questions.
- taping of key consultations, to play back later and recall what was said
- attending a Living with Cancer Program
- good communication skills of health care professionals
- a checklist of questions/issues to raise at particular times in their treatment
- open discussion on the use of alternative and complementary therapies.

Key point

Timely and appropriate information based on both evidence and women's experience will enhance women's decision-making and coping strategies.

Suggestions

There needs to be consistency in both the general and specific information given to young women with breast cancer and in the timing of its delivery.

Peer support should be used to facilitate the delivery of information to young women, and to allow them to draw on the experiences of other women.

Strategies such as taping consultations and the provision of additional pre-operative appointments will enhance women's understanding and decision-making.

2.6 The women's priorities

The women's individual priorities for service improvement were collected anonymously at the end of each focus group. A total of 119 priorities were identified and collated under seven categories; psychosocial support (both emotional and practical support), information, clinical systems or management, service environment, service provider issues and miscellaneous. Table Two below summarises the key priority areas for women. Appendix Four details women's specific suggestions under each category.

Women's priorities were for emotional and practical support for themselves and their families, dealing with hormonal issues, and better access to information. Two thirds of the women identified emotional support as one of their key priorities. These findings are consistent with the NHMRC Psychosocial Clinical Guidelines (NHMRC, 2000).

Table Two: Summary of Young Women's Priority Areas by Category

<i>Category</i>	<i>Priority Area</i>	<i>Number of responses</i>	<i>% of all responses (n=119)</i>
<i>Psychosocial Support / Clinical systems or management</i>	Improved access to emotional / psychological support for woman, partner and family.	31	26%
<i>Psychosocial support</i>	Improved access to practical support.	15	12.6%
<i>Psychosocial support</i>	Improved access to peer support.	12	10%
<i>Psychosocial support</i>	Improved information about emotional and practical support services.	6	5%
<i>Information</i>	Improved general information about breast cancer, its diagnosis and management.	17	14%
<i>Information / Clinical systems management</i>	Improved support/assistance and information about hormone/fertility/sexuality/body image issues.	9	7.5 %
<i>Information</i>	Improved information about health system and varying costs between public and private sector.	6	5%
<i>Information</i>	Improved information/communication about complementary/alternative therapies.	6	5%
<i>Service environment</i>	Improved service environment and clinical systems/protocols.	7	6%
<i>Clinical systems management</i>	Improved clinical systems/management protocols.	5	4%
<i>Service provider issues</i>	Enhanced communication with service providers.	3	2.5%
<i>Miscellaneous</i>	Increased community awareness of breast cancer in young women.	1	< 1%



3. Discussion and Conclusion

The need for young women with breast cancer to connect with other young women going through a similar experience came up constantly throughout the consultations. Isolation, lack of support, lack of time to make informed decisions and lack of information were recurrent themes.

The NHMRC Psychosocial Clinical Practice Guidelines identify younger women as being particularly vulnerable to the stresses of breast cancer. This was reinforced in our sample by the traumatic imagery used by some of the young women to describe their experiences, and the fact that they had many of the factors associated with an increased risk of psychosocial problems (ie young age; single, separated, divorced or widowed; children younger than 21 years; perceived poor social support; poor marital or family functioning) (NHMRC, 2000).

Women's identities as workers, mothers, partners and sexual beings were significantly challenged. Coping strategies that worked for some women caused great distress for others. Whilst many of the issues were similar for all women, there were some significant differences between the young women aged less than 40 years at diagnosis and the young women aged 40 to 45, which reflected both the women's age and life stage.

The younger women were more concerned with:

- issues of fertility and contraception
- the challenges of new relationships
- the impact of menopause on libido and sexuality
- longer term effects of menopause, such as osteoporosis
- issues of managing a young family.

The older young women's concerns were:

- more significant hot flushes
- the loss of libido and its effect on their marital and family relationships
- managing adolescent and young adult children.

These findings are consistent with the literature comparing women of different age groups (Dunn & Steginga, 2000; Sammarco, 2001; Mor et al, 1994; Northouse, 1994). Our earlier view that the issues were the same for the two groups of young women, but magnified in the younger age group (those less than 40 years) was not wholly substantiated. Different issues were magnified in the different age groups and the particular needs of young women between 40 and 45 year, should not be excluded from future initiatives.

Systems Issues

It was concerning that several young women had experienced difficulty in having their breast symptoms fully investigated. There is evidence to suggest that a delay in referral by a physician for assessment may delay diagnosis. Because young women often present with large tumours of high grade (Osteen et al, 1994; Xiong et al, 2001; Breaden et al, 2002) it is vital to educate them and stress to physicians the importance of prompt diagnosis (Chan et al, 2000).

