

# LIVING WITH BREAST CANCER: THE INFLUENCE OF RURALITY ON WOMEN'S SUFFERING AND RESILIENCE. A POSTMODERN FEMINIST INQUIRY

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## ABSTRACT

This paper focuses on rural living as a dimension of women's experiences of living through breast cancer. The findings presented emanate from a feminist narrative research project that examined the experiences of rural women from south-west Queensland who were long-term survivors of breast cancer. This project aimed to listen, report and interpret rural women's stories of resilience in surviving breast cancer and moving on with their lives. The participants reported that there were both positive and negative aspects of living in a rural setting, especially when ill. Eight of the nine participants, however, felt strongly that the positive aspects of rural living outweighed the difficulties. This suggests that rurality in the context of health and illness must be considered as a multifaceted dimension, with resources to support cancer survivors building on the existing strengths in rural communities.

## INTRODUCTION

The incidence of breast cancer has steadily risen in Australia, increasing by 16% in rural areas and 14% in urban areas between 1987 and 1991 (Australian Institute of Health and Welfare [AIHW] 1999). For both urban and rural women, survival rates have also increased over time (AIHW 1999), meaning that more women are living with breast cancer for many years following diagnosis. Paradoxically, whilst survival rates have increased, breast cancer is still not considered to be a curable disease and hence long-term survivors can never be absolutely certain about their health status (LaTour 1996; Crouch and McKenzie 2000). Hence, for women with breast cancer, the challenge is to live with the disease rather than beyond the disease.

Alongside the trauma of diagnosis, and the difficulties of living with breast cancer, rural women may experience particular concerns because of their geographical location. These concerns relate to their distance from metropolitan areas and specialist health services; and the specific difficulties of rural living, which have included, over the last 20 years, rural unemployment, decreasing farm incomes, drought, population decline, the closure of businesses and services, and the loss of farms by families who had long lived off the land (Coakes and Kelly 1997).

Research examining rural women's experiences of cancer is limited. However, one recent study in Queensland, Australia, has shed some light on the particular concerns of rural women with breast cancer (McGrath et al 1999 a, b; McGrath et al 1999). Twenty-eight women participated in the study, reporting that their major concerns were fear of recurrence, physical concerns, and worry about their family (McGrath et al 1999). Their distance from metropolitan areas led to further hardships such as being separated from family and friends at a time of heightened vulnerability, having to travel long distances for follow-up care, and additional financial burdens arising from travel and accommodation costs. On a positive note, the women found significant support from within the informal support networks operating in rural areas. These networks included family, friends and community, and offered significant practical and emotional support to the

woman and her loved ones through the ordeal of breast cancer (McGrath et al 1999).

McGrath's findings are largely in keeping with the significant body of research describing the psychological, physical and social sequelae of breast cancer for women. A 1998 meta-analysis of research established that many breast cancer survivors experienced significant physical, psychological and social problems (Gotay and Muraoka Miles 1998). Some studies indicate that between 20% and 66% of women will face long-term distress (Breitbart 1995; National Breast Cancer Centre 1995). Additionally, up to half of women with recurrence of their breast cancer will experience psychiatric disorders (Hall et al 1996).

To add to these burdens, there is evidence that many women with breast cancer do not feel well informed or supported. In a meta-analysis of literature on women's experiences of breast cancer, Smyth et al (1995) found that the literature consistently revealed inadequacies in the amount and quality of information and support available to women who had been diagnosed with the disease. The need to deal with this problem is highlighted by National Breast Cancer Centre in their publication *Clinical Practice Guidelines for the Management of Early Breast Cancer* (National Breast Cancer Centre 1995).

Despite the overwhelming evidence that women with breast cancer suffer greatly, a particularly encouraging finding of studies of long-term cancer survivors has been that, whilst the consequences of a cancer diagnosis never disappear completely, many long-term survivors report that they lead satisfying lives with a high quality of life (Dow 1992; Dorval et al 1998; Gotay and Muraoka Miles 1998). Clearly, many cancer survivors are able to successfully navigate the journey through cancer. How this journey is navigated was the subject of the current research, as stories of survival can offer hope and inspiration to those diagnosed with cancer, and give loved ones, nurses and other health professionals valuable insights about the survivorship experience. The aim of this study was to listen, report and interpret rural women's stories of resilience in surviving breast cancer and living with the disease whilst moving on with their lives. The research question was as follows:

What responses indicating resilience assist rural women who are long-term survivors of breast cancer to move on with their lives in the face of this adversity?

