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Cultural strengths and social needs of Aboriginal women with cancer: Take away the cancer but leave me whole.

By

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A thesis submitted in fulfilment of the requirements for
the degree of Doctor of Philosophy at the School of
Population Health

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Declaration

I hereby declare that the work presented in this thesis is to the best of my knowledge and belief, original and my own independent work, except as acknowledged in the text. The material has not been submitted, either in whole or in part, for a degree at this or any other university.

Signed: D. J. Prior

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ABSTRACT

This study aims to explore the meaning of cancer for rural Aboriginal women and the cultural context that influences their decision-making about cancer treatment and support services. The motive for this study is to understand why Aboriginal women participate in cancer screening programs but are either reluctant to return for follow-up of abnormal test results or hesitant to follow medical advice about treatment.

Cancer has been considered a lesser problem for Aboriginal women because they suffer morbidities from other systemic diseases and have a relatively short life expectancy, approximately twenty years less than non-Aboriginal women. But recent epidemiological observations demonstrate an increasing incidence of respiratory system cancers, particularly smoking related diseases, in the Aboriginal population generally and a growing incidence of cervical and breasts cancers in Aboriginal women, who also suffer a disproportionate cancer mortality rate compared to other Australian women.

This thesis reports on interviews and fieldwork observations I undertook in two rural Aboriginal communities in Queensland. I used the broad approach of interpretive ethnography as the methodology for this study. The principal method is fieldwork, which involves my spending time living in the communities and experiencing first hand the context that is the everyday world of the participants. My fieldwork data collection occurred over two years, during which I have made numerous field visits of one to two weeks at a time. To facilitate my data collection, I engaged two local women to act as field mentors and mediators, and to escort me around their respective communities. Being with these 'insiders' enhanced my research position in developing the researcher-participant relationship necessary to generate rich data and unique opportunities to observe close-up the lives of many different

participants. Data collection methods were face-to-face interviews, focus groups and participant observation. Other sources of data were medical records, historical documents and government reports. I used the conceptual frame of *cultural identity, relationship and expectations* and *cultural empowerment* from the PEN-3 model to highlight the cultural constructs that emerged from the data.

The findings are that many Aboriginal women blame the *whiteman's* invasion and colonisation of their traditional way of life and denigration of their culture for the increasing prevalence of cancer in their communities. Cancer is a dreaded disease in all societies, but, for Aboriginal women, it presents an additional threat of positioning them, as once again, vulnerable to what is perceived as the colonial mentality of Western biomedical institutions. A consequence of this tension is that the women avoid the risk of becoming entrapped in the biomedical system by, for example, denying their symptoms or ignoring medical advice about following-up abnormal cancer tests. Consequently the women are likely to present with late stage disease at the time of diagnosis, which means treatment options are palliative rather than curative.

Even with palliative care holistic options for symptom management many of the women remain ambivalent about following medical advice. The women choose instead to go their own way, which usually means returning to their rural community where predominantly primary health services are available. Another important finding is that the cultural needs of Aboriginal women for family support and care are compromised in the biomedical institution of a city hospital. A concern of the women with cancer is that being in a city or regional hospital hinders access to traditional medicine and healers, which are considered vital in the holistic care of the sick person and their families, and necessary in preparing for the transition from life to death.

I propose that public health strategies for reducing cancer morbidity and mortality rates of rural Aboriginal women should be focused on an agenda for promoting cultural empowerment which profiles Aboriginal culture in all stages of cancer related services or interventions for this population. This approach involves a program that increases understanding and respect for Aboriginal culture among non-Aboriginal health-care staff and means that culture is the central point from which services are developed. A key strategy for cultural empowerment is recognizing the cultural significance of the sick person's need to be with family and friends and in their community, particularly when in the palliative phase of the disease. I propose that a palliative care approach that promotes cultural empowerment builds on the 'cultural strength' of a community and is a service that works to complement or integrate traditional practice and healing processes rather than imposing Western methods as the dominant paradigm.

INTRODUCTION

The aim of this thesis is to explore the meaning of cancer for Aboriginal women living in rural communities. I also examine the cultural context informing women's perceptions of cancer and consequently their treatment decisions. The impetus for this inquiry is to understand why Aboriginal women participate in cancer screening programs but are ambivalent about returning for follow-up of abnormal test results and are unlikely to comply with medical advice about cancer treatment. The concern underpinning this study is the increasing incidence of cancer and the disproportional rate of cancer morbidity and mortality suffered by this population. Understanding the cultural context and values that influence women's decision-making about cancer can reframe disease management from a purely biomedical event to a process that accommodates the cultural domains of importance to Aboriginal women.

The central thesis I propose is that Aboriginal women are ambivalent about cancer treatment and choose to forgo medical advice in order to avoid being entrapped by the Western biomedical system, which they perceive as another form of colonial authority. The metaphor of colonialism relates not only to the women's view of biomedicine but also to the fact that they perceive cancer to be a threat to their physical and cultural integrity. A diagnosis of cancer compromises the women's cultural integrity on three counts: firstly, biomedical cancer treatment requires the women to leave the relative security of family and friends and their home community; secondly, while in the care of hospitals the women are unable to access traditional healers and medicines that are important to the women and their families when dealing with the serious disease of cancer; and thirdly the reductionist approach and objectivity of biomedicine are discordant with the Aboriginal women's notions of holistic health care, which aim to harmonise relationships of 'body-land-spirit' for healing and preparing for the transition to death.

The Aboriginal women are generally well informed about cancer and understand the benefits of early detection, but regardless of this, the participants of this study are hesitant to follow medical advice about treatment or to return for a follow-up if cancer screening reveals abnormalities. A consequence of the ambivalence toward cancer treatment is that the women are more likely to present with an advanced untreatable cancer when diagnosed. In addition cultural differences in perceptions of cancer and the outcomes of screening tests means that Aboriginal women receive relatively less benefit from cancer support services than their counterparts in the non-Aboriginal population.

Cancer is arguably one of the oldest human diseases remaining as a major cause of morbidity and premature mortality in developed countries. In the dawning years of the twenty-first century the aetiology of cancer is generally inconclusive and an absolute cure elusive. During the last century, cancer has replaced contagious diseases as a major biomedical and public health issue. The success of medical science in controlling contagious diseases together with public health strategies of sanitation and mass immunisation, for example, has improved the health of people in Western countries sufficiently for them to enjoy an indulgent life-style and become old enough to develop cancer. Epidemiological observations confirm that cancer in women is associated with affluent living, aging and just being a woman (Le Fanu 1999).

In poor countries, cancer is not usually considered a major health issue since people from these countries remain susceptible to diseases of contagion, poverty and malnourishment.

Currently in the twenty first century, a paradox exists where half the world's population die young from poverty-related infectious diseases and under-nutrition while in the richer, Western societies like Australia many health problems are related to over-indulgence (Campanini & Haden 2002).

Health disparities are particularly evident in Australia; this country has one of the healthiest populations in the developed world, yet the health of Indigenous Australians[1] is described as 'the least healthy of all Indigenous populations within comparable developed countries' (NATSIHC 2004 p.7). Another paradox is that Aboriginal people suffer from the lifestyle diseases of the first world like obesity, diabetes and alcoholism and at the same time continue to suffer from third world contagious diseases usually associated with poor living conditions.

In Western cultures the metaphors of warfare and social deviance are deeply entrenched in cancer discourses. Gillian Rose (Rose 1995 p. 71-2)who writes about her experience of having advanced ovarian cancer, captures what cancer means in Western cultures:

> For you, 'cancer' means, on the one hand, a lump, a species with multiple properties, on the other hand, a judgement, a species of ineluctable, condemnation.

Assumptions about what cancer means to a woman have justified the population-based approach of surveillance and monitoring of women's bodies in the interest of early detection of the disease. Currently biomedical methods for controlling or treating and supporting people with cancer seem to assume that women with cancer are a culturally homogenous population. Contained within this assumption is a taken-for-granted logic that having been diagnosed with cancer all women will wish to rigorously pursue the biomedical pathway constructed for them.

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[1] Indigenous Australian peoples are the Aboriginal and Torres Strait Islanders and are culturally distinct.

Culturally different aspirations in cancer health care are apparent through, for example, the anecdotal evidence that Aboriginal women do not benefit from the standard support program *Living with cancer* (LWC) (Todd, Roberts & Black 2002) that is designed to empower cancer patients with knowledge and coping skills. It has been observed that Aboriginal women either do not attend this program or abandon it after attending the first session. Reasons for non attendance include women's feeling of discomfort with open discussion about personal health matters that is encouraged in the program (Carrick et al. 1996). Moreover some cannot relate to the Western concepts (NBCC 2003) which is why the information appears not to be relevant to them (Jacka 2000).

Traditionally the socialisation of women with cancer has been influenced by the dominant biomedical discourse that constructs the sick-role of a compliant, optimistic, cancer patient willing to endure hazardous and invasive treatment on the basis of the medical claim that this might eliminate the disease. But it has been observed that Aboriginal women with cancer frequently contradict the expectation of this Western construct of the sick role. For example, if cancer screening reveals an abnormality, Aboriginal women seem less likely to follow-up with medical advice for further tests or clinical examination and may well abandon treatment before completing the prescribed course (Carrick et al. 1996; Kirk et al. 1998; Sullivan 2003). A consequence of non-compliance with medical expectations of a cancer patient is that the women place themselves at risk of suffering preventable or controllable symptoms of a malignant disease. In the relatively small Aboriginal communities, the negative experience of cancer sets up a self fulfilling prophecy that cancer means pain, suffering and inevitable death. Consequently when the women witness family and friends dying with cancer and there is no evidence in their community of cancer survivors, it is not surprising that their fatalistic attitudes toward cancer becomes deeply entrenched.

The problems of cancer for Aboriginal women

Cancer has often been considered a 'lesser' problem for Aboriginal women because they suffer so many other morbidities from systemic diseases (NATSIHC 2004). On the contrary, current epidemiological studies of cancer incidence in Aboriginal communities indicate a rising trend in the rates of respiratory system cancers, smoking-related lung cancer in particular, and cervical and breasts cancers in Aboriginal women and a disproportionate cancer mortality rate compared to other Australians (Condon et al. 2003; Zhoa, Condon & Garling 2004).

Explanations for rural Aboriginal women's underutilisation of cancer screening and other services have been related to logistic factors such as the geographic distance from central services, as well as assumptions about the cultural practice of needing to 'go bush'[2] when a disease is perceived to be life-threatening. Alternatively non-compliance is explained in relation to perceived preferences for using traditional medicine or even to the perception that Aboriginal people are less concerned about being healthy. These assumptions contrast with a number of reports which show that generally Aboriginal people base their health care decisions on the extent to which a problem impacts on their social and community commitments (Kirk et al. 1998; McGrath et al. 2004; Morgan, Slade & Morgan 1997; Sullivan 2003). In addition, when an Aboriginal person has a life threatening cancer, cultural and spiritual needs are vital issues (McGrath et al. 2004; Trudgen 2000). Studies demonstrate

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[2] Needing to *go bush* is a colloquial term for the country or place with which the Aboriginal people are spiritual connected; ideally it is the place of their birth or close to the land of their ancestors. (Lawlor, R, 1991. *Voices of the first day*, Inner Traditions, Rochester, Vermont.

that if medical cancer treatment is perceived to compromise the socio-cultural position of an Aboriginal woman, that is reason enough to turn away from conventional treatment (Kirk et al. 2000; Thurecht 2000).

Public health policies to redress the health disparities in Aboriginal communities are informed by low participation rates in cancer screening and high morbidity and mortality trends in this population (Condon et al. 2004; Coory et al. 2002). Surveys have also identified socio-cultural barriers to women's access to cancer services (Kirk et al. 1998). Other studies highlight the limitation of rural and remote community health services plus the logistical problems of transport and finances (Fagan 1998; Kirk et al. 1998; Reath & Usherwood 1998). However, few published studies explore the social-cultural context influencing Aboriginal women's health care decisions or examine what cancer means to the women in terms of their lifestyle and culture.

While surveys and other empirical studies provide necessary details of the extent of the problem of cancer incidence, morbidity and mortality and the degree of participation in cancer screening, they fall short of revealing the underlying psychologies and cultural influences on health behaviours. The studies of Kirk et al. (1998 and 2000) provide an explanatory framework of cultural difference that accounts for Aboriginal women's limited use of cancer services, but the study's design does not enable deep exploration of what cancer means to the women or how they perceive the disease. Nevertheless, the study of barriers to cervical cancer screening, which used qualitative methods of focus group discussion, in-depth interviews and ethnographic observation, was able to demonstrate more than the usual logistical or cultural barriers. In fact the study in question showed the real deterrent to the women had been the misunderstanding about the purpose of cancer screening (Kirk et al.

1998). The women in Kirk et al's (1998) study refused to undergo the cervical cancer test believing it to be a type of cancer treatment or a test for sexually transmitted diseases, conditions that they did not wish to be associated with. Clearly these findings indicate that adding more services or mobilising these to the communities will not necessarily address the problem of 'non-compliance'. In other studies qualitative methods revealed women's fears associated with cancer and screening were attributed to cultural mores about the privacy of women's business as well as a deep-seated fear about the outcome of screening, because these tests can reveal, from the woman's perspective, a death sentence (Kirk et al. 1998; Thurecht 2000).

Fear of cancer is not unique to Aboriginal women. The history of this disease contains the failure of medical science to find a definitive cure for cancers, or a guaranteed preventative method. Aboriginal women's perceptions of cancers need to be understood within a cultural context comprising the historical background, values, beliefs, traditions, experiences, social structures and so forth in which the fear of cancer is constructed. An important cultural distinction between the Aboriginal women in this study and their counterparts in the non-Aboriginal population is their history of colonisation that has left deep scars in the psyche of Aboriginal communities. The history of Aboriginal people since European colonisation that compromised their culture and traditional way of life, not only distinguishes them from other Australian cultures but is also an important influence on their health status and decisions about health care (Carrick et al. 1996; Fagan 1998; Kirk et al. 1998; Kirk et al. 2000; Kong 1998; Prior 1997; Reath 1999).

Cultural differences between the Western approach to biomedical health care and Aboriginal cultural ideology of holistic health care are identified by several important authorities including the National Aboriginal Health Strategy (NAHSWP 1989), which asserts: 'Aboriginal culture is the very antithesis of Western ideology' (NAHSWP, p. ix), a position reiterated in the 2004 National Strategic Framework (NATSIHC 2004). On a similar note, in the Report on the Royal Commission into Aboriginal Deaths in Custody (Johnston 1991 p. 229) Commissioner Johnston concluded:

> Over and over again we hear of serious health problems being caused or exacerbated as a result of Aboriginal people and health professionals viewing common concerns in quite different ways.

Although these cultural differences have been reported for some time, the paradigm shift necessary to accommodate or integrate Aboriginal cultural values and traditions into biomedical methods is yet to be realised. The incongruence of cultural perspectives helps to explain why Aboriginal people under-utilise specialist sectors of health care like cancer services and are reported to undergo fewer diagnostic procedures relative to their apparent needs (Cunningham 2002; Fisher & Weeramanthri 2002). It should not be concluded that Aboriginal people are less concerned with health issues or that they do not understand the seriousness of a disease like cancer. The decision to access cancer services can be related to different social priorities and motivations where decisions about health are considered from a position of the well-being of the family and community rather than an egocentric stance of 'what is best for me'.

In this thesis I argue that public health strategies designed to overcome the unequal burden of cancer for Aboriginal women have not positioned culture as the pivotal point in the design or the implementation of strategies or services (Airhihenbuwa 1995; Airhihenbuwa & Obregon 2000). The employment of Aboriginal cancer liaison health workers has increased women's attendance at screening clinics and to some degree their 'compliance' with medical advice. However, I suggest that the training programs and infrastructures supporting these Aboriginal health workers in their role equip them principally to interpret biomedical methods and jargon rather than enabling them to promote the construction of culturally centred cancer services.

Cultural perspectives of Aboriginal women are considered in some public health initiatives in Queensland, such as the *Healthy Aboriginal women in mind body and spirit* program that aims to encourage women to undergo Pap smear testing and the *Hey Tidda*[3] breast cancer health education material. Both these programs were designed and presented by Aboriginal women, some of whom have personal experiences of cancer. While these public health programs are encouraging Aboriginal women to consider how to avoid the threat of cancer, this focus on their cultural views diminishes in the biomedical sector of cancer treatment.

In this thesis I explore the cultural meaning of cancer for rural Aboriginal women in order to understand what might constitute culturally appropriate practice in curative and palliative cancer health care. My inquiry seeks to examine the basis for the women's apparent ambivalence toward biomedical treatment. I use the approach of interpretive ethnography for this line of inquiry because the methods of fieldwork and participant-observation position me to hear first-hand the stories and viewpoints of the women and to observe the context of their everyday environment.

The purpose of this research is to take a critical view of two specific concerns, firstly the cultural orientation of Aboriginal women toward the disease of cancer and secondly, the cultural orientation of biomedical institutions toward Aboriginal women. The discipline of

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[3] *Tidda* is an Aboriginal colloquialism for sister or girl.

medical anthropology provides an underlying framework for gaining an insider's perspective of health and illness (Lupton 2003). The critical perspective of medical anthropology seeks to reveal cultural differences in how health and disease are perceived and also to explore the cultural construction of biomedicine. The liberal stance of postmodern social constructionism provides a theoretical frame for critiquing the evolution of biomedicine's conceptualisation of the human body, which has informed the discourse on cancer in medical practice and in society in terms of constructing the sick role of cancer patients.

Summary

In chapter one I describe relevant moments in the evolution of medical anthropology and ethnography as its signature methodology. The purpose of this historical review is to provide a platform for elaborating on the theoretical and methodological orientation of this thesis; I also wish to acknowledge the basis for Aboriginal people's wariness toward research. I explore the principal attributes of interpretive ethnography in terms of the researcher-participant relationship of mutuality and reciprocity and argue that this relationship aligns with the decolonisation agenda of Aboriginal people. Decolonizing research requires a reflexive view of the research agenda. For me this meant listening to Aboriginal women and allowing their voice to determine the direction of my inquiry. I describe the process of gaining ethical approval and acceptance into two rural Aboriginal communities and explain my data collection methods.

In chapter two I describe the details of my fieldwork and identify the various data collection strategies I used, including face-to-face interviews, focus group discussions, observations of community life, medical charts, and artwork used by one participant to tell her story of experience with cancer.

The focus of chapter three is concerned with the conceptualization of the human body. I examine the history of medicine's colonisation of the body, imposed in its endeavour to control human disease. My discussion traces the conceptualisation of the body from the sacred mystic entity of religions to the secular mechanical object of modern medical science that has come to dominate contemporary approaches to health care. I also examine the influence of medical science in shaping the public health agenda regarding the control of the health behaviour of populations and in defining the attributes of a 'civilized' body, which discriminates against colonised Indigenous people and other racially different populations.

In chapter four I explore the biological characteristics of cancer and explain the public health strategies for preventing and/or controlling diseases. I argue that cancer is more than a scientific construct, and is equally a socio-cultural and political phenomenon, including a metaphor of larger social ills (Sontag 1991). I focus on breast and cervical cancer as these specifically concern women and are becoming more prevalent among Aboriginal women. I identify that the success of public health programs in decreasing cancer morbidity and mortality in women is so far limited to Western societies. I argue that colonised Indigenous women and other minority cultures are deterred by the methods of biomedicine that overlook important cultural aspects of cancer screening techniques and treatment methods.

In chapter five I present and analyse the ethnographic data from my research. I also introduce the PEN-3 model (Airhihenbuwa 1995) to help link my ethnographic findings with a broader public health framework surrounding cancer and minority cultures.

In chapters six, seven and eight I use the concepts of *cultural identity*, *relationships and expectation* and *cultural empowerment* from the PEN-3 model to describe participants' experiences of cancer. In order to 'evoke' a lived reality I present verbatim extracts of participants' narratives, anecdotes and colloquialisms. I intertwine points of theoretical interpretation with narratives and extracts from my reflective journal and field notes to convey the 'cooperative story' embedded in this ethnographic study.

CHAPTER ONE

DECOLONISING METHODOLOGY

Medical and epidemiological sciences have produced an abundance of studies describing the magnitude of health disparities and social problems in the postcolonial Aboriginal communities. It is known, for example, that cancer incidence in the Aboriginal population is increasing and that mortality rates of cervical and lung cancer are much higher than in the non-Aboriginal population (Condon et al. 2004). However, knowing the size of the problem will not necessarily translate into interventions that help change the situation, unless the socio-cultural and historical context in which problems or risks are constructed, is understood (Brough 2001). Quantitative evidence catalogues health risks according to predetermined criteria that inform public health policy. Unfortunately the cultural context surrounding health problems often loses its significance when expressed quantitatively (DiGiacomo 1999).

A defining point of the cultural context of contemporary rural Aboriginal society is the history of colonialism that underpins tensions and negative attitudes toward non-Aboriginal authorities as is represented by the research and biomedical paradigms. The effects of colonialism not only distinguish the Aboriginal peoples[4] from other minority groups in Australia, but is a contributing factor in the health disparities in this population (Carrick et al. 1996; Fagan 1998; Kirk et al. 1998; Kirk et al. 2000; Kong 1998; Prior 1997; Reath 1999).

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[4] The terms peoples is used to internationalise the common struggles experienced by colonized people and also recognised the heterogeneity of Indigenous cultures Smith, L, 1999. *Decolonizing methodologies. Research and indigenous peoples*, Zed Books Ltd., London & New York.
In Australian there are many different Aboriginal cultures and languages that vary according to the region whether rural, remote or urban communities and the degree of enculturation by Western socialisation.

The enduring effects of the colonial discourse is explained by Frantz Fanon's (1967, p. 39) influential post-structuralist critique on the influence of colonialism and racism in Africa, in his book *The wretched of the earth,* in which he argued that:

> ...the primary Manichaeism (dual philosophy of good and evil) which governed colonial society is preserved intact during the period of decolonisation; that is to say that the settler never ceases to be the enemy, the opponent, the foe that must be overthrown'. (parenthesis added).

Decolonisation has been part of the political agenda in contemporary Australia for several decades, but has not been as evident in either research or health care methodologies until quite recently. Colonial research has not been confined to the positivist school of the medical sciences as the positional superiority of early anthropologists had similar effects in oppressing and misrepresenting the voice of those they studied. A consequence is that colonised Indigenous peoples are generally wary of research and mistrustful of its motives and outcomes (Smith 1999). Given the appalling social, economic and political inequality between Indigenous and non-Indigenous Australians, it is not surprising that Indigenous societies often see little link between research and improved social outcomes.

In this research I use the qualitative methods of critical medical anthropology, because this approach enables me to explore beyond the measurable, objective problems of cancer incidence, to gain instead an insight into the subjective socio-cultural world in which meanings and perceptions are formed. The suitability of critical medical anthropology for this study is that its reflexive evaluation of all theory and authority, including its own, aims to decentre the traditional basis of power, that the positivist objective methods of inquiry had imposed as another form of colonisation on the subjects being studied.

The historical moments of anthropology

The relevance of this overview of the history of anthropology is not merely to map the chronology of events, but to explain the historical moments (Denzin 1997) that have influenced Indigenous colonised people's mistrustful attitude towards all research. In Australia, for example, even the word 'research' arouses feelings of suspicion and defensiveness among Indigenous populations who feel they are the most studied, measured, classified and counted people (Hunter 2001; Smith 1999; Williams 2001). Linda Tuhiwai Smith (Smith 1999 p. 1), a Maori researcher from New Zealand, sums up how Indigenous peoples feel about research:

> It stirs up silence, it conjures up bad memories, it raises a smile that is knowing and distrustful.

The origin of this mistrust and wariness toward social anthropological and other research is traced to the colonising methods imposed on societies by founding anthropologists, such as Bronislaw Malinowski, Margaret Mead and Franz Boas, and in Australia, Adolphus Elkin and Norman Tindale. For example, Malinowski's (1922 p. 8) approach to fieldwork was to *thrust* himself into every aspect of native community life even at the risk of infringing local lore, as this commentary from his ethnographic text *Argonauts of the Western Pacific* illustrates:

> Over and over again, I committed breaches of etiquette, which the natives, familiar enough with me, were not slow to point out. I had to learn how to behave, and to a certain extent, I acquired 'the feeling' for native good and bad manners.

The contribution of Malinowski's work to anthropology is that he gained credibility for ethnography within the scientific academy. Bronislaw Malinowski defined ethnography as the method of anthropology in his study of the Trobriand Islands people in eastern New Guinea during the early years of the twentieth century (Young 1979). Before Malinowski's careful work, ethnography had been little more than general accounts from missionaries, or colonial administrators, the police and traders who wrote to report their observations of the *natives* (Elkin 1954; Young 1979). In the academy of early anthropology, ethnographic texts were descriptive accounts and classifications of cultural difference such as belief systems, behaviours and symbols, which anthropologists observed during lengthy periods of fieldwork (Elkin 1954; Young 1979). An important outcome of Malinowski's work was the legitimation of fieldwork, participant-observation, fieldnotes and reflexivity as scientific methods that collectively defined ethnography as the methodology of social anthropology. The need to appease the scientific critics, who doubted the validity of ethnography, caused Malinowski to be exceptionally thorough in his data collection methods, despite the clumsiness of his intrusion into the *Other's* life.

Malinowski made what, at the time, were unusual efforts to learn and use the native language as his instrument of inquiry and, during fieldwork, separated himself from the biases and prejudgements of his white colleagues by living in a tent nearer to the living areas of his subjects (Young 1979). His ethnographic data was in the form of fieldnotes in which Malinowski recorded direct observations of what he described as the 'imponderabilia of actual life and of typical behaviour', accounts of the character or 'spirit' of the people, and what he described as – 'the natives' views and opinions and utterances' (1922, p. 20). Despite Malinowski's intention to include the voice of the *Other,* implied by this last statement, there is no evidence in the text of him seeking verification of his interpretations from the people concerned.

Fieldwork remains the keystone of ethnography that traditionally requires the researcher to separate from their usual community in order to spend a long time, months and maybe years, living with the *natives* in order to observe everyday life and gain an insider's view of the *Other's* community. Malinowksi's efforts to fit in, and his careful fieldwork, did not alter the inherent power differential between him and the people he studied, this is evident in the extract from his last monograph on the Trobriander people, whom he apparently regarded as merely of academic interest (Young 1979).

Malinowski wrote:

> Once again I have to make my appearance as a chronicler and spokesman of the Trobrianders, the Melanesian community so small and lowly as to appear almost negligible - a few thousand 'savages', practically naked, scattered over a small flat archipelago of dead coral – and yet for many reasons so important to the student of primitive humanity (Malinowski 1935 cited in Young 1979 p. 11).

The Australian context of anthropology

In Australia, Elkin (1954) undertook extensive anthropological research of Aborigines during a period of twenty years starting in 1926. Elkin (Elkin 1954, p. x and p. 321)approached his research with a desire for cultural knowledge that would be of mutual benefit to the Aboriginal and the non-Aboriginal population as is evident in his reflection:

> We have done them (Aborigines) much wrong and injury...through ignorance even more than through callousness and indifference. Our great need, therefore, is to understand them and the cultural problems, which confront them and ourselves.
>
> Our task is not merely to understand the Aborigines themselves, but also in relation to ourselves, and indeed, also ourselves in relation to them.

