

# Indigenous women's perceptions of breast cancer diagnosis and treatment in Queensland

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**B**reast cancer is one of the most prevalent cancers in Australia, with an estimated one in 14 women developing the disease during their lives.<sup>1,2</sup> The majority survive. There is little evidence related to the incidence of breast cancer among Aboriginal women and Torres Strait Islander women, but it would appear that the incidence is slightly lower; mortality rates, however, are similar to or higher than for other Australians.<sup>3-5</sup> This appears to be the result of delayed diagnosis, due to the reluctance of women to perform breast self-examination (BSE) and to attend for screening mammograms; and delayed treatment, as Indigenous women are more likely to present to health services with later-stage symptoms.<sup>4</sup> Indigenous women are also less likely to receive or complete treatment, are less likely to present for breast care and/or seek assistance with prosthetics after surgery, and are less likely to receive quality care with end-stage disease. The assumption has been that these women's decisions to accept or reject treatment are influenced by geographic and structural factors, such as access to services and economic status.

In this paper, we explore these issues and other attitudinal and experiential factors that affect screening, diagnosis, treatment and post-treatment care.

## Methods

Research was conducted over a period of nine months in 1998/99 among Aboriginal women in Queensland, in response to their requests during our previous work on

cervical cancer screening.<sup>6</sup> This research was guided by an Indigenous Steering Committee and the Indigenous researcher (Kirk) and aimed to identify cultural, gender and logistic/distance issues that affected women's awareness, detection, treatment and post-treatment care and the availability of support for women with breast cancer. Qualitative research methods, including interviews, case histories and focus group discussions, were conducted and triangulated with community feedback and discussions with the steering committee. On completing fieldwork, a preliminary analysis of the data was circulated to women from the study sites to obtain further feedback and to verify findings.

Fieldwork sites were selected purposively to explore differences among women from geographically dispersed communities in terms of their understandings of breast cancer and the effects of proximity to health services and population density on their use of health services.

In inviting women to participate in the study, Maureen Kirk drew on her personal contacts and community networks with Indigenous women and Aboriginal Health Workers throughout the State. These derived from her own relationships with families, her role as an Aboriginal and Torres Strait Islander cancer support person at the Royal Women's Hospital (RWH) in Brisbane, and her role as the Indigenous project officer in the Women's Cancer Screening Services in Queensland Health.

Representativeness was assured by the geographic distribution of communities and

## Abstract

**Objective:** To identify social, structural and personal factors among Indigenous women in Queensland associated with the detection of breast cancer, and the treatment and post-treatment care and support of cancer.

**Methods:** Qualitative research including interviews, case studies and focus group discussions were conducted, among Aboriginal women and service providers in urban, rural and remote areas of Queensland over nine months in 1998/99.

**Results:** A range of factors were identified as influencing women's willingness to perform BSE, receive screening mammograms, and receive and complete treatment compared to the non-Indigenous population. Personal history of health services, provision of information about mammography, the cost of treatment and care, and availability of personal support, all influenced women's willingness to access services and maintain treatment. Indigenous women in Queensland experience various barriers to effective and appropriate detection, treatment and care of breast cancer.

**Conclusion:** Barriers to diagnosis, treatment and care can be addressed by increasing women's awareness of breast cancer and the benefits of preventative health behaviour, and improving the quality and appropriateness of health care and counselling services for Indigenous women and their families.

**Implications:** Indigenous women's knowledge and practice relating to the early diagnosis and prevention of breast cancer may improve through outreach work with women, to encourage their confidence in preventative health. Women's commitment to preventative health will also be enhanced by improved quality and access to health care, and improved relationships between practitioners and patients.

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individuals, and the extensiveness of interpersonal connections for any Indigenous Australian. We recruited participants from urban (Brisbane and Sunshine Coast), rural (Cherbourg and Cunnamulla) and remote areas (Mt Isa, Cairns, Weipa, Kowanyama, Aurukun and Cloncurry). We planned to include Doomadgee and Burketown, but were unable to do so because of the extended wet season and lack of transport into and out of the towns. Due to financial constraints, we did not travel to the Torres Strait Islands and no Torres Strait Islander women participated in the study.