The confusion expressed over the role of BreastScreen for younger women was unfortunate. Whilst this is not an appropriate port of first call for a young woman with a breast symptom, several women identified with BreastScreen's high public profile and expected a more sympathetic response. BreastScreen may wish to consider ways to address this.

The issues of hospital facilities, crowded waiting rooms and long waiting times are neither unique to younger patients nor to breast cancer, and need to be addressed in another forum. However younger patients could be better prepared for their entry into the health (and illness) system with more forward planning.

Hormonal and Psychosocial Issues

The potential or actual loss of fertility was an issue for many of the women, and was not always addressed. The young women under 40 felt *ripped off* while those aged 40-45 felt a great sense of loss, even if they had completed their families. There was a sense of relief at being able to talk with other women in the focus groups who understood how they felt, and regret that this opportunity was not available at the time of treatment.

Contraceptive advice was inconsistent, and women were confused about the significance of their periods returning. Whilst clinicians may have had a clear understanding of the need for contraception during treatment, this was not always relayed effectively to the women, who had many other issues to deal with at the time. Similarly, advice on menopausal symptoms was inconsistent, which added to the distress of the women at their symptoms and the implications of early menopause. This in turn affected family relationships.

The women and their families needed a range of psychosocial supports at different stages along the way. Some partners struggled to come to terms with their additional or changed responsibilities, families varied in their ability to help, and relationships became strained when people could not meet the expectations of those who depended on them. The need for sensitive discussion of a range of issues and strategies with each woman was evident.

The hormonal effects of treatment and living with uncertainty significantly diminished the quality of many of the women's lives, contributing to anxiety, distress, tiredness and depression, which often went unacknowledged by service providers. The difficulties faced by these women need to be recognised and acknowledged, and strategies to help address uncertainty and tiredness need to be implemented. A formal psychosocial assessment at key points along the treatment pathway would identify some of these issues before they reached crisis point.

The end of treatment was a time of great stress for many of the young women, which is not uncommon for women of any age with breast cancer (NHMRC, 2001). This stress was accompanied for many of the women by a feeling of abandonment by the health system. While a few women had specific goals to aim for at this time (eg a holiday) others felt cast adrift. Encouragement of women to make plans for the time after treatment, and to be made aware that this is a difficult time could lessen their sense of disconnectedness. This could be undertaken as part of a formal psychosocial assessment.

Better communication with the women's general practitioners throughout treatment and awareness of local community supports would help bridge the gap and provide ongoing support for young women at this difficult time.

Information and Peer Support

There was a strong desire by participants to be provided with more general information about breast cancer, the health system and support systems, as well as information about the specific issues that they faced. Where evidence-based information is readily available, it should be provided in a timely and appropriate manner. Additional strategies, such as taping of consultations and the provision of additional appointments that will facilitate young women's understanding of information and their decision-making, should be seriously considered and trialled.

The challenge for service providers is in areas such as the hormonal impact of breast cancer, and the use of alternative and complementary medicines, where there is more limited evidence, which results in young women receiving inconsistent information and advice. Improvements in these areas are dependent on local service providers developing consistent approaches and / or protocols to guide practice.

While information provision is a very important strategy, it will not meet all women's needs. Several women in our study highlighted that while valuable, information did not always prepare them for the actual experience. Contact with another woman who had been through the experience would have been more helpful. Enhanced peer support goes hand in hand with information provision and, wherever possible, service providers must actively promote and facilitate women's access to such support.

Study Limitations

While this study provided us with rich data, we were aware of gaps where issues may have been skimmed over or conversations truncated. For instance it was difficult to discuss sexuality/intimate relationships in detail, and there was some discomfort felt at the emotional nature of some of the women's responses within the group, both by participants and facilitators. We wondered if our limited exploration of areas of emotional distress for the women might reflect what happens to women within the system (Berg & Smith 1985).

The quick succession of the focus groups across a four-day period limited our opportunity to review the data between groups. Some of the more sensitive and personal issues may have been explored better through individual interviews or smaller focus groups.

The ethnic mix of the WBSA catchment was poorly represented in the sample. This may reflect the complexity of the information sent in English and that engagement with non-English speaking women requires more personal approaches in the future.

Service Provider Issues

The lack of acknowledgement of the women's distress and concerns by some service providers may have been due to a stronger identification with younger patients and their children. This can sometimes raise unconscious concern about their own mortality, which service providers tend to cope with by distancing themselves in situations where they may experience anxiety and distress (NBCC 2003).