Elkin set out to build a body of knowledge about Aboriginal cultures in an effort to dispel the oxymoron *noble savage* originated by Rousseau's romantic imagery of a pre-civilised society (Smith 1999), which had at the time continued to influence Western perceptions of Aboriginal people. Elkin's research provided an ethnographic account (even if one sided) of the social world of an Aboriginal community in the first decades of the nineteen century at a time when what was known of the Aboriginal people Elkin described as 'superficial and scrappy' (Elkin 1954 p. v). In his book, *The Australian Aborigines* (1954) Elkin detailed the manner of life, tribal practices, beliefs and social structures that might otherwise be unknown to the current generation of Aboriginal and non-Aboriginal people. In addition Elkin's ethnographic text is an historical record of cultural practices and social organisation of Aboriginal Australian people that may otherwise have remained unknown and lost in time.

Another legacy of early anthropologists in Australia is the work of Norman Tindale who in 1928 began an anthropological collection of photographs, genealogies and a sociological mapping of Aboriginal people throughout Australia. Today the *Tindale Collection* is an historical record used by Aboriginal people seeking information about their ancestors and traditional societies, and by non-Aboriginal students of social anthropology. My initial impression on viewing a section of the *Tindale Collection* of photographs taken of the predecessors of the one Aboriginal community where I undertook this study was horror and embarrassment. I was horrified by the empty and bewildered expressions on the faces of the photographed people (suggesting that their participation was not voluntary) and embarrassed by the apparent voyeuristic nature of the images, which today would be considered intrusive and violating cultural lore. While the current residents of the community were incensed by the history revealed by the photographs, they nevertheless valued their section of the *Tindale Collection* as a historical record of family lineages and a legacy for their children.

The work of these early anthropologists can now be seen as 'windows' into the prevailing ideas of the time about Aboriginal people (Hammersley & Atkinson 1995; Mills 1997). More important though is to understand the power that these ideas exerted.

Mills (1997 p.115) argued that legitimation of knowledge as truth when it is acquired from a position of power was questionable:

> Colonial power enables the production of knowledge, and it also maps out powerful positions from which to speak.

It is by now very clear that the outcomes of traditional anthropology were of less benefit to the native *Other,* who was the subject of inquiry, and revered more for advancing Western knowledge and the academy's refinement of its methodology (Singer & Baer 1995; Smith 1999). Some consider the ethnographic text as a reminder of colonisation and the ethnocentric authority of the ethnographer (Cary 2004; Jacobs-Huey 2002; Smith 1999). Nevertheless, the subjective methods of fieldwork and participant-observation legitimated by the pioneers of anthropology are important historical moments in the evolution of anthropology (Denzin 1997).

Medical anthropology

The alliance of anthropology with medicine was an opportunity for anthropology to gain authority in the medical discourse and to be taken seriously as a scientific discipline (Singer & Baer 1995). The development of subjective methodology as advocated by medical anthropologists had initially been stilted by the need to gain credibility in the academy of positivist science where the validity of the subjective approach is most in question.

In an effort to gain acceptability, medical anthropologists were often beholden to serving the needs of biomedical institutes for information about the native *Other.* This position of subservience was described by Arthur Kleinman (1980 p. 386), the notable psychiatrist and anthropologist, in the epilogue of his seminal work *Patient as healers in the context of culture* in which he stated:

> Medical anthropology in the main has either been cut off from practical issues by having its scope restricted to the

> academic interest of anthropology departments or has followed the positivist, value-neutral biomedical approach within schools of the health sciences that…functions as an ideology supporting the interest of health science.

Medical anthropological knowledge has often been used to find ways for increasing the compliance of 'the peasants, tribal people and lower class ethnic groups' (Lazarus, cited in Scheper-Hughes & Lock 1987) with paternalistic medical practitioners (DiGiacomo 1992; Kagawa-Singer 1995; Smith 1999). In time, the *native Other* began to question and challenge the authority of science that continued to colonise their culture and their lives (Cary 2004; Smith 1999). The survival strategies of colonised Indigenous people developed through centuries of living under dehumanising, oppressive regimes and the relentless attempts of genocide, came to the fore (Fanon 1967; Smith 1999). Franz Fanon (Fanon 1967 p. 41) observed in his treatise on the violence of colonisation and decolonisation of Algerians, that the colonised were sustained by an inner integrity:

> Confronted with a world ruled by the settler, the native is always assumed guilty. But the native's guilt is never a guilt which he accepts; it is rather a kind of curse…in his innermost spirit, the native admits no accusation. He is overpowered but not tamed; he is treated as an inferior but he is not convinced of his inferiority.

The Australian Aborigines Progressive Association was one of the earlier political movements advocating for Aboriginal rights and operated from 1924 to 1927 until police harassment forced them to close (Tickner 2001). Other Aboriginal political organisations such as the Aboriginal Advancement League in the 1930 attracted support from non-Aboriginal people who usually held the leadership positions (Haebich 2000). The agenda of these socio-political movements was for citizenship rights of Aboriginal people and to improve the living conditions in the government reserves. It was not until 1967 that the Australian Constitution repealed the section that had excluded Aboriginal people from being counted in the National Census and amended another section of the

Constitution that had confined Aboriginal affairs to state governments rather than considering the issues as federal matters (Haebich 2000). Despite the 90.77% (Tickner 2001 p. 9) 'yes' vote of public support for the referendum, the effect of the amendments was more to offset international accusation about Australia's racial discrimination rather than advocating the rights of Aborigines (Haebich 2000). State and Territory governments maintained their control of the affairs of Aboriginal people including what they ate, where they lived, their religious practices and even how and if they raised their children (Haebich 2000; Tickner 2001). Various policies followed to rescind the colonial mentality of missions and segregated reserves, including assimilation, self-determination and currently reconciliation (Haebich 2000; Kidd 1997). The Aboriginal populations had many more years of struggle and protest against these policies that were intended to assimilate them into the 'civilised life' of Australia (Hasluck cited in Haebich 2000 p. 455) before the rights of Aboriginal Australians were legally recognised. A defining moment in this decolonisation process was the Aboriginal Land Rights Act of 1992 that overturned the doctrine of *terra nullius*[5], the legal justification for the imperial colonisation of the Aboriginal peoples in the 1770s (Tickner 2001). More recently, various findings of Royal Commissions and government inquiries into the effects of over two hundred years of oppression continue to fuel resentment and anger as Aboriginal people confront the injustices of colonialism. The Royal Commission into Aboriginal Deaths in Custody (Johnston 1991) and the report on the Stolen Generation inquiry (Wilson 1997), are two examples of such government inquiries.

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[5] Dr Michael Connor recently presented evidence that *terra nullius* was not the legal doctrine behind the European occupation of Australia. A legal representative of an Aboriginal legal service, who was arguing a case before the High Court, introduced the term. Terra nullius was subsequently adopted by the political discourse concerning all Indigenous issues. Connor, M,2003. *Terra nullius*, The Bulletin, Sydney.

Underpinning the history of resistance movements against anthropology today by Aboriginal societies is the extent to which the anthropology has been used to support repressive policies at the expense of Aboriginal people. Also the authority of anthropology has been to report and interpret their observations of the *Other* and claim ownership of the knowledge generated (Smith 1999). Smith (1999 p. 63) argued that the approach of the Western anthropology colonised not only the people but also the knowledge gained in the process that had an effect to: 'constantly reaffirms the West's view of itself as the centre of legitimate knowledge'.

The postmodern view of social anthropology is that ethnographic text should reflect the interactive dialogical nature of the methodology as a discourse of many voices, and as Tyler (1986 p. 126) suggested, none 'of the participants would have the final word'. Silencing or misrepresenting the voice of the *Other* in ethnographic texts is a discipline like colonialism in that it monopolises and thus suppresses the *Other* as Smith (1999 p. 69) argued the effects were:

> ...To silence (for ever in some cases) or to suppress the ways of knowing, and the language of knowing, of many Indigenous peoples (parenthesis in original).

Decolonising ethnography

Ethnographic methodology informing medical anthropology is evolutionary in that its methods change over time in response to new ideas (Denzin 1997). Currently ethnography is at a juncture that some call its 'postmodern turn' (Denzin 1997; Hammersley & Atkinson 1995 p. 256) and it's 'sixth' or even 'seventh moment' of transformation in methodology, method and writing (Denzin 2002 p. 482). In particular, Indigenous researchers and others representing colonised minorities, have nudged the evolution further to take a postmodern position of decolonising or postcolonial research. Decolonising research decentres the ethnographic gaze to take a reflexive view of the research agenda and its methods, and in that process centralises the research relationship not only in the context of Indigenous or minority communities, but any population previously colonised by research methods.

The agenda set by Indigenous researchers as presented by Smith (1999), contrasts starkly with the examples of social and medical scientific agenda that she compares. Examples of the colonising research agenda according to Smith's analysis (1999) include, patenting cultural rituals, reconstructing previously extinct Indigenous peoples, and commodifying Indigenous spirituality (Smith 1999, p.101-102). Smith (1999 p. 117) compares this with the Indigenous agenda that centres on self-determination, through healing, transformation, mobilization and decolonisation. However, the agenda of decolonising ethnography is not simply a way of giving 'voice to the voiceless' (Cary 2004, p.70) nor can the text claim to represent the *Othe*r, rather it is to evoke discourse (Tyler 1986).

Like other evolutionary moments of medical anthropology this postmodern turn presents critical tasks in resolving contentious issues of representation, validity, legitimation and praxis (Denzin 1997). The purpose of this postmodern turn of ethnography is to de-centre the motives, methods and praxis of medical anthropology; and in the process dispel forever assumptions about rights to undisputed access to anyone or anything a researcher wishes to study (Denzin 1997). Representation of the *Other* is an oxymoron to postmodern ethnography because it positions the ethnographer as the authority of the *Other's* story and thus separates the researcher from the context of the study. Tyler (1986) contends that post-modern ethnography should produce a 'cooperatively evolved' text, that is one rich with discourse to 'evoke' in both the ethnographer and their readers, an image of context of the story being told. Like poetry, the text of ethnography is, according Tyler's position, one that will 'be a text not read with the eyes alone, but with the ears in order to hear the 'voices of the pages' (Tyler 1986, p.136).

The notion of praxis has a social activist underpinning whereby research outcomes produce 'change in the world in positive ways' a methodological position according to Denzin, (2002 p. 484) marking the seventh moment of interpretive ethnography. Consideration of the praxis of research fits with the decolonisation agenda in terms of 'giving back and sharing' the knowledge in a way that ensures equitable benefits of the knowledge acquired (Kaomea 2004; NHMRC 2003).

The decolonising methods of interpretive ethnography

The signature of interpretive ethnography is the research relationship of trust and reciprocity that make this approach congruent with the agenda for decolonising research, and thus ideal for this study. Fundamental to a decolonising approach is a mutual research relationship in which participants are free to explain their perspectives and tell their stories without the constraints of more structured methods. In developing the research relationship the methods should not only suit the line of inquiry, but also be congruent with the cultural values and epistemology of the Aboriginal participants (Cary 2004; Smith 1999).

While respecting the heterogeneity of Aboriginal culture I nevertheless acknowledge what is generally known of Aboriginal epistemology. Smith (1999) and Trudgen (2000) argue that Aboriginal people tend to value knowledge as an holistic experience of social interaction, listening, observing, imitating, trial and error and interpreting meaning within the context of what is being learnt. This epistemology aligns well with that informing the methodology of interpretive ethnography whereby the essential process of data collection is through the researcher-participant interaction and by direct experiences of observation.

A further advantage of choosing ethnography is that the methods of participant-observation and dialogue, respect Aboriginal women's ways of interacting with strangers. I learnt from previous research experience that Aboriginal women can be shy and uncomfortable when asked to divulge personal information to a non-Aboriginal person and may experience a feeling they call *shame* when asked to talk about their bodies or disclose intimate feelings (Prior 1997; Thurecht 2000). Also Aboriginal women can feel daunted and overpowered by people such as a researcher or health care professional from the non-Aboriginal world, because they perceive them as representing *whiteman's* authority. This apprehension toward authorities is another remnant of colonisation when white European authorities used personal information of Aboriginal people to control every aspect of their lives (Eckerman et al. 1992; Haebich 2000; Kidd 1997; Shannon 1994; Tickner 2001).

In my research design I need to consider the different styles and cultural mores of communication that participants might use. Trudgen (2000) cautions that English is not necessarily the first language of rural Aboriginal people and if they know a word or term it does not follow that it is understood. Trudgen (2000) offers an example from his many years of missionary work with the Yulŋu people in Arnhem Land. From his experience Trudgen (2000) learnt that if the people did not understand the context or meaning of what a non-Aboriginal person said, rather than asking questions or risk embarrassment, they responded by saying *Yo, yo* (yes yes) *to anything* (Trudgen 2000 p. 68). The Yulŋu people's explanation for not questioning what a non-Aboriginal person said was: 'we think maybe they're talking about nothing, so it doesn't matter if we don't understand it anyway'. Such a response shows that the issue may not always be about power differential in favour of the dominant culture, but can be a manifestation of a cultural distance in the relationship that stifles reciprocity in the interaction.

Some general mores of communication I needed to consider in my fieldwork included; eye-engagement can be inappropriate when in conversation with some people, usually elders, that speaking to a person indirectly and using quiet tones was preferred as loudness can be considered impolite or aggressive, active listening without trying to interject or pre-empt a reply, which means there can be a period of silence after someone finishes speaking while a response is considered (Trudgen 2000). Silence and body-language are important means of communication for many Aboriginal people who regard this mode to be more 'telling' than what is said (Lynn et al. 1998; Trudgen 2000).

METHODS

Fieldwork

Ethnographic fieldwork positions the researcher within the everyday environment in a way that facilitates face-to face interactions and observation of the routines and situations of community life. Fieldwork enables the ethnographer to discover what Denzin (Denzin 1997, p. xv) described as:

> ...Multiple 'truths' that operate in a social world–the stories people tell one another about the things that matter to them.

An important distinction between fieldwork and structured methods of data collection is that the quality of data is dependent on the mutuality of the researcher-participant relationship, which is purposeful and develops through positive experiences through which a bond of trust develops. An indication of a trusting relationship is the free dialogue in which participants are comfortable in sharing local knowledge, their thoughts, opinions and feelings, which to some extent is reciprocated by the researcher (de Lain 2000; Denzin 1997; Geertz 1973; Hammersley & Atkinson 1995). The intent of the fieldwork relationship is to gain an insider's view and to carefully describe what seen and experienced of the participants lives so that hopefully in my ethnographic writing the context can be imagined by the reader (de Lain 1997 p. 124).

Moving from the position of outsider to insider traditionally involved the ethnographer in prolonged periods of fieldwork living in the community, becoming accepted, learning to communicate and 'going native' as a means of blending into the cultural scene of the people (Behar 1996; Bell, Caplan & Karim 1993; de Lain 2000). However, de Laine (1997 p. 114) argues that time and funding restraints in the contemporary world make extended fieldwork impractical, consequently a genre of 'rapid anthropological appraisals' has emerged, a method involving the ethnographers combining quantitative and qualitative methods to expedite their work. Others hold the view that ethnographic fieldwork can be completed in relatively short time periods provided that the researcher is well prepared and does not need to learn a different language.

The perspective of interpretive ethnography with a decolonising agenda, does not equate to the insider research position of becoming 'like-a-native' (Behar 1996 p. 5; Smith 1999). In fact, in the interest of protecting the community's integrity it is more appropriate to respect the boundaries of my research-relationship by acknowledging that I am an outsider with a temporary permit for an insider's view (Smith 1999). The boundary of the researcher-participant relationship in ethnography is purposeful and permission to enter a community is conditional on the researcher respecting these parameters (Smith 1999). The Aboriginal Councils who approved my fieldwork set the parameter for my fieldwork visits but also allowed me to negotiate extra time necessary for developing an appropriate researcher participant relationship.

Participant-observation

Participant-observation is the principal method for gathering ethnographic data from the fieldwork position of 'just being there' (de Lain 2000; Hammersley & Atkinson 1995). Being in the communities for reasonable periods of time gives the ethnographer a closer view of participants' lived experience and the contextual components that influence their world view. While the role of participant-observer is to get involved with participants and the context of daily life, the boundaries of the research-relationship presents the ethnographer with a paradox (Behar 1996). Over-identification as a 'complete observer' or a 'complete participant' can blur the boundaries, while a lack of engagement with participant's lives can compromise the ethical research relationship (de Lain 2000, p. 104; Hammersley & Atkinson 1995). Therefore becoming a 'complete participant' by over-identifying with participants is unnecessary and risks compromising the relationship anyway. On the other hand, the position of a decolonising research agenda demands the privileging of participants' concerns (Kaomea 2004). For example, in privileging Aboriginal people's issues about praxis of research outcomes, implies that a research-relationship could extend for some time beyond the stage of data collecting and reporting, to involvement of the researcher in future intervention or other projects working with the people.

Linda Tuhiwai Smith (1999) an Indigenous New Zealander described the experience of how people from her own community changed their behaviour when she was present with them as a researcher, rather than in her capacity as a mother and member of the community. Her normal position was as an insider with much in common with the people, but as a researcher, Smith (1999) observed how interactions were more formal and participants altered their routines, like tidying up their home as if receiving a stranger (Smith 1999). It is only as an insider that Smith could detect these contextual changes, whereas an outsider has no comparisons and therefore can only observe what participants presented. Also of consideration is that the quality of the researcher-participant relationship inevitably influences how much participants choose to present in the research environment and are guided by cultural mores about what can be shared with an outsider. Nevertheless the participant-observer ethnographer enters the field knowing their presence is bound to alter the context is some way as Devereux (Devereux, cited in Behar 1996 p.6) argued:

> The observer never observes the behavioural event which would have taken place in his absence, nor hears an account identical with that which the same narrator would give to another person.

What is important as a participant–observer is that the subjective response to what is observed and reflections on their experience of the research-relationship, become part of the data and are recorded as such in the field notes (Behar 1996).

Field notes

Fieldnotes are the primary medium for recording an uncensored description of day-to-day observations, conversations, interviews, impressions and reflections while still close to the field (Emerson, Frtetz & Shaw 2001). When re-reading fieldnotes the experiences of the occasion can be relived and emotions revived in the manner described by Ruth Behar (1996 p. 9) in her assertion on the function of fieldnotes:

> To bring the ethnographic moment back, to resurrect it, to communicate the distance, which too quickly starts to feel like an abyss, between what we saw and heard…

Reflexivity

Reflexivity is the mainstay of interpretive ethnographic methods and integral to the process of data collection and validation. In the research environment of fieldwork, reflexivity takes the form of an ongoing personal conversation about one's experiences, impression and instincts 'while living the moment' (Hertz 1997 p.viii). The reflexive process begins even before starting fieldwork with a self-reflexive moment about motives for undertaking this line of inquiry (which I present at the end of this chapter) and for confronting assumptions, prejudices, beliefs, values and apprehensions that might cloud observations or be perceived as authoritative in the research field. The tenet of reflexivity is that the researcher acknowledges himself or herself as both instrument and subject of inquiry.

Some theorists uphold the epistemological value of self-reflexivity as a source of data (Behar 1996; Bell, Caplan & Karim 1993; Reinharz 1997; Salzman 2002). Others view the self-reflexive process not as knowledge generating but as a 'path of investigation' common to any scientific field of study (Salzman 2002 p. 809). Salzman (2002 p. 7) cautioned that the reliability of self-reflexivity as a source of data is questionable because the process is dependent on the researcher's 'honesty' in declaring their position, as he explains in this statement:

> While misrepresenting oneself to others is perhaps the species' most popular sport, self-deception is one of the most valued human skills.

Misrepresentation can be a way of protecting one's emotional vulnerability as was once thought necessary for professional practice. For example, as a nurse I was taught that 'professional practice' meant being objective and distant from patient's social and emotional stories and 'not getting involved' at a personal level. Cancer, the topic of this research, has intrinsic social and emotive connotations because it is regarded as a threat to physical and social integrity. With this in mind, I could hide behind professional labels such as researcher or nurse to defend myself against the 'drain of anxiety' that may emerge from participants' stories (Behar 1996 p. 6). In taking a defensive position, I would be at odds with the epistemology of decolonising ethnography that advocates for an honest, open relationship with participants (Behar 1996; Denzin 1997; Hammersley & Atkinson 1995; Reinharz 1997), even if that meant becoming what Behar (1996) refers to as the 'vulnerable observer'.

I know from experience with previous research that Aboriginal people are astute observers of outsiders, particularly those entering the community as researchers, and would quickly see if an outsider was less than sincere in their interactions. A consequence could be that the people were less likely to engage in the research relationship or alternatively censure the information given (Smith, 1999). If the research relationship is compromised in this way, the people may either choose not to engage as participants, or be unobtainable for interviews, or more ambiguously, available but sanitize the information adopting a 'just give them what they want to hear' attitude (Smith 1999). Defending myself from the emotions associated with cancer and the experiences of Aboriginal women's lives would betray the very purpose of my research, which is to build a research relationship that facilitates a shared exploration of the socio-cultural context of the women's experiences and perceptions of cancer that I can present as a cooperative story.

The outcome of the reflexive process in interpretive ethnography is knowledge that explains different social worlds and more importantly how that knowledge was gained and by whom (Hertz 1997). In this thesis, reflexivity is used in several ways, as the path of investigation, as a method of personal reflection and data collection, and as a research process of validation.

Validating subjective data

To the critics of subjective methodologies, validation of subjective data is its weakness. Critics might ask how the researcher decides what is authentic and what is incidental amongst the eclectic representation of many voices, different viewpoints, alternative truths and the various ways of communicating these? And, if the variables of researcher bias and the research environment are not controlled, how can the data be validated? The simple response to these concerns is that there can be no single truth in a pluralist and constantly changing society. The intent, methods of the research design and quality of the researcher-participant relationship determines how validity is secured. Validity is as much a concern in the rigor of ethnography as it is in positivist designs, but it is of a different genre.

Validity of quantitative methods is assured by the strictly controlled research design that is structured by a defined theory or hypothesis and the purpose is to test this hypothesis using predetermined methods. Because quantitative data is reducible to a mathematical format it can be tested by standardised statistical formula, which ensure that research outcomes can be generalized to similar populations. On the other hand, data from qualitative methods is in the form of written texts that are *messy* (not theory bound), open, dialogical, typically voluminous and mostly subjective (Denzin 1997; Smith 1999). Quantitative research is designed for population studies and cohorts of large sample groups. While in contrast, qualitative studies typically address small groups of purposefully selected participants.

The validity of qualitative data is not constructed formulaically as in a quantitative design, but is instead a process of recursive reflexivity that is data-driven. Reflexivity in the qualitative domain is an inherent and recursive process of data analysis, validation and re-evaluation of methods to determine the directions for subsequent data collection. The validation process continues from the data gathering phase, to writing the ethnographic text where validity is best considered in terms of 'verisimilitude' which Denzin argues is a text's ability to simulate or 'map the real' (Denzin 1997 p. 10). A critical component of verisimilitude of qualitative data is that the researcher's ethical integrity and commitment to the researcher-participant relationship is sufficiently sound to ensure that what is recreated or presented as written ethnographic text is truthful, faithful and accurate (Denzin 1997; Denzin 2002). Behar (1996 p. 9) argues that while the observations and field relationships of the ethnographer cannot be reproduced exactly, the written text should 'resurrect it' to bring back those moments and keep the narrative alive. To this end, postmodern ethnography produces a 'polyphonic text' of dialogue that reflects a 'cooperative story' (Tyler 1986, p.126) of participant's narratives and interpretations rather than just the voice of the researcher as the single authority (Behar 1996; Denzin 1997; Hammersley & Atkinson 1995; Rice & Ezzy 1999; Tyler 1986). Validity or 'verisimilitude' of ethnographic data is achieved through a sustained dialogue with participants to verify interpretations and conclusions about what they said or did, a process that is dependent on trust within the researcher-participant relationship.

Trust develops over time through the experience and free exchange of information between the participants and the researcher. Developing trust in a research relationship is a process of firstly being positioned close enough for participants to assess one's trustworthiness and secondly developing an alliance by sharing relevant aspects of one's own story. Trust is no less an issue in quantitative methods in terms of ethical conduct, such as veracity and beneficence toward the subjects, but is less dependent on a personal level of relationship embodied in the qualitative approach (Beauchamp & Walters 1989; Denzin 1997). The flexibility of ethnographic methods of fieldwork, informal interviews and participant-observation provide participants with opportunities to share their stories and to be heard by someone genuinely interested in their experiences and in them, qualities which foster a relationship of trust.

Quantitative data is of necessity anonymous and objective, which in the context of health research in effect removes the voice of the sick from the discourse on health and illness. This omission has been realised by several anthropologists for example, David Rier's (2000) experience of being the *Other* as a seriously ill patient helped him realise that the voice of the sick was missing in the positivist discourse of both biomedical and sociological sciences. Rier (2000, p. 89) concludes from his 'self-ethnographic' observations as an intensive care patient:

> What we think we know corresponds all too closely to what we can readily measure... which suggests we know less than we think.

The experience of being the object of scientific methodologies and therefore neutral in the relationship led Reir (2000) to understand that 'half the story' was missing if the 'subject' or patient is not engaged in the discourse. Another anthropologist, Susan DiGiacomo had a similar experience as a cancer patient. This experience enlightened DiGiacomo (1992 p. 113) to the 'monophonic authority' of both the biomedical and the anthropological discourse that she concluded misrepresented the lived experience of the sick.

Quantitative objective methods can classify human experiences and gather large amounts of data on the incidence or prevalence of a problem, but the process of silencing the human voice in the data sanitises the information of its meaning and context. Qualitative methods on the other hand, go back to the source of the data and look for socio-cultural, contextual differences that may explain the how and why of people's responses. A limitation of qualitative methods is that the approach can only be used with relatively small numbers of people. Also a considerable amount of subjective data is generated from interviews, recorded observations and reflection, which requires more time to gather and process than a quantitative study of a similar subject area that collects and controls numerical data.

Cultural values and ethical research

A blend of ethical paradigms inform this study, these are the conventional principal ethics of consequentialism and deontology, and a postmodernist ethic which Denzin called a 'feminist communitarian ethical model' (Denzin 1997 p. 274; Walters 1989). Traditional ethics and the postmodern paradigm of feminist ethics both advocate integrity of research methods that protect the rights of participants, but the focus is different. Conventional rule-based ethics are concerned with the rights of individuals while the standpoint of the 'feminist communitarian ethic' is the integrity of the individuals but as a member of a collective or community. A distinction of this feminist position is in advocating for a relationship of 'caring and a moral commitment' to the praxis and sharing the knowledge of research outcomes. Another point of difference is that the objectivity and universality of principle-based ethics is the antithesis of the feminist ethic because the former approach demotes the research relationship.

Some qualitative theorists argue against conventional ethics on the grounds that they are determined by Western values of autonomy and the inherent rights of individuals to give their consent, assuming individuals are free to divulge cultural knowledge and have the capacity to discern the harm or benefits of a particular research project (de Lain 2000; Denzin 1997; Smith 1999). Smith (1999) argues that Aboriginal cultures do not consider autonomy in terms of an individual's rights but in the context of a community's right for self-determination and therefore consent to participate in research is still a matter of individual choice but is considered in relationship of how a decision affects the community.