The data presented here derive from interviews, case histories and focus group discussions with 101 Indigenous women of child-bearing age or older. Most were women over 40 years and eligible for breast cancer screening, but several younger women also participated in interviews and focus groups. Interviews were semi-structured and explored women's experiences of, and attitudes towards, breast cancer, health care delivery and support services. Extensive case study interviews were also conducted with women who had had breast cancer or were undergoing treatment at the time of the research. Focus group discussions allowed us to explore differences in views about services and care among community members. Interviews and discussions lasted from 30 minutes to three hours and were recorded and transcribed. Eight men also participated in interviews and discussions. All interviews and focus groups were conducted in women's homes by the researchers.

We also reviewed health care and support services in the selected communities and conducted interviews with 85 health service providers, counsellors and support workers. In this component of the study, we were interested in the organisation of health services and the relationship of the services with communities and Indigenous women. Following data collection and transcription, we identified key themes and attitudes. Data were analysed according to region, different stages of breast cancer and key themes.

### **Defining health**

Women's understandings of health and illness, including diseases such as breast cancer, are mediated by personal experiences and social, historical, cultural and structural factors. Women with limited involvement in traditional Indigenous culture tended to describe health in physical and biological terms.\* However, few had clear ideas about the biological processes of breast cancer. Throughout the State, women emphasised spirituality, connections with the land and interpersonal relationships when speaking of health: "Health is very holistic, your identity, where you belong, where you belong in the community, where your country is. That is what health is for us" (urban woman).

Although some women in remote areas gave credence to the

idea that breast cancer could be invoked through 'payback' systems,\*\* most attributed cancer to lifestyle factors, such as changes in diet, stress, smoking, alcohol and lack of exercise. At the same time, they saw the body as a locus of social relationships and focused not on disease processes, but on the impact of breast cancer on their lives, the lives of their families and the community. Women viewed health in positive terms, not as the absence of disease, but in relation to a woman's ability to perform daily activities and fulfil familial roles. Women felt it important to have good health for the sake of the family, but also saw good health as being achieved through good relations within a family. Personal preventative health behaviour, in contrast and consequently, has a low priority. Rather than taking measures to prevent illness, women respond to illness when it hinders their activities.

### **Awareness of breast cancer symptoms**

Most women could describe at least one symptom of breast cancer. Women under 40 years were generally better informed than older women in their knowledge of symptoms, but on the other hand, did not regard breast cancer as a concern to them. This was reinforced for them by BreastScreen promotional material which encourages women, especially aged 50-69 years, to present for mammography.

Many women said they would go directly to a doctor if they found a breast lump, but those who had had diagnostic mammography or had had breast cancer said that their initial reactions to finding a lump were fear, shock and the belief that 'it couldn't happen to me'. Many chose not to seek professional advice, therefore, in the hope that the lump will go away. The sister of one woman who found breast lumps but delayed seeking treatment and subsequently died said: "I think it is fear and facing up to what it might be. They find a lump. They think it might go away and when it gets worse, that is when they go to the doctor and find out" (urban woman).

Late presentation is not uncommon among Indigenous Australians and is related to the availability, use and quality of primary health services, especially preventative services and people's distrust of services.<sup>7</sup> As discussed later, Indigenous women attend screening and primary health care services less often than non-Indigenous women, and breast abnormalities are consequently less likely to be detected routinely by health practitioners. Multiple factors influence their willingness to detect anomalies in breast tissue and to seek medical advice, resulting in delays in presentation until there is advanced disease.

### **Breast self-examination**

Current evidence is that breast self-examination (BSE) does not lead to a reduction in breast cancer mortality or morbidity, most lumps identified in this way are benign and the procedure

\* In addition, women's ideas of disease etiology and treatment have often been reconfigured through exposure to biomedical concepts: "Certain herbs or grasses or berries would probably have a lot to do with the immune system which is essential to get right with something like breast cancer" (remote woman).