Because younger women with breast cancer are more vulnerable to psychosocial distress (NHMRC 2000) service providers' responses may increase the risk of women's needs not being detected or being inadequately met. If we are to be effective in developing strategies to improve services for young women with breast cancer, then the needs of service providers in terms of communication skills and professional support also need to be considered (NBCC 2003).

discussion and conclusion

Conclusion

Young women need to be informed sensitively and supportively about the many issues involved in living with breast cancer. They need to be encouraged to express their feelings and concerns and be given as much information as possible. Their management should be regularly assessed according to evidence-based guidelines that take into account the woman and her family, not just her cancer (Davis, 2002).

There are currently no consistent guidelines to assist clinicians and women in making decisions about the management of fertility and menopause related issues resulting from breast cancer treatment. Women at greater risk of developing infertility, premature menopause and its side effects and/or psychosocial problems need to be identified.

Formal psychosocial assessment must be built into the woman's early management and follow-up appointments. A complete management plan should include evaluation and management of anxiety, depression, stress and unresolved feelings about the diagnosis of cancer. Interventions should be considered at specific times, such as at diagnosis, on completion of treatment and at regular points in long term follow-up. Health care professionals may need additional training in both formal and informal assessment.

General practitioners are a vital link in the woman's ongoing care in the community. There should be regular communication with GPs at established key points along the treatment pathway and follow-up. Links with health and support services in the woman's local community should be established to keep her and her family connected and supported. Contact with other young women who have had breast cancer must also be encouraged and facilitated.

Our findings are supported by extensive literature on the treatment of younger women with breast cancer, and by the draft NBCC Recommendations about the Management and Support of Younger Women with Breast Cancer, to be released later in 2003. These recommendations have been developed concurrently with our community consultations, and will provide a framework to inform the decision-making of both clinicians and young women in their management.



4. Recommendations

The range of issues and suggestions brought up through the community consultations in Phase One of *The Young Women's Project* are far reaching. Drawing on both the focus group data and the women's own priorities, WBSA has identified three critical areas for service enhancement in 2003.

1. The development and implementation of pathways or protocols for improved referral and management of young women regarding hormonal issues, including fertility protection, contraception, breast-feeding and menopause management.
2. The development and implementation of structured approaches to psychosocial assessment and referral.
3. Development of a patient pathway/checklist for young women, to enhance their ability to make informed decisions about their care.

Current management and referral practices, specialist services and local community services are being identified in Phase Two of the project. The data will be reviewed by clinicians and project staff in order to develop improved approaches to assessment, management and referral. Communication and education strategies will then be put in place to develop the skills of key staff to deliver services in these areas. Young women will be involved in the development of their checklist.

It is hoped that the work undertaken will not only have benefit for young women, but that the knowledge, skills and strategies gained can be transferred to older women with breast cancer within WBSA and to other breast services.



References

- Arora NK, Gustafson DH, Hawkins RP, McTavish F, CellDF, Pingree S et al (2001) Impact of surgery and chemotherapy on the quality of life of younger women with breast carcinoma: a prospective study. *Cancer* 92 (5): 1288-1298.
- Bachmann GA. (1994) Nonhormonal alternatives for the management of early menopause in younger women with breast cancer. *Journal of the National Cancer Institute Monographs* (16): 161-167.
- Berg, D & Smith, K. (eds). (1985) *Exploring Clinical Methods for Social Research*. Beverly Hills: Sage Publications.
- Bloom JR, Stewart SL, Johnston M & Banks P. (1998) Intrusiveness of illness and quality of life in younger women with breast cancer. *Psycho-Oncology* 7: 89-100.
- Breaden K, Rudge T, Maddocks I. (2002): "I used to be stunning and slim": advanced breast cancer in young women. *The Australian Journal of Nursing* 3(1): 13-19.
- Chan A, Pintilie M, Vallis K, Girourd C, Goss P. (2000) Breast cancer in women < 35 years: Review of 1002 cases from a single institution. *Annals of Oncology* (11):1255-1262.
- Davis SR. (2002) How to treat - Menopause after breast cancer. *The Jean Hailes Foundation* [www.jeanhailes.org.au/research/documents/men_after_breast_ca.htm accessed 14/05/02].
- Dunn J & Steginga SK. (2000) Young women's experience of breast cancer: Defining young and identifying concerns. *Psycho-Oncology* 9: 137-146
- Ganz PA, Cosarelli A, Fred C, Kahn B, Polensky ML, Petersen L. (1996) Breast cancer survivors: psychosocial concerns and quality of life. *Breast Cancer Research and Treatment* 38: 183-199
- Ganz PA, Rowland JH, Desmond K, Meyerowitz BE, Wyatt GE. (1998) Life after breast cancer: understanding women's health-related quality of life and sexual functioning. *Journal of Clinical Oncology* 16(2): 501-504.
- Krueger RA & Casey MA. (2000) Focus groups: *A practical guide for applied research*. 3rd ed. Sage Publications, California pp 26-31.
- Lerman C, Kash K, Stefanek M. (1994) Younger women at increased risk for breast cancer: perceived risk, psychological well-being, and surveillance behavior. *Journal of the National Cancer Institute Monographs* (16): 171-176.
- Loprinzi CL, Hayes D, Smith, T. (2000) The art of oncology: when the tumor is not the target. Doc, shouldn't we be getting some tests? *Journal of Clinical Oncology* June 18 (11): 2345-2348.