Decolonising ethical paradigms

The National Health and Medical Research Council (NHMRC) Guideline for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (NHMRC 2003) supports an ethical research relationship of trust that is developed as 'a product of engagement between people' (NHMRC 2003 p. 5). These ethical guidelines assert that regardless of the research design, the researcher's relationship with, and responsibility toward, Aboriginal communities should respect cultural differences and ensure that the integrity of the people and the community is not compromised. These guidelines align with a decolonising research agenda because they centralise the cultural values of Aboriginal and Torres Strait Islanders in the ethical frame. Previously Indigenous cultural values have been marginalised because of 'difference blindness' which presupposes that all societies are homogenous or mono-cultural (NHMRC 2003 p. 4). The NHMRC guidelines privilege Aboriginal and Torres Strait Islanders' particular values of reciprocity, respect, quality, survival and protection, and responsibility', which form the ethical frame for all research. The uniqueness of this framework is the pre-eminent and central position of 'spirit and integrity' as the binding cultural value which transcends and integrates all others (NHMRC 2003 p. 9).

The decolonising approach is enhanced by incorporating in the research design these cultural values as outlined in the NHMRC Guidelines (2003), which I achieved by firstly acknowledging the cultural distinctiveness of Aboriginal participants. Aboriginal or Indigenous is an English term used by the coloniser (Thornberry 2002 p. 38) to identify the people who were the 'prior inhabitants' of countries discovered and colonised by outsiders. Before the invasion, the Aboriginal people of Australia comprised hundreds of different tribes and at least 300 hundred language groups, of which no more than 20 or 30 remain because of the coloniser's attempts at genocide (Mudrooroo 1995). Some tribal names and regions are gradually returning to the discourse on Aboriginal identity. In public forums, Aboriginal people usually now identify themselves by their tribal home and language group or tribe, for example, 'an elder of the Gunbayngir people' (Goold 2004) or 'belonging to the tribe Noonuccl from the land of Minjeribah' (Oodgeroo 1990) or as a 'Gurindji woman or Yolngu man' and so forth (Tiliakos & Derschow 2004). In addition, Aboriginal people use counter names such as Yolngu[6], Nunga, Anangu, Koori and Murri to identify regional and tribal differences (Mudrooroo 1995). In Queensland where this study was undertaken, the Aboriginal people use the term *Murri* to distinguish themselves as Aboriginal Queenslanders as opposed to *Korris* from New South Wales or *Yolngu* people from the Northern Territory.

I acknowledged the position of *spirit and integrity* as the supreme values of Aboriginal culture by ensuring confidentiality of participants' information, and by respecting the rights of individuals, families and the social groups to participate or withdraw from the study without consequence. The local women who were employed as my research facilitators also acted as mediators to protect the integrity of participants and the

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[6] Yulngu is also written as Yulŋu

community. I honoured the 'spirit' of participants and the community by respecting that certain sacred places, such as ceremonial sites of 'cultural business' and healing places were restricted areas. Other considerations for maintaining integrity were met by complying with the etiquette concerning women's business, which generally was not discussed with men, and being aware of the spiritual concerns associated with 'sorry business' (death)[7].

My researcher-participant relationship of responsible attachment, honesty and fairness that was grounded by an ethic of care and commitment to the praxis of this study, was also a strategy for securing the integrity of individuals and the community.

Finally I acknowledged the cultural values of *respect, survival and protection* as defined in the NHMRC Guidelines (2003) by preserving the anonymity of both communities. In my effort to foster a decolonisation agenda in this thesis and at the same time needing to identify the communities in some way, I have used Aboriginal names rather than English because this is contrary approach to the colonisers who used English terms to 'name and claim' the land and the people (Mutua & Swadener 2004; Smith 1999)[8]. I therefore distinguish the two communities as Coolabah, an Aboriginal name for the eucalypt tree, and Waratah which is an Aboriginal name for a native tree with red flowers (Reed 1990). Another consideration is the relatively small Aboriginal population in Queensland and the interconnectedness of families and the communities means absolute anonymity of participants would be difficult to secure if the proper names were used. Some Aboriginal communities ask to be named in research reports as

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[7] Some Aboriginal cultures avoid using the names of people who have died because they believe saying the name anchors the spirit preventing it passing on to the spirit world. Lawlor, R, 1991. *Voices of the first day*, Inner Traditions, Rochester, Vermont.

[8] The social action groups with the local Councils in both communities have renamed the state schools and other places using Aboriginal language, but to date, these Aboriginal names have not been adopted outside of the community or been used in official or government documents.

a means of being acknowledged for their contribution, however one of the Aboriginal Community Council specifically declined to be identified by their proper name in any context.

I secured ethical approval to undertake my research from the Aboriginal Community Councils, the University and the relevant Health District institutions, in whose jurisdictions my fieldwork was located. The condition of approval from the respective Aboriginal Community Councils was that I should work with the local Aboriginal health workers to adapt the standard consent form, to include an option for participants to have a local person present during our interviews, and that consent could be either verbal or written. The option for verbal consent was necessary for two reasons. Firstly, many Aboriginal women could be anxious about signing 'official looking' documents because of negative experiences under colonial rule when white authorities misused personal information. Secondly, not all Aboriginal women have the literacy skills to understand the wording or concepts without the help of a local interpreter or an Aboriginal health worker.

Research setting

I undertook fieldwork in two different rural communities in Queensland with the original idea of comparing the data, but the data analysis revealed no clear distinctions between the communities. The residents in each community shared similar histories and family connection with the original residents who were forcibly taken from their traditional homes to be placed in government reserves under the policies of colonial administration.

Coolabah is located 65 kilometres from the nearest city and central health services and has population of approximately 2305 of which 93% are Indigenous people. Waratah is smaller with a population of approximately 896 Indigenous people and 49 other residents and is located about 176 kilometres from the nearest regional town. Both communities share a history of being established as government reserves in the early 1900s when they were administered under *The Protection and Restriction of Opium Act 1897* under which the Aboriginal people were segregated from white Australians and controlled within institutional environments that included church missions (Kidd 1997; Reynolds 1989; Watson 1993). When first established, the communities had been populated with Aboriginal people from many different tribes and regions (L'Oste-Brown et al. 1995; Watson 1993). Consequently there has been a mixture of conflict and compassion between the various tribes over the years because the white authorities had not considered the traditional lore, social organisation, and way of life or cultural differences that included long standing feuds between some of the tribes.

The rural location of the communities protected the residents from uninvited intrusions by outsiders, but at the same time restricted easy access to central health care services. Furthermore the relatively small populations means a stranger would be noticed and therefore could not enter the communities surreptitiously. The locally elected and government approved Aboriginal Community Councils serve to protect the integrity of their respective communities and have the authority to scrutinize the motives and methods of outsiders wanting to undertake research (Backhouse 1999).

Gaining approval

To gain the Council's approval to undertake this study involved me in a process of scrutiny by community members who challenged my motives and questioned the possible benefits of the research. Mindful of the importance of developing trust, I presented the research proposal in person to the Councils to provide an opportunity to address their questions and other concerns in the dialogical style that reflected my ethnographic methodology. I was aware that the communities had previous negative experiences of researchers who violated the integrity of the community by publishing, for example, research findings that included derogatory comments and 'cultural business', without the authority of the community concerned. Meeting the Council members allowed them to 'check out' my trustworthiness and accountability while at the same time informing me of local protocols such as where and when I could be in the community. In addition to the face-to face meeting with Council members, I made contact by telephone and written communications to plan my field visits, strategies that proved valuable in developing my research relationship so when I started fieldwork it was not as a completely naive stranger.

A defining moment in the approval process occurred when one Council member challenged me to realise the commitment involved in undertaking this study, this person said:

> Just remember you are in this for the long haul, once you do this research don't think that's it go off and write your stuff. You are making a life commitment to the Aboriginal people.

The words brought to focus my ethical and moral commitment to the communities and clarified what Denzin (2002) meant by the 'social activist underpinnings and praxis' of interpretive ethnography. The challenge of this Councillor's statement caused me to reflect on the pathway that led me to want to undertake research with an Aboriginal community.

A self-reflexive moment

It is not my intention to romanticize this text by saturating it with personal details (Behar 1996), but to reflect on the challenge presented by the Council member, to legitimate (perhaps even justify) my motives that may expose my vulnerability in the research field.

Firstly, events of my personal history have given me a certain empathy with Aboriginal women who experienced discrimination, racism and social disadvantage because of their skin colour, culture differences and background. Born in England as a consequence of social changes associated with a world war, I had the experience of being a member of a minority; being under the control of government authorities because of my skin colour and racial background; being separated from my birth mother by the body politics of the day that denied access to information about my natural father and consequently deprived me of my African American cultural heritage. I was placed in institutional care until the authorities arranged my adoption into a mixed race English family living in a community that was generally prejudiced toward cultural differences. I am not claiming that my history is in any way as violent or as emotionally harmful as that experienced by Australian Aboriginal women who, from some perspectives, have been treated as less than human under colonial government policies. However, I relate to them as a woman of colour who understands from personal experience the emotional hurt of racism and discrimination that leaves one with an irrational feeling of inferiority when in the presence of 'white' authorities.

The second motive for undertaking this research with Aboriginal women arises from my experience as a clinical and academic nurse that has positioned me to witness the failings of Western biomedical health care to accommodate cultural differences or even to acknowledge that culture might influence health related behaviour. My first experience of nursing an Aboriginal woman was not long after my arrival in Australia in the late 1970s. The Aboriginal woman, whom I shall call May, was in the intensive care unit receiving treatment for serious injuries sustained from her involvement in a motor vehicle accident. The only information I had about May's Aboriginality was in terms of stereotypical assumptions about the cause of her accident such as 'she must have been drunk', and that May was assumed to be 'living rough' because she had no street address.

My feeling of impotence in communicating with May and her visitors remains as fresh and I recall the occasions when we communicated as being very rare. After about two weeks of intensive care May's vital physiological signs indicated that she was recovering. About this time, May was visited by an unusually large group of Aboriginal people and although no one from the group spoke to me directly, their presence made me aware it was appropriate to leave the room despite the treatment and observations needing to be done. After these visitors left I remember May appeared calm but even less communicative than before. It was as if from that moment she withdrew completely from the social world. Against the expectation of the intensive care staff, May died a few days later. The staff attributed May's unexpected death to what they called 'pointing the bone', which was a stereotypical term non-Aboriginal people often use to explain aspects of Aboriginal culture seen to be mysterious or inexplicable, however none of the staff were able to verify the cultural meaning of this act. My efforts to learn about Aboriginal culture that might explain May's experience and the cultural significance of serious illness within an intensive care environment proved fruitless. In fact, Aboriginal cultural issues and the influence of their historical journey since colonisation were not included in nursing or medical curricula until very recently.

In my role as a clinical lecturer some years later, while working in an oncology ward, I witnessed quite appalling racism toward a young Aboriginal woman who had elected to go home against medical advice. A staff member refused to provide any assistance to this young woman, and instead berated her decision on the basis that it was thought she lived in a public park, and therefore would not have facilities to maintain the treatment. My offer to help this young Aboriginal woman was accepted by her and dismissed by this particular staff member that I was 'one of them'. Whether this overt racism can be isolated to one staff member or many does not lessen its effect on the close-knit Aboriginal communities where such negative experiences are passed on as a warning to others. I must add that other staff fostered caring relationships with Aboriginal women, as with all their patients in this oncology unit. The staff's main concern was that often the Aboriginal patients refused home nursing care and rarely completed a course of treatment, saying they preferred to manage at home.

A final motivation for undertaking this study grew from my awareness from some previous research of a cultural void between Aboriginal people and the Western model of palliative (Prior 1997). In particular, I recall working with Fay a young Aboriginal woman with primary and later malignant breast cancer. Through this relationship I learnt about Fay's difficulties in reconciling the incongruence of biomedical methods of treatment and her cultural needs of healing and 'being with her people'. When first diagnosed with breast cancer Fay complied with the treatment of surgery and chemotherapy and with the support of family and her community Fay recovered and returned to work. When the cancer reoccurred some years later Fay was ambivalent about following medical advice. Although she attended for most treatment and clinic appointments, Fay's energies were diverted to seeking alternative medicines, in particular with a traditional healer. I noticed how Fay, who worked in the city, began to spend increasing periods of time away in the country to 'find peace and be with her people'. On one occasion I observed how Fay was more calm and accepting of her incurrable condition, after returning from a retreat in the country. The last time I saw Fay two months before her death, I was impressed by her radiance. I realised then how Fay's cultural needs superseded what conventional biomedical treatment had to offer. I became curious about how other Aboriginal women dealt with cancer and what was special about returning to 'country'. I also wondered what cultural needs accounted for Aboriginal women's hesitancy to follow medical advice and considered that perhaps the basis of their preference 'to go home' was not because of lack of understanding about the disease but associated with cultural needs that were accessible only in their community.

CHAPTER TWO

GOING INTO THE FIELD

In the early stage of fieldwork I took a broad ethnographic approach to include anyone who was generally interested in contributing information because as Denzin (Denzin cited in Sandelowski 1989 p. 32) argues everyone in the community is a source of data:

> Any subject belonging to a specific group is considered to represent that group. Anyone's experience, if well described, represents a slice from the life world.

Although everyone with whom I interacted during fieldwork could be considered a research participant, some were selected purposefully on the basis of what they contributed to the research questions. I recorded data from 48 participants, these include Aboriginal and non-Aboriginal women and three Aboriginal men[9] all of whom had either direct or indirect experience of cancer and of dealing with the cancer health care services. The 48 participants comprised 13 Aboriginal women with cancer, some recovered and others currently dealing with the disease; 25 Aboriginal women who had involvement through the experience of close family members who had cancer; and 10 participants including Aboriginal and non-Aboriginal women, who in their professional capacity were involved in the care of Aboriginal women with cancer. As my fieldwork progressed, the ongoing process of reflexive analysis lead me to use a theoretical sampling (Charmaz & Mitchell 2001) approach for re-selecting participants who could either build on or saturate a category of my data. Theoretical sampling was also a method of selecting participants to clarify and validate interpretations and conclusions. If a participant whom I had previously interviewed was not available to validate my

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[9] During the course of fieldwork I spoke with several Aboriginal men about cancer related issues, but have not included this data as men's perspectives are outsider the parameters of my topic as approved by the respective Aboriginal Communities Councils and the Health Districts. The three Aboriginal men whose interviews are included as data are two health workers and an elder who was also a member of the Council, whose wife was undergoing cancer treatment.

interpretations or to pursue a particular focus of inquiry, then I relied on my research facilitators to clarify any uncertainties in the data or to confirm my interpretation of what the absent participants had said.

I interviewed the following cross-section of the community:

- Aboriginal women over the age of eighteen currently dealing with a cancer diagnosis and others who were cancer survivors;
- The local Aboriginal research facilitators;
- Non-Aboriginal medical practitioners;
- Aboriginal health workers at the local care health centres;
- Non-Aboriginal and Aboriginal registered nurses;
- Members of the Aboriginal Council;
- Aboriginal and non-Aboriginal mental health counsellors;
- Aboriginal and non-Aboriginal women working in various capacities at the local schools;
- A non-Aboriginal elder who had been the hospital matron in the Waratah community;
- Other Aboriginal women without direct experience of cancer but who were willing to share their perspectives and cultural knowledge on health care generally.

Additional participants from government departments, universities and health services from outside the communities provided background information about the structure of communities, the politics and other cultural issues I needed to consider during fieldwork.

To gain variety, depth and richness of data I relied on a number of sources that included fieldnotes, participant-observation, interviews, reflective journaling, artwork, medical charts, and some relevant historical documents. My principal method of data collection was interviewing participants in their home, and at community meeting points such as outside the shops, in the health care centres and just meeting and talking around the community.

A condition of the Community Councils was that fieldwork should be limited to no more than a two-week period at one time and both Councils suggested that weekend visits would not be helpful to me as many people left to visit families and friend in other places. I found this situation to be true, when due to transport limitations, I arrived in the Coolabah community on a Sunday morning to find the central areas of the community, usually busy with people, was deserted, and only one or two patients were at the health care centre.

My fieldwork visits spanned two years. During this time each subsequent visit advanced the research–relationship closer to a position where I could gain an insider's view of community life. The benefit of taking time over several field visits was evident by the increasing depth, richness and quantity of data I could gather and an acceptance by the community of my presence as this comment from one of the local research facilitators demonstrated:

> It is good that you are seen to come back more than once, the people get to know you that way, they see you are interested in them and not afraid to stay around.

Over the two-year period my research position grew from being a cautious stranger fearful of making a cultural *faux pas,* to being treated like a friend trusted by participants with a glimpse into their lives, inner thoughts and feelings (de Lain 2000; Reinharz 1997). A further advantage of spreading my fieldwork over an extended period was that I was able to observe changes in the communities such as a new housing development in the Coolabah community and the start of an integrated primary health care service in Waratah. In some cases there were opportunities to follow-up participants progress from beginning to the end of fieldwork. Each field visit enabled me to build up a picture of everyday life in the community and to observe how participants dealt with different events such as visits from government officers and other outsiders. I also gained an insiders view of participants' interactions during the women health days when the women were invited to attend the mobile breast screening services and in the gynaecology clinics where I was allowed to be involved as a participant observer. In the Waratah community I was given a privileged position of being an observer at a public meeting that had been convened to discuss new local by-laws. This gave me a valuable insight into the character, dynamics and personalities of the community as well as introduce me to some of the local issues of concern.

Insider-outsider researchers

The richness and depth of my data collecting was enhanced by the assistance of two local people, whom I identify as Judy and Margie, who were my guides, research facilitators, mentors, and acted as mediators for the participants. Judy is a member of the Coolabah community and was nominated by the Council to work with me, and Margie is an Aboriginal health worker and resident of the Waratah community who was appointed by the health care service with the Council's approval. Their roles as research facilitators involved escorting me in the residential communities and chaperoning participants during our interviews. Among the benefits of having a local person accompanying me was that it signalled to the community that the Council had approved my study and that participants would have a local mediator to support them if necessary. Having local research facilitators gave me access to most regions of the communities and to meet women with a range of experiences of cancer as well as other social and health problems. This relationship with a local person positioned me close to a real insider who had intimate knowledge of the community (Reinharz 1997).

Both my research facilitators are respected and active members of their respective communities having lived there most of their lives. I recognized that Judy and Margie's research positions placed them in an ambiguous situation of being 'inside-outsiders' because they had intimate knowledge of the community but were working with an outsider (Smith 1999). Judy and Margie took an 'outsider' role firstly by being a witness to people's health histories as told to an outsider. Secondly, their own 'taken-for-granted insider view' of their community was frequently tested (Smith 1999, p.139). As insiders they were morally bound to protect the community's integrity by not revealing certain cultural knowledge and by respecting participant's rights to keep intimate details confidential. As Smith (1999 p. 139) explained:

> Insider research has to be ethical and respectful, as reflexive and critical, as outsider research. It also needs to be humble.... because the researcher belongs to the community as a member with a different set of roles and relationships, status and position.

Judy and Margie's ethical responsibility was to protect the community and participants from potential harm associated with an outsider's intrusions, particularly if a researcher intended to gather information about personal feelings and experiences related to the serious disease of cancer. As we walked through the community Judy and Margie, usually made the first approach to gauge people's interest in participating in my research. They ensured that we avoided protected areas and culturally important sites out of bounds to outsiders. Their role as community advocates was evident during our walks around the community as they determined when it was appropriate to continue an interview or to approach a particular person.

Engaging participants' consent

Before starting fieldwork I gave Margie and Judy a copy of the research information sheet and consent form, and explained that I did not expect that all participants would sign or read these documents. Both assured me that it would be very apparent if someone was not willing to be interviewed, as they would remain silent or just walk away. It was important to allow sufficient time for the women to talk about the research before deciding to participate. I understood that the most women would seek advice from their local Council about my trustworthiness, and the benefits of the research and acceptability of my methods. In the Waratah community I was given a golden opportunity to introduce my research to the people at a public meeting, and on another occasion by speaking on the morning program of the local radio station. With increasing frequency of my field visits, the local women showed a readiness to participate and some even offered their stories and opinions without my needing to ask.

The pertinent details of the formal consent form, which allowed for either verbal or written consent, were first explained to potential participants in the presence of a member of their family or another person such as my research facilitator. Salient points about confidentially of the data and anonymity of participants were emphasized, as was the participant's right to withdraw from the interview without consequence. I gave assurance that participants would not be identified by their own names and most gave their permission to be identified by a fictitious name. Some participants said they had no problem with me using either their real name or pseudonym. Time was given for potential participants to discuss issues about the research either with my facilitator, other women, or members of the Council or with health care staff. Many women gave their consent on the basis that the Community Council had approved my research and the methods of fieldwork.

Gathering data

The main advantage of participant-observation as a method of data collection was that it provided opportunities for me to be with participants during different times and situations. In the field I observed people from various vantage points in the township, including places around the local shops and in the hospital waiting areas. The space outside the hospitals was a good place for being seen and for observing the daily events of community life. Other opportunities for gathering data occurred while I was helping the women who were waiting for mammogram testing, assisting health workers in the gynaecology clinics and being an observer at the women's health days. The most lucrative method of data collection was walking with my research facilitators in the community where we met and interviewed women in their homes or at meeting centres like the women's shelter, the local school staff rooms and generally around the community.

Critical to the development of my research relationship with local people was my social acceptance in their community. Although my dark skin colour and physical appearance may have made me less obviously a 'white outsider', none-the-less my role as a researcher situated me (from the perspective of many participants) firmly in the Western domain of other non-Aboriginal health care staff. Some women in the Coolabah community were suspicious of my alliance with the white community. I had chosen to live in the hospital accommodation and was therefore 'geographically' associated with the small non-Indigenous component of the community. My choice of accommodation was limited since this was the only accommodation available for visiting staff and students. The perception of some locals was that because the hospital residences are located within a compound that is locked at nightfall, that this segregated white hospital staff from the Aboriginal community. Some local people reasoned that as I lived in the hospital compound I must be 'like them' (the white hospital staff). An Aboriginal councillor from the Coolabah community explained this common concern in regard to the white non-Aboriginal staff when she told me:

> I know there are some good staff there but there are some who regard the local people as low class, they keep their distance.
>
> I know they've got to be safe in their accommodation, but they should show their face in the community a bit more, they're health care staff, they should work in the community, that's where the people are.

The point made by this participant reminded me that as an ethnographer my everyday presence in the general community was critical. Much of my fieldwork was thus spent observing day-to-day activities and 'being seen' regularly in the community. Being seen around the community was important for the women also as it gave them a chance to 'check me out' either by observing me (I was always aware of being watched), or talking with me about 'everyday' subjects before deciding if they wished to be interviewed.

In depth Interviews

Interviews with participants were key elements of fieldwork that occurred mostly during my walkabouts escorted by the local facilitators who introduced me to the women. Both Judy and Margie advised against using an audiotape or even a note pad during the interviews, explaining how these interview props could deter women from wanting to talk because they associate these with *whiteman's* authority. We negotiated that I carry a notebook to record the key points and quotes from interviews in sufficient detail for me to promptly recall when writing the full interview into my word processor. At first this method of recording data proved arduous as we usually interviewed more than one person at a time and thus gathered a considerable quantity of information with each interview. I renegotiated the procedure so that after every second or third interview we stopped for refreshments, and I used this time to write up the salient details from each interview with the facilitator on hand to clarify or confirm my recollections. This writing up time provided an excellent opportunity to test the validity or 'verisimilitude' (Denzin 1997) of my interpretations with the research facilitators who had witnessed the interviews. Together we composed pseudonyms to identify participants in my fieldnotes. In addition, I needed to keep a record of participant's true names along with the fictitious one, for the purpose of identifying whom to follow-up for validating the data and my interpretations. As soon as possible after the morning and the afternoon community walkabouts I entered the details of the interviews into a word processor using my fieldnotes as prompts.

Most in-depth interviews took place opportunistically as we walked around the community, although on later field visits some women volunteer to be interviewed. In the early stages of fieldwork I was quite anxious about making mistakes or of sounding too formal when talking with the women. Initially I overcame this nervousness by asking closed questions such as 'do you have cancer tests?' Or 'do you know anyone with cancer?' Not surprisingly these questions generated either 'yes' or 'no' responses, or at best superficial information that could have been gathered from a questionnaire. As I became more confident in the researcher-participant relationship and with the guidance of Judy or Margie, the data I gathered became richer. An example of this skill development can be seen in the following scenario of my attempt to interview a group of women.

A group of women were gathered in a front yard. After some preliminary conversation about my research they agreed to talk with me. At first the conversation was stilted and did not really generate any new information on the topic until Judy came to my rescue by changing the focus from cancer to the sexual activity of young women, because she knew this was an issue of concern for many of these older women. When the topic changed the women immediately became animated in discussion, giving me a chance to observe the dynamics while at the same time listen to their opinions and stories. As the conversation about the young women reached a peak Judy suddenly refocused the group back to cancer by asking the following questions:

> Well what do you all think about cancer then, do you think we get enough services for the women here (name of community)? (My name) here is really interested to know what you think and what you want.

Pat, one of the older women in the group who had little initial interest in my research (often looking away to avoid eye engagement with me) now showed interest. Pat revealed:

> My mother died of cancer, here in the old people's home. I saw her die of cancer, she was bad, they couldn't do nothing for her, it was spread already.

Pat's statement took the direction I wanted, her response changed the focus from general to the particular and triggered a longer personal narrative about an experience with cancer. I learnt from this situation the importance of establishing a 'productive interpersonal climate' (Minichiella et al. 1992, p. 110) by not rushing in with questions, giving enough information for the participants to ponder and allowing time for us to get to know each other. I learnt the *Murri* way of going with the flow when interacting, which meant being patient and giving time for what colloquially is known in Aboriginal terms as 'yarning, tuning-in, sussing out' and for making connections by finding common ground (Lynn et al. 1998 p. 22). In *Murri* terms 'tuning in and sussing out' is a process for building relationships by finding family and cultural connections and sharing stories and generally being sociable rather than going directly to the point of an interview (Lynn et al. 1998).

The researcher-participant relationship

Being introduced to participants as a nurse–researcher gave me some advantages in that it opened up conversations about health care issues and also legitimated my line of inquiry from the participant's perspective. Initially most people were more interested in what I might contribute as a nurse rather than as a researcher and wanted to know what I could do to improve cancer services at their local health care centre. The participants' anecdotes of their experience with hospitals and the staff were recorded as valuable data about general perceptions of health and cancer care services. My fieldnotes revealed how women initially related to me as researcher-nurse, which was evident by their controlled responses as if answering a structured questionnaire. The following entry from my field notes demonstrate that relationship. The scenario took place when I asked a group of women what they knew about cancer. One woman nodded and said:

> Yep I know about cancer, I went with that group to (name of hospital) to get my mammogram done.

Then another answered:

> I had a mammogram when the mobile van visited here in the community last year.

A third woman replied:

> I don't want to get that smear test done, no way, especially when there is a man around.

A younger woman about 22 years old responded:

> I get to see my gyne doctor he checks everything then, I go regular since I had my baby.

Reflecting on the tone of these responses, I realised an imbalance of power was evident where the women participants answered questions as if I were a professional authority determining their knowledge of or compliance with medical advice. There were some mutual benefit, however, to these early somewhat stilted encounters, because the women often asked me to explain more about cancer, its causes and how to detect early signs of the disease. These interactions were chances for me to 'give back something' as well as advancing the researcher-participant relationship.