\*\* 'Payback' refers to retaliation against the perpetrator of an offence, usually carried out by a member of the family under a kinship obligation to the person against whom an offence has been committed.<sup>16</sup>

provokes anxiety.<sup>8,9</sup> Nonetheless, many Indigenous women have been taught BSE by health practitioners, it is widely promoted as assisting in early detection, and, arguably, raises women's awareness of the prevalence of breast disease and the importance of early treatment. That is, the promotion of BSE increases women's awareness about breast cancer. However, women in this study said they lacked confidence in their technique and ability to recognise symptoms, they did not self-examine regularly enough to know when there had been a change in their breasts, and they were anxious when they found a lump:

*Sometimes when I do check I think, "is that lump or is that just the way the breast is?" I think a lot of women must think that too. They think they might have found something (rural woman).*

Women also commented that it was not always possible to find the privacy to check their breasts because their houses were busy and full of people. They were amused at how others might react were they to interrupt women when they were in the shower or on a bed touching their breasts.

### **Attitudes to breast screening services**

Within and beyond the context of cancer, breasts are imbued with personal, social and cultural meanings. Indigenous women described breasts as symbols of womanhood, sexuality, reproduction and nurturing children:

*They nurture our children, and it is part of the female that belongs to us, the femininity that is ours. That's life, one of the ways that we sustain our children, for life-giving to our children (rural woman).*

Among some remote communities, breasts have a public ceremonial significance in some traditional dances, but in daily life in these communities, as elsewhere, women are modest and regard their breasts as private. Consequently, women prefer female health workers to carry out breast screening and conduct educational sessions. Even then, they said they would be 'shamed' (embarrassed) to reveal their breasts to someone for examination or screening.

Women identified the benefits of attending screening as the early detection of cancer and ensuring peace of mind. Those with a family history of breast cancer perceived a personal risk of developing cancer and attended screening services. This association was compounded for women in remote communities, including Far North Queensland, who in the past were flown to screening centres for diagnostic mammography and for whom routine screening has only been an option since 1999. Accordingly, "the women folk think it [screening] is only for people who have got lumps or for families who have got cancer" (remote woman). In addition, women fear the implications of the detection of breast cancer symptoms. This fear was acute among those who personally knew Indigenous women who had been diagnosed with breast cancer. Many women assume that the prognosis of abnormal screening results is death. Other women did not go to screening because they felt 'it couldn't happen to me':

*If I hadn't of found a lump there I would have been like anybody else (sic), I wouldn't have worried about mammograms, I wouldn't have worried about screening later in my life. What they say is*

*'don't come across it, it won't hurt you, so don't worry about it'. So I think there is heaps of women out there that do that, they wouldn't be bothered (urban woman).*

The environment in which health services is delivered influences women's experience and their likelihood to present a second time.<sup>6</sup> Women who had presented at a BreastScreen service were generally satisfied, described staff as pleasant, and felt that the radiographers had explained the screening process clearly. However, women were often critical of the location of relocatable or mobile services, and emphasised the need for services to be central and easily accessible for women who lacked access to public or private transport. In rural communities, where screening took place at Aboriginal Community Health services, women felt particularly at ease and 'safe'. Aboriginal Health Workers (AHW) were said to be important for promoting a 'culturally safe'\*\*\* environment and increasing community awareness of screening and breast cancer. Women saw the fixed appointment system as a major barrier to Indigenous women attending screening, conflicting with 'Aboriginal time' and precluding the possibility of women 'dropping in' for screening.

### **Diagnosis and assessment**

With diagnosis, women are thrown into a new and complex world within which they have to absorb and interpret complex information while coming to terms with the frightening and life-threatening nature of the disease.<sup>10</sup> This is complicated by the language used by health practitioners at diagnostic consultations, which women found alienating, intimidating and unclear, whether they spoke standard English or Aboriginal English: "They sit down, they talk to you, but the words that they say to you, you know, they don't put it in terms how I'd understand" (rural woman).

