

Woman to Woman



**A research report
on the experience of
rural women with
breast cancer and
implications for the
provision of health services**

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This research was conducted as a collaborative partnership between the Department of Human Services (DHS - Hume region), Women's Health Goulburn North East (WHGNE) and Breast Services Enhancement Program (BSEP - Hume region).

The Department of Human Services, Hume region is a key human services agency with responsibility for the portfolio areas of health, housing, aged care and community services. It leads the delivery of the government's goal of high quality, accessible health and community services, and contributes to the building of cohesive communities and reducing inequalities across the region.

The Hume Breast Services Enhancement Program (BSEP) commenced in late 1999 and was funded by BreastCare Victoria, Department of Human Services (DHS) until June 2004. This program was one of nine quality improvement programs across the State and aimed to establish a model of breast care services in line with established best practice. Key priority areas for the program included increasing access to multidisciplinary care, Breast Care Nurses and Information, Communication and Support.

Women's Health Goulburn North East (WHGNE) was established in July 2000. Previously known as NEWomen, WHGNE is the government funded specialist women's health service for the Goulburn Valley and North-East Victoria. The vision is to lead the Hume region in creating opportunities for women to experience a positive sense of self, health, safety and wellbeing.

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Researcher's reflections

The experience of breast cancer has certainly been a defining event in my life that has veered me off the path upon which I was steadily treading and onto a new one. A few years ago, I could never have anticipated that I would be undertaking research in the area of breast cancer – a topic about which I have become passionate as a result of being personally touched by the disease.

Without the support of my employer (DHS) and the expert assistance of Deb Parkinson (WHGNE) and Kate Cuss (BSEP) this research would never have eventuated. And without the willingness of the women to share their intimate experiences with me, the research would not have been possible.

I have travelled far and wide across the Hume region to interview women – sometimes across rugged bush tracks and through paddocks to remote and beautiful places that I never really knew existed before. I discovered some amazing women whose will to live, strength and courage will always be an inspiration to me.

Working with these women has been an amazing and moving experience. I related to the women on a very personal level. We not only talked together, we often laughed and cried together. I was frequently astounded to hear a woman express feelings that matched my own and now know that women need never feel alone throughout their breast cancer journey. There will always be other 'spirited sisters' who can understand some of the issues they are facing ... the pain, grief, fear ... and then the changed person one becomes who can see the world in sharper focus.

The women interviewed are all breast cancer survivors who have bravely recounted their stories in an effort to help others. They have shared their intimate thoughts and stories with me and for this I feel truly privileged.

I know that when you read this report and the accompanying stories, you will gain wonderful insight into the effect of breast cancer on rural and remote women. I hope that you will also hear women voicing their views about their care needs and that you will reflect upon what this might mean to you and others in the future.

Angela Verde

Executive summary

'Woman to Woman' is qualitative participatory research designed to explore the effects of breast cancer and breast cancer treatment on rural women. It documents the experiences of 20 women in the Hume region of Victoria who have been diagnosed and treated for breast cancer in the previous three years. The women were asked to reflect on the effect of breast cancer on their lives generally and on the nature and quality of the services they received. They spoke about what was helpful to them and gave their views on how services may be further enhanced.

The researcher conducting the interviews is herself a breast cancer survivor who disclosed her own experience of breast cancer to the women being interviewed.

The women interviewed ranged in age from 34 to 70 years. All of the women resided within Hume region, in major regional centres, smaller towns and rural settings.

This participatory research was conducted as a collaborative partnership between the Department of Human Services (DHS - Hume region), Women's Health Goulburn North East (WHGNE) and Breast Services Enhancement Program (BSEP - Hume region). A partnership agreement and work plan were developed as a basis for this collaboration, and guidance was provided by a Project Reference Group. This research report has a companion volume of excerpts from the 20 interviews, entitled, 'Woman to Woman: insights from rural women with breast cancer'.

Context of the project

The diagnosis of breast cancer is usually a traumatic event in a woman's life, and the impact of breast cancer and its demands can be significant. Breast cancer is the leading cause of cancer death in Australian women. Over 11,300 Australian women are diagnosed with breast cancer each year and 1 in 11 will be diagnosed with the disease by the age of 74.

Up to 30% of Australian women diagnosed with breast cancer live in rural or remote areas of Australia and have been recognised as having special needs and limited treatment options. High levels of unmet supportive care needs among women diagnosed with breast cancer have been reported, yet there is a paucity of qualitative research examining the needs and experiences of breast cancer patients within the rural Victorian setting.

Medical interventions – diagnosis and treatment

The women interviewed reported undergoing various treatment types in different locations, including within the Hume region, Albury and Melbourne.

Women experienced a range of side effects at each phase of the cancer treatments. Some were temporary and some are now a permanent affliction for the women affected.

It appears that there is a difference in the availability of reconstructive surgery in rural areas compared to Melbourne, with Hume region women rarely having the option of reconstruction at the same time as mastectomy. In fact, the women reported that there was very little discussion of reconstruction at all at the time of diagnosis. In retrospect, this was a concern to them.

Health system and financial issues

Just over half of the women chose to use their private health cover for a particular aspect of their treatment. Women treated in the private system were generally very satisfied with the treatment they received, although a number commented on having marked difficulty accessing services post discharge from a private hospital.

While some of the women were eligible for different forms of financial support, depending on where they lived, where they had their surgery and whether they had private health insurance, there was clearly a significant financial burden that came along with the diagnosis and treatment of breast cancer. They had no choice but to cope with this as yet another stressor.

Women's perceptions of their experience of health services

Many women interviewed felt that it had been important for them to actively participate in decisions regarding their health at the time of diagnosis and throughout subsequent treatment. Women had to be assertive to have a voice in treatment decisions. They had to advocate for their right to an opinion, or to state a preference, or to have treatment that *they* chose based on comprehensive information.

Women commented on the need to ask questions, research topics and actively seek additional information. Some women found themselves having to argue strongly and convincingly for a particular course of action.

There were mixed responses from the women about their experience of communication with professionals and access to information. Some women experienced great difficulty and reported that their views were dismissed and procedures were not adequately explained. Other women were very satisfied with the communication between themselves and professionals, and felt great confidence in their specialist treatment.

Communication between disciplines was also regarded with mixed views. Some women found this to be satisfactory whilst others reported enormous problems. Some stated they received quite conflicting information from various clinicians.

Women's perceptions regarding the manner in which they were treated were mixed. While many highly praised the specialists, the support personnel and the facilities associated with their treatment, many others were highly critical of various aspects of their care. Some women expressed dissatisfaction with the disrespectful attitude of staff involved in their care and felt a lack of trust in the competence of particular professionals. Some were unhappy with the physical environments where treatments were received.

Women appreciated the service they received from Breast Care Nurses (BCNs) in the region and were clear about needing increased access to the care, support and information offered by BCNs. The part-time nature of the BCN employment means that currently access to BCNs is limited.

Timely information and good communication with health professionals are both critical to women with breast cancer. Women are coping with physical and emotional assaults on their being and struggle with confusion and fear of the unknown.

Effects and issues of breast cancer

The diagnosis of breast cancer brought with it great challenges for each woman. Most poignant was the effect on family. Support from family and friends was essential to the

women as a source of great comfort and assistance, and for those who did not receive it as expected, as a source of great disappointment. The women spoke about fear and grief, and loss of friends who did not know how to offer support and so withdrew. Yet, along with all of this, came a greater appreciation of life and a new way of experiencing each day.

Women described concern for their children of all ages as paramount. Caring for their babies and toddlers was clearly a major issue for young women. Young children and adolescent family members often felt traumatised by the change to their family life and the risk to their mother. They feared for their family's future. There is a clear need for emotional support for them, and, at the same time, a lack of accessible counselling options.

Women with partners were very concerned about the effect of their breast cancer diagnosis on their partner. Men were frequently described as not coping well and finding it very difficult to express their feelings.

There were times when support from other family members was not forthcoming, and it was hurtful and disappointing to the women.

It is not surprising that the absence of hair (albeit temporary) and a breast or breasts would have an impact on women's self image. Some women confessed to feeling very self conscious about their appearance despite being aided by wigs, breast prostheses and reconstructive surgery. Some women experienced a loss of confidence and associated feelings of fragility and insecurity as a result of their breast cancer.

Whilst undergoing treatment, women commonly felt extremely unwell. They needed help with daily tasks and frequently had to ask for assistance. As a result, many felt that they were a burden to others.

The need to take time off work throughout treatment for breast cancer was something women dealt with differently. Some women discontinued work for extended periods. Others felt that they were able to cope with working part time.

The impact of rurality on Hume region women with breast cancer

The stereotypes of rural life appear to be true, as women spoke of the calm atmosphere of the country and friendliness and stoicism of country people. They appreciated the greater support from small communities, where people know each other and you're treated as a person and not just a number; where the breast care nurse and the district nurse call in to offer advice and support.

The flipside is that, where everyone knows each other, it is impossible to keep things private. As a result, some women felt forced to tell their children and family of their breast cancer before they were ready, and felt branded by their illness.

The women's experiences of accessing treatment and support services differed according to whether they lived in one of the four larger provincial towns, in smaller country towns, in tiny hamlets, or on farms in rural and remote areas. Those who felt best served were the women living in or close to Albury-Wodonga which has radiation and chemotherapy treatment centres. It is the only centre in Hume region to offer both.

For most of these Hume region women, treatment for breast cancer involved extensive travel and the occasional need for accommodation. For women living in rural areas some distance from a provincial centre, travel to and from appointments depended on having a car and, perhaps, a friend to drive them, as public transport was either not available or very limited in the times it was offered. Women spoke of having to set aside half a day or a whole day to

attend appointments. When the appointments were for radiation, for some women, they were scheduled on each weekday for six weeks.

Strategies

There were many strategies which women indicated had helped them along their journey with breast cancer. They ranged from changes in lifestyle and attitude - the way they viewed life, its trials and tribulations - through to accessing assistance via information sources, counselling, support for themselves and family members, and practical strategies to alleviate physical discomfort. A key strategy was a determination to live life to the fullest.

Counselling was seen as a very effective strategy to deal with the emotional trauma associated with the disease for the woman and her family. Access to and affordability of counselling services was again underscored as an issue in rural areas.

Conclusion

This research sought to gain an insight into the experiences of women in Hume region living with breast cancer and their experience of health services in its treatment. The purpose of the research was to improve health services to rural women. This report is for health professionals to read and consider. It is for the funding bodies of health services to inform their decisions. It is for the women who informed this research; for women living with breast cancer; and for those who will be diagnosed in future months.

The experiences of the 20 women who informed this research identified clear avenues for improved services. Implementation of the recommendations in this report will go some way to delivering improved experiences of health service provision for rural women with breast cancer.

Introduction

This qualitative research was designed to explore the effects of breast cancer and breast cancer treatment on rural women. It documents the experiences of women in the Hume region who have been diagnosed and treated for breast cancer within the last three years. Semi-structured, in depth interviews were undertaken with twenty women. The women were asked to reflect on the effect of breast cancer on their lives generally and on the nature and quality of the services they received. They were also asked about what was helpful to them and about their views regarding how services may be further enhanced.

There were four objectives:

- to examine and document women's stories of their experiences of breast cancer and treatment in rural Victoria
- to analyse the data to identify common themes and patterns and to identify exceptional experiences
- to understand and document the particular implications for rural and remote women of a breast cancer diagnosis
- to gather ideas and take direction from women living with breast cancer about what would be useful for them in terms of service system development.

Context of the project

Breast cancer is the leading cause of cancer death in Australian women. Over 11,300 Australian women are diagnosed with breast cancer each year (AIHW 2003 in NBCC 2004 p 7) and 1 in 11 will be diagnosed with the disease by the age of 74.

Rural Victorian women of all ages have slightly higher breast cancer incidence and mortality rates than urban Victorian women, although not statistically significant differences.

The diagnosis of breast cancer is usually a traumatic event in a woman's life, and the impact of breast cancer and its demands can be significant.

Women with breast cancer living in rural and remote areas of Australia have been recognised as having special needs and limited treatment options. In terms of the Hume region, rural is defined as including regional centres and large country towns in rural areas (Davis et al 2003 p 29). There is evidence that identifies a discrete culture within rural communities (Davis, Williams, Redman, White & King 2003 p 27). Some researchers have proposed that the rural lifestyle is associated with a greater self-reliance and independent lifestyle, and therefore people from rural health may define health in more practical and functional terms (NBCC & NCCI 2003 p 120).

Australians living 'in the bush' have lower overall cancer survival rates than people living in metropolitan areas (AIHW 2003), and the burden of cancer on consumers, their families and carers is a particular challenge in rural communities that do not have the full complement of services (Wooldridge 2001 p 1; Olver & Selva-Nayagam 2000 p 213; Furnival 1997 p 1; McMurray 1998).

Up to 30% of Australian women diagnosed with breast cancer live in rural or remote areas where there is often limited access to specialists and diagnostic, supportive and therapeutic services (Zorbas et al 2003 p 528-9).

High levels of unmet supportive care needs among women diagnosed with breast cancer have been demonstrated in a rural Australian setting, particularly in the information and

psychosocial domains (Girgis et al 2000, Wilson et al 2000). A more detailed literature review on issues of rurality is found in Appendix 1.

A few qualitative studies (McGrath et al 1999a; McGrath et al 1999 b) conducted on the needs of rural Queensland women, have highlighted the emotional and financial difficulties experienced by rural women with breast cancer.

Other national and international studies (McGrath et al 1999, Grigis et al 2000, Wilson et al 2000, Clavarino et al 2002, Davis et al 2003, Koopman et al 2001, Ferrell et al 1996, Davis et al 1998, Sanson-Fisher et al 2000) have identified issues of concern for consumers including:

- access to information
- psychological issues
- financial worries
- relationship issues
- work issues
- physical/functioning problems
- availability of specialist care
- family disruption
- dissatisfaction with health professionals

Although there is some research that has documented the added burdens of living with breast cancer in a rural or remote geographic location, there is a paucity of research that has examined the needs and experiences of breast cancer patients within the Australian context and in particular, within a rural Victorian setting. There is clearly a need for research to document the unique issues facing rural women with breast disease.

Research can be an instrument by which health care consumers are given a voice, their issues and concerns raised and inequities brought to attention. Participatory research (those being researched are involved in the research process) can empower consumers to be involved in project planning and design, methods of data collection and analysis and use of research outcomes (Macaulay et al 1999 in Bourke 2002 p 246). This also has the benefit of local values being incorporated into the research, rather than imposed from the outside (Travers in Bourke 2002 p 247).

Several researchers have found participatory research can develop successful interventions at the local level (Cornwall et al, Drevdahl & Riley et al in Bourke 2002 p 247), and is particularly suited to rural development (de Koning & Martin in Bourke 2002 p 247). It has been said that having local consumer and health care professional involvement in a participatory process 'builds knowledge, not of elite researchers but of communities' (Bourke 2002 p 251).