- Maunsell E, Brisson J, Deschenes L. (1992) Psychological distress after initial treatment of breast cancer. Assessment of potential risk factors. *Cancer* 70(1); 120-125.
- Mor V, Malin M, Allen S. (1994) Age differences in the psychosocial problems encountered by breast cancer patients. *Journal of the National Cancer Institute Monographs* (16): 191-197.
- National Breast Cancer Centre (NBCC) (1999) *Report from the conference: Actions recommended by women with breast cancer for the benefit of the Australian community*. Australia's First National Breast Cancer Conference for Women; 1998 October 16-18; Canberra, Australia.
- National Breast Cancer Centre (NBCC) (2003). *Recommendations about the management and support of younger women with breast cancer*. Draft.
- NHMRC (2000) *Psychosocial clinical practice guidelines: information, support and counselling for women with breast cancer*. Commonwealth of Australia.
- NHMRC (2001) *Clinical practice guidelines for the management of early breast cancer* 2nd ed. Commonwealth of Australia.
- Northouse LL. (1994) Breast cancer in younger women: effects on interpersonal and family relations. *Journal of the National Cancer Institute Monographs* (16): 183-190.
- Osteen RT, Cady B, Friedman M et al. (1994) Patterns of care for younger women with breast cancer. *Journal of the National Cancer Institute Monographs* No. 16: 43-46.
- Saarto T, Blomqvist C, Valimaki M, Makela P, Sarna S, Elomaa I. (1997) Chemical castration induced by adjuvant cyclophosphamide, methotrexate and fluorouracil chemotherapy causes rapid bone loss that is reduced by clodronate: a randomized study in premenopausal breast cancer patients. *Journal of Clinical Oncology* 15(4): 1341-1347.
- Sammarco A. (2001) Psychosocial stages and quality of life of women with breast cancer. *Cancer Nursing* Aug; 24(4): 272-277.
- Schover LR. (1994) Sexuality and body image in younger women with breast cancer. *Journal of the National Cancer Institute Monographs*; (16): 177-182.
- Shapiro CL, Manola J, Leboff M. (2001) Ovarian failure after adjuvant chemotherapy is associated with rapid bone loss in women with early-stage breast cancer. *Journal of Clinical Oncology* 19(14): 3306-3311.
- Victorian Cancer Registry 2002. Personal communication.
- Wang X, Cosby LG, Harris MG, Liu T. (1999) Major concerns and needs of breast cancer patients. *Cancer Nursing* 22(2): 167-163.
- Xiong Q, Valero V, Kau V et al. (2001) Female patients with breast carcinoma age 30 years and younger have a poor prognosis. *American Cancer Society* Nov; 92 (10): 2523-2



5. *Appendices*

5.1 *Focus Group Interview Schedule*

5.2 *Participant Information and Consent Form*

5.3 *Focus Group Participants Demographic Information Form*

5.4 *Strategies for Service Improvement. Participants' Priority Areas by Category.*



Appendix One: *Focus Group and Interview Format and Questions*

Please note that the wording for the interviews will be adjusted to reflect that this is a one to one discussion rather than a group.

Preamble

Thank you for coming along to the discussion today. You have been invited to take part in this focus group/interview because you are a young woman who has had breast cancer within the last 5 years and either live in or have been treated by a service within the Western Breast Services Alliance – a group of hospitals covering western Melbourne.

We understand from talking with and reading about young women with breast cancer that there are some specific areas of concern, which may be different from those of older women with breast cancer. With your help we would like to explore some of the issues that have had an impact on your life since your breast cancer diagnosis and see if there are any other ways that services can be improved to deal with these issues better.

The information we gain from the discussion today will inform service providers about the issues of most concern to younger women with breast cancer and help them think more creatively about how to deal with them in the future.

There are no right or wrong answers to the questions we/I will be asking you. We would like to hear about your experiences and views. No two people are the same and everyone's experiences will be different. It is important that we hear all views.

As mentioned in the information and consent form we sent to you, the session will be recorded on audiotape. Notes will also be taken to help clarify what is said on the tape. The tape and notes will be kept in a locked filing cabinet in the project office at Western Hospital, and will only be available to project staff. No information will be reported that will identify you in any way, and the information gathered from our discussion today will only be reported as group responses.