Many women know little about breast cancer treatment until diagnosis, and as a result of the shock of diagnosis and difficulties in understanding medical advice – with respect to terminology and to the treatment procedures – they were often unclear about their treatment options and efficacy: "We just know about how to find lumps in the breast, not about surgery. They don't go into that. I'd like to find out now though so I know what to expect. I think one of the reasons that women leave check-ups too late is because they don't know these things" (rural woman).

One woman, for example, had had a mastectomy, but said she had not understood her treatment options and recognised neither the term 'mastectomy' nor 'prosthesis'. Another woman said that the consultant who conveyed her diagnosis had not explained to her that the disease could be cured, and she assumed she would die from breast cancer. Indeed, many women equate breast cancer with death: "It is a killer to me. A lot of people say that they can treat it and get rid of it, but they can't. You always hear on the

\*\*\* See Dyck and Kearns<sup>17</sup> for a discussion of cultural safety in New Zealand. Indigenous Australians use the term to include both cultural sensitivity and appropriateness, and personal security.

news that they have found a treatment for it, but I think cancer is one thing that they can't find treatment for" (rural woman).

Breast cancer is usually surgically treated within a few days of diagnosis. Many women said they would want to be treated as soon as possible, as delay between diagnosis and treatment would only increase their anxiety. Others, however, felt rushed into making a decision and felt they were not given adequate time to adjust to diagnosis, reflect on how their lives might be affected or make practical arrangements.

### **Treatment**

Treatment for breast cancer is available through hospitals and institutions in Brisbane and some regional centres. In rural and remote areas, however, treatment services are limited and women are generally referred to large regional hospitals. Women who had been treated for breast cancer, and their families, found the process to be disjointed and disorienting:

*Doctors can diagnose, but they don't follow up with it properly. Or they refer you on to someone else and you don't have time to build up a rapport with anyone. You don't know where you are, you're confused, you've got low self-esteem because you're feeling bad about yourself, all this fear comes into it (remote man).*

Some treating centres involve an Indigenous Hospital Liaison Officer (IHLO) in the planning of care. Their role includes coordinating support, organising subsidised transport and accommodation, liaising with treatment staff, talking through treatment options, and mediating between patients and staff. Women who had been assigned IHLOs said their support was invaluable. However, the limited number of IHLOs means that few women have access to their support.

Women perceived treatment as a time of great stress. While most took the pragmatic view that surgery was a necessity, some women were uncertain of the effectiveness of biomedical treatment to cancer, and were concerned with the effects of disfigurement. Women agreed that it would be difficult to deal with surgical removal of a breast. To lose a breast is to lose its symbolic associations to womanhood, sexuality and nurturing children. Some women also feared that their partners would withdraw love and support:

*Losing a breast is a big thing to cope with, that part of womanhood, having a breast. If you were young and you lost it you couldn't breast feed, so that is taking a part of your motherhood, a part of nature away from you, and that is a lot to deal with. Then again, your husband is going to look at you stupid because you are only half a woman (young remote woman).*

Many women from rural and remote areas have limited experience of visiting major regional centres and medical services. Hospitals were described as cold, impersonal and intimidating, and the treatment pathway a potentially negative experience. Women with experience of tertiary care centres reported being treated by hospital staff in inappropriate, racist or disrespectful ways, and tended to be overwhelmed by the environment. Women also reported a lack of a sense of participation and control of their treatment because of their unfamiliarity with the disease, medical procedures, and terminology:

*I think it is scary for an Indigenous person to go down to the city and have no one there supporting them ... sometimes the doctor can speak to them and they would not understand what they had been told ... I mean they will probably really want someone from their family (rural woman).*

Women's treatment decisions are often influenced by family considerations, such as a given treatment requiring women to be away from their homes and families.<sup>11-12</sup> This is particularly true for women from remote communities, who were reluctant to place their personal health above the welfare of their children and family, and to leave their community and travel to health services for treatment. "If a person who has cancer has to go away for treatment, it not only affects the person, but the whole family. There are a lot of factors then impacting on that decision to go away to Brisbane for a week of treatment – looking after elderly people in the family, looking after other people in the family with problems" (remote woman).