Participatory research is well suited to work with consumer/survivors (Nelson et al 1998 in Ochocka et al 2002 p 385). Participation of these consumers embraces 'the experience and partnership of those we are normally content to simply measure' (Schwab & Syme 1997 p 2050 in Bourke 2002 p 246).

But this notion of consumer as researcher can also be viewed as transgressing science's rules about objectivity, validity and reliability (Platzer & James 1997 p 630), and lays researchers open to the charge of bias thought to be inherent in going native, or rather in this case being native' (p 626). Qualitative researchers caution that bias and issues unique to insider research can occur that put the trustworthiness of the study at risk (Field 1991, Tilley & Chambers 1996, Thomas, Blacksmith & Reno 2000 in Asselin 2003 p 100).

The researcher conducting 'insider' research must be aware of pitfalls that can threaten the credibility of the study. By building systems into the study design and analysis, the research team can preclude issues of bias associated with insider research and actually enhance the credibility of the study (Asselin 2003 p 103). Our position, too, is that insider knowledge has strengthened this study by the perspectives we have collectively brought to it. In this rural breast cancer research project, safeguards to protect credibility were implemented, including NHMRC sanctioned ethics approval, a professional researcher as a member of the research partnership, and all members of the partnership were involved in planning, coding, analysis and writing. The reference group further enhanced credibility of the research project.

A more detailed literature review on participatory/insider research is found in Appendix 1.

This research project has provided insight into the breast cancer experiences of women within a rural Victorian context. The rich data may assist health practitioners, managers, planners and funders of breast cancer services to inform future decision-making and practice for rural women. The project also adds to the findings of previous work undertaken within Hume region three years ago, involving investigating consumer perspectives via a written, and primarily quantitative survey (Bourke, 2001).

Methodology

This qualitative research involved in-depth interviews with twenty women with breast cancer. It was conducted as a collaborative partnership between the Department of Human Services (DHS - Hume region), Women's Health Goulburn North East (WHGNE) and Breast Services Enhancement Program (BSEP - Hume region). A working group with a representative from each organisation met regularly throughout the project. A partnership agreement and work plan were developed as a basis for this collaboration.

Guidance was provided by a Project Reference Group comprised of the following key stakeholders:

- Two consumer representatives – one young woman with breast cancer and another woman with advanced disease
- BreastCare Victoria Evaluation Adviser
- Breast Care Nurses, Northeast Health, Wangaratta
- Acute Health Project Officer, DHS, Hume Region

Data collection and analysis

Women were recruited as participants in this project through breast care nurses (BCNs) linked to the Hume Breast Services Enhancement Program. An information flyer regarding the project was posted by these BCNs to women within Hume region who met the criteria of being over 18 years of age and having experienced breast cancer within the previous three years.

Once interested women contacted the researcher, they were provided with a verbal explanation of the project and were posted an explanatory statement. If a woman decided to participate in an interview, an additional explanation of the project was given at the commencement of the interview and another copy of the explanatory statement was shown to the woman at that time. The background and objectives of the project were outlined. Each woman gave written consent to participate prior to the commencement of the interview.

The interviewer disclosed her own experience of breast cancer both at the time of initial phone contact with women and again, prior to the commencement of each interview. Although the self disclosure may have contributed to the interactive nature of the interviews, the interviewer did not provide a detailed description of her own experience until the completion of each interview in order to prevent influencing the responses of interviewees. Following the interview, the researcher shared her own experience if this seemed appropriate or was requested by the interviewee.

The twenty interviews were conducted between August and October 2003. The interviews were conducted using a semi-structured conversation style format with a clear set of topics to be covered and questions to be answered (Appendix 2). There was considerable flexibility in terms of the order in which topics were considered and questions were open ended with relevant new lines of inquiry pursued as they arose.

All women interviewed were offered emotional support as required during the interview as well as referral to trained counselors if they considered that further discussion about the issues raised during the interview was necessary.

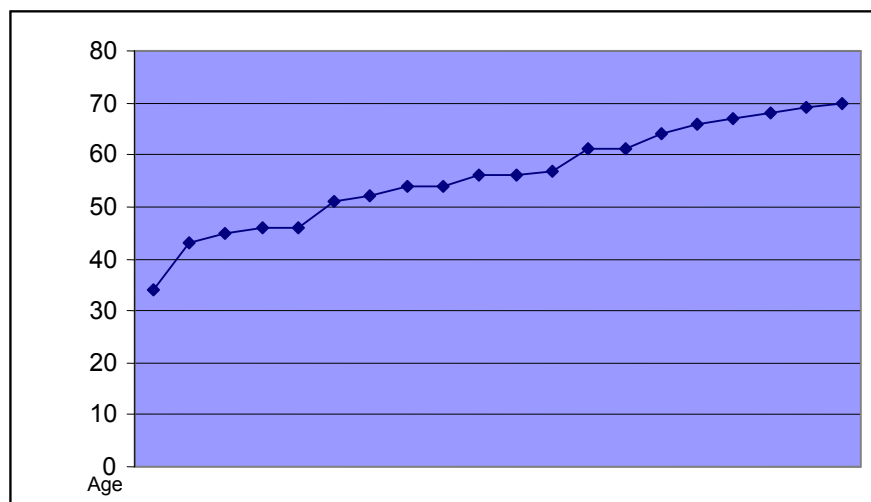
Most of the women were interviewed in their own homes (on two occasions another adult relative was present - a husband on one occasion and a daughter on another). Depending on the nature and complexity of issues discussed, interviews lasted for between 50 minutes and 2 hours. All women consented to having their interviews audio-taped. This freed the researcher to engage with women and focus on their narratives and allowed accurate descriptions of experiences as interviews were transcribed verbatim.

Inductive analysis of seven interviews informed the development of eight major categories, each with a number of sub categories reflecting recurrent themes and patterns. To enhance the consistency of data analysis, the three researchers met regularly and coded the first interview together.

The sample

The women interviewed ranged in age from 34 to 70 years, with one in her 30s, four in their 40s, 7 in their 50s, 7 in their 60s and one in her seventies.

Table 1: Age



All of the women interviewed reside within Hume region. Six women live in the major regional centres of Wodonga, Wangaratta and Shepparton/Mooroopna. Eight women live in the smaller towns of Yarrawonga, Benalla, Myrtleford, Corryong, Bright, Tatura and Whitfield, and six women live in rural settings in the shires of Mitchell, Moira, Indigo and Alpine.

Table 2: Location

| Major regional centre | Smaller town | Rural setting |
|-----------------------|--------------|---------------|
| 6 | 8 | 6 |

Eleven live at home with their partners (with adult children living away from the family home). Four women live with their husband and children, with one of these women having three daughters under the age of six years and another having three daughters under the age of eight. Two of the women interviewed live at home with children and no partner and three live independently.

Table 3: Living arrangements

| Live with partner | Live with partner and children | Live with children | Live independently |
|-------------------|--------------------------------|--------------------|--------------------|
| 11 | 4 | 2 | 3 |

In terms of work status, eleven women are not currently working although two are actively seeking part time employment. Seven women are currently working part time and a further two are in full time employment. All women currently working who had undergone chemotherapy and / or radiotherapy reported having reduced their workload or temporarily discontinuing work for varying periods whilst undergoing and following treatment.

Table 4: Employment

| Not employed | Employed part-time | Employed full-time |
|--------------|--------------------|--------------------|
| 11 | 7 | 2 |

Four of the women interviewed have bachelor degrees (with two of these attaining additional qualifications at Diploma level). A further three women had diploma qualifications and two had certificate qualifications. Two other women had completed some study at college level (i.e. Business and Bible College) and the remaining nine women had no formal post secondary studies or qualifications.

Table 5: Education

| Degree or higher | Diploma | Certificate | Business/ Bible study | No formal quals |
|------------------|---------|-------------|-----------------------|-----------------|
| 4 | 3 | 2 | 2 | 9 |

Medical intervention

Diagnosis of breast cancer

The period prior to diagnosis when women have detected a possible problem can be a very difficult time. One woman interviewed in particular, was highly suspicious that there was something wrong, but felt unable to disclose her concern to anyone for some months.

'I used to go into the bathroom, look in the mirror, and then I used to step back and think, oh no, you know, it's just a trick of the light because of the position of it, and think, you know, there's nothing really there. But I did not decide to mention anything to the doctor just in case there probably was something there,...I probably wasn't ready to acknowledge that there could be... I still kept looking in the mirror every now and then, my husband didn't know, nobody else knew, it was only me...'

The actual diagnosis of breast cancer varied for women. For ten women screening diagnostic tests detected an abnormality requiring further investigation. Five women had an abnormality detected during a routine BreastScreen visit, with another five women undergoing screening mammography and ultrasounds for varying reasons, including the existence of a family history of breast cancer or a previous experience of cancer.

The other ten women found lumps or abnormal breast tissue which resulted in them seeking medical attention. Two women reported a delay of many months between detecting a lump and visiting their GP. One of these women had discovered a lump while she was pregnant and delayed seeking medical attention until some months after the baby was born. She commented that 'my primary thought at the time was for my unborn baby. If there was something wrong, I didn't want anything intervening. I wanted to have her or him and then I would deal with whatever after.' Another woman diagnosed while breastfeeding initially detected an abnormality but suspected it was related to lactation. She commented that 'I think that the worst part of my cancer diagnosis was actually having to give up feeding.'

Two women reported on receiving very efficient diagnostic services with their mammogram and ultrasound followed immediately by a biopsy (within an hour or so). However others reported a much more extended process, and some experienced delays of up to ten days for pathology results.

Most women were told about their breast cancer in a face-to-face situation. Two women received their diagnosis via telephone, one because she had a close working relationship with the surgeon, and the other as she was in a bushfire situation and unable to travel for a medical appointment.

Women described their feelings of shock and absolute disbelief at the time of diagnosis. They talked about feeling 'stunned' and 'numb', wondering why this could be happening to them and describe this early period (the first week) as a 'turbulent time.'

'My head was spinning by that time. I was.....in shock.'

'You're in a daze, you just think – this is not happening to me. It can't be happening to me. Yes, of course it's happening to me.'

The majority of women reported receiving good explanations of their condition and many were offered choices in terms of treatment options. However a number of women were concerned about the advice they were given. For example, one woman recalled being told by her oncologist 'You've got the worst possible cancer anyone can get. You've got two months to live.'

This was in 2001, and although the woman has advanced breast cancer, she is still alive and active today.

Some women were offered a choice between a lumpectomy and a mastectomy. Following much deliberation, one woman decided on a mastectomy but was discouraged by her specialist who advised 'Women are very vain, and if you're going to have to look into the mirror every day of your life and see that something's gone that didn't have to...'

Treatment type

The women interviewed reported undergoing a range of treatment types in a variety of locations, including within the Hume region, Albury and Melbourne.

Tables 6 and 7 list the treatment types and locations, and further detail is available in Appendix 3.

Table 6: Treatments received by women

| | |
|-----------------------|----|
| Lumpectomy * | 13 |
| Mastectomy * | 10 |
| Breast Reconstruction | 2 |
| Chemotherapy | 14 |
| Radiotherapy | 11 |
| Oophorectomy | 2 |
| Hormone Treatment | 11 |
| Herceptin | 2 |

* Two women had a lumpectomy followed by a mastectomy, and one woman had a mastectomy due to a previous cancer.

Table 7: Location of treatment

| Treatment | Hume | Albury | Melbourne |
|-----------------------|------|--------|-----------|
| Mastectomy | 6 | 2 | 2 |
| Lumpectomy | 7 | 4 | 2 |
| Breast Reconstruction | - | - | 2 |
| Chemotherapy | 9 | 3 | 2 |
| Radiotherapy | 8 | - | 3 |

Of the two women who had breast reconstructions, one was immediate and one was at a later date. Both of these operations were performed in Melbourne. Two women, one of whom had a family history of breast cancer, also chose to have the non-affected breast removed (prophylactic mastectomy).

Side effects

Women experienced a range of side effects at each phase of the cancer treatments. Different side effects occurred while women were undergoing various procedures and treatments and afterwards. Some were temporary and some are now a permanent affliction for the women affected.

Temporary side effects included pain and physical discomfort, particularly immediately following surgery, and nausea and vomiting, especially during chemotherapy treatment. Although anti-nausea medication alleviated symptoms, they were not completely prevented.

'Two days after the surgery....I just felt like there was a big watermelon stuffed under my arm, and it was just so uncomfortable.'

'The exercise with the arm was something I'd never realised could hurt so much.'

'I used to be very, very sick. I would vomit and vomit and diarrhea and not eat and it was terrible.'

Hair loss was experienced by most women who underwent chemotherapy and was accepted as inevitable. The impact of losing hair affected women in very different ways. Some women felt that it was the hardest thing to have to deal with in terms of side effects, whilst others happily wore hats, scarves or wigs and reported that it didn't bother them too much. Women generally found it difficult to endure the process of 'big clumps of hair coming out' and found relief by hastening the process by shaving or cutting their hair. One woman suggested that it was 'better to lose my hair than to lose my life'.

Mouth ulcers seemed to follow chemotherapy treatments for some women, and the ulcers sometimes extended to the throat. In some cases relief was found by salt water washes and mouth washes. One woman described how, during her final chemotherapy session, she was advised that sucking on ice blocks during the administration of the chemotherapy might help to prevent the subsequent development of mouth ulcers. She did, in fact, find this to be the case but was disappointed that she had needlessly suffered many months of ulcers before finally receiving this useful piece of advice.

'I have a top plate and I couldn't use it because my mouth was so sore.'

Longer term and permanent side effects included limited mobility - which affected the ability to perform even routine household tasks - and lymphoedema.

'I found there were complications with hanging out washing. I couldn't move my arm as high as the line. Stretching for things.....I couldn't.'

'It was hard to cut vegetables and things.'

'I didn't realize that it meant that this arm's not going to be able to do anything for some time.'

Lymphoedema is the accumulation of lymphatic fluid in the tissues causing swelling. Women are at increased risk of developing lymphoedema following the removal of their lymph nodes – a procedure routinely performed to check if cancer cells have begun to spread from the breast. The women interviewed were not always given appropriate information about lymphoedema or its treatment.

'I've had lymphoedema in this arm since the first op. Now nothing was ever done about it.'

'I didn't get much information.....the arm used to wake me up at night, I'd just about be in tears it was so sore.'

Other longer term side effects included depression, fatigue and memory dysfunction. Women described themselves as falling into depression because of the strain of living with breast cancer and its treatments and implications. One captured her own experience in the phrase, 'an emotional roller-coaster'. Fatigue varied between overwhelming tiredness to feeling lethargic. Women often suffered interrupted sleep patterns and decreased energy levels resulting in reduced strength and stamina. They observed increased forgetfulness and problems concentrating and some consider these memory problems as long term and ongoing.