## METHODOLOGY AND METHODS

A feminist postmodern narrative methodology was used. A postmodern approach to research rejects modernist notions of 'truth' as being observable and measurable (Lyotard 1983). It was argued that women's experiences of surviving breast cancer have been marginalised in a scientific community which founded on modernist notions, and which has focused on medical diagnosis and treatment. This inquiry is feminist because

it is critical of the marginalisation of women's voices, which has meant that decisions about breast cancer care are frequently made without understanding the implications of such decisions on a woman's life. The research aimed to alter this situation by privileging women's voices so that they are honoured and listened to by those charged with the responsibility of caring for them.

A narrative methodology, which is congruent with feminist epistemological principles, was used to allow rural women who have survived breast cancer to tell their own stories, and give voice to their own experiences and the meanings they have drawn from those experiences.

The nine participants in the study were women who had been diagnosed with breast cancer (excluding cancer in situ) at least five years ago; had completed any medical treatment associated with their disease; lived in rural south-west Queensland; and, agreed to participate in in-depth interviews. Participants were recruited via media releases inviting women to join the study and via rural community nurses. The age of participants ranged from 44 to 75 years. They were between five and 32 years post breast cancer diagnosis. All participants had a mastectomy to treat their breast cancer, with four also having radiotherapy and one having chemotherapy.

Data was collected by in-depth interviews. Feminist research principles informed all stages of the study, with a strong commitment within the study to privilege women's voices and acknowledge their wisdom in relation to their own experiences. The University of Southern Queensland Human Ethics and Research Committee granted ethical approval for the study. Interviews typically took between one and four hours, and were conducted in participants' homes. Follow-up interviews were conducted by telephone. The interviews were unstructured, with participants simply asked 'How did you get through?' Interview transcripts, and the narrative (story) constructed from these, were returned to participants for member checking.

Emden's guidelines (1998) for conducting a narrative analysis were used in this inquiry to present and interpret the stories of rural women who have survived breast cancer. This involves close and repeated readings of the interview transcript, followed by deletion of all interviewer questions and comments, as well as extraneous content (words and sentences not relevant to the key ideas). The next stage is the identification of items that are part of subplots (themes), which are moved together to create a cohesive story or set of stories. The final step is to return the story to the participant and ask if it is accurate, or if any changes should be made.

Emden's second strategy is one of emplotment (1998). This means finding one or more plots within the story, in order to make sense of that story.

Issues of rigour in this study were addressed in relation to Steinar's argument that traditional criteria of 'truth' need to be reconceptualised in response to postmodern

critiques of knowledge (Steinar 1995). Steinar defined validity as being derived from the quality of craftsmanship in an inquiry, with quality control at each stage of the process. Using a coherent theoretical framework (postmodern feminist); gathering data by indepth interview, with appropriate attention to issues of power and relationship; paying continuous attention to reflexivity; using narrative analysis to ensure that each participant's story was accurately and faithfully represented; member checking; returning to the data continually during the process of interpretation; and, the use of 'thick descriptions' to support the data analysis were central aspects of the research process in this inquiry which demonstrate quality of craftsmanship.

The results of this study revealed significant findings about women's roles and how these interface with resilience, survivorship and the cancer experience, which will be reported elsewhere. The focus here is on the dimension of 'rurality' as a factor influencing participants' experiences with breast cancer, and their responses to it.

## FINDINGS

Participants discussed both the positive and negative aspects of being a rural woman living with breast cancer. Living in a rural area means living away from specialist health services, yet for these participants it also means living within a close-knit community that provides significant emotional support and solace. However, the downside of the closeness of rural areas is that, for some, it limits opportunities for personal privacy and confidentiality at times of stress. Some participants felt their connections with the land helped them to heal. Finally, participants felt that their previous experiences as rural women had made them strong enough to deal with breast cancer.

In this section, discussion of these elements of living with breast cancer in a rural setting is supported by 'thick descriptions' (Geertz 1973), which are drawn from the participant's stories, and are italicised for clarity.

### When you're out in the bush... you're miles away

The participants in this inquiry faced particular difficulties relating to their distance from specialist services, similar to difficulties previously reported in the literature (Humphreys and Rolley 1991; McGrath et al 1999). All but one of the participants had travelled significant distances for surgery, radiotherapy and follow-up care, and this was disruptive and financially costly at a time of great personal upheaval. For example:

*In the country the biggest problem is going backward and forward for your tests every three months and every six months and every 12 months for 10 years. It's very expensive - Ruth.*

Evidence of professional support for the women after their return home following surgery and, for some, radium

treatment, is conspicuously absent in the participants' stories. All participants reported that their GP was their primary health care provider, and none had been referred for counselling, support, physiotherapy, domiciliary nursing or any other health service. This may be related to the lack of such services in rural areas. It is worth reiterating that some of the participants were telling their experiences of 20-30 years ago, when access to mobile health teams and other services was significantly less.