Treatment adherence may also be affected by women's understanding and experience of the treatment process, including the side effects of chemotherapy and radiotherapy, such as nausea, vomiting, fatigue, and weight and hair loss,<sup>13</sup> and impaired arm movement after surgery. This does not fit with the women's view of health as feeling well and being able to care for one's children (or grandchildren). Accordingly, women may choose to discontinue the treatment: "I know that my aunt had chemotherapy for breast cancer, but I don't know how well it treated it. She had it a couple of times but then stopped it. It made her sick. She didn't feel that it was doing her any good" (remote woman).

### **Breast reconstruction and prostheses**

Few women have experience of breast prostheses and reconstruction. Women, particularly from rural and remote areas, said they would not choose to have reconstructive surgery in order to minimise the time spent away from their community and family. Women can also be fitted with an external breast prosthesis, but while fitting services operate in major regional centres, in rural and remote areas there are a few stores that sell prostheses or have qualified prostheses fitters. Furthermore, women may feel too shy to present for a fitting, may be unused to wearing or buying bras, and particularly unused to having a fitter assist them to purchase underwear. On the other hand, women frequently said that if they had a breast removed, they would no longer feel 'whole' or 'womanly', feared that their partners would withdraw love and support, and speculated that breast prostheses and reconstructive surgery would improve their self-esteem and body image.

### **Counselling**

From the time of diagnosis, counselling is important to help women and their families adjust. Emotional responses to diagnosis, surgery and treatment reported by women included depression, anxiety, confusion, a preoccupation with changes to their health and difficulty with usual role functions. Emotional and practical support during illness is often regarded as the role of family members.<sup>11</sup> However, women are wary of burdening family and friends with their concerns and needs, and may prefer to

talk with a professional counsellor who is emotionally removed from the situation: "There wasn't too much that she would say to us and in the end she couldn't talk. But she needed to say a lot of things to somebody, but could never do it for fear of upsetting the family" (remote woman). There is little appropriate professional counselling for Indigenous women and their families,<sup>4</sup> and hence, as one participant explained, "A lot of people mourn in silence. They have got no-one to go to and no-one to talk to and there is quite a few that are really quiet and they don't know how to get around. And they get sicker I reckon if they can't talk" (remote woman). Women want counselling to be available from the time of diagnosis through to the post-operative stages of breast cancer, especially when they have to travel away from established networks to receive treatment and, therefore, experience additional stress and loneliness.<sup>14</sup>

Mainstream counselling services can meet women's general needs, but they are not always appropriate for Indigenous people: "She had a support worker but she was white and she didn't want to ring her, didn't want to talk to her. She wanted someone that was from the same culture. There was no-one up here. I tried looking for someone and there was nothing" (urban woman). Women felt that an Indigenous counsellor would understand cultural issues and communication styles, and would be easier to relate to. Other women felt it more important that the counsellor have a rapport with, and commitment to, the community, and respect confidentiality.

Stories of the emotional struggle of families of women with breast cancer were recounted in all communities. Such accounts included alcohol abuse, family conflict, stress, family members having difficulty adjusting, and the need for counselling and/or support: "The brothers and partners went through a lot of pain. I felt really sorry for them, they had no-one outside the family to talk to, and even the family didn't know how to cope with it" (rural man).

## Conclusion

Indigenous women in Queensland experience a range of barriers to effective and appropriate detection, treatment and care of breast cancer. These barriers can begin to be addressed by increasing women's awareness of breast cancer and the benefits of preventative health behaviour, and by improving the quality and

appropriateness of health care and counselling services for Indigenous women and their families. Many women perceived the locus of control for improving health care and health status as lying with health practitioners and government bodies. However, a number of women are calling for increased community participation in health care services. This supports the National Aboriginal Health Strategy, which said that community control of health programs was crucial to the wellbeing and health of Indigenous communities.<sup>15</sup> Improved screening, detection and treatment for breast cancer and the care of women with the disease requires health practitioners to better serve the needs of Indigenous people and Indigenous people to take an active and participatory role in their own health and health care.

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