'I had a shocking time coming to grips with the fact that I was depressed, and I had a counsellor.'

'Shocking tiredness like you wouldn't believe.'

'I used to be as sharp as a tack and I remembered everything but that's no longer the case.'

Weight gain has been associated with drugs prescribed during chemotherapy and hormonal therapy and was a concern to women.

'Huge weight gain. Yes, I've put on two stone since I've been on the tablets.'

'In the first three months I put on a lot of weight, but I only found out this time that one of the anti-nausea drugs has got steroid in it, and I blame that. I begged this time not to have it, but X still insisted that he wanted to use it. So I went along with it.'

Chemically induced menopause is associated with chemotherapy treatment and can pose particular problems for women who have not yet had children. Although none of the women interviewed shared this concern, many were faced with debilitating symptoms such as depression and hot flushes which disrupted both day activities and sleep at night.

'You just get so hot and then you're cold...and it's at night.'

'The hot flushes were shocking and the night sweats were incredible.'

A number of women developed unexpected, serious complications as a result of treatment including a golden staph infection; a broken Hickman's line with a piece lodging in a heart valve; haemorrhaging; and an allergic reaction to morphine. As a result of these complications, women required longer hospital stays or re-hospitalisation for periods of time.

One woman recalled her 'case of major panic' when emergency surgery was required to stop bleeding.

'As they were wheeling me up to the theatre someone said, "Oh we didn't get her to sign anything. Quick, shake her awake and get her to sign this." And I'm going "Oh, I can't see what I'm doing." "That's alright" she said "just draw a cross."

Health system and financial issues

Twelve women interviewed had private health cover, and eleven of these women chose to use their private cover for some aspect of their treatment.

A number of women who were treated privately believed they could access services more promptly and in a more convenient location appropriate to their needs. They sometimes compared the facilities available at public versus private institutions.

'I think being a private patient....it does really make a difference. I know the chemotherapy [in this public hospital] seats somewhere from ten to thirty people and I'd hate to be a number.'

However, although women treated in the private system were generally very satisfied with the treatment they received, a number of women commented on having marked difficulty accessing services post discharge from a private hospital. The services which were only available if they paid for them (which would have been free when discharged from a public hospital) or for which they were simply not eligible, included:

- ∇ home help and meals on wheels
- ∇ post acute nursing care
- ∇ counselling
- ∇ breast prostheses

This added to their financial burden, and women made the point that having private health insurance does not necessarily mean there are no financial concerns.

'So that was the thing I found going through the private system, different to the public, that I was not eligible for home help despite having a six-month old baby and two other children, young children, unless you paid for it.'

'And because you're in a health fund doesn't mean to say you're made of money.'

A seventy year old woman living alone and on a pension commented:

'Because I came from a private hospital I could not get a breast prosthesis. I had to pay for it at two hundred dollars, which I'd have got free if I had come from a public hospital. And I also had a problem ... in getting help from the shire.'

There is a significant financial burden that comes along with the diagnosis and subsequent treatment of breast cancer. Women have no choice but to cope with this as yet another stressor. Treatment is lengthy and intensive, sometimes only accessible after travelling long distances, and is invasive as most women are unable to continue their lives as before. Taking time off work meant loss of income for many women – especially after any leave entitlements were exhausted. When women relied on their partner to assist with care, there was a loss of dual income.

'And at a time when your mind is just boggled with other things, and you think – even though you've got sick leave or an income – you just think well where's the money going to come from? You know you've got to have this treatment, it's all going to cost money, and that's a real concern.'

'My husband had taken time off work, I wasn't working...[and] one of the nurses said, 'You can pay for it. Would that be a problem?'. ... And I kind of just had to sit there and look at her and think, 'Well what do you think?'

Several of the women interviewed had lobbied for the inclusion of Herceptin onto the Pharmaceutical Benefits Scheme (PBS), and while this was refused three times, a special listing by the Minister for Health now sees this drug available to eligible patients under a scheme similar to PBS. The cost of chemotherapy treatments for breast cancer ranges from a nominal charge for those drugs listed on the PBS, to thousands of dollars per dose for those not covered under a pharmaceutical scheme or private health insurance.

Women often had to find funds to pay for prostheses and lymphoedema garments. Different women might be eligible for different forms of financial support, depending on where they live, where they have their surgery and whether they have private health insurance. A first prosthesis rebate is provided by the public hospitals after surgery, but in the private system, only some health funds cover them under their extras benefits.

The scale of treatment required for breast cancer highlighted for some women the inadequacy of the Medicare system. The 'gap' between the scheduled fee and what is actually charged rapidly accumulates with the sheer number of health professionals involved in a woman's treatment. The safety net was of little assistance for (at least) one woman who had an emergency bleed in hospital. She later received accounts from each of the doctors attending her and was told this was 'because it was not booked'. (The safety net applies only to non-inpatient services.)

While women with private health insurance faced all of these costs, additional costs for them included local government services such as home help and meals on wheels. These services are free to public patients under post-acute care, but women discharged from private hospitals are required to arrange and pay for such services.

For women living in Hume region who do not live in the town where their treatment is offered – and this is the great majority – travel is required. Some travel reimbursement is available where more than 100 kilometres one way must be travelled. (See also, *The Impact of Rurality* section.) While financial concerns included the cost of travel, other concerns were limited ability to access alternative therapies due to cost; and difficulty accessing superannuation.

'How to get your superannuation, because they won't give it to you unless you're dead and that was one thing I was really cross about... I wanted it now. No-one else was going to spend my superannuation....and no-one talks to you about stuff like that.'

Even accessing information regarding financial assistance was challenging. One woman reported that it wasn't until she started 'fossicking around in the cupboard' that she finally became aware that some support was available via the Cancer Council.

Women's perceptions of their experience of health services

Many women interviewed felt that it had been important for them to actively participate in decisions regarding their health at the time of diagnosis and throughout subsequent treatment. Women had to be assertive in advocating for their right to state their opinion and preference to clinicians and to have treatment that they chose based on comprehensive information.

Women commented on the need to ask questions, research topics and actively seek additional information. Some women found themselves in the position of needing to argue strongly and convincingly for a particular course of action such as a prophylactic mastectomy or a mastectomy (versus lumpectomy). All women who had been assertive firmly believed that this approach had been critical to their ongoing welfare.

'So you just don't do what they want you to do. You've got to get them to work. I saw mum walked all over, and she thought the doctors were Gods, and they're not. This is my body, this is my life, and this is how I want to live, and they have to work around me as a person. ...Being assertive is doing what's right for yourself, because you know your body better than anyone else.....They were calling me Dr X because I knew what was best for me.'

'I had to go looking. I had to search it out. If I didn't search it out, it wasn't going to be provided for me.'

Women commonly read books, researched on the internet, used personal and professional networks and phoned the Cancer Council in order to equip them with information they required.

One woman even advocated for women's rights at a political level. She wrote letters to both state and federal politicians regarding the unavailability of a particular drug through the PBS.

Women's perceptions regarding the manner in which they were treated were mixed. All 20 women were satisfied with some aspect of their care and five of these were happy with every aspect of their care. Six women highly praised some aspects of their care, including specialists and support personnel.

'The health system has just been fabulous.'

'It (chemotherapy) was a lot of fun. And so instead of dreading going in there, you felt like you were going home to a family. So it was just wonderful.'

'I couldn't speak more highly of the treatment I received at [my hospital] and the staff was excellent.'

'We could ring (our GP) if we needed to, anytime of day or night. Yes, he was wonderful.'

Ten women were dissatisfied with some aspects of their care and three women were highly critical of many aspects of their care. Eight women expressed dissatisfaction with the physical environments where treatment was given, for example chemotherapy.

'I think I spent twelve hours on the trolley shaking in Emergency before they could find a bed for me.'

'The area in the hospital here is very small. It is absolutely ridiculous, because the kitchen trolley has to give way to the nurses' trolleynow you can imagine when after you've had two and a half hours of intravenous and you have to go to the loo, by the time you stand up and have your little trolley following you, and you're trying to get all the other trolleys out of the way....and the door ...it's like lead....'

Six women expressed dissatisfaction with the disrespectful attitude of staff involved in their care and four women felt a lack of trust in the competence of particular professionals.

'...I think basically the staff definitely need a course in PR skills. I have an issue with their attitude.'

'My only complaint is about (one surgeon) treating me like a dumb female.'

'I believe the bedside manner of doctors needs to change for women because when I had my first operation, the amount of specialists that came and viewed my body....I felt like a lamb that was laid out to the slaughter.'

'I was so concerned about their attitude that I was paranoid about getting the wrong treatment because they were so quick and fast, and in and out and in and out that I actually made my daughters read exactly what was on the bags.'

Three switched from a male to a female doctor following their diagnosis of breast cancer, and two of these did this so they could be treated by a female. One woman felt particularly uncomfortable being treated by a male assistant whilst undergoing radiation treatment.

Communication with health professionals

Timely information is critical to women with breast cancer. Women are coping with physical and emotional assaults on their being and struggle with confusion and fear of the unknown. Effective communication with health professionals and easy access to information are essential.

There were mixed responses from the women about their experience of communication with professionals and access to information.

Some women experienced great difficulty and reported that their views were dismissed and procedures were not adequately explained. They faced what they believed to be unprofessional behaviour and arrogant attitudes from the health professionals whose role it was to support and treat them.

'He more or less treated me like a bit of a dill, a bit of a dope.'

'I had no communication from the day I started chemo....from the day after my first chemo until I left. Nothing. Absolutely nothing.'

'I would have felt more comfortable with a better degree of communication....you really had to prise the information out of this particular doctor.'

'They (medical professionals) don't seem....they don't tell you enough. And then on the other side of the coin they don't listen either. Yes, I think they could improve a lot in those areas.'

Other women were very satisfied with the communication between themselves and professionals, and felt great confidence in their specialist treatment. Some specialists made themselves accessible at all times and this was very much appreciated by women.

'I have the utmost confidence in both my surgeon and my oncologist.'

'And I rang him on the Sunday at home, actually. He gave me his mobile number which was nice.'

Most women who were provided with written material were very appreciative of this information, although two women declared a preference for receiving a minimal amount of information indicating that they were somewhat frightened to know about the details and mortality statistics.

'(The surgeon) was terrific. Very thorough. Drew little diagrams and answered lots of questions and gave me books to read.'

'He was very good....explained what the process was, and where I would go and he wrote it all down for me because he said, "I know you won't remember all this when you're at home.'

'Swags of books and...perhaps I want to bury my head in the sand, I don't know, but I just found them a little bit scary and depressing. Yes, I'd just rather let it happen. Yes, I mean there's a certain amount you have to know of course, but I didn't want to know too much of the nitty gritty.'

Communication between disciplines was also regarded with mixed views. Some women found this to be satisfactory whilst others reported 'enormous problems with communication between medical oncologists, surgeons and other staff'. Some stated they received quite conflicting information from various clinicians.

Difficulty accessing a second opinion

Three of the twenty women interviewed reported having to be quite demanding and assertive in order to obtain a second opinion. With a diagnosis of breast cancer, it would appear reasonable to seek information from a practitioner who specialises in breast cancer. Such practitioners are usually Melbourne based. The alternative was to accept the opinion of local practitioners who deal with all forms of cancer. These three women who sought a second opinion faced resistance and an unsupportive attitude for this course of action by their medical practitioner. There seems to be an attitude amongst medical practitioners that rural people need to support the clinicians who practice in rural areas – even if they are not offering the same level of expertise as breast cancer specialists.

'He got quite narky about that when I said I wanted a second opinion.'

'I realised that he dealt with all forms of cancer radiation, not just specializing in breast cancer. And that did concern me....'

'And they rang and they were really quite nasty when they found out I was having [radiation]) in Melbourne....I felt like an outcast because you don't need that. You don't need that.'

Breast care nurses

Women appreciated the service they received from BCNs in the region. This varied from practical advice, written information, advocacy, and taking the time to talk about their concerns and questions through to emotional support. The timing this service was offered ranged from the point of diagnosis until after the treatment phase, and included other family members as appropriate.

'I was to go to the hospital to book in for my surgery and she (BCN) met us there. She'd obviously got a call and met us at the hospital and spoke to both (husband) and I at length about the procedure, and their role, and so on and so forth. So she was part of...part of our journey, I suppose, from the start.'

The specialist knowledge and skills of some of the BCNs was highly valued, and the emotional and psychosocial support from the BCN was a key benefit for women.

'... her knowledge and experience and help was just unbelievable. And I dealt with her because she had hands on knowledge.'

'...she had more input before the mastectomy. She was fantastic with that. I think I grilled her on the phone for about half-an-hour... She called in to see me after the mastectomy in hospital, which is good.'

'I think that's what we should have for a breast cancer nurse. Someone who's either had experience in it – not necessarily nursing experience – but people's welfare experience.'

'But with them (BCNs), I felt as though I could say "I feel rotten", and "I'm miserable", and things like that. ... Instead of having to sort of shoulder it all and not give it out, when they were there I could.'

'... the breast nurse came past and she said "Are you alright?" and I said "No, I'm not" and I just burst out howling, and she just cuddled me and I was alright.'

BCNs advocated on behalf of women's specific issues in helping women to access more timely treatment and more appropriate services such as counselling.

'... she actually went and advocated for me to get in sooner because I was really sitting...I felt like I was sitting on hot coals, that I was a time bomb.'

'...one of the breast care nurses had come around. She knew that I was having the procedure done so she came around just to make sure that I was okay, and found me in this dribbling mess. I was in tears, and she just said, 'No, this is enough, she's not having anything else done.'

Women who utilised the services of a BCN appreciated this at various stages of their journey, and some wished they had used the service more often. They also valued that they had received referrals to the BCN from other health care professionals. Care from the BCN post treatment was sometimes missing for women. The months following treatment, when they are no longer in constant contact with health professionals, can be a time when women experience a feeling of emptiness and depression. The BCN can help fill this void.

'...the day I actually found out that the diagnosis was positive from the surgeon...the breast care nurse met my husband and I that day and that was...very, very helpful. ...everything was just so confusing and it was just good to talk...Yes, and good to talk to someone else...just someone with a bit more time.'

'I think when you're in the acute phase you just need that service. And post the acute phase, too, because you always have a question or a problem that you're not sure of and she's always just a phone call away, so I think that's been invaluable.'

'...she used to ring about once every three months. Well more regularly than that to start with, probably once every two months, and she persisted with that until the end of last year. I found that useful, too. Just someone that knows what it's all about, and caring for you, taking interest.'