Some participants reported that they did not want professional help anyway, but for others, this support would have been welcomed. For example, Heavs felt that counselling might have helped her come to terms with her experience earlier, and Florence felt that, because of her geographical isolation, she was often alone with her fears. She felt angry with the local GP because of how he had handled her diagnosis, but did not have reasonable access to another medical practitioner.

*When you go out to the bush and you're miles away from your... the doctor that you've had, and I was annoyed with the local doctor and I didn't go back to him for years and years... so you sort of hesitate to ask anybody and you're wondering what the heck's wrong with you ... and nobody had told you that it would be like that - Florence.*

At the same time, participants spoke of the nurturing and support they found within rural communities, their identities as rural women, and, for some, a sense of peace and harmony, which they did not find in the city. The absence of specialist services is keenly felt, yet all but one of the participants would not have traded the benefits of rural living.

### Here, you speak to everybody

The informal yet highly effective systems of support available to rural people have been well documented (Brown 1990; McGrath et al 1999). Kate Brown (1990, p.52) wrote of the 'paradox' of rural health, whereby rural dwellers define health as the capacity to stay independent, yet believe that they are able to achieve good health, and hence independence by being dependent, through connections to the community via community activities. Hence, individuals in a rural community contribute to their own health by staying connected, and it is this very strategy that also ensures the health of the community. This 'connected independence' is apparent in the stories of participants in this inquiry. All but two (Maree and Florence) of the participants spoke of the support available to them from family, friends and neighbours in their communities, and felt that this support was very important to their capacity to overcome their illness. For example,

*I came home and... I didn't have any traumas after that because everybody supported me, you know the family all turned up and they'd bring tea... I mean even though I had five children I virtually had all the cousins and my sisters and my friends all feeding us and looking after us - Margaret; and,*

*In the city you can live next to somebody for 12 months and probably never exchange a word with them, where here, you speak to everybody, and people come up and say 'How are you, I'm thinking of you' - Ruth.*

Conversely, a problem associated with rural living which appeared to be more strongly felt by some participants was that of 'being alone' with their experiences. For some, this was related to the lack of professional support, whilst others reported that they felt unable to speak of their true feelings because they wanted to protect loved ones, or because they felt a real lack of privacy and confidentiality in their communities.

For the majority of the participants in this inquiry, telling their story at interview was their first opportunity to speak at length of what they had endured. Whilst two of the participants regularly attended breast cancer support group meetings, where they were encouraged to speak of their experiences, the other seven said that they rarely spoke about their ordeal. For some, it was simply too difficult to speak of:

*For a long time I couldn't [speak of it]... the only reason I ever tell anyone... I would say you know that they should go and... have checks and so forth - Margaret.*

Another reason for maintaining a silence was the need to protect loved ones, whom they perceived to be suffering:

*I feel that it affected Bill more than it affected me, not losing the breast but the fact that I had cancer... he'd just sit beside the bed and he wouldn't say anything - Ruth.*

Heavs felt unable to share her experience with others, because she felt that no one else had any idea of what she was experiencing. Embarrassment at having only one breast was also an issue for some and this was exacerbated in a rural town where anonymity is difficult. Anne found this aspect of rural living difficult at a time when she was trying to adjust to her altered body image:

*You do feel self-conscious. You feel like they're all looking at you - Anne.*

Maree, who, as a migrant woman, had no extended family to turn to, also experienced this sense of isolation related to being a relative newcomer in the town and not knowing who she could trust:

*We've been on our own, you know basically. We've got plenty of acquaintances, but there's nobody I can go and have a cup of tea, and just tell them how I'm feeling and that, and know that it will stay just there. I don't find living in a rural town good because everyone cares. It's not - Maree.*

### **Balance in the bush**

Another aspect of rural living touched on by some was that of a sense of peace related to a personal connection with the land. As an exemplar, Louise Jay's feelings about her strong connection to the land are evocative:

*I feel a balance when I'm in the bush. I'd rather be at home... there's something sort of very peaceful about it all and that's what I meant by healing. Come back to where you're familiar and your mind hopefully gets back to where it used to be sort of thinking. You feel you're free... you can just look at the world out there... and it's a very peaceful sort of sensation. And perhaps there'll be a goat coming up to rub up against you, and he's sort of saying it's okay too, it's good - Louise Jay.*

Louise Jay's words are fascinating - she was describing a connection to the land that has often been discussed by indigenous peoples in Australia, but it is not often acknowledged in public forums that this same sense of spiritual connections can occur for others who love the land and have often spent their lives living with, and working on, the land.