When discussing concerns with my research facilitators about participants' restrictive responses, Margie reinforced the point that I should allow time. She advised, 'don't rush it, you don't need to start with questions', and Margie stressed the importance of allowing people time to ask me questions about the research and about myself. Margie told me that people were curious about my background that gave me a good place to start a conversation. Reflecting on Margie's advice I understood Fine's (1994, p. 70 and 2) concept of working the 'self-other hyphen', described as:

> That is the hyphen that both separates and merges personal identities with our inventions of Others. Qualitative researchers are always implicated at the hyphen.

At this stage of my fieldwork the hyphens linking the researcher-participant relationship were more formal and unidirectional than reciprocal and circular. In order to foster a research-relationship of mutuality I needed to 're-work the hyphen' (Fine 1994), to bring participants and myself closer to our common ground as women. I knew my appearance as a woman of colour and my surname, (that is a common name in one community) gave me some advantage to opening conversations as participants often started by inquiring about my family connections. Conversations typically started with the participants asking: 'Where you from? Or 'Are you one of the (my surname) family from 'round here?' The women continued to probe if they were either unsatisfied or disappointed with my answer. Sharing my personal anecdotes in this way aroused empathic responses from participants as these entries from my fieldnotes demonstrate. After hearing a bit of my personal story one participant said:

> That's like our people, they were taken, from their families, and put in those dormitories, you're like us.[10]

And another observed:

> You look like your from around here, you could be you know. Aboriginal men were in that war in England.

Sharing personal stories with the women strengthened the linking 'hyphen' in our researcher-participant relationship with empathy and mutual respect. Of course I ensured assumptions about my association with the Aboriginal culture were always corrected.

Recording my data

I varied the format of fieldnotes according to the opportunities for writing in private and undisturbed. I recorded as much as I could during the day. Then either later in the day or at night I filled out the details by expanding the fieldnotes into a word processor. During the very hot summer months I was given space to work in an air-conditioned

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[10] Indigenous children have been kidnapped and exploited since the earliest days of European occupation in the 18th Century. It is estimated that between 1910 and 1970 one in three and one in ten Indigenous children were forcibly removed from their families and placed in dormitories, missions or other institutions where they were acculturated in European values and work habits and trained as servants and farm workers to the colonial settlers. (Wilson, R 1997. *Bringing them home. The Report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from their Families*, Human Rights and Equal Opportunity Commission.
Commonwealth of Australia, Canberra..

office, which was more comfortable but less private. The advantage of working in this office, apart from the air-conditioning, was being situated in a central part of the health care center made me visible and accessible to more people who stopped to talk about the study and they got used to my presence. The down side was the risk of having onlookers read my fieldnotes and misinterpret my writing.

Reflective journaling

Reflective journaling is the medium for critical internal dialogue (Hammersley & Atkinson 1995). I used this medium to examine thoughts and emotions aroused by my encounters within each community. The importance of the reflective process was that it freed up emotions or thoughts that might otherwise have immobilized or biased my research position. In other words reflective journaling is a biography of vulnerability and a medium for reflecting on positive and negative experiences that arise during fieldwork (Behar 1996).

As my fieldwork progressed the fieldnotes became more reflective in that I not only recorded my observations but also by reviewing them, looked again at my first impressions and began to see newer meaning. This development in my reflection and insight is evident in the following extract from my fieldnotes in which I recorded the first experiences of visiting participants in their homes. I recorded the scenario as follows:

> We stopped at the stairs of a high-set home it was filthy. The garden was overgrown, messy with rubbish and dog shit all over it. I hoped I wasn't showing my disgust and fear.
>
> Judy introduced me to three women; one had a baby with her. The house was filthy and smelt, like bad food, not really a feacal smell but just a stink. The walls were black; the windows were either broken or boarded up.

> We were invited to sit on this disgusting couch, and I kept thinking I'm a guest I'm a guest I must be polite! I hoped they wouldn't offer me a drink, I was glad we always carried water bottles.
>
> Judy didn't seem at all perturbed and started talking with the women quite naturally. The women were interested in my research and we got talking quite easily, one of the women had a *cancer scare*, she had surgery to have a tumour taken out of her stomach, she didn't think it was cancer because she said, they only put her on tablets.

Reflecting on this scenario it was apparent that I witnessed the reality of these women's lives. The home that initially I found so unpleasant, was where a woman, who may have cancer, will return to after hospital treatment, perhaps having to cope with complex treatment regimes and medications. In the reflexive moment I realised the privileged position of being trusted enough to be invited into someone's home and given an opportunity for a closer insider view of the context of community life. I became aware of my own values and how these values might pull me back towards an outsider viewpoint. The next entry recorded my feelings after listening to the harrowing story of Mary's life:

> To think I only wanted to know why Mary had left it so late before getting diagnosed (with an advance stage of cervical cancer). Where would my questions fit in her life? I felt immobilized and that my research was out of place here in (name of community).
>
> I could just report Mary's stories in an objective manner by just giving the medical facts and not get too close to her humanity, or the spiritual sadness of her story. But if I don't feel, I can't tell the whole story or explain why cancer had such little importance in her already damaged life.

The dilemma of my vulnerability is shown in the next entry:

> I feel immobilized, stuck and that my research is out of place here in (name of community). How can I represent the women's stories?
>
> How can I talk with these women about cancer and what my research is about, when their lives are such a mess, and so vastly different to mine? I am not in their league. They

> must think of me as a prissy city academic, who can't understand their lives.

Emotional reactions to participant's stories are an inevitable consequence of the researcher-participant relationship in an ethnographic study about cancer. Also the ethical underpinning of the methodology advocates that the ethnographer's relationship with participants be open and honest and that the empathy aroused by face-to-face contact may 'break one's heart' (Behar 1996; Denzin 1997; Liberman 1999 p. 48). I realised the meaning of my position as the 'vulnerable observer' in close contact with 'far-out lives' (Geertz cited in Behar 1996 p. 7).

Some postmodernists take the standpoint that a 'blurring of boundaries' between the personal and professional selves is inevitable if one is to accept this vulnerable position, which makes one receptive to all the experiences of fieldwork (Behar 1996; Denzin 1997; Liberman 1999; Sherif 2001). Ruth Behar (1996 p. 177) defined the emotional position of an ethnographer that I found myself in:

> ...anthropology that doesn't break your heart just isn't worth doing anymore.

My dilemma of how to process emotional reactions to participants' stories that are 'far outside' my own, revealed the need to clarify the parameters of my personal subjectivity, which I inevitably brought to the research relationship (Behar 1996; Reinharz 1997). I am a construct of multiple identities in my personal and professional life that are present as integral parts of myself in this researcher role. The multiplicity of these roles was evident by my reaction to Mary's sad story. For example, when I reacted to Mary's story as a nurse I instinctively want to help but felt helpless, I observed and listened to her story as an ethnographer and then at least had something to write, but as a women, Mary's story filled me with empathic emotions. I faced another dilemma, how am I to represent stories like Mary's as data? How can I interpret my reactions? Pat Caplan's (Caplan cited in Reinharz 1997 p. 4) words offered some answers in this observation:

> There are ...a number of factors which determine the kinds of data we collect, and our interpretation of them. One of the most important of these is our positionality - who are we for them? Who are they for us? Such questions have to be considered ... in terms of such factors as our gender, age and life experience, as well as our race and nationality.

Being an ethnographer means studying the self as well as the other. My research position is a construct of many domains of myself, that through reflexive practice can become adaptable and at times transparent, but most importantly my researcher self is authentic, in harmony with who I am. I used Reinharz's (1997 p. 4) framework to analyse my 'selves' in fieldwork in order to understand my role as the key research tool. Analysis of my fieldnotes and journals revealed several aspects of myself that became relevant to the research context because theses represent what Behar (1996, p. 13) called the 'filters through which one perceives the world and...the topic being studied'. In other words, reflecting on the domains of the self is important for understanding what aspect of myself influences the research environment (Behar 1996). Those I identified in my journal are:

Research-based selves: that includes being a research student, being an academic, being a nurse, being an observer, being a recipient of two scholarships, being an interviewer, communicator, teacher and writer.

Foundational selves: that includes being a wife, being a mother, being a woman of colour, being culturally adaptable, being removed, being adopted, being middle aged, being a golfer and a walker.

Situationally created selves: that includes being a friend, being a stranger, being a transient, being anxious about living in rural communities, being a helper, being vulnerable, being from a different way of life, and being emotional.

The constituent of my collective 'researcher-selves' became more evident in fieldwork when for example participant's talked easily with me about health concerns because of my nursing self, and while I minimized my academic position because of previous negative comments by some about this role, my teacher self was called upon when participants asked for health related information. My 'foundational selves' provided common ground for developing the researcher-participant relationship, as previously mentioned. There were times when I needed to reconfirm my research position to participants when, for example they asked about their health concerns, or gave information about cancer that I knew to be incorrect or misleading.

Reflective journaling became a source of data because when re-reading and thinking about some entries I experienced moments of insight about an issue that furthered my knowledge and understanding. An example is an entry capturing a situation that caused me to feel scared because of someone's aggressive behaviour. The situation involved a young woman who came into a participant's house while Judy and I were interviewing. The young woman burst into the house yelling and swearing at no one in particular and looking very enraged. Although Judy and I were not directly involved, I was frightened by this violent outburst. I recorded the feeling of being trapped in an unfamiliar aggressive situation and acknowledged that I just wanted to get away, even though we were still interviewing. Later when the woman calmed she showed interest in the interview, offering information about her personal 'scare' with cancer and sharing her view about why women feared hospitals.

On reflection I realised the basis for my fears were preconceived rather than being about anything I knew about this woman. The process of writing and reflecting helped me gain insight into how stereotypes based on assumptions about others can cloud one's perception and in turn how the defensive behaviour of Aboriginal people can easily be misunderstood. My final journal entry of this incident was:

> My initial impression of (name of person) was as a frightening, loud and aggressive person. I didn't want to stay there.

And then reflexively:

> I think I learnt not to be too judgmental…I think many people use the aggressive manner as a defence, to protect themselves from others who might try and take control of them, or use some other ways of overpowering them.
>
> I have no idea why this woman was so angry. Maybe people just want to let us (non-Aboriginal people) know that they are angry.

When I began writing the details of the interviews into a word processor, I was able to separate the journal entries from the field notes. Furthermore, as the volume of interview data increased it became more important to keep fieldnotes and reflective journal entries as separate events, although the reflexive process intertwined all elements of data collection methods. Usually I wrote my journals late at night after completing the transcription of that day's interviews. This became necessary because the process of writing often renewed personal emotions that belonged in my reflective journal. My reflective journal became my sanctuary and place for storing fears, anxieties, self-doubts and the mistakes I had made in the field.

Artwork

Artwork is a popular medium for expressing meanings and illustrating experiences, histories and 'deeply felt convictions' (Hume 2002 p. 95; Stockton 1995) which for one participant had been the preferred way of telling her story along with some narratives to interpret what the art work represented. I had a fortunate introduction to Julie,[11] a young Aboriginal artist and teacher, who agreed to share her perceptions of cancer and the effect of the disease on her community in a collection of paintings. Julie produced artwork that comprised twenty-five paintings and several sketches that illustrate the emotions, perceptions and spiritual journey of her Aunt who had breast cancer. Julie traces her Aunt's story from when she was first diagnosed, through the ordeal of treatment until her passing on from the physical to the spiritual world. Julie gave me her pictorial story of cancer relatively early in the journey of this research, yet the parallels between what the artwork conveys and the stories of subsequent participant's is very apparent, which is why I have included some of the paintings to illustrate the common themes evident in the narratives of other participants. My plans to engage the artistic expressions of other women's experience of cancer did not eventuate although I went equipped with art materials just in case such an opportunity arose.

Secondary data

In both communities I had access to participant's hospital charts, which allowed me to clarify details of pathology tests and other medical interventions including treatments and relevant information about participants health and social histories. Other documents I referred to include the state health department's strategic plan for integrated health care services in both communities; historical reports from the days when the communities had been governed under the colonial protectionist administration; and literature and press cuttings about significant historical events relevant to the communities.

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[11] I have permission from Julie to use her real name in acknowledging her as the artist and to include selected painting in this thesis.

Managing the data

All interviews, rough fieldnotes and reflective journals entries were entered into a word processor to secure the data while also providing easy access for analysis. Storage and retrieval of the data files was secured by transferring the text into The Ethnograph software, an interactive *code-and-retrieve* computer program designed to assist qualitative researchers with management and analysis of data (Fielding 2001 p. 454). A significant benefit of using the Ethnograph program was the page formatting that allowed space for jotting ideas, themes and interpretations when reading and analysing the data. Built into the Ethnograph program is a system for coding and linking concepts and themes, which facilitates analysis. However, while the Ethnograph program provided a good way of managing and storing data and identifying conceptual patterns, I did not rely on all the program's features for analysis. I needed to feel close to and enmeshed in my data, which was best achieved by reading and re-reading the transcripts and constantly reviewing the moment of data collection in order that the experiences of my fieldwork be kept alive.

Analysing the data

True to the craft of ethnography, an interim level of data analysis was ongoing, cyclic and an integral part of fieldwork (Denzin 1997; Huberman & Miles 1994). I used an eclectic approach of 'theoretical triangulation' (Denzin cited in Hammersley and Atkinson 1995, p.214), which combined interpretive, heuristic, subjective and intuitive styles of analysis that were context-dependent (Crabtree & Miller 1992; Hammersley & Atkinson 1995). This meant that the data collection and analysis processes involved me in three inter-related phases during and after fieldwork. These were; review and theory development, theme-focused data collection, analysis, validation, and confirmation (Hanson 2001). The process of entering interview details into a word processor enabled me to note common patterns and emerging themes that could be explored further, as well as unanswered or new arising questions which helped to redirect my focus for selecting participants purposely (Charmaz & Mitchell 2001). It was important to the decolonisation agenda of my research that the dialogue with participants, the local research facilitators and the communities was ongoing in the analysis process. I achieved this by giving regular oral and written reports of my progress to the respective Aboriginal Councils and consulting with the local research facilitators and some of the health care staff about my interpretations and my progress. During the recursive process of data collection, analysis and writing, and the many readings of the final transcripts, I became immersed and thoroughly familiar with my data.

Summary

The aim of this study was to explore beyond the known biomedical factors that contribute to the increasing cancer burden for Aboriginal women. In order to explore the deeper layers of meaning and the cultural constructs that influence Aboriginal women in their response to a diagnosis, I needed to position myself within their everyday environment. The ethnographic position of fieldwork was however dependent not only on my physical presence in the community but also more importantly on the quality of the researcher-participant relationship and my use of the reflexive process. I have outlined here the various ways I attempted to be aware of my 'self' as the core research instrument of this ethnography.

CHAPTER THREE

COLONISATION OF THE BODY IN MEDICINE

The primary concern of medical anthropology is how the human body, as a socio-cultural phenomenon, is conceptualized in health and illness by different societies. In Western societies the biological body and its behaviours has been the primary concern of medical science, which in turn influenced the agenda of social anthropology. In defining the body's problems as medical diseases, medicine became the dominant authority in the regulation and surveillance of the social and biological functions of the body. In this chapter I examine the history of medicine's colonisation of the body that was justified in the interest of the scientific endeavour to control human disease. My discussion traces the conceptualisation of the body from sacred mystic entity of religions to the secular mechanical object of medical science that came to dominate contemporary approaches to health care. I also examine the authority of medical science in the public health discourse on controlling health behaviours of populations, and defining the attributes of a civilized body; which became inherently discriminating against colonised Indigenous people and other racially different populations.

The rise of the Western medicine's authority over the human body is traced to the Age of Enlightenment when political, economic and industrial structures opened the way for discovering new knowledge, which marked the era of modernity (Smith 1999). Before the revolution of modernity, medicine had been confined to allopathic remedies like bleeding, purging and herbal concoctions that had mainly ineffective in controlling diseases (Le Fanu 1999). The new industrial technology gave medical science the instruments to examine the microscopic structures and anatomical organs of the body, and lead to the discovery of the nature of human diseases. From this point, the medical knowledge and its scientific methodology displaced previous esoteric rituals of medicine, and challenged the claim to truth of religious concepts of the sacred body.

The sacred body

In pre Enlightenment times of Ancient Greece, philosophers had been divided on how they conceptualised the body. Some glorified the body, valuing its physical pleasures over mental solace, while others considered the mind to be superior to the physical body. Socrates viewed the body as a 'hindrance' to the soul and Plato went further in suggesting that the soul was 'entombed by the evil body' (Synnott 1993 p. 9). Aristotle perpetuated Plato's notion of a body-soul dichotomy but also viewed the body more positively and as worthy of care for the sake of the soul. Christian teaching professed the body as sacred and the divine embodiment of Christ, a doctrine reflected in 1-Corinthians 6:19-20:

> Don't you know that your body is the temple of the Holy Spirit, who lives in you and was given to you by God? You do not belong to yourself but to God; He brought you for a price. So use your bodies for God's glory.

Clearly the doctrine of Christianity, as represented in this biblical passage, separate the body from the self and even colonised the thinking mind to enslave the body in God's name. This theological construct of the sacred body gave theologians uncontested authority to preach the doctrines of asceticism, for example, as acts of dedicating the body to God. In that era, committed Christians demonstrated their devotion to God by serving penance such as celibacy, enforced poverty and absolute obedience, practices respected in some religious sectors of the Western and Eastern worlds today (Synnott, 1993). In the thirteenth century the theologian Thomas Aquinas advocated the inherent morality and divine goodness of the body because of its alliance with the deity of the soul.

In the new age of modernity, however, medical science's methods of anatomical dissections and mechanical descriptions to explain the structure and functions of body parts dispelled the sacred mysticism of the body. At this point, scientific conceptualisation of the body as a secular object signified what Bauman (1992) described as: 'The withdrawal of God ... the triumphant entry of Man' (Bauman 1992, p. x).

The invasion on the body

The colonisation of the body by medical science was advanced by science's disregard for the mind's capacity to influence and interact with the inner and outer world, thus the medical institution, similar to the disciplines of theology before, had an unimpeded monopoly of the human body.

The body-mind dichotomy that characterised medical methods, was attributed to the philosopher René Descartes' proclamation in the 17th Century that:

> *Cogito, ergo sum* - I think therefore I am... this 'I' that is to say the mind, by which I am what I am, is entirely distinct from the body (Synnott 1993).

However, Descartes remained faithful to his Catholic values, and so did not completely dismiss the soul or the mind in his declaration, but rather acknowledged the theoretical difficulty of having and being a body (Lawler 1991). Descartes' belief in the soul was clear in this quote from the Second Meditation:

> That I was nourished, that I moved about, and that I engaged in sense-perception and thinking; and these actions I attributed to the soul (Cottingham 1984).

Descartes' *Cogito, ergo sum* is none the less immortalised in the Western world for the 'body-mind split' which came to be known as Cartesian dualism. In the 1970s biomedicine made efforts to reconcile Cartesian dualism with the biopsychosocial model as an holistic concept for medical practice. The functionalist underpinning of the model, however, was of separate systems and a hierarchy that placed biological and psychological structures in 'higher systems' levels (Engel 1980, p. 543) to that of social and cultural systems. Consequently the biopsychosocial model continued, or further confused, the body-mind divide.

The mechanical body

While Descartes struggled with the coexistence of the body-mind-soul relationship (Lawler 1991) his conceptualisation of the body as a machine was influential in the medical discourse on the mechanisms of the human body. Descartes (Descartes cited in Cottingham 1984 p. 17) is reported to have said:

> That I had a face, hands, arms and the whole mechanical structure of limbs which can be seen in a corps, and which I called the body.

The industrial revolution, defined by the design of machinery, power and engines, provided the new modern medicine with the language to explain what it discovered about the body's functions and structures. The use of mechanical metaphors to describe body parts also informed the medical discourse on the maintenance, repair and management of the dysfunctional or diseased body. For example, the heart was described as a pump, the lungs as bellows, and the structures of skeletal joints were compared to the pivots and articulating surfaces or moving sections of machinery. In the twenty first century, medical science has advanced to a point where the dysfunctional body can virtually become a machine. Mechanical ventilators, renal dialysis machines, joint and cardiac prosthetics and cardiac pace makers are examples of the body-machine alliance.

The new technologies gave medical scientists the instruments to both view the body's smallest cellular structures and to invade its anatomy. The microscope enabled science to discover disease-causing microorganisms and to see the biological effects on the body. Discovery of germ theory was a defining moment for medical science, and with the natural sciences of microbiology and chemistry, medicine had the knowledge to control contagious disease in the individual body and in society (Lupton 2003). From here medical science evolved to become biomedicine the scientific discipline of human biological manifestation of and response to disease.

The scope of biomedicine to control previously deadly communicable diseases, and to correct biological dysfunctions, enhanced its position of superiority in a grateful society. In the last century, some defining achievements of biomedicine have been: the discovery of vaccinations that almost eliminated life-threatening disease like poliomyelitis, diphtheria and whooping cough, tuberculosis and smallpox; the development of surgical techniques to replace or repair diseased organs; cardiopulmonary resuscitation to sustain life, invitro fertilisation and pre-natal diagnosis to advance life; design of synthetic and natural drugs for controlling serious diseases like hypertension, cardiac failure and cancer and drugs to supplement organ deficiencies that caused, for example, diabetes or hypothyroidism (Kleinman 1995; Le Fanu 1999). A marker of biomedicine's success has been considered in term of the extended life expectancy in the Western world, which have increased by more than twenty years in the last century (Learner 1980). More cynical views are that advances in biomedicine has only helped people to live longer and relatively healthier lives, but new and chronic disease associated with aging replace acute disease, and consequently the burden on health care resources also increases (Fries 1980; Le Fanu 1999). Nonetheless, in Western societies the social and political standing of biomedicine has been revered, and its authority to separate the physical body from the intangible human mind and soul has gone unchallenged until very recently.

Western biomedicine's mechanical representation of the body is not shared by colonised Indigenous and minority cultures, that view the body in more holistic term of nature and relationships between the physical body and the metaphysical world. For example, the Chinese view the body as part of a Yin/Yang cosmology of elements that interact to find balance with other forces such as hot/cold/ dry/moist and male/female (Freund & McGuire 1991; Scheper-Hughes & Lock 1987). Many Indigenous cultures conceptualise the body as a continuum of relationships with nature, the land, the people and spiritual forces. Well-being is considered in the Indigenous paradigm as a state of harmony in these relationships (Lawlor 1991; Smith 1999; Trudgen 2000).

The different ways of conceptualising the body inevitably will influence people's perception of what health means and how the sick body is to be managed. For the Western medical doctor the sick body is like a damaged machine that can be repaired, corrected or the body parts replaced, providing the framework is not too worn from age. The Indigenous and non-Western approach on the other hand look to heal the sick person with medicines, rituals or ceremonies and other methods that promote harmony in relationships between people and their environment and the spiritual world.

Such has been the authority of biomedicine, however, that the Indigenous and non-Western approaches to health care have been marginalised and even denigrated by the dominant institution (Trudgen 2000). The hegemony of modern biomedicine undermined what was considered non-scientific methods of healing or harmonising and instead professed empirical science to be the definitive methods for studying and managing the human body (Fox 1993). Not until the emergence of anthropology that defined a cultural and then the social body, and later disciplines like psychology and sociology toward the end of the 19th Century, was the biomedical conceptualisation of the body as a mechanical mindless object challenged.

The new disciplines reconfigured the body-mind capacity for interaction with the environment in ways that influenced the context and thus the culture of a particular society. Although the new social-psychology thinking reframed the body-mind relationship, the methods of inquiry initially followed the laws of empirical science in objectifying human existence. This was evident in psychology theories of conditioning and behaviourism that assumed individuals could be programmed or manipulated to learn, and that human actions were motivated by the body's basic physical needs for survival. Even early modern social theories viewed humans as voids to be socialised into structural and functional systems of society (Berger & Luckmann 1967; Schutz 1967). An example was Talcott Parsons's (Frank 1991) construct of the sick role in the 1950s that was primarily to ensure social stability and medical compliance. Parsons viewed sicknesses as a social deviance, and the sick therefore had an obligation to seek and comply with expert medical directives. The sick role from the social functionalist perspective was essentially a transitory status that ensured the afflicted promptly returned to health in order to fulfil their social responsibilities, such as child care or paid work (Frank 1991; Germov 1999; Singer & Baer 1995).

Civilising the body

By the late nineteenth century medical science's conceptualisation of the secular body also became the focus of social sciences seeking to civilise the body. An alliance of medical and social sciences developed another agenda for surveying and regulating the body as an object, in the interest of public health. Sanitary science, for example, changed its methods of quarantining the geographical places where disease occurred, to focus instead on the behaviour of individuals. This changes was prompted by the discovery of germ theory, which idenfied the body's excretions as vectors of environmental pollutants and the agents of contagious diseases. Monitoring and controlling the passage of the body's excretions to the external non-corporeal space then became the realm of sanitary science and public health (Armstrong 2002). The social discourse on civilisation dictated that self-control of bodily functions and privacy for dispelling body products, were the defining behaviours of a civilised society (Lawler 1991; Synnott 1993). In the interest of civilisation special places were designated for human excretory functions, which effectively separated people both ideologically and physically from their body and its natural products.

Elias (Elias cited in Lawler 1991), argued that the social discourse on civilizing the body led to a conspiracy of silence about body functions as well as promoting notions of privacy and individualism. Added to this were the effects of industrialization and urbanization movements, which further segregated societies, as Elias (Elias cited in Lawler 1991 p. 75) argued:

> More and more, people keep the functions (excretory) to themselves, and all reminders of them, concealed from one another. Where this is not possible– as in marriage for example- shame, embarrassment, fear, and all the other emotions associated with these driving forces of human life are mastered by a precisely regulated social ritual and by certain concealing formulas that preserve the standard of shame.

Paradoxically, the public health doctrine on controlling the body's functions was similar to the early Christian teachings about the dealings of 'a shameful and dirty body' that science had once sought to dispel (Lawler 1991; Synnott 1993). In a way, the public health reforms of the 19th Century on civilisation had for a moment, realigned the secular and the sacred body.

The ideology of civilisation that advocated individualism and privacy were a construct of white European society. In the era of public health reforms, the scientific thinking of Western society had less influence on non-European countries. When the other societies were 'discovered' by the Europeans, the way of life of the foreign people were compared with the Western construct of civilisation and judged to be inferior, thereby giving the explorers and scientists unchallenged authority to capture and colonise the *uncivilised Other.*

The colonised body

European colonisation of foreign lands in the sixteenth century and onwards, had been missions to impose imperial rule on newly discovered countries and to claim sovereignty over the inhabitants. Scientists who accompanied these voyages examined the botanic and organic life forms, which included the bodies and social habits of the *native Other*. The discovery of non-white people in these foreign lands extended the interest of scientist beyond the body's biology, to examine and catalogue differences in the social habits as well as the physical features of colonised non-white people. Scientific curiosity about the black or coloured people set the agenda for social racism by classifying different physical characteristics and social behaviours as primitive and inferior to those of white Europeans. A compelling example was the work of zoologists George Cuvier (1769-1832) and Henri de Blainville (1777-1850), who exploited many non-white people as objects for scientific manipulation. Cuvier and his colleagues' disregard of the humanness of non-white people was exemplified by his infamous mistreatment of a black South African woman called Saartje Bartman who he caged in order to study her biological and social behaviour, in a similar manner to his caging of laboratory animals. The exploitation of this black woman continued even after her death, with a cast of her body and actual skeleton being on display in a French museum as recently as the early 1980s (Fausto-Sterling 1995).