There was some confusion about the role of the BCN, and a difference in perception of the skills and abilities of some BCNs. Some women found other health care professionals, such as oncology nurses, helped fulfil their needs.

'I still, to this day, after 12 months, don't know what the role of a breast cancer nurse is. I don't know what that role is. I haven't seen much of her, and it's never been discussed what the issue is.'

'I can't even explain how good the BCN has been. And the oncology nurses. They were more than just oncology nurses, they became my friends and helped me...'

Others did not use the BCN services, for various reasons, such as utilising other services or not wanting to know too much information.

'The breast care sister did ring a couple of times and said she could come over but I just really felt that I didn't need her. And she was a lovely little girl...but they put the fear up me because they told me so much that could happen that they frightened me.'

'...I haven't had much contact from the breast care nurse..., but I haven't missed it because I tend to ring the Cancer Council...'

The part-time nature of the BCN employment was an issue and it was felt that women needed greater access. The capacity of nurses to offer breast care ranges from them undertaking this work as a small part of their other nursing roles, through to dedicated BCN hours in larger regional centres. However, no full-time breast care nurse positions exist in Hume region.

'I think the only other thing is the hours of the breast care nurse. That maybe that needs to be either a full-time position or someone that's on call or something like that.... I just think that it's a really good service and needs to be expanded.'

Effects and issues of breast cancer

The diagnosis of breast cancer brought with it great challenges for each woman. The women spoke about fear and grief, and loss of friends who did not know how to offer support and so, withdrew. Most poignant was the effect on family. Yet, along with all of this, came a greater appreciation of life and a new way of experiencing each day.

New perspectives on life

For many women, especially younger women, breast cancer had a huge impact upon their lives. They described taking on a changed perspective with a greater appreciation of life itself. They stopped worrying about insignificant matters.

'I just don't let anything worry me.... Before.... I would lay all night worrying about things that I could not change. And now I just say to myself, 'I can't change this. It's not my problem'....In a way it's better, it's had a big effect. It's taught me to appreciate life, really.'

'I don't feel I'm as serious as I was. I feel we're very lucky people. We're given the chance to get our lives in order, and we appreciate so much.'

'It's changed my whole life, really. It changes what's important to you, outwardly and inwardly...oh, you just think what's more important in life. You value your friends more and your family.'

Family and friends

Women described concern for their children as one of the most poignant aspects of their breast cancer diagnosis. They attempted to protect their children and grandchildren by shielding them from their true feelings both emotionally and physically. They gave the appearance of coping with the cancer for the benefit of the family.

'I try not to let them worry about me. I try to be very blasé about everything that's being done, and yes I'll be fine, because I don't want them worrying about me.'

'This friend of mine [asked how my husband was going], and I said, 'He's okay as long as I'm okay,' and she said, 'How are the kids coping?' 'They're okay as long as I'm okay,' and she said, 'Gee, that puts a big responsibility on your shoulders.'

Two younger women interviewed were diagnosed whilst breastfeeding. For both, their primary concern was for their babies, and recalling this aspect of their breast cancer was a very emotional experience.

'And I think that was the worst part of my cancer diagnosis, actually having to give up feeding because I'd fed my other girls and I was such a pro-breast feeder, like I've always had great beliefs in breast feeding.'

Caring for their babies and toddlers was clearly a major issue for young women. Grandparents and the extended family were often actively involved in caring for children and it was noted that although support in the form of childcare could be made available, in-home support was not an option.

'...the issue with my children was the biggest thing for me because all my friends wanted to take my kids and look after them and everything, but they would come back and they weren't my kids. Like, they were killed with kindness, they were given everything they wanted, and ... after a week I had lost that control a bit, and I didn't want that. I wanted them with me. I wanted to keep my influence over them.'

Young children and adolescent family members often felt traumatized by the change to their family life and the risk to their mother and their family's future. There is a clear need for emotional support for them, and, at the same time, a lack of accessible counselling options.

'They're going through hell because they don't know whether you're going to live or die.'

'Teenage girls find the whole breast cancer thing extremely traumatic, and they're a bit forgotten in this. I remember people would say to my 16-year-old who was at home, 'I hope you're looking after Mum. I hope you're helping Mum.' You know, as if she wasn't already loaded up with grief and worry and 'What can I do?' and 'What's going to happen?' You know? And she needed... they need to talk, too. They need support.'

'I really think there needs to be something done for the children of people that suffer cancer, because there's this huge hole, and a lot of the young mothers that have breast cancer say there's this huge hole. Their kids do suffer the same symptoms as mine. They're angry, they're aggressive, their mood changes, they get upset, they think you're going to die.'

Women with partners were very concerned about the effect of a breast cancer diagnosis on their partner. Men were frequently described as not coping well and finding it very difficult to express their feelings. They would assist with the practical tasks such as cooking and gardening, however, women found their partners' difficulty communicating about the breast cancer to be quite distressing.

'He didn't cope at all.'

'... he gets very cross about the whole deal. Like me, I accept yes, this is my lot in life. But he just thinks it's so unfair, and 'Why is it happening to you?' ...I think it probably affected him in some ways a lot more than it affected me.'

'[A friend] couldn't really get him to talk in-depth about it, and all he would say to me is, 'You'll still be here when I'm dead and gone'. And it was like he was in denial of the situation.'

For women without partners and living alone, there was the additional practical layer of concern. Treatment options were considered with this in mind, and for one woman, it determined the kind of treatment she took up - she decided against chemotherapy because she was living alone.

'I'd have been living on my own if I had [chemo], and I didn't think six months of that, for that small percentage, was good enough.'

There were times, too, when support from family was not forthcoming, and it was hurtful and disappointing to the women when those they thought they could count on were not there for them. Children were often too wrapped up in their own lives to give the attention and support their mothers wanted.

'I didn't want people here waiting on me hand and foot, but I would have liked a phone call...'

'Probably just to have a phone call from my children a little more often just to say, 'Hi Mum, how're you doing? I'm thinking about you. I love you Mum.' And I missed it... And I thought, 'Hey, how come my friends can remember that I'm having chemo and ring me up, and my own children can't?' It was so disappointing.'

'But not once has she come in to see me or driven me to Wodonga in those three years. And I've said to her a couple of times, 'Why don't you come and have a cup of coffee?' She said, 'Oh, I don't like hospitals, Mum.' And I said, 'No, (daughter), neither do I.'

Other times support was offered with the best of intentions, but women mentioned not being well enough to cope with the company or activities, or wishing there could be more honesty in the communication.

'[My husband] organised a holiday, too. That was half-way through chemo. I remember vomiting all the way...'

'And then my sister would come and take me. She took me (away) one weekend,...but sometimes you're so tired you don't want to be dragged around.'

Friends were crucial to the women's sense of being cared for. A number of women described being devastated by the loss of friends they previously had. They felt let down by the lack of support offered to them in their time of need and by their friends' avoidance of them. This happened too, for women who had a community focus.

'And the whole deal certainly sorted out your friends. People that I thought would stick by me let me down. Badly.'

'[A friend now] avoids me like the plague. Can't cope. Cannot cope. Isn't it sad? You know, when people do that. Oh, I haven't got leprosy.'

'They're still my friends but I have a totally different outlook on them as being really close friends because they let me down when I needed them most.'

'But also, something I found very disappointing, is people dodge you... Absolutely distressing. I mean people think you're dead already...They didn't phone. They just avoided me like the plague'

'I was very disappointed by the church because ... the people didn't come near me – because I know them all. I mean they'd go and visit a stranger but they wouldn't come and visit me. Because they thought this poor little old lady up the hill was invincible, never going to die. You know she laughs, she jokes. Fancy her being sick. Fancy cancer hitting her.'

Women with cancer themselves also have to face the loss of friends to cancer. One woman, with advanced breast cancer, described her loneliness following the death of a soul mate due to cancer.

'She was very up-front about the fact that she was going to die, and we used to have daily contact... and that was good... You had someone on the road with you. But since she's gone, there isn't anyone on the road.'

During and after treatment, women are often advised by friends and family to be positive. Women found this advice quite grating. This was particularly so for one woman who felt that she had remained strong with a positive attitude, and yet her breast cancer had recurred.

'...people just keep telling you to be positive and I said, 'I was positive for six years and it didn't stop it coming back.' I said, 'I'm as positive as you can get. But I also deal in realities. I'm fully aware of what can happen.'

'And as I say, these very, very good friends of ours, and she's a positive woman...but she positive-ed me out at times, I felt guilty if I wanted to cry...'

'... while I was having treatment and that, I hated the word positive. Because everybody used to say to you, 'Be positive. Be positive.' And I just absolutely detested it. I used to tell people – not to their faces but to other people – and I'd say, 'Look I hate it – I can't stand it.' I mean, what does 'positive' – what does it mean? Being positive? And nobody could answer me. And I said, 'Well I prefer the word be 'realistic'. And I said because what's going to happen...like I said 'I know the cancer can come back.'

A further annoyance to women was the apparent difficulty others can have in terms of dealing with the truth. People will often ask after a woman's welfare but before being able to respond, a woman is told that she looks well and wonderful. Women, who are feeling quite unwell at the time, find these superficial comments quite disappointing.

'But people actually don't want to hear that you're sick, they want to hear that you're getting better. So people will enquire and ring and speak to you, and 'How are you? Oh, you're looking well,' and it really isn't appropriate to kind of tell them, 'Well, I'm not actually.'

'And everyone...says, 'You look so wonderfully well. You look healthy,' you know, 'You're so young.' And you know, they say all these wonderful things but within you you're saying, 'You haven't got an idea of what the hell's going on in here...'

'But now the questions...you don't get asked normal questions. You get asked questions about how you're feeling, and 'Oh, you look great,' and all that sort of superficial stuff, and you just wish you could fit back into the little hole that...'

One woman who stated 'my family finds it hard to accept me as a sick person' went on to describe how her family had organised two wedding anniversary parties during the middle of her chemotherapy treatment. She found it very difficult to meet the expectations of her family. Although feeling most unwell, she was expected to get dressed and go to the parties.

Emotions

Some women remembered being overwhelmed with grief at various stages of their breast cancer journey.

'I just thought I had breast cancer and I was going to die..... I wasn't prepared to do anything at home, I didn't want to plant trees, I didn't want to do anything because I thought...'

'I remember walking out of the oncologist's and sitting in my car and just absolutely howling my eyes out.'

One woman diagnosed with advanced breast cancer described having to face up to her own grief and feelings of anger at the situation and the loss of future.

'I didn't realise until I faced up the fact that I didn't have a future, how that then removes you very much from people who are all the time talking about things that they're doing in the future.'

'And certainly when you're signing yourself up for palliative care, that's a big trauma. That's a real...oh...very, very, difficult thing.'

Women's bodies had let them down and this made some feel very angry. There was specific anger with the quality of treatment that they had received, and with particular members of

their treatment teams; there was one woman's anger about the impact of breast cancer on her baby; and a more nebulous anger about the loss of control over the future.

'... they stuck me in A & E and left me there. I didn't see anybody. I was just so annoyed. They were so busy.'

'I thought, 'Right about this time I'd like to get my hands on (specialist's) neck and choke him.'

'I was pretty angry about [(having to give up breast feeding)... I was so anti giving a little baby that age formula, and so that was pretty hard.'

'I actually faced up to my own anger and grief at the situation, and the loss of future.'

Fear was clearly an emotion experienced by women at various points throughout their breast cancer journey. There is the initial shock of a breast cancer diagnosis and fear of imminent death. There is fear for the health of their daughters. There is fear of recurrence. Women live with this ongoing fear of recurrence, which 'rises and falls with different intensities' and is heightened in the lead up to medical checkups and associated diagnostic tests.

'And heaven forbid that [my daughters] ever get it, but the chances of them getting it are very high these days.'

'Well I've got to put this doubt aside and just get on with living. It doesn't take much, it could be some aches and pains or just... feeling a bit below par and you think, you know, there's something developing here that insidious, that I'm not going to know about until it flares up in some sort of major way. So you live with that little shadow and I guess I just had to accept that that shadow's there.'

'Because there's so many around me with it, and so many that I know and you hear that they've got it back and that the prognosis isn't very good, and that sort of thing, and I mean you do get that little touch of fear every now and then.'

'I think it hangs over me like a black cloud all the time but I try not to dwell on it. But yes, it does affect you and it affects your kids and your husband, your...everything. Yes, it certainly does affect your life.'

'I was very depressed. And I thought, oh, it's only building up... to that appointment with the oncologist [when] you think, 'Oh, God, is it going to be yes or no.' And that's a bad thing. That week leading up is a real bad thing. Yes, ... I was very distressed.'

Women spoke about feeling guilty in a range of circumstances. One woman stated she felt guilty about wasting a clinician's time with various tests and had even cancelled appointments because of feeling like this.

'I felt, you know, that all of this hoo-ha and there's nothing wrong. I was upset...I was upset about it, I suppose, but I felt as though I was wasting people's time.... and I cancelled the appointment because I felt like a fraud.'

Older women sometimes felt guilty when exposed to younger women with breast cancer. They felt that it was more difficult for these women especially where they had younger children.

'They upset me because at least I've had another 25 years of my life ... And it's their children that...they'll learn to cope, I suppose. You've got to.'

Surprisingly, women said they felt guilty for being alive whilst others around them were dying of the disease. These guilt feelings were more pronounced when coming into contact with the loved ones of the deceased women.

'I felt guilty being alive and his wife gone. And yet if you'd seen our cancers, they were exactly the same. If you'd seen her... It is the most.....nerve-wracking...I can't put that one into words. Well this poor thing had exactly the same treatment. Six months of chemo, five weeks of radiation. Exactly the same as me. Same stage. She dies, I'm still alive. It's unbelievable.'

Self image and loss of confidence

It is not surprising that the absence of hair (albeit temporary) and a breast or breasts would have an impact on women's self image. Some women confessed to feeling very self conscious about their appearance despite being aided by wigs, breast prostheses and reconstructive surgery. Their own body image can constantly pervade their thinking – especially when they look in the mirror, take a shower, put clothes on, or are intimate with a partner.

'You'd look at it and think, 'Oh, that's disgusting,' when you'd look in the mirror. Your body image wasn't good and you'd look at yourself...you didn't feel well within yourself.'

'...and I've got to face the issue of telling that person (possible new partner) I don't have breasts... And there's that image that's portrayed in society, you know. Body image is important... I don't think women talk about it but we think about it nearly every day. It's there when you have a shower or you stand before the mirror, or you don't stand before the mirror...you know?''

Some women experienced a loss of confidence and associated feelings of fragility and insecurity as a result of their breast cancer. Careless or intentional remarks by others can be unusually hurtful when women are already feeling uncertain.

'...you go there trying to be brave and someone can tip you up real easy.'

'There's still that insecurity, I suppose. I'm not as strong as I come through. People don't realise, they think because I've got a strength...'