[Focus group only]

Because we may be talking about some very sensitive issues today, we would ask you to respect the privacy of the other women in the group, and not discuss their personal details with other people outside this group.

At the end of this session, refreshments are available. This is an opportunity for you to talk with each other more informally. If you would like further information or support, please don't hesitate to talk with Bronwyn, who is a breast care nurse (or equivalent support person).

Group Discussion Guidelines [focus group only]

Because everyone's contribution is valued, we ask that only one person speak at a time.

That way everyone can hear what is being said and the tape will be easier to understand. We do want you to share your views and discuss differing points of view.

We will be directing questions to you as a group, and you don't have to answer any question that you do not feel comfortable with.

Questions

Ice breaker

Quick introduction – Name, something about themselves

Many women find after a diagnosis of breast cancer that their lives change in some ways.

Looking back on your own experience, what parts of your daily life have changed since your diagnosis of breast cancer?

Can you say how these changes have affected you?

What about your partner and/or your family? – How have they been affected?

In comparison with all women with breast cancer, what are some of the specific issues that you as a younger woman have had to face?

Considering the lives of your friends who have not experienced breast cancer, how is your life different?

Looking back, what were the issues for you *when you were first diagnosed* with breast cancer? How did you deal with them?

What has been the hardest thing to deal with *during* your treatment? What do you think might have helped to make it better for you?

If you have *finished* your treatment, what are the issues for you now? What do you think might have helped you to cope better or made it easier for you to cope after treatment?

Note: If early menopause, fertility, sexuality, body image and/or psychosocial issues have not been brought up by this stage, the following standby question will be asked:

[We understand from talking with young women that some of the physical aspects of early menopause are a concern for them. Fertility, sexuality and altered body image may be issues too. There are also emotional effects due to hormonal changes and longer-term effects of breast cancer treatment. Perhaps we could discuss how some of these issues affect you.]

If there were just one thing that you could improve in your experience of breast cancer and its treatment, what would it be?

What advice would you give to healthcare professionals (doctors, nurses, specialists, etc) that might help them to help other young women with breast cancer?

What issues are there that relate specifically to your culture or language that need to be better addressed?

If another young woman came to you for advice, what would you tell her about coping with a breast cancer?

Is there anything else you would like to add? Any other comments you would like to make.

Summation

We have identified some key points which most of you found difficult during or after your treatment for breast cancer. We will be holding other focus groups/interviews to identify other issues. We will then report back to the doctors, nurses and other health professionals in our services and work out ways to improve the way we deliver some of our services around some key issues.

We may be contacting some of you for further information, if you have consented for us to do so.

Debriefing

I appreciate that it may have been difficult for you to talk about some of these issues. If you feel you need to talk to someone about anything we have touched on today, please feel free to ring one of the numbers in the handout, or contact your local doctor, breast care nurse or community health nurse.

Thank you again for your time.

[Focus group]

We now have a little while for refreshments. You may leave if you would like, but we are happy for you to stay and talk with us. We have some information on some of the breast cancer support groups and networks around Melbourne. Please feel free to take the pamphlets home.

Bronwyn (Breast Care Nurse) would be happy to talk with you about specific concerns.

Please ring one of us, or the support organisations listed in your handout if you have any further concerns.



Appendix Two:

Participant Information and Consent Form

Headed with Institution's Name or on Institution's Letterhead

Participant Information and Consent Form

Version 4

Dated 03/10/02

Site:

Melbourne Health, Western Health, Melbourne Private Hospital

Full Project Title:

Young Women's Project: How can health care providers better respond to the specific needs of young women with breast cancer?

Principal Researcher:

Mr Bruce Mann

Associate Researcher(s):

Mr John Collins, Ms Meron Pitcher, Dr Delwyn Goodrick, Dr Narine Efe, Ms Mary Bartlett, Ms Sheila Hirst

This Participant Information and Consent Form is 7 pages long. Please make sure you have all the pages.

1. Your Consent

You are invited to take part in this research project.

This Participant Information contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.

Please read this Participant Information carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. Purpose and Background

The purpose of the Young Women's Project is to improve services in the Western Breast Services Alliance to better meet the needs of young women diagnosed with breast cancer.

The Western Breast Services Alliance (WBSA) is a group of hospitals including The Royal Women's Hospital, The Royal Melbourne Hospital, Western Hospital Footscray, Sunshine Hospital, Williamstown Hospital, The Freemasons Hospital, Frances Perry House, Melbourne Private Hospital and Western Private Hospital.