It was common practice for scientists accompanying the European explorations, to collect body parts and the remains of non-white people together with specimens of mammals, reptiles, fish, botanical specimens and other life forms. Even today in the twenty first century, specimens including whole skeletons of Indigenous colonised people that had been taken by the nineteenth and twentieth century explorers, remain objects of scientific interest in European museums and laboratories. Australian Aboriginal people are currently embroiled in controversy with several British museums about their right to claim the remains of their ancestors taken or as some say, 'stolen' (Rodney Dillon quoted in Shanahan 2003) by European scientists. The human remains of some Aboriginal Australians were recently returned to their country by a relative of the Swedish entomologist Eric Mjoberg. Apparently in 1910 Mjoberg had led an expedition that desecrated Aboriginal burial sites in several regions of Australia, without any regard for the cultural concerns of the Aboriginal people. The ancestral remains of twenty people originally smuggled out by Mjoberg, were handed back to a delegation of Aboriginal people who travelled to the Museum of Ethnography in Stockholm where the remains had been stored (Barnett 2004; Davis 2004).

The practice of colonising and classifying foreign non-white bodies gave Western science a position of power over the *native* body (Fausto-Sterling 1995). For example, George Cuvier (Coleman 1964), in reporting his studies of non-European people, made judgements that implied he considered some to be less than human:

> It is not for nothing that the Caucasian race had gained dominion of the world and made rapid progress in the science while the Negroes are still sunken in slavery and the pleasures of the senses and the Chinese (are lost) in the (obscurities) of monosyllabic and hieroglyphic languages. The shape of their head relates them somewhat more than us to the animals. (Parenthesis in original).

Coleman (1964) noted that Cuvier's commentary was an objective scientific observation not intending to convey the social stance of a white supremacist, a position that Curvier actually opposed. Indeed, from the perspective of empiricism, Cuvier's scientific description was distant and objective, however his judgement of the people, was not. It was Cuvier's classification of the physical differences, such as the size and shape of the cranium, the denigration of non-white people's social behaviour, and cataloguing these finding in the same reports as those on his animals studies, that relegated these non-white people to an inferior status to white Europeans (Fausto-Sterling 1995).

Scientists were not alone in their position of supremacy over black and other non-white people. Influential philosophers had already set the precedent. Three examples from Dinesh D'Souza's book *The End of Racism* (1995, p.28-29) are quoted here to emphasise the extensiveness of this authority, which doubtlessly influenced the thinking and attitude of the scientist and explorers when encountering the *native Other.* Examples include the moral philosopher David Hume (cited in D'Souza 1995 p. 28):

> I am apt to suspect the Negroes, and in general all the other species of men, to be naturally inferior to the whites. There never was any civilized nation of any other complexion than white, nor even any individual eminent

> in action or speculation. No ingenious manufacturers among them, no arts, no sciences.

In 1764, Immanuel Kant's (cited in D'Souza 1995 p. 28-29), epistemology that privileged the mind as the originator of experience and thus knowledge, does not appear to extended to the capacity of non-white people:

> The Negroes of Africa have received from nature no intelligence that rises above the foolish. The difference between the two races is thus a substantial one: it appears to be just as great in respect of the faculties of the mind as in color.

The social philosopher George Hegel (cited in D'Souza 1995 p. 29) ascribed an inferior social status to non-white races on the basis of their difference:

> The Negro race has perfect contempt for humanity. Tyranny is regarded as no wrong, and cannibalism is looked upon as quite customary and proper. The polygamy of the Negroes has frequently for its object the having of many children, to be sold, every one of them, into slavery. ...The essence of humanity is freedom....At this point we leave Africa, not to mention it again. For it is no historical part of the world; it has no movement or development to exhibit.

The positional superiority (Said 1993) so prominent in these philosophers views and the scientists of modernity, diminished any chance of accurate representation of the non-white *Other* by social anthropologists of the day who themselves were striving to be accepted by the scientific institution.

The functionalist methods of classifying people on the basis of particular phenotypes and social behaviours influenced the early anthropologists like Malinowski who viewed individuals as functional entities in an organised social system (Malinowski 1944). Colonized Indigenous people like the Australian Aborigines were deemed to be uncivilised and even lesser humans because according to the European observers, they lacked social order. Albert Memmi (Memmi cited in Smith 1999 p. 28) for example used a process of negation to determine the civilised status of Indigenous people in this explanation:

> They were not fully human, they were not civilized enough to have systems, they were not literate, their languages and modes of thought were inadequate.

The legacy of positional superiority and colonisation, was Indigenous people's inherent distrust of and caution toward Western authorities as represented by medical institution and research (Smith 1999). The scientist and explorer Captain James Cook description of Aboriginal Australians as 'noble and courageous' indicated an initial respect for the people (Broom 1982). Subsequent settlers changed this view, however, on deciding that Aboriginal cultural practices were barbaric and savage (Smith 1999). The relatively recent anthropological writing of A.P. Elkin (Elkin 1954 p. 22) also reflected a certain respect for the differences in Aboriginal society as evident in this statement:

> Their (Aborigines) social organization, marriage rules, taboos, philosophy and ceremonial life are, in some respects, no lower or less complicated than our own.

An inherent air of superiority is however, apparent in Elkin's book *The Australian Aborigines: How to understand them* (1954), which includes several photographs of Aboriginal 'types', illustrating different physical features, identified as 'primitive'. Elkin (1954 p. 21) wrote:

> Physically, they have some primitive features, for example, the thickness of the skullcap, the shape of the faces, the retreating nature of the forehead and the comparatively small brain.

Elkin's (ibid.) photographs presented Aboriginal peoples as scientific objects in a similar way to that used to demonstrate what Cuvier determined as structural difference of skin pigmentation, nose and lip size, hair texture, facial bone structure and shape of the head (Coleman 1964).

The healthy body

A healthy body from the objective stance of biomedicine means the mechanical order and absence of biological diseases, while from a sociological perspective health is viewed in terms of an individual's functional abilities to fulfil a social role. Until the latter part of the twentieth century biomedicine had been less concerned with the healthy body than with examining and repairing damaged, diseased or dysfunctional bodies (Madjar 1997).

Biomedicine's challenge to explain how disease manifested as a social condition or why there were variables in individual's response to illness turned the inquiry to social theories of anthropology and constructionism. An example was Kleinman's (1980) theory that health related behaviours, are cultural constructs developed through processes of socialisation and individuals experience within three interconnecting health care systems (Kleinman 1980). These are; the primary or popular system; folk health care system; and the professional system of health care. The primary or popular system is where meanings related to health and diseases are formed according to values, beliefs or traditions of a particular group or community. Decisions about illness and sick role behaviour at the primary level determine if and when an individual stays within the folk level of health care or moves on to professional health care. The folk system comprises, for example; healing, sacred practices, Shamanism and cultural specific rituals, which can traverse other 'health care systems', although in Western societies, systems of folk health care have been marginalised and thus confined within the primary domain, or alternatively become extinct (Kleinman 1980). In moving to the professional health care system an individual is generally expected to take on the value system of the dominant culture, which can mean leaving behind their folk traditions of medicine and healing.

Until recently the biomedical discourse on health care had undermined folk and popular health care system of other minority cultures, discounting what Kleinman (1980) referred to as the subjective reality of illness, because these were not scientifically verifiable.

Despite the apparent dominance of the professional system of biomedicine, studies demonstrated that individuals were not irrevocably bound by the biomedical determinants of health or illness. An example was Blaxter's (1990) groundbreaking *Health and Lifestyle Survey* in Britain that involved a survey of over nine thousand 'subjects'. The conclusion from the study was that women particularly defined health in terms of their relationships, the ability to perform social functions and the absence of medically defined symptoms. For some, health was perceived as their capacity to cope with chronic diseases like diabetes and physical disabilities (Blaxter 1990;, 2001). In fact the ability to get on with life despite mechanical body dysfunctions was viewed as a moral virtue worthy of social respect (1990). Blaxter's (1990) study also revealed that people from the higher socio-economic strata considered qualities of harmony, inner peace and personal awareness as attributes of health, while manual workers placed more importance on the functional ability to work. A national survey of how Aboriginal people perceived their health, demonstrated that regardless of a medical diagnosis or current use of medical treatment, eighty eight percent of those surveyed rated themselves as healthy, ten percent reported they had fair health and only two percent considered their health to be poor (Madden 1994).

Colonising health

Frantz Fanon (1965 p. 121) considered the effect of Western medical science on colonised people to be 'one of the most tragic features of the colonial situation'. Fanon (1965) argued that colonised people were always 'diffident' toward Western system of medicine because medical practitioners represent the culture of the colonisers who had denigrated native customs (Fanon 1965 p.126).

While the colonised Aboriginal people of Australia might welcome the technological and practical advancements of modern biomedical health care, their wish to follow medical advice or willingness to entrust their body, as a compliant patient cannot be assumed. Their manner of dealing with and responding to biological diseases, following Fanon's reasoning, will be influenced by their interpretation of the effects of colonialism plus the degree to which contemporary Aboriginal people have access to traditional folk practices and Western health care.

Senior (2001) demonstrated in her study of the Ngukurr Aboriginal community of Southern Arnhem Land, that people with conditions like diabetes and renal failure followed medical treatment orders only as long as they believed these were improving their condition. These Aboriginal people relied on traditional medicine and healing methods in addition to or instead of conventional medical treatment (Senior 2001). The Ngullurr Aboriginal people expressed health as being free to do what they wanted and needed to do, to fulfil their social responsibilities. A household survey in the same Ngukkurr community reported that the people also valued education and having control of their personal lives as attributes of being healthy (Taylor, Bern & Senior 2000). An important value for Ngukkurr people was to be in control of their health matters which included having access to traditional medicines and healers (Senior 2001).

A possible alternative explanation for why some Aboriginal people might report themselves to be healthy despite their medical diagnosis could be that this was a way of avoiding contact with Western system of health care. The attitude of white non-colonized people when presenting for medical treatment can be expected to be one of confidence and willingness to comply with medical directives. In contrast, the colonised Indigenous people are likely to approach the medical encounter with an anxiety about how to escape the situation and thus resolve to give little information away (Fanon 1965; Smith 1999). The colonising mind of biomedicine is evident when an Aboriginal person who refuses or does not follow medical advice is labelled as being non-complaint or uncooperative (Humphery, Weeramanthri & Fitz 2001). Where as a decolonizing approach would be to understand the context influencing an Aboriginal person's health decision. The context could be that health care decision were made in consideration of their family's wishes and social priorities, or because they feared losing control in the biomedical system, or because of lingering doubt about the essential efficacy of biomedical methods (Fanon 1965; Trudgen 2000).

The body with cancer

The biomedical conceptualization of the body invaded by cancerous cells is as a sick body, and the afflicted person is the victim obliged to accept medicalisation of their life and to comply with an ascribed sick role. In the biomedical institution, the body is viewed as the cancer *host* (Casciato & Lowitz 1988) and as such, is relegated to the passive role of being a patient (Souhami & Tobias 1995). The Concise Oxford English (1991 872) dictionary defines 'host' as a receptacle of parasites or symbiotic organisms and the term 'patient' embodies calm endurance of hardship, pain, delay and life's difficulties. Taking on the persona of a patient, the sick person with cancer relinquishes their body to the biomedical artillery of chemical, radiological and surgical treatments necessary to re-establish the homeostasis of the sick body (DiGiacomo 1992; Lupton 1994; Sontag 1991). The cancer patient's subservience to medical treatment was evident in Susan DiGiacomo (1987 p. 219-320) statement about being a cancer patient: 'I certainly could not control my body; that was now in the hands of my doctors'.

Biomedicine's expectation of the compliant cancer patient overlooked the intervention of body-mind interaction that constructs meaning and motives of self-determining in decision-making. The biological disease of cancer has no meaning on its own because, as Merleau- Ponty and other constructionists postulate, nothing has meaning without social interaction of people with the object (Berger & Luckmann 1967; Bulhof 1980; Crotty 1998). So how does an individual interact to form a meaning relating to a mutated cellular object called cancer that secretly invades their body? The answer lies in the social discourse through which individuals construct meanings from tacit knowledge and experiences of their community and the socialisation processes of interaction between the inner and outer worlds.

The 'mindful body'

The biological dysfunctions or changes in the body's structure manifested by a cancer may well appear objectively as a lump, or present symptoms that can be measured, but a person's response to these indicators is a subjective construct of the *mindful body* (Scheper-Hughes & Lock 1987). The concept of the *mindful body* proposed by Scheper-Hughes and Lock (1987) is a process of interaction between three separate and converging 'bodies', comprising the mind-physical body in relationship with the social body and body politic. The *mindful body* is therefore a representation of three epistemological and theoretical positions, where the concern of the individual body is the existential subjective elements of mind, matter, soul, self and identity that are like filters mediating between the inner and outer body in the process of forming meaning. The individual body cannot form meaning in isolation, but involves interactions with the natural and structural elements of the social body, that is society, and with the functionalist body politic of law and order (Scheper-Hughes & Lock 1987). In fact in the context of health care, the individual body is in many ways subordinate to the social body. As Douglas (cited in Blacking 1977 p. 4) argues, the social body influences how the physical body is perceived and in the context of public health, the body politic has the greater authority to control and regulate both the individual and social bodies (Scheper-Hughes & Lock 1987).

The authority of the body politic is evident in the public health discourse on health promotion that advocates a population approach for the surveillance of individual and societal health behaviours, as for example in the mass immunisation program for infants, and breast cancer screening of women over a certain age. In the democratic world of Western societies, however individuals have reasonable degrees of liberty to engage the *mindful body* in decision-making and thus compliance with the public health agenda becomes a subjective response. Autonomous societies and individuals can balance health risks and the context of lives in deciding to comply or rebel against public health directives. An example is the current controversy over people's rights to smoke cigarettes in public places, or the rights of parents to choose not to have their child vaccinated despite public health evidence of the dangers.

Conversely in the world of oppressed colonised people, the body politic of public health once used paternalistic approaches that fostered dependency rather than self-determination in health behaviour (Fanon 1965). For example, in the history of Australian Aborigines since European colonisation, the jurisdiction of public health extended to control every aspect of the people's lives and subjugated folk and traditional health care practices, which left the people dependent on the Western methods as the apparent only option (Kidd 1997; Smith 1999; Trudgen 2000). The meaning of health and diseases like cancer can be expected to vary according to different cultural knowledge, beliefs, values and traditions that distinguish one society from another, what Franz Boas classified as cultural relativism (Kleinman 1980; Mazrui 1986). It seems incongruous therefore, that the authority of Western biomedicine remained the dominant institution of health care. In contemporary Western society, other health care methods such as the traditional healing and medicines of Indigenous people and other minority cultures have either been marginalised or remain subjugated by the colonial mentality of power inherent in the Western culture of biomedicine (Fanon 1967; Smith 1999; Trudgen 2000).

The tension between different cultural perspectives is not confined to the colonised Indigenous people's reticence toward biomedicine. There is a steady movement of Western people who are also disillusioned and resentful of the hegemonic position of biomedicine in health care, and they are turning to alternative approaches including holistic practices of some minority cultures.

Disillusionment and hope

The postmodern critique of biomedicine's authority was not only occupying the academic discourse, as disenchanted cancer patients began questioning the claim to truth of the dominant institution. People with cancer began to defy the medicalisation of their bodies and life and sought alternative approaches to how their disease and sickness was managed. Many cancer patients and their families challenged what they perceived to be the false truth of biomedicine's rhetoric on curing and preventing cancer. This rebellion was partly because, despite complying with medical advice, people still succumbed to the disease and the debilitating side effects of treatment. Other patients might well share the disappointment in the promise of biomedicine to control cancer, but the voice of cancer patients that have been strongest in the discourse on alternative approaches in health care.

The sick and the well began drifting toward alternative therapies such as naturopathy, homeopathy and the Eastern medicines, because the 'whole body' approach of these modalities transformed the sick role from passive compliant patient to a resourceful agent of self-healing (Kleinman 1995; Lupton 2003). Biomedicine instinctively dismissed many of the alternative therapies as quackery because they were seen to lack scientific basis. By the turn of the twenty first century, however, the enormous popularity of holistic and natural therapies convinced the medical academy that these had a place in cancer health care (Buckman & Sabbagh 1993; Le Fanu 1999). What the alternative medicines actually offered was the human touch that biomedicine had lost in pursuit of a scientific explanation for all diseases and cures. A phenomena observed by Michel Foucault (1973 8) in his critique of biomedical practice:

> In order to know the truth of pathological fact, the doctor must abstract the patient: ....the patient is only an external fact; the medical reading must take him into account only to place him in parentheses.

The shift toward alternative therapies has been effective in decentring the problem from cancer as just a pathology, to considering also the socio-cultural context of the *mindful body* that constructed cancer as more than a biological disease (DiGiacomo 1992; Scheper-Hughes & Lock 1987).

Where the predominant concern of biomedicine was pathology and disease management, the mantra of alternative therapists was health and self-healing, which sick and well people welcomed as an opportunity to regain control of their bodies. The alternative therapy movement promised to liberate the sick with the realisation of what Kierkgaard and other existentialists had professed since the nineteenth century, that truth was individually constructed (Kaufmann 1975). Existentialism promoted the notion that being an individual meant being free to make choices and that an autonomous decision was truth, as opposed to what the authorities, in this case biomedicine, claimed as truth (Kaufmann 1975). When free from the oppression of a single truth, the discourse on cancer moved the focus form purely the biological disease to engage the human experiences. The dialogue between body and liberated mind manifested, what Seale (2001) called 'struggle language' of the sick in terms of, 'the inner enemy', and a 'threat to the social identity', and other existential meanings such as a 'challenge to the spirit' (Armstrong 2002; Hoffman-Goetz 1999; Lackey & Brown 2001; Seale 2001; Skott 2002).

As free agents, people with cancer were able to gather sufficient information to make choices about alternative therapies which chose to either replace or complement conventional cancer treatment. Many cancer institutions have integrated therapies such as massage, music and aromatherapies and relaxation to complement biomedical treatments, especially when the aim of medical intervention is for palliation of symptoms rather than curing the disease. Acceptance was evident in the domain of palliative cancer health care where biomedical practitioner have acknowledged that 'some' complementary therapies were useful for psychological support and could mediate between the technology of treatment and the human experience of sickness (Buckman & Sabbagh 1993; Lupton 2003; Reed, James & Sikora 1990).

While many people with cancer welcomed the complementary or alternative therapies, it cannot be assumed that the benefits were universally appreciated or that the self-healing mantra was appropriate for everyone. Self-healing, that underlies the philosophy of many alternative therapies, places the responsibility back onto the sick, and in so doing potentially adds a burden of guilt and blame if the sick person fails to recover or the well become unhealthy (Buckman & Sabbagh 1993; Rose 1995). Gillian Rose, a scholar of philosophy at the time of writing about her experience of having incurable ovarian cancer, was critical of the alternative therapies that advocated 'a mind over cancer approach'. Rose (1995) argued that the doctrine of self-help and becoming 'exceptional', which was the mantra of certain popular self-help literature, burdens of the sick with, as she defined it: 'the individual soul with an inner predestination: you have eternal life only if you dissolve the difficulty of living' (Rose 1995 p. 97). Rose concluded that the vulnerable cancer patient faced rejection from both sides. Biomedicine apportioned blame to the patient who had not heed medical advice on preventing cancer or who failed to respond to medical treatment, and then the 'mind-over-cancer' fraternity reminded the hapless individual that they were somehow responsible for their disease or lacked the will-power to conquer it. Susan Sontag (1991 59) summarised the effects of this punitive approach of alternative crusaders in the fight against cancer when she wrote:

> The illness is the culprit. But it is also the cancer patient who is made culpable. Widely believed psychological theories of disease assign to the luckless ill the ultimate responsibility both for falling ill and for getting well.

Reframing health care

By the nineteen sixties when technical innovations of biomedicine began to accelerate, the seminal work of Glaser and Strauss (1965) *Awareness of dying* brought to light the social and psychological plight of patients whose disease could not be cured. At the time the Glaser and Strauss study, professionals were preoccupied with the heroics of curing diseases and with the new technology for resuscitation, and thus had been distracted from the needs incurable and dying patients (Glaser & Strauss 1965). Glaser and Strauss's (1965) findings that health care professionals avoided the incurably sick and dying and betrayed the patient's trust by neglecting their psychosocial needs and even lying to the patient, challenged health care professionals to review their practice. The initial response to Glaser and Straus (1965) study came from the sociology, psychology and psychiatry academies that took up the cause by advocating for a more holistic approach that considered the psychosocial context of dying in institutions like hospitals.

The formation of the hospice and palliative care movement in the 1960s was influenced by the research of social psychologists and some medical clinicians who acknowledged the shortcomings of the biomedical system. Example were the work of, Elizabeth Kübler-Ross, John Hinton and Collin Murray Parkes, who alerted health care professionals to the psychological response of the dying patients which they asserted could be better supported by professional care. The contribution of Kübler-Ross, (1970) who was a medical doctor specialising in psychiatry, was a model that delineated the stages of dying that she had observed in clinical work. The model comprised five stages, denial and isolation, anger, bargaining, depression, and acceptance, which were defined as the processes of psychological and behavioural adjustment to dying.

Hinton (Clark & Seymour 1999) observed how terminally ill patients' mental and physical distress correlated with their social background and history of coping with life-challenges. Murray Parkes (Worden 1982) first mapped the grieving journey of the bereaved and his work lead to development of grief support services. Although the contribution of these scientists changed thinking and to some extent practices in the care and support of dying patients in hospital as well as the bereaved, their influence was not sufficient at the time to revolutionise the curative orientation of biomedicine. The hegemonic position of biomedicine in the 1960s meant that although the social and psychiatric sciences revealed the shortfall in cancer health care, the paradigm shift necessary to change methods and attitudes of practitioners and to embrace the psychosocial domains took some while to evolve.

A postcolonial turn in biomedicine

In the 1940s Dame Cicely Saunders, who had then been a hospital almoner[12] and former nurse, envisaged a specialist approaches for the care and treatment of the incurably ill and dying cancer patients, but it was not until she qualified as a medical doctor that Saunders realised her vision (Du Boulay 1984). Saunders was considered to be the first medical doctor to specialise in care of the dying and to pioneer principles of continuous pain control. This approach to pain management was considered radical at the time because Saunders's advocated for regular administration of analgesic drugs instead of the 'as necessary' orders of *pro re na'ta* (p.r.n.) that were common practice. The principle of Saunders's approach to regular and continuous analgesic medications was

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[12] Hospital Almoners were the precedents of the discipline of Medical Social Workers that was established in 1964. Stacey, R & Collis, A, 1987. *Catalogue and guide to the archives of the predecessor organisations, 1890-1970*, British Association of Social Workers, Birmingham.

that it reduced the patient's dependency on both the drugs and the staff who needed to administer the treatment (Du Boulay 1984).

As a medical doctor Saunders effected changes in practice for symptom control for patients with advanced cancer and also considered the context of symptoms holistically. An example was her concept of 'total pain', which included the social, emotional and spiritual aspect of the experience. Saunders modus operandi was firmly grounded by Christian values of spiritual care as embodied in devotion, compassion and the religious practice of prayer that were central to her practice in the institutional care of the dying (Du Boulay 1984). Saunders (1984) restored human subjectivity, the heart and soul, to health care, that had been overlooked in the pursuits of objective scientific truth. Western Christian ethics were reflected in Saunders use of the term *hospice* to define the philosophic grounding for the method of providing peaceful, medical/nursing, psychosocial and spiritual care for cancer patients who were dying.

Throughout history religious orders had provided care and shelter for the poor, destitute and dying in institutions called hospices, some of which had medical support. The medical hospice movement, founded by Saunders, upheld the Christian philosophy of the religious order hospices and combined this with conventional medical practices. In the era of Saunders's medical reform, the plight of cancer patients was a principal concern as the disease became more prevalent and patients had fewer options other than treatment that caused debilitating side effects. While biomedicine pursued the search for a cure, cancer patients were the objects of often aggressive treatment including radical mutilating surgery, high dosage radiotherapy and a crude cytotoxic therapy of nitrogen mustard, which I had witnessed caused immense suffering without the reward of a cure or even a decent remission. At the time of Saunders reforms in medical practice, the transition markers between curative and palliative approach to treatment of cancer were ambiguous and patients endured the cure-orientation of medical treatment almost to the point of their death. The modern hospice movement sought to reverse this situation by not only providing a Christian-based haven for the terminally ill cancer patient but also generated new research and education upon which the discipline of palliative care as a subspecialty of medicine and nursing was founded.

In contemporary Western countries palliative care is the holistic paradigm of biomedical cancer health care, although there are concerns that the approach medicalized the dying process by institutionalising death and consequently hiding this natural event of life from society (Avellanet et al. 1999; Byock 1998).

Palliative care for non-Western cultures

Although fairly well established in medical, nursing and some allied health curricula, palliative care in Australia is reported to serve only 37.5% of people who died as a result of expected deaths (*Policy Consultation Paper* 2004). Furthermore, although there is no reliable data on the cultural or racial identity of palliative care patients, anecdotal evidence is that many minority cultures including Indigenous Australians are underrepresented in this patient population (Sullivan 2003).

The cultural monopoly of palliative care users was demonstrated in a British survey which showed that in a population of 10, 242 hospice-palliative care inpatients, 98.4% were white Caucasians (Eve, Smith & Tebbit 1997). A similar study in America concluded:

> With notable exceptions, it appears that hospice (palliative care) has been unsuccessful in serving non-white communities proportionally to their presence in the potential hospice population (Harper 1995, p. 3).

Recent studies indicated that the disproportionate use of palliative care services by cultural minorities has not changed. This has been attributed to factors that included the lack of cultural competency of the staff, inaccessibly of services; cultural issues related to death and dying were not accommodated (Doorenbos & Schim 2004; Lyke & Colon 2004).

The assumption has been that the Christian ethic underpinning the philosophical approach in palliative care is generic and thus adaptable (Voltz et al. 1997) to people's race, religion or cultural or any other orientation. The oversight has been in acknowledging that the modern palliative care movement is fundamentally a Western construct of biomedicine and its basic concepts of holistic, psychosocial care and multidisciplinary methods are not necessarily congruent with the values of non-Western cultures. The fact that a patient's cultural or ethnic identity is not routinely recorded in hospital documents (Harper 1995; Sullivan 2003) suggests that culture differences have not been a central focus to palliative care practitioners or received the same level of attention as patient's demographics profile, social circumstances and their religion.

A survey comparing how palliative care was received in America, Germany and Japan, demonstrated similar levels of satisfaction from the patients and their families with the palliative approach, but there were variations in how and when patients accessed the services (Voltz et al. 1997). However, the conclusion of this survey that the hospice philosophy was independent of cultural background and adaptable to cultural difference is misleading. As the patients in this survey had been receiving palliative care in their own countries, it was more likely therefore that services were acculturated to suit that population. Had the patients from these different cultural groups received care in a foreign country the results may have been less positive.