'You lose your confidence for travel and being away from your chemo. You just lose your confidence.'

'[When] I didn't have any hair, some of the cruel remarks were unbelievable. Well, one was my sister-in-law ... it was summer and I was in my own house and I didn't have my hat on and she just walks in and says, 'Oh for God's sake get your hat back on, will you,' - that type of thing. Well it hurt...hurt like you wouldn't believe.'

'I was introduced to someone who was quite a nice person and I thought, 'Oh, this could have possibilities.' And anyway just in casual conversation it was mentioned that I'd had treatment etc, and he just spun around and said, 'Thanks, but no thanks. I've already buried one wife with breast cancer,' and that was the last I heard of it.'

Whilst undergoing treatment, women commonly felt extremely unwell. They needed help with household duties, gardening, driving etc and frequently had to ask for assistance and consequently felt that they were a burden on others. Whilst women really appreciated the help with which they were provided, they nevertheless, resented their lack of independence and reliance on others. Some women spoke of craving the security of their own mother to comfort them.

'Well this is one thing that really hit me once I'd had the treatment was I had to ask people for help, and that sort of...I was very overcome with feelings of 'I'm a burden to people,' and that really worried me..'

Work issues

The need to take time off work throughout treatment for breast cancer was something women dealt with differently. Some women discontinued work for extended periods, taking up to seven months off before returning to work in some capacity. Others felt that they were able to cope with working part time and one woman who did not work during treatment, commented that in retrospect, she wished she had.

'Possibly in retrospect I probably could have done a bit of work while I was having chemotherapy and maybe another time I'd consider that...I hope there isn't another time...but first...you know, first time round you're not sure how it's going to affect you...'

Some women felt that they had returned to work prematurely and found that they did, in fact, require a longer break.

'I went back to work thinking, 'I'm all right.'... I lasted two or three weeks and that was it. Oh, it was tiring. I couldn't teach properly, memory loss was really bad. And when you're teaching you can't afford to do that.'

It was common for women to reduce their workloads to part time on an ongoing basis and a number of women spoke about having completely changed career aspirations post breast cancer. They want to continue working but are searching for something different, less demanding and stressful. These women have worried about the effect that returning to work will have on their health and have opted out but feel unsettled in terms of not yet having found their niche.

'Well it's certainly...it certainly stopped my life in the sense that the goals that I had and what I had envisaged for the future has certainly changed dramatically. With lots of things. Like I had career aspirations of where I wanted to be and those certainly aren't going to happen now, for probably a couple of reasons. The first reason probably being that I don't know whether I can handle that stress, you know, the stress that I was under.'

'I never left my work at work. So I just don't think that that's going to be very good for me at the moment, or maybe ever. So I've sort of been trying to think of something else I can do, but I suppose it's like everything, you've done something for so long you just think it's just the easy way out of it. I'd like to sort of think of something else to do..... I don't want to just do anything. I want to do something that counts but I don't...'

Women had different experiences in terms of supportive work environments. There were those that were very accommodating and others that were problematic. In one instance, a hostile work environment was encountered by one woman who ultimately resorted to union intervention for assistance.

'I went and asked for part-time...the school refused because they didn't have enough teachers, so I kept on going, and then something happened and they pushed me to an extent where I got really angry... I rang up the Union and the lady up there said, 'Look, why are you suffering?... 'We'll deal with it and you can go on point six.'

'I started taking up preaching on Sundays again at that point, so that I was working on the weekend, and I did a few little bits and pieces during the week but I didn't over-extend myself. But I was able to attend meetings and be involved in planning, and a little bit of pastoral visiting, because I was past the toxic phase by then and sort of felt that my immunity could cope.'

'My principal supported me all the way.'

One woman who ultimately resigned rather than return to work, outlined the difficulty she had returning to work and confronting her colleagues.

'...if I could have got to the front of the shop and said, 'Hi... I'm well. I'm cured and I'm doing well,' but everywhere you went in the shop, every staff member, even customers – because I'd been there that long – they'd be asking, 'How are you?' and 'Where are you up to?' and you'd sort of want to hand out a newsletter.... and then some people you're very friendly with...there's more tears, and there's more tears, and they made you cry. So I had trouble confronting going in to the store.'

The impact of rurality on Hume region women with breast cancer

The stereotypes of rural life appear to be true, as women spoke of the calm atmosphere of the country and friendliness and stoicism of country people. They appreciated the greater support from small communities, where people know each other and you're treated as a person and not just a number; where the breast care nurse and the district nurse call in to offer advice and support.

'It doesn't matter whether you live in the city or in the country, breast cancer is breast cancer. But I do think that the calmer atmosphere of back in the country and the more friendly composition of the people does help you more. I always think I was better off in the country.'

'A lot of rural people handle it all by themselves. I think it's something that country people do.'

'People will see you in the street, and they know I'm having treatment, and one of the good things, one of the main supporting things is living in a small town and having most of the town keeping an eye on how you're going.'

'All I can say about this area is that I've had far greater support from the breast cancer nurse, the district nurse and the community health centre here than I ever got in the big world of Melbourne.'

The flipside is that, where everyone knows each other, there is no way to keep things private. As a result, some women felt forced to tell their children and family of their breast cancer before they were ready, and felt branded by their illness.

'Living in a small community..., everybody knows, and it can become a big invasion in your life. Like you go out and you just want to be who you used to be...'

Distance and isolation

All of the women interviewed lived in the Hume region, which meant they lived in one of the four larger provincial towns, or in smaller country towns, in tiny hamlets or on farms in rural and remote areas. Their experience of accessing treatment and support services differed according to their living situation. Those who felt best served were the women living in or close to Albury-Wodonga which has radiation and chemotherapy treatment centres. It is the only centre in Hume region to offer both. Provincial centres such as Wangaratta and Shepparton offer chemotherapy only.

'Here I could stay in my own home and do lots of things that were normal, and just go and do these other things when it was necessary. Wangaratta for chemo, or

Wodonga for radiotherapy, and I was very grateful for that. And also grateful not to have to go to Melbourne.'

However, if women wanted to see clinicians who specialised in breast cancer, they had no choice but to go to Melbourne. Locally available clinicians are *generalist* clinicians.

Women in Shepparton were surprised that a provincial city of its size did not offer radiation treatment.

For most of these Hume region women, treatment for breast cancer involved extensive travel and the occasional need for accommodation. For women living in rural areas some distance from a provincial centre, travel to and from appointments depends on having a car and, perhaps, a friend to drive them, as public transport is either not available or very limited in the times it is offered. Women spoke of having to set aside half a day or a whole day to attend appointments. When the appointments were for radiation, for some women, they were scheduled on each weekday for six weeks.

'Up to Wodonga Monday to Friday, every day. Six weeks. Yes. I woke up early in the morning, mighty early!'

'You have to block the whole day out to do it. It's the travel.'

'To go to see the plastic surgeon was... a huge day. I'm not that good at driving, so I'd get the train and you'd have to leave here at about six or something, and you don't get home until half-past nine or something at night.'

To minimise the effect on her family and save on travel costs, one woman chose to have radiation in Melbourne which meant she stayed at the Peter MacCallum Cancer Treatment Centre for six weeks - without coming home.

The disruption to family and work life, and the additional stresses on a woman already very unwell is evident.

Decisions about travel and accommodation were complicated by uncertainty about the illness itself. Women were often not able to predict how they would feel after the treatment. One found that she could not travel the long distance home after each chemotherapy treatment. This influenced her choice of where to have treatment. Another decided against having chemotherapy at all because of the difficulties it posed in getting there.

'I said, "I'm too far away this time to go home, or go to someone else's house and be sick there. I want to be in hospital". Because [from home] to Melbourne is a pretty long drive. It's a long drive.'

'[Distance to chemo] did come into it because I possibly wouldn't have been able to drive myself under treatment.'

Ultimately, decisions about which health professional, what treatment, and where, were pragmatic for the women interviewed. Practicalities of how to get to appointments seemed the principal deciding factor for most. Many were not confident to drive in the city, and for some rural women (and some partners), this extended to provincial cities like Albury. The thought of having to locate various treatment centres in the city, driving in city traffic, and perhaps, find accommodation was overwhelming for some – especially as they were unsure how sick they would be following treatments. For all of the women interviewed, choice was limited. And it was limited by rurality.

'I wouldn't have gone down on my own on a tram or a train or anything like that, because I...you know...put me in a big city...I would be terrified to be in the likes of Melbourne, but out here in the sticks with a... Well, if I have to face bushfires and whatever... Yes, that is my area. I'm at home in that. But Melbourne freaks me out.'

Costs related to rurality

The financial cost of prolonged treatments was of concern to women. While some were able to access a travel reimbursement fund where the treatment place was more than 100 kilometres from their residence, and assistance with accommodation in some circumstances, there remain significant costs. For many women, this occurs when they are not able to work and often have inadequate sick leave for the intensive and lengthy procedures of breast cancer treatment.

'And at a time when your mind is just boggled with other things, and you think – even though you've got sick leave or an income – you just think well where's the money going to come from? You know you've got to have this treatment, it's all going to cost money, and that's a real concern.'

With the exception of the major centres, most rural areas do not offer heated swimming pools. Several women stated they greatly assist in the healing process and that it is a great disadvantage for women who have great distances to travel to use heated pools.

Access to choice of prostheses was non-existent for one woman. She sensed that she was given a prosthesis because that's what the hospital had rather than because it was what she needed. It was uncomfortable for her and too big. She felt it would be ideal to have a shop within the local hospital with prostheses to allow women the choice.

'If you don't give people choices to go to Melbourne, bring the services to the country. Offer them the same services, the same facilities, so people can stay in their own homes.'

Reconstruction

The ideal for every woman is to have access to services available locally, so that she can stay in her home, close to family and friends. Reconstruction is not available to rural women at the same time as their mastectomy as is the case in the city.

Only two women interviewed, both in their forties, underwent breast reconstruction surgery post mastectomy. It is noteworthy that both women had this surgery in Melbourne as it is not readily available in Hume region. One woman had a mastectomy followed by an immediate reconstruction (during the same operation) in a Melbourne public hospital. The other woman underwent a mastectomy locally and later travelled to Melbourne the following year for her reconstructive surgery which required a number of separate procedures.

Women compared the availability of reconstructive surgery in Melbourne with the lack of options in rural areas. It appears that rural women are rarely given the option of reconstruction at the same time as mastectomy. For these women living rurally, there was generally very little discussion of reconstruction at the time of diagnosis and, in retrospect, this was a concern to them.

'In Melbourne you can have it (reconstruction) at the same time as a mastectomy, but up here you have to wait twelve months.'

'You've got options when you first get diagnosed but just everything happened in such a short period of time that you don't really have time...to consider what might happen down the track. For example...a prosthesis, [or], if you wanted to have a reconstruction.... I think although they were mentioned, they were only briefly mentioned and maybe a little more time needs to be spent in that area. ... it might only take an extra half an hour, but I think that that needs to be discussed with the couple or with the person at the time.'

Support groups

The availability of support groups varies across the region. In many towns, there are no support groups. One woman started a phone support system with the help of a local doctor, and a 'little cup of tea group'. The doctor would advise women with a new diagnosis of this group, and give the contact number to them.

'There was one girl phoned me the other day... she was very upset and I said, 'Look, we won't talk on the phone. Give me five minutes and I'll come up.' She'd just been diagnosed and she's having radiation.'

The women spoke of very limited support or information in smaller country towns in particular. Specific support groups, such as those for women with advanced breast cancer or young women's groups are even rarer. Both kinds of specialised support groups meet in Melbourne, but it is too difficult for rural women to get there.

Courses such as *Living with Cancer* and *Look Good, Feel Good* are also not universally available for women.

'...another thing that might have been hard for people is...Living with Cancer courses. That was a useful thing, run by the local hospital. And that was kind of hard to get to because you're in the country. Because that was down at the hospital, and on a different day to chemo and, you know, quite an effort to get there. But very worth having.'

'I think with we're very disadvantaged. I really do. Support groups, for one.'

Strategies women found valuable

Support from family and friends was often mentioned by the women as a source of great comfort and assistance, and for those who did not receive it as expected, as a source of disappointment. (See also, *Family and Friends* section.) Many cited examples of support that was appreciated, from company during treatment, to rallying around and sharing the journey, as well as family and friends seeking information or providing services. Having someone accompany them to and during treatment was noted as a great support, as were dealing with other practical aspects of their journey.

'I had someone with me every time... I didn't ever go alone...my brain went fairly soggy so I was unable to drive. Yes, so I had support all the way through'

'The bushfires were still raging out of control... and I thought, 'If we get a hot north wind while I'm in hospital, I'm going to come home to nothing.' And I had quite a lot of animals still here, and so basically I had to call on as many friends as I could and evacuate as many animals as I could. My goats went down to a friend's place at Emerald, so they had a beaut holiday. ... I organised for a cousin to come in and just feed what animals were left. And the rest were drafted off into five different places'

'I said to (my grandson), "You know Gran may not have a long time to go now. When my time comes, would you like to be a pall bearer?" and he said, "Nan, I'll carry you on my shoulder on my own." And he was quite serious'

It was important for women to have non-judgemental people to lean on and talk to, to be honest about what they were experiencing and how they were feeling. They wanted to talk about their emotions and fears and the possibility of death. Women identified that their need

for a network was high and, as a coping strategy, sought this out with family and friends. This was particularly true for women without partners.

'...I've got my friends and I talk to them. Not so much now, but I did talk a lot and I felt that they were my emotions that these poor unfortunate friends were coping, and they accepted it'

'...I've had a couple of good friends just come and put their arms around me and they'll cuddle me, you know, and they're my backbone'

' "When my time comes," I said, "I'd like to die at home." And I said, "You people will live on, bugger yous, but I'm not. And I'd like to die with you all round me," and they've all accepted that'

There were any number of other strategies which women indicated had helped them along their journey with breast cancer. They ranged from changes in lifestyle and attitude - the way they viewed life, its trials and tribulations - through to accessing assistance via information sources, counselling, support for themselves and family members, and practical strategies. One strategy was a determination to live life to the fullest.

'I had to change my attitude. I can't do perfect things... So that's how I'm coping. Personally, it's made me think about my life. And I suppose you become very philosophical. I became more calm and look at the problems and...you know, before even a little problem is a big problem...but now even a big problem is a little problem'

'And you do, you learn to appreciate life. And the small things, you know, the small pathetic things that you used to fight about, you look at and you go, "That is not worth it" '

'And I've learned, through having breast cancer and all these obstacles, that you step back and you weigh it up, and what's best for you and what's best for the family rather than who's right and who's wrong'

Women found that helping others seemed to take their minds off their own issues and concerns about breast cancer. This held plenty of rewards for the women who used this as a strategy.