Although most breast cancer occurs in women over 50 years of age, younger women are diagnosed with the disease. While breast cancer and its treatment affect all women, the impact may be greater in younger women. Currently services may not always meet these needs.

To improve services for young women, we are wanting to consult with women about the issues that younger women with breast cancer face and ways in which services could be improved. A total of 30-50 women aged between 18-49 years of age will participate in this project.

You are invited to participate in this research project because you are a young woman who has been diagnosed with breast cancer (at age 18 to 49 years) within the last five years. You also either live in the area covered by the Western Breast Services Alliance or you have been treated at one of the hospitals.

The results of this study may also be used to help researcher Mary Bartlett to obtain a Postgraduate Diploma in Community Health.

3. Procedures

If you agree to take part in this project you will be asked to:

- Complete a brief questionnaire with the signed consent form. This information will help in organising the focus groups.
- Attend a focus group (a meeting of 6 to 10 young women who have all had breast cancer) to discuss aspects of your treatment. A list of questions will be asked and members of the group will talk about their own experiences. This will take about 90 minutes and will be located at a place and time convenient to you. You will be contacted to confirm the time and place. The session will be audio-taped and there will be someone taking notes, as well as a facilitator leading the discussion. No doctors will be involved in the group discussion.
- Fill in a questionnaire with some further details about yourself, prior to the focus group. This will take about 5 minutes.
- In addition, after the focus group, you may be contacted for a follow-up telephone interview to clarify any information raised.

4. Possible Benefits

The information that you give about your experiences will be used to find ways of improving the quality of care for younger women with breast cancer.

We cannot guarantee or promise that you will receive any immediate benefits from this project. However we expect that WBSA health professionals will gain a better understanding of the specific needs of younger women with breast cancer. This will help them to develop ways to better meet these needs and to share this with other breast services for the benefit of other young women.

5. Possible Risks

Talking about their breast cancer treatment and experiences may be upsetting for some women who participate in this study. A breast care nurse or another health professional who has experience in supporting women with breast cancer will be at the meeting to help you if needed.

If you need to talk to someone after the group or interview, you may also contact:

The *Breast Cancer Network of Australia* is run by and supports women who have had breast cancer. Their telephone number is (03) 9803 2500 or 1800 500 258 (weekdays 9am – 5 pm)

The *Cancer Council of Victoria* has trained telephone counsellors you can talk to on the Cancer Helpline (phone 13 11 20 - weekdays 8.30 am – 5.30 pm). If it is hard for you to speak English, they use a telephone interpreter service so you can speak in your own language.

Lifeline provides 24-hour telephone counselling by trained counsellors (phone 13 11 14).

You may also contact project staff, Sheila Hirst or Mary Bartlett on 03 8345 6974 (weekdays 9 am - 5 pm).

6. Alternatives to Participation

If you are not able to come to a focus group or do not feel comfortable talking in front of other people, an individual interview or a telephone interview can be arranged. Notes will be taken by the interviewer during any telephone interviews. Face-to-face interviews will be audio-taped.

You do not need to participate in this project to receive any treatment or counselling that you may require.

7. Privacy, Confidentiality and Disclosure of Information

Any information that can identify you will remain confidential and will only be disclosed with your permission. If you give us your permission by signing the Consent Form, information obtained from all study participants will be grouped together. The information will only be used in a way that ensures that no individual woman or their responses can be identified. This information will only be available to non-clinical project staff Sheila Hirst and Mary Bartlett.

No identifiable information will be made available to medical staff *including* those on this project team.

All women who participate in the focus groups will be asked to respect the privacy of the other women in the group and not to discuss personal details with other people outside the group.

The results of the study will be shared with WBSA health care providers in order to improve services to younger women. We will also share the information with other breast services around Victoria and publish our results to the wider healthcare community. In all reports or publications, information will be provided in such a way that you cannot be identified.

All information about this project will be kept in a locked filing cabinet in the project office for the life of the project and will then kept in a locked filing cabinet in a secure office in the Department of Surgery at the Royal Melbourne Hospital for a total of seven years. According to Australian Privacy Laws, you have the right to access information collected and stored about you.

8. New Information Arising During the Project

During the research project, new information about the risks and benefits of the project may become known to the researchers. If this occurs, you will be told about this new information.

9. Results of Project

At the end of the project, a summary of our findings will be available to participants. If you would like a copy, please tick the box on the consent form.

10. Further Information or Any Problems

If you require further information or if you have any problems concerning this project, you can contact the principal researcher, Mr Bruce Mann on (03) 9342 7704, or WBSA BSEP Program Manager, Ms Sheila Hirst on 03 8345 7964.