### **Living in the bush... it makes you strong**

A third aspect of participants' stories which relate to the positive influences of rurality relates to the women's perceptions of themselves as 'rural women', which they then used as an interpretive lens through which they described their resilience in the face of breast cancer. A number of participants defined themselves as 'rural women', and felt that this implied a sense of strength and stoicism, developed through experiences of rural living which had required them to work hard and cope on their own:

*Living in the bush... I think it's a much harder life and you learn to live with it. You're isolated and you work very hard physically. And people do things for themselves. When you're away from the city, you have to do everything yourself - Florence; and,*

*We've always lived on the land. It makes you strong. I think it is because you go out and you milk cows, and you feed - help feed pigs, you help feed the cattle, you come in, you look after your family, like after milking at night, you come in, you put your tea on, you bath your kids, you feed them, get them to bed, and then you feed yourself and you wash up and you bath and you go to bed. You get up in the mornings and it's the same thing all over again. You got no time to sit down and think of yourself. And I think that helps build you up - May; and,*

*I think country women are more positive and can get through a lot more things because they've handled the children and that, you know. And they've had to learn to cope themselves - Evelyn.*

## **DISCUSSION AND CONCLUSION**

The stories of participants in this study revealed that rurality is a complex factor for women living in rural areas who are confronted with a health crisis such as breast cancer that, for survivors, becomes a chronic illness. The women in this study were vocal in expressing their love of rural living, and their dislike of 'the city'. They acknowledged the particular difficulties they faced as rural

women, yet did not depict themselves as 'victims' living marginalised lives in communities beset by hardship. This challenges the conventional wisdom that rural life is more difficult than urban living, and is a cause of ill health.

A similar finding was reported by Wainer (1988). She asked rural women to discuss their perceptions of health and illness. She found that they described themselves as healthier than urban women in Australia, despite having less access to health services and living in more hazardous environments.

Similarly, in a recent study involving 394 randomly selected participants in Queensland, Australia, women who lived in major rural towns reported fewer symptoms of stress, anxiety and depression than women in urban, remote and smaller rural areas (Rogers-Clark, Bramston and Hegney 1998). Whilst women in smaller rural towns and remote areas reported more symptoms of psychological distress than women in major rural towns, the extent of their symptoms was similar to women in urban areas. This suggests that location by itself may not be an important factor in predicting the degree of emotional distress in a community (Rogers-Clark, Bramston and Hegney 1998).

These findings are significant because discussions of rurality that identify only the difficulties associated with rural living (for example Humphreys and Rolley 1991) are missing half of the story. This positive dimension of rural living tends to be ignored in scholarship and research about rural living. This is understandable, however, given the well-documented problems in rural communities, which include downturn in rural economies, a decreasing population, and lack of services (Humphreys and Rolley 1991; AIHW 2000).

Perhaps some rural women have found ways to survive through difficult life circumstances. Rural women might be able to draw upon a number of strengths to empower their responses to psychological and social stressors. These strengths could include a pride in the achievements and traditions of rural living, a culture of self-reliance, strong family connections, and a strong sense of community (Bigbee 1987).

It is ironic that, in the drive to highlight the significant social and economic problems that rural communities are experiencing, the positive aspects of rural living are dismissed and replaced with images of decline and hardship. Inadvertently, this could actually be adding to the declining populations of rural areas and the inability of rural communities to attract professionals like nurses and medical practitioners to their areas.

In relation to rural women with a history of breast cancer, it is vital that any interventions seek to build on the strengths of rural communities in relation to lifestyle and support, rather than assuming that rural communities are defined by their absence of specialised services. This study has determined that the informal supports available in rural communities are often highly effective in assisting people

through a health-related crisis. Hence, future programs to support rural women should have a partnership framework, with a key strategy being to identify and work with these informal support systems.

The specialist breast cancer nurse role has been evaluated in Australia, and found to be highly effective in supporting women with breast cancer (Liebert 1998). The establishment of specialist breast care nurses in key positions where they can provide ongoing information and support to women in rural and remote areas would provide direct services to rural women. In addition, a key aspect of the specialist breast care nurse role is to facilitate the development of better links between tertiary health and rural health facilities, which includes referral to community health services and specialist allied health services as well as to the woman's general practitioner, ensuring holistic continuity of care for the rural woman confronting breast cancer.

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