'[The nurse] who was in charge up there, she'd say to me, "What are you doing here?" [I'd say I'd just come to see the old man from the church and she'd say] 'Look, I think you should go home.' I said, "Listen, it doesn't hurt me [but this] man doesn't have anyone here." He was a man 79 to 80 then.... And I said, "If I open my eyes from being sick, I'd like someone to be sitting there," and I said, "If it's only just one little thing that you can do.....to help"'

'At some future time I'd like to be able to offer support, maybe through that same Cancer Helpline...I see some strengths...having been through a particular process myself I can actually draw from that in offering care to others. I'd hope I could offer something to others that's more real because I've been through it myself. So I think that while it's in some respects a negative experience, I like to see it for myself as actually enhancing some of my skills that I can then offer on to others.'

In accessing information and practical support, the Cancer Council of Victoria, the Internet and other sources of written information were highly valued. Audio taping consultations with health professionals was mentioned as helpful for the woman and her family to replay when there were questions or clarification was sought.

'The Cancer Council line were terrific, but they're not 24 hours a day, or Saturdays or Sundays'

'I did do a lot of Internet work at that time and for me having access to the internet... was good'

'...one of the chemo nurses told me that the Cancer Council has accommodation for holidays for people with advanced cancer and I could ring...and organise some supported accommodation. So they let me go off to Mt Buffalo with my girls, to the snow. ...I mean, it was only something like twenty per cent support... They helped'

Other women did not want too much information and did not want to focus too much on their breast cancer.

'I can talk about it. I don't have any problem talking about it, but to sit down and read literature and, you know, to chew over it, I can't handle that'

'But for me, I found those groups and all that information terribly depressing. I'd get into the first or second line of anything and I'd go, "I can't handle this." I just could not read any of it. And to go along and sit with that cancer group ... I just couldn't handle it...For me, the best medicine is doing things here, and the meditation, and the painting. If I focus on the word "cancer" and everything that goes with it, I start spiraling downhill'

Counselling was seen as a very effective strategy to deal with the emotional trauma associated with the disease, for the woman and her family. Access to and affordability of counselling services was noted as an issue in rural areas.

'[The counsellor] was very good, and just taking away the scariness, I suppose, of dying...my eldest girl was not sleeping well and talking about dying all the time... so she came and spoke to her... at length about dying ...And even when my youngest girl was very ill in hospital she would say to me, 'Is (my sister) going to die?'...I think she's got a bit of an understanding of it. She's five.'

'I've had to have my children in counselling. I feel there needs to be a connection for them to be able to let out their anxieties and frustrations.'

'I've just had a couple of private counselling sessions with her, and she's very specifically on, you know, grief and trauma associated with facing up to this, and it's been very helpful. But it's there for everybody and I don't know why more resources aren't put into helping people. And look, a lot of people aren't into counselling but, as I said, when you get this you do reassess your whole life, and at least it should be offered and promoted as something that's useful.'

'...once I finished my chemotherapy ... I sort of started to panic a little bit and I think I got quite depressed at that stage. And I think just finding the right person to talk to, like I didn't want to sort of burden my family any more, and I just needed to find someone that I could just open up and have them give me some strategies of how I could deal with it, and I saw a counsellor...she saw me only two or three times...she just made such a difference.'

Breast Cancer Support Groups met the needs of a number of women interviewed, while others felt it wasn't for them or didn't meet their specific needs, such as those of younger women.

'...it was within a few weeks of being diagnosed that one of the members of the support group rang me... I already knew of the group but felt that I wasn't really ready to go and actually declined going for a long time. I actually started going to the group ...And I think I've done really well learning from them.'

'I was also going to the breast cancer support group then and the interaction was wonderful. Yes, and then just talking to the other women...I think I got a lot out of it.'

*'I really think also there needs to be significant help for **young** women with breast cancer because they have a young family. There's a great hole in the network for young women with breast cancer...there needs to be a support system there, and there's not'*

'...actually I don't mean to criticise but the support group was not for me.'

Community and church groups were often a source of practical and emotional support, even though, as already reported, those sources of support were not always there for them when needed.

'...I'd have to say not only the local church community either. Somehow the news sort of spread,... by word of mouth... so we were actually getting emails and phone calls and notes from all around Australia, from church people that, at some point on our journey we'd interacted with. ...I suppose I'm a Christian and I believe in the support and the power of prayer, and to know that there were people... Yes, upholding me in prayer from all these places, that was almost tangible in its support.'

Retreats, residential workshops and local seminars, such as the *Look Good Feel Better* program or those put on by BSEP, were helpful to women and their families, as were services and programs accessed after discharge from the hospital, such as home help. There is, however, no universal access to these, as mentioned earlier in this report.

'And with this group, we go away once a year... for a weekend and our facilitator does a lot of work, emotional work and meditation, and we eat...we all take really good healthy food and we share...we talk about what makes us angry depending on which level we're at. You know, some ladies have been diagnosed with secondaries and all that so we do a lot of brainstorming and writing and drawing and walks, nice walks.'

Other women found keeping active through exercise and sport, and staying involved in hobbies such as crafts, singing and the like, were practical strategies to engender a sense of wellbeing and keep them on track. Writing workshops were another source of healing and inspiration.

'...keeping your weight down and exercise and...I've done a Tai Chi class. Oh, it's really good, actually.'

'Between chemo and radiation I worked really, really hard at getting myself physically fit so that I could be ready to cope...'

'...when I was feeling better between the doses I'd potter in the garden, and I knitted my husband a jumper. So, you know, I tried to have little projects on the go that I could have a sense of achievement about even though I wasn't working.'

Complementary or alternative therapies, and various changes to lifestyle were actively explored. Women embraced meditation, relaxation and dietary changes.

'So I gave up my beautiful block of chocolate that I had weekly, cheese and dairy products.... I've stuck to that and I've been well.'

'I pursued the alternative doctors as well, to get their opinion on what I need to be doing to prevent it from happening again...So I'm not saying it's got to be one or the other, I'm saying I'm trying to work on a balance of both and then I can look back and say I've done everything I can to prevent it coming back. Which includes trying to keep yourself in a happier state of mind, because if you let your stress and your emotions and everything get on top of you then...'

'...she also introduced me to meditation, which has been fantastic for me. It's given me an inner peace through all this turmoil.'

Discussion and recommendations

✚ Accessible treatment for BC

The key recommendation is that women in Hume region have access to best practice care for breast cancer. Crucially, women in rural areas should not have to leave the support and comfort of their families and communities for this to happen. They should not have to travel long distances for treatment or have the added financial burden of travel and accommodation costs. Support services and information should be available to them as to their city counterparts.

Whilst acknowledging workforce issues and the infrastructure costs involved in providing this level of care to women in rural areas, investigation of the feasibility of a second radiotherapy facility in Hume region would be welcome.

The experiences of the 20 women who informed this research identified clear avenues for improved services. Implementation of the following recommendations will indeed go some way to delivering improved experiences of health service provision for rural women with breast cancer.

Tables 8 to 11 on the following pages provide a quick checklist for health professionals, government policy makers, health administrators or executive, and for peak bodies, as recommendations relating specifically to each field are grouped together. The last column in these tables indicate the source of evidence for each recommendation.

Table 8: Recommendations relevant to *healthcare professionals*, and evidence source

| Health care professionals | No. | Evidence supporting the recommendation |
|---------------------------|-----|---|
| | | <p>1.1 Strongly supported by this research data and the literature</p> <p>1.2 Supported by the literature</p> <p>2.1 Supported by this research data; strongly supported by the literature and professional experience</p> <p>3.1 Strongly supported by professional experience</p> <p>3.2 Strongly supported by professional experience</p> <p>4.1 Strongly supported by the literature and professional experience</p> <p>4.2 Strongly supported by professional experience and the literature</p> <p>5.1 Supported by this research data, the literature and professional experience</p> <p>5.2 Supported by the literature and professional experience</p> <p>5.3 Supported by this research and professional experience</p> <p>6.1 Strongly supported by professional experience and supported by the literature</p> <p>6.3 Supported by the literature and professional experience</p> <p>7.1 Supported by professional experience and this research</p> <p>8.1 Strongly supported by this research, the literature and professional experience</p> <p>9.1 Strongly supported by this research, the literature and professional experience</p> <p>9.2 Strongly supported by the literature and professional experience</p> <p>9.3 Supported by the literature and professional experience</p> <p>10.1 Supported by the literature and professional experience</p> <p>12.1 Strongly supported by this research, professional experience and the literature</p> <p>12.2 Supported by professional experience and strongly supported by this research</p> <p>12.3 Supported by this research</p> <p>12.4 Strongly supported by the literature and professional experience</p> <p>12.5 Strongly supported by the literature and professional experience</p> |

Table 9: Recommendations relevant to *policy makers*, and evidence source

| | | |
|--------------------------|------|---|
| Government policy makers | No. | Evidence supporting the recommendation |
| | 2.1 | Supported by this research data; strongly supported by the literature and professional experience |
| | 5.3 | Supported by this research and professional experience |
| | 6.3 | Supported by the literature and professional experience |
| | 7.2 | Supported by this research and professional experience |
| | 8.1 | Strongly supported by this research, the literature and professional experience |
| | 9.1 | Strongly supported by this research, the literature and professional experience |
| | 10.1 | Supported by the literature and professional experience |
| | 10.2 | Supported by the literature and professional experience |
| | 11.1 | Strongly supported this research and by professional experience |
| | 12.1 | Strongly supported by this research, professional experience and the literature |
| | 12.2 | Supported by professional experience and strongly supported by this research |
| | 12.3 | Supported by this research |

Table 10: Recommendations relevant to *peak bodies* (e.g. NBCC, CCV, BCNA), and evidence source

| | | |
|-------------|------|--|
| Peak bodies | No. | Evidence supporting the recommendation |
| | 1.1 | Strongly supported by this research data and the literature |
| | 1.2 | Supported by the literature |
| | 4.2 | Strongly supported by professional experience and the literature |
| | 5.2 | Supported by the literature and professional experience |
| | 6.2 | Supported by the literature and professional experience |
| | 12.2 | Supported by professional experience and strongly supported by this research |
| | 12.5 | Strongly supported by the literature and professional experience |

Table 11: Recommendations relevant to health administrators or executive, and evidence source

| Health administrators or executive | No. | Evidence supporting the recommendation |
|------------------------------------|-----|---|
| | | <p>1.1 Strongly supported by this research data and the literature</p> <p>1.2 Supported by the literature</p> <p>2.1 Supported by this research data; strongly supported by the literature and professional experience</p> <p>3.1 Strongly supported by professional experience</p> <p>3.2 Strongly supported by professional experience</p> <p>5.2 Supported by the literature and professional experience</p> <p>5.3 Supported by this research and professional experience</p> <p>6.3 Supported by the literature and professional experience</p> <p>7.1 Supported by professional experience and this research</p> <p>8.1 Strongly supported by this research, in the literature and professional experience</p> <p>9.1 Strongly supported by this research, the literature and professional experience</p> <p>9.3 Supported by the literature and professional experience</p> <p>10.1 Supported by literature and professional experience</p> <p>10.2 Supported by the literature and professional experience</p> <p>12.1 Strongly supported by this research, professional experience and the literature</p> <p>12.3 Supported by this research</p> <p>12.4 Strongly supported by literature and professional experience</p> <p>12.5 Strongly supported by the literature and professional experience</p> |

1 Communication

Communication between consumers and health care professionals is a significant dimension of health care, with evidence suggesting it can affect patient outcomes and behaviours. For cancer patients, better communication of information and improved consumer-clinician relationships, particularly shared decision-making, are noted as some of the most important facets of their treatment.

In clinical practice however, women have reported that communication between themselves and their health care professionals can be problematic. Despite health care professionals often being the preferred information provider for women with breast cancer, many individuals were dissatisfied with the communication and information they received from them.

It would appear that women who had a positive communication environment with their health care professionals experienced reduced emotional distress, anxiety and depression. Sound two-way communication between clinicians and women can lead to women feeling more satisfied with their overall breast cancer care.

There is a clear need to improve the communication skills of nurses and doctors. This includes refining expertise in the processes of communication to complement and strengthen, not replace, expertise in the content communicated.

It is recommended ...

- 1.1 That health professionals be trained in effective communication techniques between themselves and women and families; and between each other as health professionals
- 1.2 That health professionals be required to update their communication skills on an ongoing basis

2 Integrated care

A team approach to treatment (known as multidisciplinary care) leads to better outcomes for women with breast cancer, both emotionally and physically. The way in

which services and health care professionals communicate with each other in the multidisciplinary care of a woman may affect the quality of discussion and the level of collaboration among team members in treatment decisions. The establishment of protocols, referral pathways and communication strategies for continuity of care is to be encouraged, as are multidisciplinary breast team meetings.

Health care professionals must be able to integrate a range of different supports (both formal and informal) for patients and their families so that their difficulties during treatment are minimised. Health care professionals need to be aware of, and develop linkages with, various support services and mechanisms (such as breast care nurses, financial and transport assistance through to support groups) in their particular communities. Integrating multiple supports can result in a more coordinated system of support, reducing the time and distress a woman and her family has to endure when trying to access these services.

Referrals made between health care professionals indicate a level of professional respect and acknowledgement of the expertise that each discipline makes to holistic care of the patient. Further strengthening referral linkages may provide improved care to consumers in terms of treatment options. These referrals occur both within communities and between Melbourne and the local community, when women who have received treatment in the city return home.

It is recommended ...

- 2.1 That a team approach to multidisciplinary care should be available for all women diagnosed with breast cancer, to enhance continuity of care

3 Shared decision making

Women experienced resistance to their requests for a second opinion and had to be assertive to be given referrals, or to express a chosen treatment option. Women have a role to play in decision making about their own health care. At a time when they are already feeling vulnerable, women felt pressure to accept the opinion of various clinicians, without adequate information, time to absorb the information and other professional opinions.

It is recommended ...

- 3.1 That a culture of upholding the rights and desires of women regarding their treatment be created
- 3.2 That the right of anyone to a second opinion is accepted by health professionals and facilitated by them

4 Information

With few exceptions, women wanted more information than they tended to receive, and on a broader range of topics than simply disease and treatment options. Information provision is a fundamental component in the effectiveness of partnerships between consumers and their health care providers. For people to feel enabled to participate in decisions about their health care, they must be adequately informed. Health care professionals arguably have a responsibility to provide patients and their families with the specific type of information necessary for informed decision making to take place. Providing adequate information to women with breast cancer is of particular importance as a choice of treatment exists in many cases.

Many women reported that they wanted more information from the point of diagnosis onwards, and that surgeons provided inadequate information for their needs. The fact that not enough information was provided at the time of diagnosis was compounded by the part-time nature of breast care nurse employment in the region, so that contact was delayed until sometime later in many cases. During these critical early weeks, then, some women felt they suffered from a lack of information.