The researchers responsible for this project are:

Mr Bruce Mann Principal Researcher, Breast Surgeon. WBSA BSEP Clinical Coordinator 03 9342 7704 (work); 0408 594 593 (mobile) or 9387 1000 (pager number)

Ms Sheila Hirst Program Manager 03 8345 6974 or 0409 258 223

Ms Mary Bartlett Project Officer 03 8345 7120.

Mr John Collins Breast Surgeon 03 9342 8528 or 0408 247 801

Ms Meron Pitcher Breast Surgeon 03 8345 6027 or 0410 984 138

Dr Delwyn Goodrick Senior Evaluation Consultant, BreastCare Victoria, Dept of Human Services (03) 9616 2131.

Dr Narine Efe Breast Surgeon, Royal Melbourne and Freemasons Hospitals. (03) 9417 7188

11. Other Issues

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

Dr Angela Watt, Secretary - Human Research Ethics Committee, Royal Melbourne Hospital. Telephone: 03 9342 7550.

You will also need to tell Dr Watt the name of the Principal Researcher for this project, given in Section 10 above.

12. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with any of the services in the Western Breast Services Alliance.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify a member of the research team before you withdraw.

This notice will ensure that you are not contacted again by members of the project team.

13. Ethical Guidelines

This project will be carried out according to the National Statement on Ethical Conduct in Research Involving Humans (June 1999) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of the Royal Melbourne Hospital.

14. Reimbursement for your costs

You will be paid \$40 for your participation to reimburse for any travel costs or other expenses.

Consent Form

On Institution's Letterhead or Name of Institution

Consent Form

Version 4

Dated 03/10/02

Site:

Melbourne Health, Western Health, Melbourne Private Hospital

Full Project Title:

Young Women's Project: How can health care providers better respond to the specific needs of young women with breast cancer?

I have read, or have had read to me in my first language, and I understand the Participant Information Version **Four** dated **03/10/02**.

I do not wish to participate in this project

tick box

OR

I freely agree to participate in this project according to the conditions in the Participant Information.

YES tick box

Yes I consent to take part in a focus group discussion

tick box

Yes I consent to an individual interview after the focus group if needed

tick box

Yes I consent to be interviewed individually only.

tick box

If I agree to participate in this project:

I will be given a copy of the Participant Information and Consent Form to keep

I would like a copy of the results to be sent to me at the end of the project

tick box

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Participant's Name (printed) _____

Signature _____ Date _____

Name of Witness to Participant's Signature (printed) _____

Signature _____ Date _____

Researcher's Name (printed) _____

Signature _____ Date _____

*Note: All parties signing the Consent Form must date their own signature.
Please complete the brief details form overleaf as part of this consent form.*

Young Women's Project – Brief Details Form

On Institution's Letterhead or Name of Institution

If you agree to participate in the Young Women's Study, please complete this brief questionnaire and return it as part of the completed Information and Consent Form. The information provided will assist us in organizing the focus groups and interviews at a convenient time and location.

Name _____

Address _____

Telephone Number(s) Daytime _____ Evening _____

What is the best time to contact you? _____

1. Are you ? (Please tick) Single Married / partnered Divorced / Widowed

2. Do you have children (Please tick) Yes No

3. Were you born in Australia? Yes No

4. If no, where were you born? _____

Here are some possible dates, times and places for focus groups to be held.

Please indicate your preferences (1 for first preference, 2 for second preference and so on).

<i>Date</i>	<i>Time</i>	<i>Place</i>	<i>Preference</i>
Wednesday 30th October	1.15 pm – 2.45 pm	Footscray	
Tuesday 19th November	10.00 am – 11.30 am	Footscray	
Wednesday 20th November	7.15 pm – 8.45 pm	Carlton	
Friday 22nd November	1.15 pm – 2.45 pm	Sunshine	

If none of these times or locations suits you, please tell us what day, time and place you would prefer, and we will try to accommodate you.

Thank you for agreeing to participate in this project. A member of the project team will contact you to let you know when and where your focus group/interview will take place.

Template “A” Revocation of Consent Form

(To be used for participants who wish to withdraw from the project.)

(Attach to Participant Information)

On Institution’s Letterhead or Name of Institution

Revocation of Consent Form

Full Project Title: Young Women’s Project: How can health care providers better respond to the specific needs of young women with breast cancer?