Summary

The mechanistic conceptualisation of the human body in health and illness by Western biomedicine has been another form of colonisation. The objective stance of biomedicine that promoted the body-mind split enabled medical science to categorise diseases and human responses unimpeded by the intervention of human subjectivity. The success of medical science in controlling biological disease extended its authority in the public health discourse on not only controlling health behaviour but also in determining the criteria of a civilised society. The authority of the public health discourse on civilised behaviour consequently set an agenda for colonising the health practices of non-Western populations on the basis of the different lifestyles and physical phenotypes. The analogy of biomedicine as a coloniser is justified when considering the construct of compliant cancer patients who are expected to relinquish their own folk or traditional health care methods to the monopoly of biomedical methods. Cancer patients disenchanted by biomedicine's claim to truth are moving to reclaim control of their bodies, and seeking sanctuary in the holistic paradigms if alternative medicine because these aim to realign the body and soul in health care.

The social movement of cancer patients and the sociological revelations about the plight of the dying in hospitals influenced a paradigm shift in biomedicine in the form of the hospice-palliative care movement. The success of the new biomedical paradigm has been in acknowledging the social-psychological and spiritual experiences of sickness and dying. However, despite over forty years of evolving as a discipline of palliative care, Aboriginal people and other minority groups are under represented in this patient population. This suggests that cultural perspectives of Aboriginal and non-Western people are not accommodated by the generic-holistic approach of biomedical palliative care, or alternatively there is some aspect of practice that is culturally incongruent.

CHAPTER FOUR

COLONISING THE ENIGIMA OF CANCER

Cancer is arguably the oldest human disease that remains an enigma to biomedical science, and a major threat to the social stability of contemporary societies. Throughout the history of modern biomedicine, the elimination or at best the control of cancer has been a constant yet unattained goal, one reason being that the disease does not follow the predictable, cause-effect or mechanistic laws of empirical science. Because of its resistance cancer has become more than a scientific construct of a biological disease, it is a socio-cultural-and political phenomenon and some say a metaphor for the ills of the world (Sontag 1991). Records show that by the sixth century cancer was sufficiently common for physicians of Hippocrates' era to classify and name the disease and speculate about causes and treatment (Nery 1986; Olson 2002). The appearance of a cancerous tumour with its swollen blood vessels spreading like tentacles to invade normal tissues, prompted Hippocrates to name it *karkinos* a Greek word for crab, from which the western name of carcinos, carcinoma then cancer evolved (Le Fanu 1999; Olson 2002).

The disappointment in western societies is that despite the considerable achievements of modern medicine in controlling other diseases and extending life expectancy during the last fifty years, cancer remains unconquered. In 1943, cancer was reported to be the principal cause of death (Podolsky 1943) and fifty seven years on cancer (listed as malignant neoplasms) in western societies remains a leading cause of mortality, second only to cardiovascular diseases (Anderson 2002; Greaves 2001). Cancer is viewed in western societies as a demonic predator that has no respect for social class or status, ethnicity or race, religion, achievements or wealth (Greaves 2001). Fear of cancer occupies the thoughts and influences the actions of all classes of people throughout the developed world and is becoming an additional concern for people in less advantaged worlds of colonised Indigenous people, and others who continue to struggle with diseases of poverty, social deprivation, and poor living conditions.

In biomedical terms, cancer is an irregular proliferation of cells occurring because of a chromosomal mutation of the genome, the aetiology of which is not fully understood (Greaves 2001; Hesketh 2002). The epidemiological observations in the 1950s and 1960s that environmental pollutants, human life-style habits, exposure to asbestos and tobacco smoking, were significant cancer causing agents, justified biomedicine's influence on public health reforms. Public health policies aimed to educate and persuade individuals and society as a whole to play their part in the war against this deadly disease.

Despite population cancer screening programs and education on risks factors, incidence of cancer remains an important cause of social disharmony associated with premature mortality, to the point that most people know someone, either a friend or relative who has cancer or who had died from the disease.

The considerable advancements in understanding the biology of cancer and the development in medical diagnostic and treatment technology, encouraged society to be optimistic that a definitive cause of all cancers would be discovered and the cure assured. The popular media's sensationalising of every glimmer of a breakthrough in cancer research supports society's expectation that the elusive cancer cure is imminent. For this reason people throughout the materialist western world remain willing to donate considerable funding for cancer research as a means of sustaining their belief that scientific diligence will prevail over wayward cancer cells. In reality, science can confirm only that the risk of cancer increase substantially with ageing, a situation that is hard to prevent in the non-Indigenous world anyway, and can claim that biomedical treatment is proven effective in eliminating a few types of cancers providing these are detected early. Examples are skin and cervical cancers, and some childhood cancers (Greaves 2001; Le Fanu 1999). Biomedical treatments have increased survival rates and extended the periods of remission from other types of cancer, but these medical successes have not been enough to placate society's fear of the disease because many other common malignancies do not conform to the conventional cure model of biomedicine. Breast cancer probably history's oldest human disease (Olson 2002), for example, remains the most common malignant disease to cause premature death of women (Pitot & Loeb 2002; Souhami & Tobias 1995). The problem is that despite women's compliance with cancer screening programs, the main underlying cause is related to ageing and to woman's own hormonal physiology, both of which are unpreventable (Greaves 2001).

In western societies the discourse on cancer continues to construct its social meaning as a shocking disease that society has a responsibility to prevent by heeding medical advice about risk factors, or if afflicted, the individual is expected to comply with the biomedical agenda to control the deadly disease. This can expose the cancer patient to a barrage of noxious treatment that may abate the cancer growth but in the process causes unpleasant side effects such as physical disfigurement, painful symptoms, and medicalisation of the person's life.

Exploring the biology of cancer

Since the days of Hippocrates mystic and esoteric theories on cancer have abounded (Greaves 2001). From the humoral theories of *black bile* as the cause of cancerous growths, to dietary causes, and in the modern era, that cancer in women is because of a sedentary life and a 'melancholic disposition' (Greaves 2001 p. 14).

The invention of microscopes allowed the medical scientist to discover the cellular structures and mechanism of cancerous growth (Cooper 1992; Olson 2002). The logical expectation had been that the empirical evidence of cancer's biological mechanisms gave science the information to control or destroy the invader.

Cancer is a serious threat to life because its atypical structure and unregulated cellular growth competes for the nutrients of normal cells and will eventually kill them. Furthermore, the cellular proliferation of cancer can metastasise to other parts of the body by travelling through the blood and lymphatic systems depositing cancer stem cells where they can colonise other normal tissues and organs. The difficulty for biomedicine is that cancer is not an homogenous disease but varies in histological, biological and immunological characteristics. Histological variation refer to the degree of differentiation or change from the normal host cells, thus a poorly differentiated tumour has a less optimistic prognosis than a well-differentiated growth, which in theory means that it is relatively contained within the host organ (Gasparini et al. 2002).

The biological mechanism of cancer can be discovered in the living body with the use of scientific tools of the microscope, computer and imaging technology, which expose the micro level, and x-rays, tomography and fiberoptic endoscopes, that present the macro view of cancer's effect on the body. Mechanical examination of the body and tumour is the biomedical method required to classify cancers according to the cellular type, stage of growth and cell differentiation. This classification provides an indication of the prognosis, and the goals and type of treatment that may be curative or palliative (Gasparini et al. 2002). A critical prognostic factor is the stage of the cancerous growth at diagnosis and whether it has metastasised to other organs. When the intention is to cure, an individual may endure an onslaught of prolonged treatment justified because of an expected positive outcome of long-term remission or total cure. A successful cure is currently considered in terms of being cancer free for five years. Palliative treatment on the other hand is considered in terms of the risks and benefits of any intervention with the ultimate goal being to enhance the individuals' quality of life (MacDonald 1995)

Cancer as a biological object has no inherent meaning or subjective reality that is no more than other cellular structures, yet throughout history cancer has been used as a metaphor for evil, corruption, ungodliness and other negative social deviances (Greaves 2001; Sontag 1991). It is also ironic that the biomedical discourse on cancer inscribes an inherent psychosocial meaning to the disease, one that arouses subjective emotions in society. This is demonstrated in Podolsky's book *The war on cancer,* in which he describes cancer as if it were a social deviant. Podolsky (1943 p. 8) a medical doctor professed:

> Cancer is nothing more or less than a lawless, uncontrolled growth of cells, which refuses to obey the natural laws of structure and function.
>
> Cancer cells failing to observe the community interests of their neighbours run riot, invade the surrounding cells and cross boundaries which they should respect.

Podolsky's (1943) description presented cancer as a deviant enemy to biomedicine probably because the disease did not obey the natural laws of empirical science. Cancer cells defy the laws of cause and effect that usually inform the scientific method, the basis of biomedicine's authority in controlling human disease. Cancerous cell even deviate from the systems theory rule of homeostasis, whereby physiological fluctuations are usually regulated by internal mechanisms (Guyton 1982). Such is the anomaly of cancer that these delinquent cells can produce substances that mimic normal physiological enzymes or regulatory hormones, and interfere with other sites of the body, a condition known as paraneoplastic syndrome (Cooper 1992; Haskell, Lowtz & Casciato 1988). Some types of breast cancer, for example, secrete substances that produce neuromuscular symptoms in a site remote from the primary breast tumour. The recalcitrant nature of cancer cells incited medical science, society and the body politic to join force in declaring war against life threatening disease (Cooper 1992; Lupton 1994; Podolsky 1943).

Public health against cancer

The positional superiority of biomedicine initially confined the battle against cancer to laboratories as society and individuals were not considered as autonomous agents, able to influence or navigate the public health domain (Lupton 2003). The principal concern of the public health movement in late 19th and early 20th century was the reformation of hygiene practices of social and individual bodies in the effort to control the spread of contagious diseases, rather than involving lay society in the complex scientific arena of cancer (Lupton 2003). In that era the body politic of public health had the authority to quarantine entire households and neighbourhoods if surveillance officers attributed an infectious disease to a particular group or district (Lupton 2003). The general population were not implicated as agents in the discourse of health reform until the moral crusade on personal hygiene during the Victorian era, and even then the poor and lower class people were coerced to comply with public health laws by punitive actions (Lupton 1995;, 2003).

The opportunity to engage society in the quest to control cancer was presented as far back as 1775 when Sir Percival Pott, a surgeon in London, first described occupational and environmental causes of cancer. Pott observed a link between cancer of the scrotum and the occupation of chimney sweeping, and later described the cancer causing agents of dye works and coal mining (Greaves 2001). In 1795 cancer of the lower lip affecting long-term pipe smokers was linked to the practice of smoking, although tobacco was not considered the primary cause so much as the pipe's heated bowl and stem (Greaves 2001; Nery 1986). Medical scientists warned of the dangers of tobacco smoking and snuff inhalation in the mid sixteenth century, but it was not until the 1950s when Sir Richard Doll, an eminent cancer epidemiologist, published his research, that decisively linked smoking with lung cancer, that the public health discourse on cancer prevention and tobacco smoking changed. Dolls' findings shifted the focus of public health toward a population approach for changing smoking habits and controlling environmental smoke attributed to coal and industrial combustion (Le Fanu 1999; Lupton 1995; Nery 1986).

Toward the later part of the twentieth century, subsequent scientific evidence that many cancers were caused or exacerbated by people's life-style and habits like smoking, redirected public health back to individuals with the message that cancer was preventable and that people had a responsibility to change cancer risking behaviour. In the last few years, however, the focus has reverted back again to the population approach of including the social and the body politic in the responsibility for controlling cancer risks by legislating against cigarette smoking in public, and air pollution, use of asbestos and other carcinogenic agents as well as promoting the individual's social obligation to heed medical advice on cancer prevention (Lupton 1999; Peto 2001).

Since Doll's groundbreaking report in the 1950s, public health has reformed the culture of smoking in western societies, to the current situation of pending international legislation for regulation of all sectors of the tobacco industry, from production to the point of sale and consumption (WHO 2004). The effect on health of smoking has been a subject of debate for most of the twentieth century and in the last fifty years the discourse evolved from promoting the benefits of cigarette smoking, to the present contemporary social stigma against those who persist with the habit. Yet in the Second World War, for example, cigarettes had been included in soldier's rations as comforters, and even some of the medical profession offered cigarettes to their patients, as Doll (Doll & Williams 2004) himself recently recalled:

> Certainly I remember patients with chronic obstructive lung disease saying, 'Oh they had to have a cigarette to help them bring up the sputum in the morning' and there were a few doctors, many psychiatrists I think that used to offer patients a cigarette 'to put them at their ease' when they came and consulted them. (Punctuation in original).

But today in many western countries successful public health strategies have made smoking illegal in most public places, which has relegated the unrepentant smoker to cowering in often dingy outside areas in order to indulge their habit. In Australia's Indigenous communities as with colonised minorities in other parts of the world, smoking remains endemic. In the year 2001 the National Drug Strategy Household Survey demonstrated that about 19.5% of Australians over the age of 14 years smoked tobacco regularly, but this was minor compared to nearly 50% of the population of

Aboriginal people who either smoked or chewed tobacco on a daily basis (AIHW 2002).

A further significant contribution of Doll (Le Fanu 1999) to the public health discourse on cancer was his theory that in addition to tobacco, all cancers could be attributed to the western diet and thus cancer was avoidable by simply eating healthy foods. Twenty-five years since Doll published his theory, the debate on cancer causing diets such as, high fat and low fibre, processed foods, added chemicals, non-organic food and so forth is inconclusive. Nevertheless while the debate continues society has some way of remaining engaged in the quest to prevent and control cancer.

Women's cancers

Throughout history, the propensity of women to develop cancers has been a subject of scientific and social inquiry. Popular theories to explain the high incidence of cancers affecting female breasts and reproductive organs have also evolved through history. Examples include that cancer is related to fluctuations in female reproductive biology, or is the manifestation of a neurosis associated with women's 'civilised life', or that wearing undergarments restrictive of female anatomy aggravated cancer (Greaves 2001). Some influential medical practitioners of the 18th.and 19th century attributed cancer to the stress of modern life, and considered that cancer was predominantly a women's illness as the following extract (Richard Guy, cited in Greaves 2001 p. 14) from a medical physician demonstrates:

> Women are more subject to cancerous disorders that men especially such Women that are of sedentary, melancholic Disposition of Mind, and meet with such Disasters in Life, as occasion much trouble and Grief.

Attributing the burden of cancer to the disposition of women possibly arose because female breast cancer was the earliest observed cancer, probably of its obvious appearance (Olson 2002). The more contemporary theories relate women's cancer to the chemical manipulation of the female hormone physiology for birth control or for managing biological changes associated with the menopause, and just aging (Greaves 2001 p. 143; Olson 2002).

The attention on women's cancer continues to have prominence in medical and social discourse. One reasons is because breast is continues to be a major cause of morbidity and mortality and cervical cancer is one of the most common cancers of women worldwide (Braun & Gavey 1999) This is despite advancements in screening programs, sophisticated medical treatments and extensive public health education on early detection and limiting risk factors (Jemal et al. 2003; Souhami & Tobias 1995). Breast and cervical cancers are becoming increasing concerns for Indigenous women in all parts of the world, where once these minority groups had been thought to be at less risk from developing this disease because of their natural, unencumbered way of living, higher fertility and because of the relatively shorter life expectance in these populations (Ganz 2002; Greaves 2001; Mittra 2001).

The history of breast cancer

Female breast cancer is possibly history's oldest disease (Olson 2002) that remains women's most dreaded diagnosis because it attacks a visible and sexually important part of the body. In Australia as in other westernised countries, breast cancer is the leading cause of death for women in the 20-59 year age group (AIHW 2003; Veronesi, Goldhirsch & Yarnold 1995). The prevalence of breast cancer is related to known risk factors most of which are linked with just being a woman, getting older and possibly a way of life associated with one's country of residence (Boyd 2002; Kulka & Davies 2002; Le Fanu 1999).

Since 1890 when surgical treatment of breast cancer was pioneered by William Halsted, and in later years the additional treatment of radiotherapy and cytotoxic chemotherapy, the chances of surviving the disease has not improved significantly (Greaves 2001; Le Fanu 1999; Olson 2002). Several hypotheses about the aetiology of breast cancer currently occupy biomedical research. Among these are: that high fat diets have carcinogenic properties; that cancer is linked to levels of sex hormones specifically, progesterone, oestrogen and prolactin; that exposure to radiation damage leads to cancer; and that some people have a genetic predisposition to cancer (Kulka & Davies 2002; Pitot & Loeb 2002).

In the latter years of the twentieth century an important breakthrough for biomedical research was the discovery of a genetic predisposition. The faulty genes labelled as BRCA1 and BRCA2 are thought to account for up to 10% of all breast cancers, increasing women's risk of developing the disease by fifty per cent (Greaves 2001; Kulka & Davies 2002). The genetic theory of breast cancer is still inconclusive and social studies caution against over optimistic expectations, yet some women have heeded the medical determinants of their risk status and agreed to the extreme precaution of undergoing prophylactic mastectomies (Hartman et al. 1999; van Dijk et al. 2003). Voluntarily undergoing such drastic, mutilating surgery surely epitomises the lose degree of authority biomedicine has over women's bodies. Not only does the woman a physical feature of her femaleness on the basis of objective and depersonalized risk assessment, but also her life thereafter is destined to be medicalized

(Gifford 1986). Viewed from the objective stance of biomedicine, a woman's risk of cancer is determined by epidemiological generalisation from population studies rather than the specific risks of an individual woman's circumstances. By contrast, a woman's assessment of her risk of developing cancer is made from the position of social and personal contexts which includes her willingness to modify risk taking behaviour or to comply with medical advice (Gifford 1986). The notion of risk for developing breast cancer is largely a construct of the biomedical discourse that few laywomen are in a position to refute. In other words, it can be argued that prophylactic mastectomy reduce the risk of increasing cancer incidence from the medical perspective but does not necessarily bring social benefits in terms of the woman's overall well being, and almost certainly places the woman under the gaze of medical surveillance for the duration of her life.

Biology of breast cancer

The abnormal cell growth causing breast cancer most frequently arises from the glandular epithelial lining of the lobes and ducts of the breast. It is a life threatening condition when the cellular growth becomes invasive, proliferating to other systems of the body. At the non-invasive stage breast cancer may be either a lobular carcinoma *in situ* (LCIS) that is detectable by self-examination as a lump, or a ductal carcinoma in situ (DCIS), which is not palpable (Kulka & Davies 2002; McCready 2002). A painless lump is the typical biological feature of a lobular breast cancer at the pre-invasive stage that can be detected by using a particular technique of palpating the breasts. Not all breast lumps are necessarily cancerous but can be a benign fibrous tumour, a calcified fibroadenoma, a clump of fat necrosis, or a residual inflammatory mass or cyst, all of which can be felt as a palpable mass (Kulka & Davies 2002; Souhami & Tobias 1995). Some benign growths like hyperplasia occur in the lobes or ducts of breast tissue and are considered to be a pre-cancerous condition, particularly if the woman has a family history of the disease.

Finding breast cancer

Discovering any type of breast abnormality is invariably distressing for a woman, mainly because public health messages generally emphasise cancer as the underlying reasons for doing self-examination and medical assessment, without clearly acknowledging benign conditions. Over 80% of all breast cancers are invasive lobular carcinoma that may be felt as a new, hard, ill-defined lump within the breast. If the tumour spreads along the suspensory ligaments of Cooper (strands of connective tissue) between the breast lobes it causes a tension on the overlying skin that is visible as a dimpling or pitting effect. Extreme skin pitting is known as *peau d'orange* because the texture of skin on the affected breast resembles that of an orange peel. An inverted nipple is another indication that a tumour has spread along the ducts and is pulling the associated areolar tissue. At more advanced stages the cancer spreads to the lymph glands in the axilla and to the underlying muscle of the breast that may be evident as swellings (Veronesi, Goldhirsch & Yarnold 1995).

Approximately 10% of breast cancers are invasive ductal carcinoma, which have similar characteristics to invasive lobular carcinoma, but with a more diffuse spread, and therefore less evident as a discreet palpable tumour. Detection of a breast lump by self-examination alone is not reliable, particularly as ductal carcinoma *in situ* may not form a palpable mass and is accurately detected only by mammography, which illustrate the characteristic pattern of calcification, and confirmed by a needle biopsy of breast tissue and exudate, which is microscopically examined (McCready 2002; Souhami & Tobias 1995). A small number of lobular carcinomas can go undiagnosed until they erode through the skin of the breast appearing as a fungating ulcer, exuding an offensive odour and causing considerable pain for the woman. Although not commonly seen today, one still hears from the clinical field of women presenting with a fungating breast cancer having overlooked, either through fear or ignorance, the early signs of a breast lump or other changes.

The invasion

From the biomedical perspective, the success or failure of treatment is dependent on women's participation in breast screening and early detection practices. This is because the critical prognostic factors are the staging of disease and the age of the woman at diagnosis. The incidence of cancer is more likely to increase in older women but generally the disease is less aggressive and slower growing, so treatment may be more conservative (Greaves 2001). From the woman's position the significance of staging breast cancer is that it determines how much of her body is sacrificed to the disease and the degree of disfigurement and debilitation she has to endure on the chance of being cured.

In the minds of most women, a diagnosis of breast cancer is synonymous with the physical mutilating surgery of mastectomy. The radical mastectomy pioneered by William Halstead in 1890, was hailed a biomedical success because his technique of surgically excising all the breast tissue, the surrounding lymph nodes and local chest muscles, in medical terms, improved survival rates (Olson 2002). While Halstead's mastectomy in some cases successfully interrupted the progression of cancer, from a social perspective it left the women feeling mutilated, disfigured and often with other debilitating condition of lymphoedema and cellulitis of the affected arm (Olson 2002; Souhami & Tobias 1995).

The recent biomedical discovery that breast cancer mortality is most likely caused by systemic spread rather than the localised disease, has given women a reprieve from the mutilation of mastectomy, and in theory an option of breast-conserving surgery. Today women may be given the choice of either a lumpectomy or simple mastectomy that spares some lymph nodes and chest muscles depending on the type and stage of the cancer (Souhami & Tobias 1995). Nonetheless, many cancer specialists continue to advocate mastectomy with axillary lymph node clearance as the preferred treatment, because this method reduces the clinical risk of a recurrence of the localised disease in the remaining tissue (Haskell, Lowtz & Casciato 1988; Veronesi, Goldhirsch & Yarnold 1995). Secondary treatment options depend on the type and stage of the breast cancer, and may include radiotherapy without surgery, chemotherapy, hormonal therapies, and immunotherapy (Veronesi, Goldhirsch & Yarnold 1995).

From a social-cultural perspective, any breast cancer treatment alters a woman's physical and psychosocial body in dramatic ways that can impede her functional role as a woman in society. The biomedical view of a woman's psychosocial or even cultural experience of having breast cancer has of necessity been a secondary concern to the medical objective of destroying or abating the cancerous growth. This objective position is evident in a medical textbook on cancer that included a small paragraph on the psychological and sexual 'disturbance' that might affect some women after a mastectomy. In the discussion on breast reconstruction surgery, the authors stated that the psychological incidence of depression after mastectomy was more of problem for women 'who place particular emphasis on their body-image' (Souhami & Tobias 1995 p. 262), the basis of this assumption is not made clear in the text.

The silent invader

Where breast cancer threatens the visible female body, cervical cancer silently invades the hidden, secret domains of the sexual and reproductive organs. The disease may take several years before manifesting as symptoms that are troubling enough for the woman to seek medical advice. Unlike breast cancer, cervical cancer mortality can be avoided if pre-cancerous or pre-invasive cell changes of the cervix are detected early (Hunter 2002). The visible part of the cervix, seen through the vagina, is the ectocervix from where a sample of cells can be either scraped or brushed to be examined microscopically using a Papanicolaou (Pap) stain. The procedure is commonly known as the Pap smear pre-cancer cytology test (Benedetn et al. 2001; Hunter 2002).

Precancerous changes of the cervix, in biomedical terms, are easily detectable with Pap smear testing, and by visual inspection using colposcopy (Hunter 2002; Sankaranarayanan, Budukh & Rajkumar 2001). For a woman, the Pap smear test is an emotional experience of embarrassment, vulnerability and fears about the outcome (Bush 2000; Thurecht 2000). The Pap smear test is used to detect early cell changes; determine the stage of abnormal cervical cells if detected, and identify precancerous infection like Human Papilloma Virus (HPV). When abnormal cells are confined to the epithelial layer they are classed as cervical intraepithelial neoplasia, which is known by the acronym CIN and staged as CIN I-III according to the depth of tissue involvement. Findings of stages CIN I and CIN II indicates that the first and middle epithelium layer are involved, while CIN III has invaded the full thickness of the epidermis and should be excised if an invasive cancer is to be avoided (Benedetn et al. 2001). At the CINI-III stage of pre-cancerous change simple excision is by a therapeutic cone biopsy, which from the objective standpoint of biomedical theory, does not interfere with a woman's sexuality or reproductive functions. The subjective experience of a woman, however may be at variance with the biomedical view, because having an abnormal Pap smear places the woman in the high-risk category for developing cancerous changes, and consequently subjects her to ongoing medical and self-surveillance.

Epidemiologically observed risk factors for cervical cancer, while giving useful pointers for public health education, also added a social stigma to the disease in that risk was linked to women's sexual activity and their socio-cultural status. Studies demonstrated that cervical cancer was rare in celibate women, compared with women who had multiple sexual partners, or had married young. It was also found to be more prevalent in women from cultural minority groups and those from poor socio-economic backgrounds (Hunter 2002; Souhami & Tobias 1995). The more recent discovery that sexually transmitted human papilloma virus (HPV) is a significant causative agent of cervical cancer (Walboomer, et. al 1999) added to the stigma and apprehension of women, especially older women, about undergoing the Pap smear test (Braun & Gravey, 1999). The classification of HPV as a sexually transmitted disease has been underplayed in public eduction about cervical cancer risk factors because of the concern that the knowledge might deter rather than encourage women to have cervical smears tests (Braun & Gravey 1999).

Colonising the invader

Surgical treatment of cervical cancer ranges from a simple local excision via a cone biopsy, cauterisation with laser or cryosurgery, to a radical hysterectomy with complete excision of local lymph glands and bilateral oophorectomy. If the disease is already very advanced, surgery may extend to a pelvic clearance that involves removal of the urinary bladder, lower bowel and vagina (Hunter 2002). Such radical surgery inevitably reduces the unfortunate woman to being dependent on medical interventions and being socially compromised for the remainder of her life.

Radiotherapy in combination with the less radical surgery is another treatment option and exposes the woman's body to an external beam of radiation in combination with an intra-cavity insertion of radiotherapy rods (Hunter 2002). Ironically, radiation is a carcinogenic agent and therefore surviving the initial radiotherapy treatment increases the woman's risk of later developing another cancer in the treated area. Even during the initial treatment, radiation-induced injury to otherwise healthy tissue is an expected consequence, commonly associated with side effects of, increased bowel movements, diarrhoea and incontinence, which have the effect of socially disfiguring the woman's life. Although there is less visible evidence of the surgical mutilation in treatment of cervical cancer than is the case with a breast cancer, radical surgery can render the women infertile and interfere with sexual functions and self-identity regardless of her age. Factors considered in biomedical treatment options are the woman's age, stage of the disease and 'her general medical condition' (Hunter 2002 p. 1848). Scientific objectivity enables the surgeon to extract the cancerous invader without interference from the woman's subjective reality of the disease or consideration for the potential loss of the woman's social-cultural identity.