The benefits to consumers of written information to complement and support that received by other means, such as verbally, has been widely acknowledged. Written information leads to increased understanding and gives the opportunity to refer to this written information as required by the woman and her family. While women expressed the desire for professional support around breast cancer information provision, many of them pursued multiple strategies to inform themselves, including the Internet, information seminars, Cancer Council Helpline, and the use of personal and professional networks.

Although many health care professionals believe they are providing adequate information to their patients, this study and others conclude that most women with a

breast cancer diagnosis are not receiving the amount or type of information they require, at the time they need it.

Ongoing information about side effects of treatments and strategies and services to alleviate suffering is vital to women as they cope with many months of radiotherapy, chemotherapy and/ or surgeries.

The pressures of life and income don't stop with a breast cancer diagnosis or its treatment. The pressure of the illness is compounded for most women by financial concerns. It is critical that women be advised of entitlements they may have to financial assistance for travel, accommodation, prostheses, home help and other support services.

It is recommended ...

- 4.1 That a range of timely information be made available to women regarding their specific treatment options; side-effects; available services; and entitlements through health professionals as primary conduit for information. Local resources should also be promoted such as the Albury-Wodonga Resource Kit, the Wangaratta Chemotherapy Packs and the Hume Breast services website.
- 4.2 That general information about cancer diagnoses; treatment options; side-effects; advantages and disadvantages of particular choices; available services; and entitlements be easily accessible to women through government funded and other agencies including Breast Cancer Network Australia, Cancer Council Helpline and BreaCan. The methods could include hard copy information for fax and post; email and website information; and by telephone or personal contact.

5 # Reconstruction

Women who have had a reconstruction generally find it leads to improved body image and helps them to recover emotionally following a mastectomy. Information offered about reconstruction appears to be either inadequate to allow women to make informed choices, or is non-existent. Women compared the availability of reconstructive surgery in Melbourne with the lack of options in rural areas. For Hume region women, opting for reconstruction usually means treatment must be taken in Melbourne. Early advice about options is therefore critical to decisions about reconstruction. While reconstruction is not for everyone, women should be informed that it is an option available to them.

It is recommended ...

- 5.1 That information about options for reconstruction be provided by health professionals to women at the time of diagnosis and at each consultation where treatment options are discussed
- 5.2 That information about reconstruction be generally available to women
- 5.3 That reconstructive surgery be available at regional centres within the Hume region, for example, through visiting specialist surgeons

6 Lymphoedema information

Awareness amongst clinicians and the general public about lymphoedema is still variable. Not all women have access to information, education and treatment.

It is recommended ...

- 6.1 That information about lymphoedema and risk minimisation strategies be provided by health professionals to women throughout their cancer treatment
- 6.2 That information about lymphoedema and risk minimisation strategies be generally available to women
- 6.3 That women have greater access to lymphoedema education and treatment through:
 - (a) supporting physiotherapists and nurses to become specialist trained lymphoedema therapists
 - (b) increased hours for publicly funded lymphoedema services

7 Health system information

The health system is confusing for many women in this research. There were unexpected bills to pay and surprise at non-eligibility for post-acute care services such as home-help. The *gap* payments required by specialists and health professionals quickly added up to substantial amounts. The *Safety Net* was misunderstood. Our enquiries found that it applies only to out of hospital care. Some women could access needed drugs and others couldn't – depending on their health insurance coverage.

It is recommended ...

- 7.1 That information about public and private health systems and the Pharmaceutical Benefits Scheme be given to women at the time of diagnosis and hospital admissions
- 7.2 That the State and Federal Governments produce short, plain-English pamphlets with key points, and provide a 'one-stop' phone contact for follow up information

8 Support for special needs

The concerns and specific needs of young women with breast cancer, and women with advanced breast cancer, have been apparent in this research.

Women with advanced breast cancer wanted local support groups specific to their particular needs.

Isolation and a sense of being alone were expressed by the younger women, in addition to concerns about fertility, treatment induced menopause, raising family, finances, work body image, sexuality and self-esteem. There was a perception amongst the younger women that general breast cancer support groups did not cater to their needs due to the different issues related to a breast cancer diagnosis at their young age.

Suggestions that more supportive care should be directed to these younger patients to reduce psychological stress have seen the establishment of two sub-regional support groups specifically for younger women, one in Albury-Wodonga and one in Wangaratta, with a third planned in the Goulburn Valley area.

It is recommended ...

- 8.1 That funds and in-kind support be sought from government and philanthropic trusts to increase support provided locally for younger women with breast cancer and for women with advanced breast cancer, through a range of measures including:
 - 8.1.1 the further support and development of existing and newly created support groups in Hume region
 - 8.1.2 the establishment of such support groups in localities across the Hume region

8.1.3 teleconference linkage to existing city-based support groups for younger women and women with advanced breast cancer

8.1.4 additional support for women caring for a young family, such as in-home child care and home help

9 Supportive care

There is growing evidence that providing supportive care for those with breast cancer leads to better outcomes, both psychologically and physically. Navigating the multitude of services and agencies, which a woman with breast symptoms or disease may have to deal with, can be a harrowing experience, and the support and knowledge of a breast care nurse can be invaluable.

Women want increased access to breast care nurses and supportive care services, every weekday at a minimum, and some after hour's access. Increasing the paid hours of breast care nurses across the region, and having other options available when a breast care nurse is unavailable, are key strategies. This supportive care could encompass assistance from oncology nurses, counsellors, and telephone helplines and be more available to women at the time they need the service.

The women interviewed have expressed the importance of the advocacy role that breast care nurses play in a journey with breast cancer. Many cited examples of the practical and emotional ways that breast care nurses have assisted them. Their involvement as members of the multidisciplinary team is critical as breast care nurses can advocate on behalf of a woman, particularly where the consumer has expressed their desired treatment choices or in cases where there are psychosocial issues of which other team members may not be aware. As equal members of the multidisciplinary care team, BCNs can enhance continuity of care for the women.

Breast care nurses have the potential to free up the time of medical specialists while providing expert and timely care and support to women. There is much scope to increase the profile of services available from breast care nurses in Hume region - those based in the major regional hospitals as well as those in community health, district nursing or palliative care. An increased profile would lead to more referrals from clinicians and other health care professionals to breast care nurses.

Many of the learnings and models of breast care nursing are equally transferable to other diseases and cancers. Certainly the loss or disfigurement of a breast has

unique issues in terms of femininity, self-image and sexuality and these can be better dealt with by a specially trained breast care nurse. There are however also other psychosocial and practical issues, such as anxiety and depression or financial and transport matters, which may impact on many cancer diagnoses, not just breast. Therefore the nursing models of supportive care, provision of information and referral linkages are equally valid for other cancer types.

It is recommended ...

- 9.1 That women have increased access to breast care nurses through services providing more specifically funded breast care hours which may be as part of a cancer nurse specialist role
- 9.2 That clinicians and other health professionals increase referrals to specialist trained breast care nurses from the point of diagnosis through the continuum of care
- 9.3 That breast care nurse services and availability are promoted to clinicians and other health professionals through marketing, in-service professional development opportunities and clinical meetings

10 Professional support

Given that the majority of breast care nurses in the region do not have dedicated hours as breast care nurses, and many health care professionals are extremely busy, it is imperative to have a network which provides them with resource updates and current breast care knowledge. It is equally important for health care professionals to know what services and products are available for their consumers in their local community, the region and elsewhere. Networks offer a great deal to health professionals and contribute to good practice. They can act as a debriefing mechanism; transfer learnings and outcomes from other events; offer a broad experience base; and importantly, provide a sense of belonging, which is essential for health professionals working in isolation.

There is an opportunity for networking and professional development for breast care and oncology nurses and other health professionals to be formally coordinated. This role is best taken on by people with a genuine interest in supporting the benefits of networking; who believe in continuous quality improvement through learning and its application to professional practice; and who are able to foster environments conducive to networking.

Determining the needs of health care professionals, engaging appropriate guest speakers, coordinating venues and catering and promotion of the sessions can be done by people with organisational and marketing skills.

The benefits to health professionals of sharing knowledge and expertise through networks, and ongoing professional development are well documented. The flow on benefits to consumers is equally clear.

It is recommended ...

10.1 That professional development, networks and networking opportunities be made available and taken up by rural breast care nurses and other health professionals in their own region

10.2 That the Breast Care Nurse Networking Days established by Hume Breast Services Enhancement Program be sustained within the Victorian and NSW Cancer Framework implementations, and be expanded to include professional development opportunities for oncology nurses and other health professionals

11 Travel assistance

Despite the existence of several schemes for assisting rural women to receive funding for travel, accommodation and access to the full range of breast cancer treatments, there is still considerable variation in the access women have to this assistance.

Many women travel extensive distances within the region for treatment, for example 190 kms roundtrip each day for five weeks of radiotherapy, yet they are ineligible for travel reimbursement. Some women indicated they were less out of pocket by choosing to travel to Melbourne for treatment, than travelling within the region and staying where their support systems were in their community. The anomaly of travelling further to the metro area for treatment arises when women live less than the required claimable 100 km radius to their closest treatment centre. Frequency of travel - not just distance per trip – should be counted in determining eligibility for assistance. Number of kilometres per month, for example, would be one way of more equitably determining travel reimbursement.

It is perhaps worth considering a cost-benefit analysis of providing services within the region where the woman lives in comparison to reimbursing costs associated with travelling to Melbourne for extensive treatment.

It is recommended ...

- 11.1 That frequency of travel be considered in determining eligibility for travel assistance

12 # Holistic approach

Increased access to affordable counselling services, and family focussed care were significant issues for women. Women wanted care that met the needs of children, partners and other family members, and they wanted counselling for themselves and their families. This holistic approach to a woman's care was frequently identified as an issue in this research.

Women valued one-to-one support and advocacy from a peer. This kind of individual and intimate contact with someone who has been through a similar situation was a comfort to women - distinct from support within a group setting.

While many women appreciated the personal and emotional support they often received during chemotherapy treatment, there were negative comments about the physical environments where treatment was given. Where capital works improvements are required, these could be planned for, and intermediate minor renovations and new furnishings could be budgeted, or lobbied for within service clubs and other community organisations.

It is important that psychosocial issues be taken into account during management of breast cancer and treatment decisions. Both editions of the Psychosocial Clinical Practice Guidelines (*Adults with Cancer and Women with Breast Cancer*) are a sound resource for health care professionals and encourage awareness of life issues for women beyond the illness.

Multidisciplinary breast team meetings have been established within Hume region. A focus on psychosocial issues could be promoted within these team meetings. Strategies could be developed and implemented to forge links and encourage the sharing of resources and knowledge amongst clinic members and counsellors, social workers, psychologists, grief counsellors and palliative care workers.

Perhaps further investigation could be done into the clinic agenda forms designed by Inner & Eastern BSEP to incorporate psychosocial risk factors from the clinical guidelines, with a view to adapting them to the Hume clinics.

It is recommended ...

- 12.1 That free or minimal cost counselling be accessible within two weeks of contact for Hume region women with breast cancer and/ or their family members
- 12.2 That every woman diagnosed with breast cancer who wants support be given access to peer support, for example, through the Cancer Connect Program of the Cancer Council or BreaCan's free call support program or arranged locally
- 12.3 That the physical environment of the areas where treatment is administered should be examined to ensure adequate space, comfort and privacy, and improvements planned where necessary
- 12.4 That multidisciplinary breast care teams encourage a psychosocial approach both within their practice, and amongst health and community networks. The Hume region multidisciplinary breast clinic agenda forms should also be revised to incorporate psychosocial risk factors
- 12.5 That education and training sessions covering psychosocial factors and communication be offered to regional health professionals to ensure appropriate skill sets

Conclusion

The purpose of this research is to improve health services to rural women. It is for health professionals to read and consider. It is for the funding bodies of health services to inform their decisions. It is for the women who informed this research; for women living with breast cancer; and for those who will be diagnosed in future months. It is our intention that the experiences of rural women - in the face of a breast cancer diagnosis - will be better.

Appendix 1 – Literature review

The purpose of in-depth qualitative research

This research project is inside phenomenological practice, with the purpose of in-depth interviews being to understand the lived experiences of these 20 women with breast cancer (Platzer & James 1997 p 630).

Insider or participatory research

Research can be an instrument by which health care consumers are given a voice, their issues and concerns raised and inequities brought to attention. Participatory research (those being researched are involved in the research process), can empower consumers to be involved in project planning and design, methods of data collection and analysis and use of research outcomes (Macaulay et al 1999 in Bourke 2002 p 246).

It has been stated that 'the key element of participatory research lies not in the methods but in the attitudes of the researchers, which in turn determine how, by and for whom research is conceptualized and conducted'. This also then involves sharing power and control with consumers, groups and communities (Cornwall and Jewkes 1995 p 1667 and Travers in Bourke 2002 p 247). This also has the benefit of local values being incorporated into the research, rather than imposed from the outside (Travers in Bourke 2002 p 247).

Several researchers have found participatory research can develop successful interventions at the local level (Cornwall et al, Drevdahl & Riley et al in Bourke 2002 p 247), and is particularly suited to rural development (de Koning & Martin in Bourke 2002 p 247).

The term 'insider research' is used when the researcher "conducts studies with populations, communities and identity groups of which they are also members" (Kanuha in Asselin 2003 p 100).

With the increased emphasis on consumer/survivor participation and involvement in service delivery, it is not unforeseen that consumers/survivors have slowly become more involved in research (Ochocka, Janzen & Nelson 2002 p 380). This has been evident in mental health (Ochocka et al 2002, Rempfer & Knott 2001, Champ 2002, Howard 2001, Reeve et al 2002), gay & lesbian experiences of nursing care (Platzer & James 1997), recovery from serious illness (Denz-Penhey 1997), relationships between maternal & child health nurses and mothers (Scott 1997), and cancer: kidney (Taylor 2002) and Hodgkin disease (Zebrack 2003).

Our literature search (using a variety of the most popular health research databases) did not find any other published articles on breast cancer consumers/survivors who undertook insider research. The exception was one other participatory research project in the Hume region which involved BSEP consumers. The lead researcher in this project felt that having local consumer and health care professional involvement in this participatory process 'builds knowledge, not of elite researchers but of communities' (Bourke 2002 p 251).

Participatory research is well suited to work with consumer/survivors (Nelson et al 1998 in Ochocka et al 2002 p 385), who contends that these people have a basic right to active participation in research about services intended to be supportive of them (p 386). Participation of these consumers embraces "the experience and partnership of those we are normally content to simply measure" (Schwab & Syme 1997 p 2050 in Bourke 2002 p 246).