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with *any breast service connected with the Western Breast Service Alliance.*

Participant’s Name (printed) _____

Signature _____ Date _____



Appendix Four

Strategies for Service Improvement. Participants' Priorities by Category – Detailed Responses

<i>Domain</i>	<i>Priority Area</i>	<i>Number of responses</i>	<i>% of all responses (N=119)</i>
<i>Psychosocial Support / Clinical Management</i>	<p><i>Improved access to emotional / psychological support for woman, partner and family eg:</i></p> <ul style="list-style-type: none"> • Affordable counseling; • More long-term follow up re: mental health issues • Emotional support during chemotherapy • More support at diagnosis and post-operatively • How to share news with family and friends • Better handover of emotional care after chemo and radiotherapy • Support for family members who are not coping • Who supports the husbands, they need help. • Counselling for partners to enable them to cope with woman affected • Support with relationship issues • I found that the second time in hospital for breast cancer, there was not the support in hospital or at home. It was like I didn't need help again • Family support re: emotions • Understanding of what is ahead. Explanation to family members about coping mechanisms • More support once treatment is finished, or at least made aware of the emptiness feeling at the end of treatment • Counsellors available to those who want a bit more support or just to talk to • More specialist nursing care • Health care providers take care of your emotional needs as well as treatment of illness 	31	26%
<i>Psychosocial support</i>	<p><i>Improved access to practical support eg;</i></p> <ul style="list-style-type: none"> • Support with house / childcare during treatment • Family support and childcare assistance • Access to childcare and house cleaning • Access to financial support available 	15	12.6%

<i>Domain</i>	<i>Priority Area</i>	<i>Number of responses</i>	<i>% of all responses (N=119)</i>
<i>Psychosocial Support</i>	<p><i>Improved peer support eg:</i></p> <ul style="list-style-type: none"> • Meeting other women to discuss issues • Need for young women's support group • Younger women's issues are entirely different to others. Need a mentor program • Assistance in community for younger women • Provide contact number for young women's support straightaway • Meetings arranged on regular basis during and after treatment to ask questions – perhaps with women of same age and with BCN 	12	10%
<i>Information</i>	<p><i>Improved information about emotional and practical support services eg:</i></p> <ul style="list-style-type: none"> • More awareness of what is available for assistance • Knowledge of services / support available eg: home help / childcare • Women needed to be told what help and resources are around. Sometimes we don't know what to ask for and what's out there for us • Help with children so they know what's happening 	6	5%
<i>Information / Clinical systems management</i>	<p><i>Improved support / assistance or information about hormone / fertility / sexuality / body image issues ~</i></p> <ul style="list-style-type: none"> • Greater information re:sexual relations; intimacy, menopause; sexuality and fertility; on menopause, changes in your body; fertility and chemotherapy • Improved access to gynaecologist care • Help with breast feeding – how to wean • More information about hair loss, clothing etc • How to manage weight loss, weight gain, value of exercise programs 	9	7.5%
<i>Information</i>	<p><i>Improved information about health system and varying costs between public and private sector eg:</i></p> <ul style="list-style-type: none"> • Let people know about any Medicare Cover Gap when starting treatment • Costs involved in treatments • Improved understanding of health system • Need more info from staff about options and costs 	6	5%

<i>Domain</i>	<i>Priority Area</i>	<i>Number of responses</i>	<i>% of all responses (N=119)</i>
<i>Information</i>	<p><i>Improved information / communication about complimentary / alternative therapies eg:</i></p> <ul style="list-style-type: none"> • Highlight the possibilities of alternate therapies in conjunction with the traditional. • Alternative medicine to support chemo treatment 	6	5%
<i>Service environment</i>	<p><i>Improved service environment</i></p> <ul style="list-style-type: none"> • Separate chemo room for young women • Better car parking • Improve access to specialist nurses • Improve clinic appointment times • Improve clinic environment – waiting room is like a cattleshed – needs to be humanized. • Improve visual surroundings • More private waiting room pre-operatively 	7	6%
<i>Clinical systems management issues</i>	<p><i>Improved clinical systems / management protocols</i></p> <ul style="list-style-type: none"> • Don't phone with diagnosis. Maybe go through local doctor (I was rung at work) • Improved access to BCN • More time with BCN to discuss specific issues • More time for decisions and extra appointment before treatment. • Increased awareness of breast cancer in young women to reduce diagnostic delays 	5	4%
<i>Service Provider Issues</i>	<p><i>Enhanced communication with service providers eg:</i></p> <ul style="list-style-type: none"> • Improved bedside manner of doctors • Improved communication with GPs • Improved personal contact with doctors / nurses • Improve timing of information eg ask patients if they are up to discussing treatment options straight after surgery • Ability to get a second opinion without being 'told off' • Doctors recognize individual needs and listen to you • Service providers explain how we change on the inside eg: talk about feelings 	3	2.5%
<i>Miscellaneous</i>	<ul style="list-style-type: none"> • Increased community awareness of breast cancer in young women. • Community awareness. Do people understand cancer issues when it suddenly affects someone they love? 	1	<1%