Public health surveillance

By the late twentieth century medical science had evidence that female breast and cervical cancer was preventable if lumps were detected and cell changes identified early enough. These claims justified public health programs for the surveillance of women's bodies in the interest of science's war against cancer. Women's sexual organs and reproductive functions, once considered private matters, were profiled in the public domain as subjects of everyday dialogue in the public health discourse.

In the early 1990s governments in western countries endorsed policies for population-based breast cancer screening every one to two years beginning at age forty and annually for women over fifty and cervical Pap smears for all sexually active women (Smith, et. al. 2003; AIHW BreastScreen & NCSP 1999). In addition women were expected to practice self-surveillance of their breasts and sexual functions and present their body for annual health assessment and clinical examination of breast and pelvis by a medical practitioner. Toward the end of the 1990s, an Australian review concluded that screening women in the fifty to sixty-nine age group would be of greater benefit in terms of preventing breast cancer mortality and thus the policy was amended (*National Cancer Prevention Policy 2001-03* 2001 p. 64).

The population approach to cancer screening is based on the premise that breast and cervical cancers are treatable and serious morbidity avoidable when cell changes are detected at the pre-invasive stage, or while the tumour or mass is localised, often prior to symptoms developing (*National Cancer Prevention Policy 2001-03* 2001; Smart, Byrne & Smith 1997). The problem is that pre-cancerous cell changes do not always present symptoms or signs sufficiently troubling for women to volunteer for medical investigation. Alternatively women with a history of menstrual irregularities such as abnormal bleeding, painful coitus or vaginal discharge, or those who have a history of lumpy breasts, may not distinguish between what is normal for them and new symptoms. The ambiguity of physical signs and symptoms justify population cancer screening programs because this approach increases the chance of detecting 'unsuspected disease' rather than relying on the individual to take the initiative (*National Cancer Prevention Policy 2001-03* 2001 p. 56).

Cancer screening is more than a clinical strategy of monitoring the female body, as by necessity it involves the social body and body politics. The social body is implicated in terms of influencing attitudes and behaviours that may increase cancer risk such as sexual practices, while the body politic is responsible for funding, resources and ensuring equity of access to screening programs. Both the social and body politic advocated policies for coercive methods such as the call-recall and follow-up systems, and publicity campaigns via the popular media, intending to increase women's participation and compliance with medical advice about cancer screening (Bush 2000; Howson 1999).

The biomedical and social-political discourse on the need for cancer screening persuades women of their responsibility, even duty, to undergo the recommended early detection practices and tests (Bush 2000; Gifford 1986). Women who do not comply may be regarded as social deviants because they threaten the success of biomedically proven methods of reducing cancer incidence (Howson 1999: Bush 2000). Women's social obligation in the fight against cancer was demonstrated in Bush's (2000) study of how white (western) women viewed the Pap smear examination. The women, who were from two contrasting socio-economic communities in England, used terms like 'ought to' and 'just accept' it when referring to the 'dreaded' Pap smear test (2000 p.434). Despite the women's collective dislike and feeling of embarrassment associated with the gynaecological examination, they felt obligated to undergo the procedure saying it was 'the right thing to do' (Bush 2000). The coercive element of the cancer screening policy was in the 'call-recall system' that monitored women's compliance with the cervical screening schedule, checking that they attended for follow-up of an abnormal Pap smear test result (Bush 2000). Only a few women in Bush's (2000) study expressed an objection to the coercion implied in the call and re-call system. The women's objection was on the basis of their right to choose whether to participate, provided they were sufficiently informed about risks and consequences (Bush 2000). A similar study in America concluded that telephone counselling, information giving and sending out invitations for women to participate in cancer screening were neither well received nor effective methods of promoting mammograms to women from lower income groups (Crane et al. 1998). In Australia Aboriginal women objected to the follow-up and recall system for Pap smear testing because of concerns about confidentially particularly in the relevantly small rural communities (Kirk et al. 1998). The Aboriginal women believed that confidentially should mean that only the health care practitioner who undertook the cervical screening test should be privy to the results. Local Aboriginal health workers administering the follow-up and recall system were perceived by the some local women to be breaching confidentially and made the women feel like objects of medical interest (Kirk et al. 1998).

The population surveillance of women's bodies as a strategy for reducing cancer incidence continues into old age particularly if the woman has at any time been sexually active. Yet to date, there is no corresponding screening program of men's sexual organs despite the link with sexually transmitted infection and cervical cancer (Bush 2000). There is an emerging movement in the popular media to promote men's cancer issues with several high profile men telling their stories of having prostate cancer, but to date there is no population approach to cancer screening for men.

The disadvantaged in cancer control

The effectiveness of population cancer screening is evident by the impressive decline in cervical cancer mortality rates and the significant increase in the early diagnosis of breast cancers and therefore subsequent reduction in mortality from this malignancy (*National Cancer Prevention Policy 2001-03* 2001; Sankaranarayanan, Budukh & Rajkumar 2001; Smith, Cokkinides & Eyre 2003). The benefits of cancer screening in reducing cancer mortality are not universally appreciated because it has generally only been a success in affluent western societies. The World Health Organization (WHO) reports there is no significant decline in cancer incidence among cultural minority groups, and those medically uninsured, or living in poor underdeveloped countries that are medically and technologically under resourced (Robles 2001; Ward et al. 2004).

The disparity in cancer incidence is evident in Australian where since the early 1990s cancer screening programs resulted in a 40% decline in cervical cancer mortality rates and a less impressive but steady decline in breast cancer mortality at a little under 4% for all women (*National Cancer Prevention Policy 2001-03* 2001; AIHW 2003; Madden & Strong 2000). In contrast, there is evidence of an increase in cervical and breast cancer incidence and mortality rate for Indigenous women in the jurisdictions where reliable cancer statistics for this population are published (Zhoa, Condon & Garling 2004).

In theory all Australian women have access to public health information on cancer and screening programs, however, studies demonstrate that Aboriginal women are under represented in cancer screening services for various social and cultural reasons. From the perspective of Aboriginal women the methods of cancer screening that require them to expose their breasts and genitals to others, particular if these are non-Indigenous people or men, is incongruent with cultural beliefs about a woman's private body and her relationships as a wife and mothers (Kirk et al. 1998; Thurecht 2000). Other explanations for why Aboriginal women's relatively low participation in cancer screening included difficulties of access to central services for those living in rural and remote communities, cultural taboos about touching the body in the manner advised for breast self-examination and just the fear of receiving a cancer diagnosis (Kirk et al. 1998; Thurecht 2000). The women in these studies reported that they avoided cancer screening to protect themselves from learning they had a disease, generally perceive to be fatal (Kirk et al. 1998; Smith 1999; Thurecht 2000). The fatalistic attitude toward cancer was reinforced in the small rural communities where everyone witnessed many bad experiences of family and friends who suffered the effects of cancer that often ended in a painful and distressing death (Kirk et al. 1998; Thurecht 2000). The lack of knowledge about the biological process of cancer and a misunderstanding about the outcomes of cancer screening were idenfied as other reasons for Aboriginal women's reluctance to participate in early detection programs (Kirk et al. 2000).

Other studies demonstrated that Aboriginal women who did undergo cancer treatment reported feeling isolated and alone in this experience because there was no social network in their community of cancer survivors or others currently having treatment (Carrick et.al. 1996; Fagan, 1998). This added to the women's assumption that cancer screening is unnecessary as there was no obvious evidence of the disease in their community.

The under utilisation of cancer screening and the resultant high cancer morbidity and mortality rate affecting Aboriginal women reflects a similar situation to that of women from less industrialised countries such as Sub-Saharan Africa, South Asia, Latin America and the Caribbean where cancer monitoring facilities are under resourced (Mittra 2001; Robles 2001; Sankaranarayanan, Budukh & Rajkumar 2001). There is an apparent anomaly in Australia whereby Aboriginal women who in principle have access to well resourced, technically developed cancer-screening services, yet have mortality and morbidity rates on a par with women from poorer, less developed and medically under resourced countries.

Aboriginal women and cancer

Until recently, Aboriginal women had been considered at less risk from developing cancer because of their relatively shorter life expectancy and because they often have competing co-morbidities from other diseases. The literature on early research of Aboriginal health problems was concerned with public health issues of tropical disease, contagious infections and infestations, such as leprosy and yaws (that at the time were rare in the white Australian society), rather than cancer pathology (Doherty 1974).

The earliest published studies on cancer testing of Aboriginal women appeared in the 1970s. An example is the comparative study of cytological screening that came to a null hypothesis that the life-style and environment of 'full-blooded' (sic) Aboriginal women, living in 'tribal or semi-tribal' environments, was associated with a higher incidence of abnormal cervical dysplasia than white Australian women (Connon & Madill 1976 p. 476). To the contrary, Connon and Madill (1976) demonstrated much lower incidence of abnormal cervical smear tests and the relatively normal appearance of the cervix among the Aboriginal women despite the implication of the researcher's hypothesis that the sexual activities of these women increased their risk of developing cancer. The tone of the article suggested that the basis of the researcher's supposition that the 'life styles and environment' (Connon & Madill 1976 p.476) of these Aboriginal women placed them at higher risk of developing cervical cancer, was most probably based on negative stereotypical images of the day, that the 'wild native women' was synonymous with promiscuity, rather than on any empirical evidence.

Current published statistical data on cancer incidence in Aboriginal communities demonstrates an increasing trend in rates of respiratory system cancers, smoking related lung diseases in particular, cervical and breasts cancers in Aboriginal women and a disproportionate cancer mortality rate compared to other Australians (Condon et al. 2003; Zhoa, Condon & Garling 2004). The increasing problem of cancer in Aboriginal communities is reflected in the latest National Strategic Framework for Indigenous Health (NATSIHC 2003), which lists cancer as one of six chronic diseases prioritised for more services. Where as in the earlier 1989 National Aboriginal Health Strategy the focus had been on primary care health that aimed to increase knowledge about cancer and promote screening and early detection practices (Condon et al. 2003).

The significance of the problem of cancer in Indigenous communities was the focus of a forum in Darwin in March 2004, hosted by the Cancer Council of Australia. The conclusion of this inaugural forum in which the disparities in mortality and morbidity for all types of cancer were again highlighted, was that while the problems are identified, the causes and cultural aspects underlying the problems were not well understood (Condon et al. 2004; Lowenthal & Coates 2004).

The extent of the problem and use of services

A National Health Survey (NHS) of 54,576 women in Australia records information from only 151 women identifying themselves as Aboriginal or Torres Strait Islanders (*National Health Survey* 2001). The NHS suggested that of small sample of idenfied Indigenous women, 52% reported doing regular breast self-examination, compared with 63% of non-indigenous women. Other significant disparities were that 50% of Indigenous women compared to 72% of non-Indigenous women reported having a clinical breast examination but only 26% of eligible Indigenous women reported having had a mammogram (Carrick et al. 1996). It is arguable that the target age of fifty to sixty nine for mammograms should be lowered to accommodate Aboriginal women's relatively lower life expectancy, which is about twenty years less than non-Aboriginal women.

Aboriginal women were also less likely than non-Aboriginal women to volunteer for regular Pap smear tests (Kirk et al. 2000; Thurecht 2000). In South Australia it was estimated that 32% of eligible Aboriginal women had not been screened for cervical cancer and of those who had, 27% did not return for follow-up of abnormal test results (Reath & Usherwood 1998). Participation rates were higher in the Central Sydney district where a little over 53% of Aboriginal women reported attending for biennial Pap smear tests (Jackson & Ward 2000).

Studies showed that the excessive cancer morbidity and mortality of Aboriginal women was related to their reluctance to participate in early detection programs, leading to late presentation with advanced disease at diagnosis (Kirk et al. 1998; Kirk et al. 2000; Thurecht 2000). This trend was seen in the analysis of breast cancer incidence in Queensland, that demonstrated a similar incidence rate for all populations, but a significantly higher cancer mortality among Aboriginal women (Coory, Thompson & Ganguly 2000). Cervical cancer incidence in Aboriginal women was at least four to six times higher (with regional variations) compared to other Australian women, and was a major cause of morbidity and early death in this population (Guest, Mitchell & Plant 1990; Reath & Usherwood 1998; Zhoa, Condon & Garling 2004).

Although more recent anecdotal reports from practitioners suggests an encouraging increase in the number of Indigenous women participating in breast and cervical cancer screening, there has been no published evidence of a corresponding reduction in morbidity and mortality or increase in the number of Aboriginal women successfully completing a course of cancer treatment.

One of the concerns motivating this research is the evidence that Aboriginal women present with symptoms of advanced malignancy but turn away from conventional biomedical treatment and are under-represented in palliative care sectors that offer symptom control and supportive care (Fagan 1998; Kirk et al. 1998; Kong 1998; Prior 1997; Reath 1999; Sullivan 2003). The apparent disparity in Aboriginal women's use of cancer services raises the principal question guiding my research that is, what are the social, cultural and personal reasons why Aboriginal women delayed or avoided cancer diagnostic procedures and seem ambivalent about completing biomedical treatment?

The unequal burden of cancer

Several studies demonstrate that cancer disparities in terms of incidence and survival rate of women from minority cultures, were attributed to several variables including, biological factors, such as body mass index, co-morbidities and genetic predispositions (Cui et al. 2002; Lai et al. 2003); and socio-economic, psychosocial, structural and cultural differences (Jemal et al. 2003; Kagawa-Singer 1995; Lannin et al. 2002; Trewin

2001). Most studies concurred that poor levels of education and socio-economic deprivation had a greater influence on women's risk of developing cancer and of having an advanced stage of disease at diagnosis, than did biological difference (Krieger et al. 1999; Lui, Deapen & Bernstein 1998; Ward et al. 2004).

A study under the auspices of the World Health Organisation (WHO) reported that of women who presented with advanced stage of cervical cancer at diagnosis, over 50% were women from socio-economically disadvantaged backgrounds with low levels of education (Robles 2001). The rate of cervical cancer mortality was also reported to be higher or unchanged in countries where cancer-screening programs were either unreliable or sporadic, as was the situation in Sub-Saharan Africa, South Asia, Latin America and the Caribbean, compared with a general decreased mortality from the disease in industrialized, countries within the same region (Mittra 2001; Robles 2001; Sankaranarayanan, Budukh & Rajkumar 2001).

The United States of America, generally considered to be the embodiment of western materialistic technically advanced health care organisation, nevertheless reported disparities in cancer incidence, mortality and survival in the cultural minority and socially disadvantaged communities (Ward et al. 2004). Of particular significance was the disproportionate rate of cancer deaths of African Americans compared to white Americans that had increased despite the political commitment of funding for the cause since the President Nixon's declaration of war against cancer in 1971 (Le Fanu 1999). In the 1970s cancer mortality of African American women was reported to be lower than in the white community, but in 1999 the situation was reversed to being 3% higher (Ghafoor et al. 2003; Smith, Cokkinides & Eyre 2003; Ward et al. 2004). The increasing cancer incidence and mortality rate in the African American and other cultural minority groups was also linked to the prevalence of risk behaviour in these populations in particular smoking, physical inactivity and obesity. These problems were compounded by the relatively poor levels of eduction and other socio-economic disadvantages that limited peoples' access to information about cancer and health promotion messages that were often irrelevant or culturally inappropriate (Ward et al. 2004).

The culture of fear and fatalism

Fear, fatalism and silence toward cancer, apprehension about navigating the health care system, lack of adequate health insurance and other life priorities were shown to be common barriers to African American women's participation in the various stages of cancer health care, from self-examination and screening to biomedical treatment options (Philips 1999; Philips, Cohen & Tatzian 2001; Ward et al. 2004). Philips, Cohen and Tatzian's (2001) phenomenological study of African American women's expectations of breast screening demonstrated that the fear of disfiguring treatment and how it would impact on significant relationships, were common reasons why the women avoided screening or any procedure that might reveal they had cancer. The African American women that had a fatalistic view of cancer, also perceived any treatment options as another 'futile fight against insurmountable odds' (Philips 1999,p.1002). The incidence rate of breast cancer was reported to be higher in Caucasian women but mortality from the disease among African American women was disproportionably greater (Philips 1999). Five-year survival for breast cancer was achieved in 71% of African American women compared to 80% of Caucasian women (Philips, Cohen & Tatzian 2001). An explanation for the disparity in cancer survival was that African American women presented, as do Aboriginal Australian women, with advanced cancer at diagnosis, and many chose not to progress with treatment.

Low survivorship of African American women with breast cancer related to external socio-cultural as well as internal physical variables (Joslyn & West 2000). The external variables were those associated with the women's cultural beliefs about the causes and consequence of cancer, plus their socio-economic and educational disadvantages, that limited their capacity to navigate health care institutions. It was not evident in the study by Joslyn and West (2000) whether cultural beliefs were a greater influence on the African American women's decisions about cancer than their lack of health insurance or other socioeconomic barriers. The outcome was, however, that the socially and educationally disadvantaged women delayed reporting breast symptoms and did not present for cancer screening tests which meant they had a malignant disease at the time of diagnosis (Joslyn & West 2000).

Interestingly, a study of Mexican-American women showed that the degree of influence of cultural belief was meditated by the level of education and the women's socio-economic status (Borrayo & Jenkins 2001). The lesser-educated Mexican-American women were correspondingly less knowledgeable about cancer and therefore more likely to rely on their cultural beliefs and traditional folk practice for keeping healthy. Some of the Mexican-descendent women considered that having breast screening was shameful because of their belief that cancer was preventable if cultural practices of breast-feeding, avoiding breast injuries and 'praying for divine protection' were followed (Borrayo & Jenkins 2001 p. 876). Therefore, admitting the need for cancer screening was evidence of an omission of cultural practices. On the other hand acculturated middle-class Mexican-American women were found to be more knowledgeable about western health issues and cancer and often motivated to attend for breast screening because they were less bound to traditional practices (Borrayo & Jenkins 2001). A further important finding of this grounded theory study of Mexican-American women was that cultural beliefs about cancer screening or any medical intervention were seen to be unnecessary when people were 'feeling healthy' (Borrayo & Jenkins 2001 p. 815). The women defined 'healthy' in terms of a subjective feeling of wellbeing and a perception of not being at risk or vulnerable to developing cancer (Borrayo & Jenkins 2001).

Choudhry, Srivstava, & Fitch (1998) explored the knowledge, attitude, beliefs and cancer self-surveillance practice of a population of South Asian migrant women living in Toronto, Canada. The women were all over forty years of age, first generation migrants from India or Pakistan who spoke one of four native languages, either Hindi, Punjabi, Gujarati or Urdu. The study used a questionnaire to determine the women's attitudes and beliefs, health care motives, including perception of benefit associated with breast cancer screening, susceptibility to and seriousness of cancer, social-demographic factors and their actual breast health care practice (Choudhry, Srivstava & Fitch 1998).

The investigators needed to accommodate the participants' superstitions and cultural belief that talking about cancer could 'bring on the dreaded disease'. To overcome these concerns, the investigators reframed their questions so those relating to personal susceptibility or experience of cancer were posed using the third person tense (Choudhry, Srivstava & Fitch 1998 p. 1696). The study demonstrated that 60% of the South Asian women participants knew about breast screening but only 10% gave a correct description of the procedure. Sixty seven per cent of the study population of fifty-seven women reported they had not received information about breast screening techniques. Amazingly 54% of the Asian women in this study said they knew little about breast cancer and 49% reported never having had a clinical breast examination or a mammogram (Choudhry, Srivstava & Fitch 1998).

The South Asian women perceived barriers to breast cancer screening services included gender, ethnicity and age of the health care staff who provided the service, language difficulties, and their women's unfamiliarity with the dominant culture (Choudhry, Srivstava & Fitch 1998). Similar types of barriers inhibited Aboriginal women in Australia from accessing the various sectors of cancer health care (Carrick et al. 1996; Fagan 1998; Kirk et al. 1998; Kirk et al. 2000). The same paradox existed where Aboriginal women who understood the need for cancer screening and early detection were deterred from participating in these programs because of the barriers of western language and style of information that they perceived to be unrelated to the context of their lives, and to cultural beliefs about women's health care (Kirk et al. 1998).

Keeping quiet about cancer

A fear of tempting fate or of admitting that the disease is a concern for the communities are common themes in the studies of why women from minority cultures were reluctant to talk about cancer (Kirk et al. 2000; Philips, Cohen & Tatzian 2001). African American women, for example, considered breast cancer to be a 'white woman's disease' (Philips, Cohen & Tatzian 2001 p. 564) but not in the same way that Aboriginal women (Kirk et.al 1997) believed cancer was inflicted on their community through contact with white people. African American women considered cancer as a white women's disease because people seldom talked about cancer in their communities. Whereas in contrast white women discussed their cancer more openly which reinforced to the African American women that cancer only affected white women (Philips 1999; Philips, Cohen & Tatzian 2001).

Family health histories in African American communities were often shrouded in secrecy to a point that subsequent generations had no accurate record of the nature of illness or type of cancer that might have afflicted their predecessors (Philips 1999). Philip explained that African American women's hesitancy to about talk about cancer as well as health concerns, was associated with their fear of 'isolation or retaliation' (Philips 1999 p. 1002) once they entered the white domain of a health care institution. The African American history of enslavement, discrimination, racism, segregation and general opposition to any advancement of the people, and a real fear of being research objects, clouded African American women's perception of the dominant health care system (Philips 1999). The conspiracy of silence about a serious disease like cancer was partly a consequence of the history of oppression of African Americans by the colonial mentality of white authorities that used punitive measures on the sick when they were unable to work. Memories of these times continue to haunt contemporary African American society (Philips, 1999). The resistance to cancer screening and cancer health care services was compounded by the dominant hospital system's disregard of the significance of African American cultural values and spiritual beliefs (Philips, Cohen & Tatzian 2001). A particular concern was the lack of acknowledgment of religious beliefs and practices and that spirituality was central to African American culture (Philips, Cohen & Tatzian 2001).

The lack of respect for or acknowledgement of cultural beliefs and differences were also concerns for Aboriginal Australians when admitted to hospital (Eckerman et al. 1992).

The western hospital presented Aboriginal people with a number of stressors including, the isolation of being away from the family, the hospital customs and routines, a feeling of being confined, professional jargon and communication styles, and a fear of being trapped (Eckerman et al. 1992). A further stressor was the incongruence of dealing with a single body part, as is the practice for breast screening or cervical Pap smear tests with Aboriginal cultural beliefs of holism embodied in the value of the body-land-spirit relationship (Kirk et al. 2000).

Indigenous Australian history is, like African American history, littered with atrocities attributed to imperialism and colonisation of people's lives and traditional cultural expression and practice (Eckerman et al. 1992; Kidd 1997; Kirk et al. 2000; Senior 2001). Like the African Americans, many Indigenous Australian communities adopted a conspiracy of silence, secrecy and indifference toward western medical authorities (Kirk et al. 1998; Smith 1999). Another explanation for keeping secret about a cancer diagnosis was the culture belief that such a serious disease was manifestation of 'bad spirits' or sorcery suggesting the afflicted person had violated a cultural lore or that there existed disharmony between relationships, a situation that brought *shame* to the family (Kirk et al. 2000).

Western culture and cancer

The culture of western society is defined by its relative affluence, materialism, individualism, technology and an insatiable desire for everything new (Bauman 2000). In this context, cancer is viewed as a demonic predator because it defies the dictum of the materialist world that everything can be manipulated or bought for the betterment of society. Western cultures are forever optimistic that by donating considerable amounts of funds to the ongoing biomedical quest, eventually cancer will be conquered. The irony is that cancer is intrinsic to old age, so as more people achieve longevity because of biomedical and public health advancements in the last fifty years, there is bound to be a corresponding increase in cancer incidence.

In the quest to defeat cancer, the biomedical discourse constructs the sick role of the optimistic cancer patient, willing to comply with medical directives about treatment and at the same time uphold the stoicism of a heroic cancer victim. The popular media use celebrities stories and those of ordinary people, to promote the message that cancer can be beaten by following medical advice about early detection, with positive attitudes and the courage to endure what ever unpleasant treatment is necessary (Lupton 1994; McKay & Bonner 1999). The brave struggle of those who die from cancer is acknowledged in the newspaper death notices and frequently include affirming phrases like, 'died after a long battle with cancer aged 58 (Anonymous 2003) or died aged 47 after 'a courageous battle with lung cancer'. It would be unusual to read of someone dying from cancer without medical intervention.

The abundance of eduction and resources available for people with cancer leaves no excuses in western society for not getting involved in the battle. In the age of Internet technology, for example, most people have access to global resource as I demonstrated by a quick Internet search site on the topic 'breast cancer support' which identified 350, 620 results worldwide and almost 15,000 in Australia. The topics of these Internet sites, ranged from individuals sharing their personal cancer stories, to academic papers and official government documents on clinical practice guidelines.

While the popular media abounds with heart rendering and inspirational cancer stories, the voice of people with cancer until recently had been rarely heard in the professional literature of biomedical and sociological sciences. The popular media is helping to reconceptualise the image of life after cancer that has the potential to change social attitudes from fear and fatalism to realistic optimism, in a similar way that social perception of cardiac disease has changed with the advent of bypass surgery almost to point of complacency about the procedure.

With a slow the trend of professional writers intellectualising their personal stories of cancer and publishing these in both professional and popular literature the 'missing' voice of cancer is reaching the academies. One of the earliest scholarly perspectives was Susan Sontag's critique of cancer as a metaphor of the world's 'contamination' (Sontag 1991 p. 72) which she wrote during her own experience of breast cancer. Susan DiGiacomo (1987) a medical anthropologist took an ethnographic position to critique her personal encounter with biomedical cancer treatment, and another scholar was Gillian Rose, an esteem philosopher at the time, who intellectualised the subjective reality of having advanced ovarian cancer. DiGiacomo (1987) realised what she called the 'monophonic authority' of the biomedical and the anthropological discourse. DiGiacomo (1987) argued that biomedicine misrepresented the authentic lived experience of having cancer because the voice of the sufferer was missing. Gillian Rose (1995 p. 72) viewed her experience of dealing with an incurable cancer philosophically by transcending the objective-subjective void between medicine and the human experience that she viewed as a creation of biomedicine, as this extract from her book *Love's work* illustrated:

> To the bearer of the news, the term 'cancer' means nothing: it has no meaning. It merges without remainder

> into the horizon within which the difficulties, the joys, the banalities, of each day elapse.

To Rose (1995) cancer meant a condemnation of her previous way of life and viewed her experience as a betrayal of the medical rhetoric that promoted the benefits of enduring a gruelling artillery of cancer treatment. Eventually regaining control of her body, realising her life sentence was now measured in months and not years, Rose (1995, p. 95) liberated herself from the authority of conventional biomedicine and declared:

> Medicine and I have dismissed each other. We do not have enough command of each other's language for the exchange to be fruitful.

Rose (1995) expressed a contrary position to the biomedical expectation of a compliant yet optimistic patient, consequently a tension developed in the relationship with medical staff who were not used to such assertiveness from a cancer patient. DiGiacomo (1987) experienced similar discordance because she prepared herself with sufficient information to develop a collegial relationship with her cancer specialists, an act that caused her to be viewed by them as an 'intelligent, difficult patient' (DiGiacomo 1987 p. 321).