Consumer participation can also influence the research questions and methodology in such a way to make them more relevant to the actual lived experiences of that particular group (Rogers & Palmer-Ebbs 1994 in Rempfer & Knott 2001 p 153). Champ (2002 p 20), himself a consumer researcher, feels that slowly, researchers are embracing the challenges and fresh insights that consumers can bring to their work.

'Insider' status can reduce many of the challenges associated with conducting sensitive research in terms of access, rapport with subjects and ethical concerns (Platzer & James 1997 p 626). Lee (1993 in Platzer & James 1997 p 627) considers that sensitive research is 'that which poses a threat to those involved in it, whether they are the researcher or the researched'.

Titchen & Binnie (1993 & 1994 in Platzer & James 1997 p 630) also discuss how the insider status of researchers can lead to an increased commitment by research participants to participate and disclose. This can also serve to strengthen the investment of the research subjects toward the researcher and the project itself (Danley & Ellison 1999 in Rempfer & Knott 2001 p 153).

While there is still relatively little research done by consumers as researchers, it is an increasing phenomenon and one that can serve to highlight the different agendas and concerns for consumers and professional researchers (Shaw & Epstein 1997 in Champ 2002).

But this notion of consumer as researcher can also be viewed as transgressing science's rules about objectivity, validity and reliability (Platzer & James 1997 p 630), and lays researchers open to the 'charge of bias thought to be inherent in going native, or rather in this case being native' (p 626). Qualitative researchers caution that bias and issues unique to insider research can occur that put the trustworthiness of the study at risk (Field 1991, Tilley & Chambers 1996, Thomas, Blacksmith & Reno 2000 in Asselin 2003 p 100).

Some feminist researchers contend that 'the experience (of research) involves so much of the self that it is impossible to reflect upon it fully by extracting the self' (Okely 1992 p 8 in Scott 1997 p 130). Some other researchers check on the inherent 'bias' that pervades the research process by closely looking at oneself as a researcher, 'in order for the final data to be trustworthy, the investigator must evaluate himself or herself as a data collection instrument' (Ramos 1989 p 60 in Scott 1997 p 130).

The researcher conducting 'insider' research must be aware of pitfalls that can threaten the credibility of the study. By building systems into the study design and analysis, the research team can preclude issues of bias associated with insider research and actually enhance the credibility of the study (Asselin 2003 p 103).

In fact, one consumer researcher found her personal experience, rather than demonstrating bias, enabled a more productive and sophisticated analysis of the research data, which was corroborated by Strauss & Corbin (1990 in Denz-Penhey 1997 p 55). This consumer researcher found it allowed acknowledgment of factors and concepts within the data that clinicians may have dismissed as individual or irrelevant to their biomedical point of reference. Denz-Penhey found that these alleged individual and irrelevant factors were in fact common in all her participant's stories and became central to her final research theory (Denz-Penhey 1997 p 55).

One other man who was diagnosed with cancer at the age of 25 has since earned a PhD and become a researcher at a world renowned cancer centre. It has been a positive standpoint, in his view (Zebrack 2003 p 2708):

'I often reflect on how my own experience with cancer influences my work as a scientist. As a cancer survivor who conducts cancer research, I believe that these dual roles offer a unique perspective into the impact that cancer has on the lives of patients, survivors, and their families. The images and memories of my own experience with cancer inform my work and assist in my understanding of what patients and survivors say about how cancer has affected, and often continues to affect, their lives.

Taylor, himself a kidney cancer patient and researcher, defers to Carl Rogers philosophy, stating it is vital to recognise that both the researcher and the subject encounter each other as persons. He goes on to say that in the sociology of cancer, there has previously been some discussion about this issue from the viewpoint of the researcher, but the patient's perspectives have generally not been acknowledged (2002 p 203).

It is this research process that leads to an accord that is a fusion of the views of the researcher and the participants (Haggman-Laitila 1999 p 13).

Exploitation versus therapeutic benefits of participation in sensitive research

A concern of feminist research has been the ease with which women can get women to talk about private and upsetting aspects of their lives. It could be said that in its own way, this ease of access is potentially abusive and exploitative (Finch, Leonard, in Platzer & James 1997 p 631). But Edwards (in Platzer & James 1997 p 631) declares this possible exploitation can be minimised by having a 'reciprocal relationship with the interviewees and disclosing something of oneself'. It has been acknowledged that better data about people's feelings and experiences is produced when the researcher has an open and reciprocal relationship with the people being interviewed, and involves disclosure on the part of the researcher. The common bond may be helpful as a basis upon which to build the researcher-participant relationship (Asselin 2003 p 100).

Other benefits and positive effects of participation in research on sensitive topics which may evoke emotional distress include self acknowledgement (validation of self-worth), self awareness, empowerment, a sense of purpose (helping others), healing and being heard (Hutchinson, Wilson & Wilson 1994 in Burke Draucker 1999 p 162).

Fears that research participants are unnecessarily traumatised by disclosing or reliving emotionally disturbing events are countered by participants who often claim that the interview was a positive and cathartic experience (Brannen 1988, Edwards 1993, Renzetti & Lee 1993 in Platzer & James 1997 p 631; Newman, Kaloupek, Keane & Folstein 1997 in Burke Draucker 1999 p 161). Taylor (2002 p 203) declares this therapeutic dimension results when the patient begins or continues self-exploration and self-revelation through the interview process.

The risk with a single research interview is that it can arouse emotions in the person that remains unresolved at the end of the interview, possibly causing subsequent worries for the person (Taylor 2002 p 203). To guard against this possibility, all women interviewed in this breast cancer research were given the name of local professionals where they could access counselling, paid for by the research project. The researcher was also expected to avail herself of this counselling.

Understanding the implications of having consumer/survivors fully involved in a research process and its findings is still limited (Ochocka, Janzen & Nelson 2002 p 380; Reeve, Cornell, D'Costa, Janzen & Ochocka 2002 p 403).

Rurality and breast cancer

There is evidence that identifies a discrete culture within rural communities (Davis, Williams, Redman, White & King 2003 p 27). In terms of the Hume rural region, rural is defined as including regional centres and large country towns in rural areas (Davis et al 2003 p 29).

Some researchers have proposed that the rural lifestyle is associated with a greater self-reliance and independent lifestyle, and therefore people from rural areas may define health in more practical and functional terms (NBCC & NCCI 2003 p 120).

There is a paucity of research regarding the obstacles to implementing Evidence Based Practice (EBP), especially within rural contexts (McCarthy & Hegney 1998). Regardless of what actions or initiatives are implemented to improve health services in rural settings, it is essential they are based on evidence and further evaluated (Patterson 2000 p 287).

The disparity between rural and other communities is most powerfully revealed in the poorer health status of people living in rural and remote communities. This can be seen particularly in the higher mortality rates, higher rates of hospitalisation and disadvantage in terms of access to health services. Rural Australians have mortality rates between 10 and 40% higher than for the nation as a whole (NRHPF & NRHA, 1999: 38). Related to these findings is the general lack of medical services in rural communities. An Australian Institute of Health and Welfare survey indicated that rural doctors made up only 16 per cent of the medical workforce, even though around a third of the population live in the bush. Metropolitan residents are serviced by 325 doctors per 100,000 people compared with only 142 per 100,000 people in rural areas (Northern Daily Leader, 26 July 1997, p 1). One more recent study found that only 17% of female GPs are located in rural areas despite the fact that 27% of the female population lives in rural or remote areas (Young and Byles 2001 in Manaszewicz et al 2002).

An evaluation of the Rural Communities Access Program also found that stress related problems are on the increase. Rural health workers reported increased substance abuse; low morale and depression; and long hours of work that lead to greater risk of accidents and withdrawal from community activities and involvement. With the closure of support services and the difficulty of accessing medical services, families have less access to help (1997, p 7).

Australians living 'in the bush' have lower overall cancer survival rates than people living in metropolitan areas (Australian Institute of Health and Welfare), and the burden of cancer on consumers, their families and carers is a particular challenge in rural communities that do not have the full complement of services (Wooldridge 2001 p 1; Olver & Selva-Nayagam 2000 p 213; Furnival 1997 p 1; McMurray 1998). Rural women have slightly higher breast cancer incidence and mortality rates than urban Victorian women, although the differences are not statistically significant (BreastCare 1999 p 7).

Almost 30% of Australians (around 5 million people) live outside metropolitan areas, almost 25% of cancers occur in rural and regional women, and a further 1.5 million women are at risk of breast cancer in country areas (Furnival 1997 p 1). Up to 30% of Australian women diagnosed with breast cancer live in rural or remote areas where there is often limited access to specialists and diagnostic, supportive and therapeutic services (Zorbas et al 2003 p 528-9). Little research however has been undertaken that explores breast cancer issues and services for women outside major metropolitan centres (Furnival 1997 p 1; Hatzell et al 1999 p 261; Cancer Strategies Group {CSG} 2001 p 40; Wilson, Andersen & Meischke 2000; Tulloh & Goldsworthy 1997 p 26).

It is conceivable to expect that patients living in rural areas may be more likely to have unmet needs than their metropolitan counterparts, due to factors of geographical isolation and difficulty accessing health services. Research suggests that women with breast cancer living in

rural areas of the USA have the greatest need for help with interacting with health care professionals, personal care, coping with changes and information needs (Girgis et al 2000 p 167).

People in regional and rural Australia face many difficulties as a result of their relative isolation from metropolitan centres and major health care facilities. Amongst the most common obstacles are lack of access to a full range of treatment options, lack of availability of appropriate medical and other support expertise, the need to travel long distances for some treatments, separation from families and support systems during treatment, increased costs due to travel and accommodation, and difficulty accessing information and support services (NBCC p 1).

Rural breast cancer survivors, regardless of stage at diagnosis, reported needing more education about their disease and more emotional support after diagnosis (Wilson et al 2000 p 667). Other research has found that, compared to their city counterparts, rural women receive less financial support and are less likely to ask for assistance that they are eligible to receive (Davis, Girgis, Williams & Beeney in Bourke 2001 p 1). Rural women who have experienced breast cancer have also been found to have more needs in terms of physical and daily living than their urban counterparts but are less likely to seek assistance or report unmet needs (Girgis, Boyes, Sanson-Fisher & Burrows in Bourke 2001 p 1).

Issues affecting rural women with breast cancer were one of the discussion topics at the Second NSW Breast Cancer Forum held in Sydney in October 2000. In addition to the issues already mentioned in this report, problems arising as a result of lymphoedema and advanced breast cancer, concerns of younger women, treatment pathways and information and communication needs for rural women were noted. This forum clearly highlighted that ways that consumers can have their voices heard, as well as identification of opportunities for taking part in decision making in research, medical, support and service delivery, as well as government areas, all relate as much to rural women as to their metropolitan counterparts (Bell 2001 p 20).

Issues of privacy, confidentiality and choice are also exacerbated within the confines of small town living (Manaszewicz et al 2002; Bell 2001 p 19; Shepherdson).

The researchers of one Australian study became aware of differences in knowledge and utilisation of services of women who had surgery at public hospitals compared to those at private hospitals, however at that time no further published articles were found addressing these disparities (Chisholm et al 2000 p 113-114).

Appendix 2 – Research questions and interview schedule

Research questions

1. How have Hume region women been affected by their breast cancer experience? (What is the effect of a breast cancer diagnosis on their lives?)
2. What aspects/ strategies have Hume region women found useful in terms of managing their breast cancer?
3. Are there specific issues experienced by rural Victorian (in particular Hume region) women in relation to their breast cancer?
4. What, if any, changes to the service system would Hume region breast cancer survivors like to see both in terms of their acute intervention and ongoing care?

Interview schedule

1. I'm interested in hearing about your experience of diagnosis and treatment of breast cancer. Can you tell me what it was like for you?
2. How do you feel a diagnosis of breast cancer has affected you?
3. What strategies and/or supports did you find useful?
4. Can you tell me about your experience of service provision?
5. Do you feel that you experienced any particular issues in relation to having breast cancer and living in a rural setting?
6. Do you have any recommendations regarding changes to improve care? (Was there anything missing for you that would have been helpful?)

Is there anything else that you think is important to understanding your experience of breast cancer that we have not discussed?

Appendix 3 – Treatment type

| | Private Ins | Lumpectomy | Mastectomy | Axillary Clearance | Chemotherapy | Radiotherapy | Hormone Treatment | Herceptin | Sentinel Node Biopsy | Oophorectomy | Reconstruction |
|----|-------------|-----------------|----------------|--------------------|---------------|--------------|-------------------|-----------|----------------------|--------------|----------------|
| 1 | ✓ | | Private/Albury | | | | ✓ | | Private/Albury | ✓ | Melb |
| 2 | ✓ | Private/Albury | | Private/Albury | | Hume | ✓ | | | | |
| 3 | | | Pub/ Wodonga | Pub/ Wodonga | | | ✓ | | | | |
| 4 | ✓ | | Private/Melb | Private/ Melb | Public/ Wang | | | Wang | | | |
| 5 | ✓ | Private/ Albury | | | Pub/ Albury | | ✓ | | | | |
| 6 | | Pub/Shep | Prev cancer | Prev cancer | Pub/Shep | Pub/Melb | | | | | |
| 7 | | Pub/ Albury | | Pub/ Albury | Pub/ Albury | Hume | | | | | |
| 8 | ✓ | | Priv/Wang | Priv/Wang | Wod | | ✓ | | | | |
| 9 | Hosp only | Priv/Shep | | Priv/Shep | Public/Shep | Hume | ✓ | | | | |
| 10 | ✓ | Private/Shep | | Private/Shep | Private/Shep | Hume | | | | | |
| 11 | | Public/Shep | Public/Shep | Public/Shep | Public/Shep | | | | | | |
| 12 | ✓ | Public/Wang | | Public/Wang | Public/Wang | Hume | | | | | |
| 13 | ✓ | | Private/Wang | Private/Wang | | | | | | | |
| 14 | | Public/Wang | Public/Wang | Public/Wang | Public/Wang | Hume | | | | | |
| 15 | | Public/Albury | | Public/Albury | Public/Albury | Hume | ✓ | | | | |
| 16 | ✓ | | Private/Albury | Private/Albury | | | ✓ | | | | |
| 17 | | | Public/Melb | Public/Melb | | | | | | ✓ | Public/Melb |
| 18 | | Public/Benalla | | Public/Benalla | | Hume | ✓ | | | | |
| 19 | ✓ | Private/Melb | | Private/Melb | Private/Melb | Melb | | ✓ | | | |
| 20 | ✓ | Private/Melb | | Private/Melb | Private/Melb | Melb | ✓ | | Private/Melb | | |

Prev canc – refers to treatment for a previous cancer, more than 3 years before interview for this research
Please note – two women (Nos. 14 &18) had prophylactic mastectomies 1 woman (No. 18) had Zoladex

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