Summary

Cancer is a biological disease of antiquity that has the capacity to colonise every construct of the 'mindful body' (Scheper-Hughes & Lock 1987) in westernized and Indigenous societies. Like the colonisers who invaded the land and societies of the *native Other,* so the irregular cellular growth of cancer attacks and eventually annihilates the healthy cells and tissues of the body. Unlike the colonised people who have survived centuries of attempted genocide to raise their voice in the contemporary discourse, the body with cancer will in most cases, eventually succumb to the unwanted enemy. The effort to control this delinquent disease extends beyond the scientific domain and into the public health arena of surveying, monitoring and influencing the health behaviour of populations, particularly women. Cancers affecting women have been the focus of public health and medical discourse for ages, and at one time cancer seemed to be a women's disease probably because breast cancer attacks a visible part of the female body. The success of biomedical treatment is dependent on the women's participation in the early detection programs that ensure the disease is found early, and fulfil their responsibility as cancer patients willing to comply with medical advice.

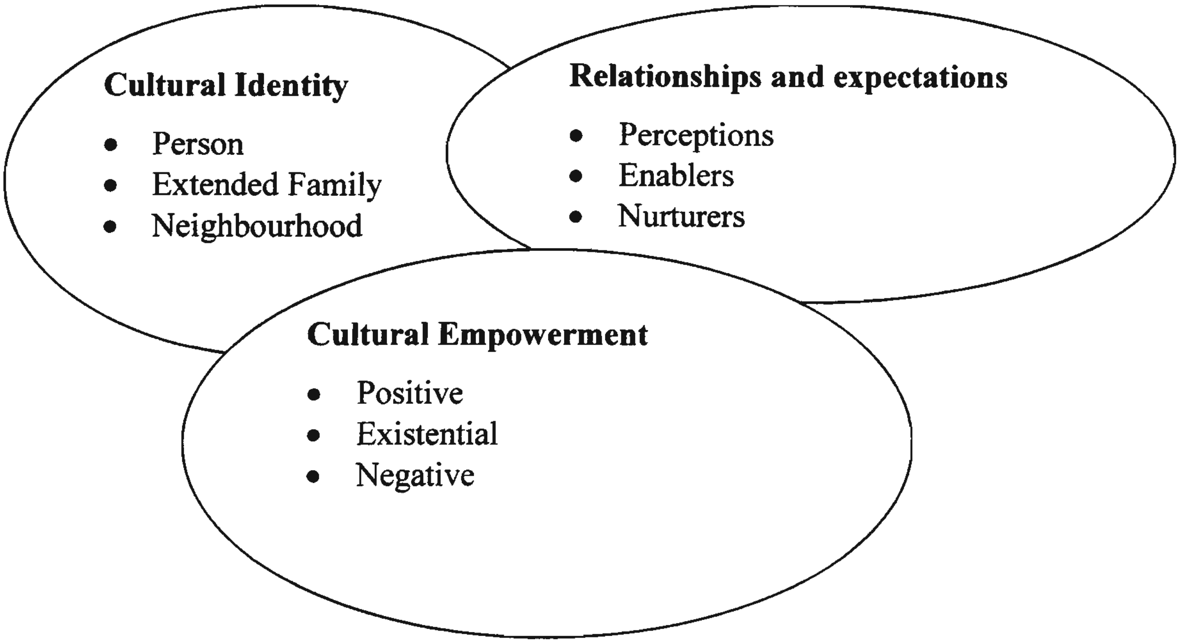
While public health strategies have been effective in reducing breast and cervical cancer incidence and mortality in western society, the same positive results are not seen in the colonised Indigenous population or in other disadvantaged societies. Explanations for the cancer disparity in these minority populations include socio-economic and educational disadvantage and demographics that limit people's access to public health resources for cancer. Other important distinctions are the cultural difference in how people perceive cancer and their expectation of cancer screening or treatment. The difference in how people conceptualise and respond to cancer can be expected, given the influence of socialisation and culture. It follows that decision-making about health and any disease is a construct of socialisation within a particular cultural and social context. This is evident in the study of Mexican American women who believed that adherence to traditional cultural practices obviated the need for cancer screening (Borrayo & Jenkins 2001). And the South Asian migrant women who believed that personalising conversations about cancer could cause the disease to occur, should influence the tone of public health messages. The culture of fear and fatalism toward cancer as demonstrated in the African American and Aboriginal Australian societies and others cannot be overcome unless the cultural context of these fears is understood.

CHAPTER FIVE

CULTURE CENTERED ANALYSIS

The purpose of this study is to understand the cultural context that influences Aboriginal women's perception and meaning of cancer, and how this determines decision-making related to acceptance or rejection of conventional treatment and supportive services. To highlight the cultural constructs that emerged from the data I have referred to a conceptual framework called PEN-3 (Airhihenbuwa 1995). The conceptual framework of the PEN-3 model is formed by three interrelating domains; *cultural identity, relationships and expectations, and cultural empowerment* (Airhihenbuwa & De Witt Webster 2004),[13] that each comprise three subcomponents from which the acronym PEN-3 is formed as shown in diagram 1 that follows:

Diagram 1. The structural domains of the PEN-3 model



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[13] The three domains of the prototype PEN-3 model developed in 1989 were more specific to health education and thus the domains were originally called, *health education, educational diagnosis of health behaviour* and *cultural appropriateness of health behaviour*. The modified PEN-3 model shown in diagram one, has evolved through its applications in different stages of planning and appraisal of public health programs in cultural minority communities.

The PEN-3 model positions culture at the centre of the public health agenda for colonised Indigenous and minority cultures. The PEN-3 model was developed by Collins Airhihenbuwa as a template for the design, analysis and appraisal of culturally appropriate public health HIV/AIDS programs in Nigeria, Zimbabwe and African American communities (Airhihenbuwa & De Witt Webster 2004). This model has also been used to develop a child survival program in Nigeria (Airhihenbuwa 1995). Of closer interest to this thesis is the application of the PEN-3 model in a program to increase African American women's participation in cancer screening (Erwin et al. 1999) and as a guide for the development and analysis of cancer intervention and support programs for Hispanic/Latina women in America (Erwin et al. 2004).

The principle underpinning the PEN-3 model, according to Airhihenbuwa (1995 p. 34), is that public health programs 'should address what is and not what ought to be'. Airhihenbuwa (ibid.) argues that too often public health programs aim to change behaviours that are deeply ingrained in the cultural psychic of the people. The approach offered by the PEN-3 model respects cultural beliefs, values and social structures, treating them not as barriers to be overcome but as strengths to be affirmed. In other words Airhihenbuwa (1995) advocates that public health programs which, rather than trying to change culturally important entities or overlook the influence of social structures such as the extended family, centres these cultural values as the pivotal point from which to build or alternatively, negotiate health care interventions. My purpose in using the conceptual framework of PEN-3 is to link my ethnographic description more purposefully within a public health approach for reducing the cancer incidence, or cancer morbidity and mortality experienced by rural Aboriginal women.

It could appear incongruous to the postmodern qualitative methodology of this research to use a structural model, because in so doing there is a potential for forcing interpretations of the data (Hammersley & Atkinson 1995) and thus compromising the ethnographic story. On the contrary, the PEN-3 model allows me to give prominence to cultural themes evident in the data in a way that is more readily transferable to the public health realm.

A further attraction of applying the PEN-3 model's approach is that by centralising culture in the public health discourse, the effect of colonisation in health care institutions in terms of subjugating or marginalising minority cultures is potentially reversed. The colonial mentality of paternalism, for example, has positioned the Western public health discourse as the dominant authority of health care behaviour, determining how and when health care is delivered. In the process the Western authority has overlooked the benefits of health care traditions of non-Western cultures. A culture-centred focus, on the other hand, respects the philosophy and methods of non-Western health care approaches and acknowledges their relevance to different cultural contexts. The culture-centred health care paradigm considers ways of integrating other traditions within the dominant paradigm. Airhihenbuwa (2004) offers an example from his work with a Nigerian community where common practices are using an amulet placed around a child's neck to ward off evil spirits, and applying palm oil and indigo to soothe the fever of measles. By acknowledging the cultural significance of these practices and the involvement of the family, the paediatric physicians associated with Airhihenbuwa's work were able to incorporate this into standard medical practice. The paediatricians supported the use of the amulets on the condition that the doctor was the only one to remove them, thereby ensuring the parents would return with their child for follow-up visits (Airhihenbuwa & De Witt Webster 2004). In this example, the cultural practices of folk health care that involved the family were affirmed along with the conventional practice of Western medicine.

The PEN-3 model has evolved from traditional theories/models but shifts the focus from the attitudes and beliefs of individuals as predictors of health behaviour, to the cultural context that informs how perceptions and behaviours are constructed. Theories such as The Health Belief Model and the Social Learning theories traditionally used to predict participation in cancer screening, or to explain health inequities, have been biased toward Western cultural values. An important cultural distinction is that, from a Western cultural perspective, health decision-making is assumed to be an individual undertaking whereas for many non-Western cultures family and community decision-making is the norm (Airhihenbuwa 1995).

Furthermore Western theories about health behaviour often identify different cultural beliefs or characteristics as barriers to be overcome, rather than considering these as important determinants of health behaviour and decision-making (Airhihenbuwa & Obregon 2000; Baldwin 1996). So, for example, the barrier of language difference is overcome with translators and multilingual health promotion literature. The problem of different cultural styles of learning can be addressed by using pictorial learning tools or cultural images. However, while these strategies are potentially helpful, they are often presented without consideration of when and how the information should be used in a given cultural context (Airhihenbuwa 1995; Rajaram & Rashidi 1998). The public display of women's health issues, for instance may be considered culturally inappropriate in some communities. The heterogenous nature of Australian Aboriginal cultures, for example, means the use of the same pictorial image in health information literature may not be appropriate for all Aboriginal communities.

The domains of the PEN-3 model

The domains of *cultural identity, relationships* and *expectations* and *cultural empowerment* that form the conceptual structure of the PEN-3 model, as shown in diagram one, will be explained further.

Cultural identity

Cultural identity is the 'application or transformation' (Airhihenbuwa & De Witt Webster 2004 p. 4) domain that public health practitioner can use to identify with a community, the starting point for interventions. The subcomponents of *cultural identity* are People, Extended Family and the Neighbourhood and the task is to determine the identities, organisational structures, and community characteristics that influence decision-making about health. The principle informing the domain of cultural identity is that health care behaviour is a manifestation of multiple interacting identities or a *hybridity* that embody history, culture, ethnicity, language, race, gender, social organisation and social roles (Airhihenbuwa 1995; Airhihenbuwa & De Witt Webster 2004). In explaining the concept of multiple identities, Airhihenbuwa (Airhihenbuwa 1995; 2004) refers to W.E.B. Dubois's notion of 'double consciousness' once used to define the ambiguous cultural identity of a black man living in both black and white cultures (Airhihenbuwa & De Witt Webster 2004). 'Double consciousness' has considerably more complex aspects in the contemporary world of Western and minority cultures that include socio-economic status, education level, employment position and political authority, country or location of residents whether rural, remote or urban.

The domain of cultural identity clearly cannot be considered separately as just a structural entity because the notion of identity is inherently a social construct of inter-relationships between people, families, the community and socio-political environment. In the context of public health planning, the value of defining cultural identity therefore, is for mapping or delineating the parameter of a community and to understand who will be involved with and affected by health interventions.

Relationships and Expectations

The second domain of the PEN-3 model is *relationships and expectations* which looks for the relationships between the identities of a community and the task is to determine how these interrelationships condition perceptions of health and disease (Airhihenbuwa & De Witt Webster 2004). In the context of health behaviour, the most influential relationships are those of families and social networks, because these represent the primary level of socialisation where perceptions, attitudes, social roles, and health behaviours are shaped. In the PEN-3 model the subcomponents of *relationships and expectations* are Perceptions, Enablers, and Nurturers that are the cultural factors which either support, discourage or encourage health behaviours (Airhihenbuwa 1995). These subcomponents are essential constructs of the cultural context, because 'Perceptions' embodies the knowledge, beliefs, values and traditions. And the 'Enablers' are the social systems, structures, politics, socio-economic status, resources and availability of services within a community, which can enhance or hinder health interventions. The third subcomponent the 'Nurturers' is concerned with the amount of influence of families, social groups and the community have in shaping health beliefs and behaviours. The 'Nurturers' can be supportive of change or discourage new thinking if the belief is that a program or health intervention contravenes cultural values. The *relationships and expectations* domain is interconnected with the *cultural empowerment* domain of the PEN-3 model because both are used for the 'assessment or appraisal' of a community's health behaviour (Airhihenbuwa 1995).

Cultural empowerment

The *cultural empowerment* domain is at the heart of a culture-centred public health approach because it respects the uniqueness of a culture, and 'harnesses' its 'power' (Airhihenbuwa 1995 p. 113) by affirming values, beliefs and traditions, while also acknowledging the beneficial as well as potentially harmful elements. The tenet of *cultural empowerment* is that whatever health hazard befalls a person the positive, existential, and negative aspects of their culture are likely to be a constant (Airhihenbuwa 1995; Fanon 1967). The subcomponents of *cultural empowerment* are therefore, Positive, Existential and Negative, which cross-link with the Perceptions, Enablers and Nurturers of the *relationships and expectations domain* (Airhihenbuwa 1995). In table one I use the example of beliefs about cancer evident from the literature, to demonstrate the interlinking of these subcomponents of the PEN-3 model.

Table 1: The cross-link of subcomponents of the PEN-3 model in presenting the beliefs about cancer.

Relationship and expectations and cultural empowerment domains of the PEN-3 model			
PEN-3 → COMPONENTS ↓	POSITIVE	EXISTENTIAL	NEGATIVE
PERCEPTIONS	Curable if detected early	Caused by spiritual forces,	Fatal disease regardless of interventions
ENABLERS	Mobile breast screening services	Use of traditional medicines. Spirituality	Conspiracy of silence about cancer
NURTURERS	Women cancer survivors willing to be role models and sharing their experiences.	Accessibility to traditional healers and Supportive networks of families	Social stigma based on a link between cervical cancer and sexually transmitted diseases that discourages cancer screening

The notion of 'negative enablers and negative nurtures' shown in table 1, may seem contradictory, but the position presented by PEN-3 model is that enablers and nurtures can be supportive or discouraging of public health reforms. So for example 'conspiracy of silence about cancer enables the community to avoid or deny the need for screening and consequently disenables current methods of public health programs. A social stigma associated with cervical cancer and sexually transmitted disease nurtures negativity toward cervical screening and deters particularly older women from having Pap smear tests.

There is a danger however, when cultural beliefs or practice are considered to be negative just because these either contradict the public health norms or are judged from the Western perspective, to be harmful to individuals or social groups. When the cultural beliefs and traditions are regarded as negative barriers to conventional health care often in public health the focus of interventions is to 'educate' people in order to change their perceptions, as if the Western biomedical approach to health care was the only paradigm.

The domain of *cultural empowerment* promotes cultural characteristics or traditions, as the unique or existential qualities of a culture and as such the core of culturally appropriateness in health care. In other words cultural practices are acknowledged and integrated in culture-centred health care programs rather than being marginalised or ignored (Airhihenbuwa & De Witt Webster 2004). Existential behaviours are the beliefs, practices, behaviours or traditions that characterise a culture. Examples of 'Existential' qualities are; spiritual beliefs, traditional healing and medicines, and the role of families in health care.

An example of how existential values can be integrated in public health strategies is seen in *The Witness Project* a program designed to increase breast-screening participation of African American women. *The Witness Project* uses existential issues of spirituality and practices of faith, as the point of intervention (Bailey, Erwin & Belin 2000). *The Witness Project* is a faith-based approach that is informed by the understanding that a vital aspect of the *cultural identity* of this population is the 'spiritual environment' of the church (Erwin et al. 1999). The mantra of *The Witness Project:* 'In Church people witness to save souls. At The Witness Project® they witness to save lives!' affirms the particular cultural values of the African American population it serves (Erwin et al. 1999).

'Negative nurturers' on the other hand are those that give no benefit to the individual and can potentially harm the community. An example might be the Mexican American women who avoid breast screening because they believe adherence to traditional practice obviates the need for this procedure (Choudhry, Srivstava & Fitch 1998). The potential harm of denying the benefits of cancer screening is obviously the risk of higher mortality from undiagnosed disease, as well as the harm of perpetuating this belief through socialisation of younger women. Another example is where there are cultural taboos about using condoms or indulging in a risk taking sexual practice that inevitably increase the risk of spreading HIV/AIDS in a community (Airhihenbuwa & De Witt Webster 2004). Culture-centred public health strategies to address these 'negative nurturers' could not effectively transform or change thinking at the individual level, but would need to examine the cultural context of this belief. This is where the domains of the PEN-3 model become intertwined, because to influence new thinking about cancer screening as an example, public health needs to start by determining the *cultural identity* of a community and the extent that *relationships and expectations* influence beliefs about cancer prevention and other factors relating to the disease.

Application of the PEN-3 model

I have used the three domains of the PEN-3 model as a broad conceptual framework to present this ethnographic study of the meaning of cancer to rural Aboriginal women. However, my application of the PEN-3 model is not as a deductive tool but rather a means of inductive analysis whereby the data determines the focus. I do not use the PEN-3 model in a formulaic manner; rather I am more concerned with emphasising the philosophical underpinnings of the model. The centralisation of culture for better public health rather than culture as a barrier in health services is in keeping with the purpose of this research. Colonial anthropology was founded often on a notion of describing exotic cultural spaces before they became extinct in the face of 'progress'. My interest here is in a postcolonial 'decolonising' project of describing a cultural space around Aboriginal women and cancer because this is the way forward in progressing toward better and appropriate health care for Aboriginal people.

In using the PEN-3 model here I refer only to the subcomponents that reflect the themes inherent in my data. As will be demonstrated, the domains of *cultural identity* and *relationships and expectations*, of the PEN-3 model are too closely interlinked to be discussed as separate entities. Therefore while I define the constructs of *cultural identity* in terms of women's Aboriginal culture, the family and the community (neighbourhood), my focus is the relationships and interactions that shape perception and meaning of cancer in the context of their lives. I also present the historical and social backgrounds as a construct of *cultural identity* and as important influences on relationships with families, social groups, and in shaping attitudes toward western health care.

Finally I use the *cultural empowerment* domain of PEN-3 to present the values, beliefs and practices that are considered paramount to the health care of Aboriginal women with cancer, especially in the palliative stage of the disease and at the end-of life.

CHAPTER SIX

CULTURAL IDENTITY AND COLONIAL HISTORY

In the following three chapters I present the data on what the Aboriginal women shared about their experience of cancer and its meaning in the context of their lives in rural communities. In order to evoke (Tyler 1986) an accurate image of the context and dialogue that informed the data, I present verbatim extracts of participants[14] narratives, anecdotes and colloquialism that demonstrate the common issue of concern relevant to the topic, and I also include selective entries from my reflective journal and fieldnotes to convey the *cooperative story* embedded in this ethnographic study.

Constructs of cultural identity

The constructs of cultural identity evident from the data are how the women identify themselves, including their Aboriginality, gender, social roles and family structures, and religious and spiritual beliefs; the relationship with and expectation of the extended family, social networks and the general community and how these influenced decisions about cancer health care.

Aboriginal identity

All but one of the women identified as Aboriginal and most called themselves *Murris* to denote that their birthplace was Queensland. One participant is from the Torres Strait Islands and since she had married into a local *Murri* family, considered herself part of the Aboriginal community. Although I did not specifically ask participants their age, a scan of the medical records showed that the majority of women I interviewed were under sixty years with possibly four or five being over seventy years, I know that at

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[14] I use the term 'participant'(s) to denote both men and women who contributed data, otherwise I indicate when I am referring specifically to the women's stories and narratives.

least six were under thirty-five years. The social standing of the women was indicated by how others addressed them, whereby those respected for their knowledge of traditional lore and cultural practices and for their contribution to community functions were referred to as the elders. The older women in general, whether elders or not, were called Aunty as a term of respect for their age and position in the community as having the overall responsibility of raising and caring for the children. All the other women usually used their first or Christian names, and some used a traditional name, in everyday communication and in professional interaction with health care staff.

The women's identities

The truism of Franz Fanon's words: 'Colonialism forces the people it dominates to ask themselves the question constantly: 'In reality, who am I?' (Fanon 1967 p. 200), was evident in the women's stories. Most women in this study seemed to struggle with the *double consciousness* of being Aboriginal by their cultural heritage and shared histories, but socialised by Western education and policies that once regarded Aboriginal culture as inferior. Although some women have overcome the inferiority barriers imposed by successive paternalistic policies, and now compete with their Western counterparts in education, health care and government and other significant positions, these women faced the dilemma of being ostracised by their own people who feared a too close alignment with the Western ways of the *whiteman.* Doreen gave the example of her position as a local councillor which sometimes caused tensions when her professional responsibilities of implementing local and state policies appeared to conflict with the expectation of her extended family and her community. Doreen lamented: 'I'm expected to please everyone'.

The multiplicity of identities (Airhihenbuwa & De Witt Webster 2004) of women in this study was summarised by Annette, a non-Aboriginal senior health care professional. Annette had worked with Aboriginal health services for many years and had also grown up in the neighbourhood of the Waratah community where she currently worked and therefore knew the people very well. Annette offered her view of Aboriginal women's social role:

> It's about being a woman, their self-image as a woman, and their place in the community, which is validated when they have children.

According to tradition, women take the responsibility as primary carers of children and grandchildren. According to the Aboriginal and non-Aboriginal health care staff, this is now becoming a burden for many older women. Health staff refer to the older women as victims of 'elder abuse' because caring for adult children as well as the grandchildren involves them in everyone's problems, potentially to the detriment of the older women's health. Elder abuse is a Western construct of a problem, which Indigenous women may see differently. The older women in this study did not identify with the concept of elder abuse, although several admitted to being physically tired from caring for their young grandchildren and having a 'house full of children'. They nevertheless accepted this as their social responsibility. That is not to say that the older women were not struggling with some of the complex problems of their children's lives, however, the significance of this role was central to their position as older women in the community. Consequently intervention aiming to ease or support the older women in an effort to reduce the risk to their health would need to respect the significance of their social position and accommodate this rather than tyring to take over this role.

The importance of the women's nurturing role is evident in Aunty Amy's story. Aunty Amy cited her responsibilities toward her children as the reason for not seeking medical advice when early signs of breast disease presented. Aunty Amy, who had given birth to ten children (not all survived) explained:

> I felt lumps in my breasts even when I was feeding them, but I was busy with the kids, I didn't have time to be looking at that until they were all grown.
>
> Then a lump got bigger and it got sore, so I got it checked up and next thing they sent me to hospital to get it cut out.

An alternative response was from Aunty Em whose decision to undergo treatment for breast cancer was not so much for her own well-being but more to ensure she could fulfil her childcare responsibilities. Aunty Em explained:

> I was real sick though, especially with that chemo, made me feel reel bad, but I wanted to get right, I had kids to think of to get back to them. They didn't know why I was gone for so long when I was away.

Aunty Em's decision to distance herself from her children while dealing with cancer treatment seemed contrary to what others had said about the importance of family support in such times of crisis. Aunty Em explained that there was always the network of other women in the community to care for her children: for herself there were other family members who lived in the same region of the hospital that treated her and as Aunty Em said, 'there was always someone with me'.

Another important dimension of a woman's identity is the relationship with their husband or male partner. Some men expect to have input into women's decisions about health care, particularly when it concerns her sexual body. Women's decisions to participate in cancer screening or complying with cancer treatment, are often heavily influenced by male partners. Aunty Pam explained this situation:

> There is the relationship thing with the husband or partner; some want that control of what their women do and where they go. Some women need their husband's permission or support to come for a pap smear or have a mammogram done. So they don't talk about it.
>
> It's not so bad now there is a full time female doctor here, but there are still male hospital staff and the husbands get suspicious about who will examine their women. It's all about control some men still see themselves as dominant over the women.

The experience of the health care staff was that some women used surreptitious means to present themselves for a clinical examination by a nurse or doctor if their male partner made it difficult for them to attend at normal clinic times. Examples of ploys women use when presenting at the hospital late at night include a pretext of needing attention for a minor injury, or arriving intoxicated, which the staff interpreted as: 'It is as if the alcohol was giving her courage'.

Margie was optimistic that men's attitude toward the women's health issues is changing as the men become better informed and more understanding about cancer. Margie gave the example of how a man recently instigated his wife's attendance at the women's clinic to undergo a Pap smear test and clinical examination. This husband had shared his concerns with an Aboriginal health worker about his wife's gynaecological symptoms of pain and bleeding after sexual intercourse. His concern was such that he gave permission for the Aboriginal health worker to approach his wife and encourage her to attend the gynaecological clinic. Margie recalled the event:

> I had an unusual case when one man talked to a staff member about his worry that his wife had bleeding during sexual intercourse. She had never said anything when she came up to the women's clinic. But then he told us we were able to go and see her with his help and get her to come and get checked-out.

Margie added:

> It makes it better for the women, having their husband's support. I think some of them are afraid of their husband's response as much as the disease.

Women's health business is men's business too

In both communities the notion of *woman's business* was a belief asserted by some and discounted by others. Lyn, an Aboriginal nurse, stated assuredly:

> There is too much of this women's business and men's business, it's *gamon*[15]. It might be true for the older women who know the traditions and follow the old ways.
>
> But that is not so strong now, sure there is women's health issues which they prefer to keep private like pap smears and checking their breasts, that is for the women and maybe talking about sex, some older women don't think its' right to talk about that openly with men.
>
> But when it comes to cancer that's everyone's business, the men should be involved they can support their wives, and encourage them to come for screening.

Bill, an Aboriginal mental health worker felt strongly that the myth of 'men and women's business' was detrimental to the promotion of Aboriginal health care. Bill said:

> Some may believe there are certain things for men and for women, but this should not be perpetuated. Sure there are different health issues which concern men and women differently, but in pre-primary care we should be getting them (men and women) together.
>
> Diseases like cancer should involve both men and women. The women would be encouraged to get checked out more and look after their health if the men supported them and they knew it (cancer) was also a problem for men.

Julie, who presented her story in artwork, symbolised in the painting the belief that a husband's support of his wife in dealing with cancer helps to keep the ravages of cancer

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[15] Gamon is an Aboriginal colloquialism to imply something is nonsense or to indicate what is believed or said is untrue.

cells at bay. This is shown in the following painting in which Julie represented the cancer cells as red and black circles situated outside the embracing couple.

Figure 1. Partners against cancer (Rogers 2000)

During my fieldwork, I spoke with several Aboriginal men wanting to know about cancer and how it affected them. In the Coolabah community, Judy arranged a focus group meeting of ten men and two women. Initially my lack of experience in talking with Aboriginal men about personal body functions made me apprehensive. Also I was cognisant that some believed it was culturally inappropriate for women to talk with men about certain health issues. However, with Judy's support and her brief on using appropriate terms such as *ball bag* instead of scrotum and *belly run* instead of bowel changes, the meeting generated considerable discussion and several questions about causes and early detection methods for cancer affecting men and women.

Donald, who looked to be about 50 years old, alluded to the men's feeling of being excluded from public health information on cancer saying they did not receive sufficient information about the effects of cancer on their wives, and what to expect. Donald asserted:

> Everything seems to be for the women, when a woman gets cancer all the information and support is for the women, there is nothing for the men, we don't know what's going on, don't know what to do when they get moody or don't want intimacy.

Aunty Pam, who was in this focus group, added:

> That's where you get the problems, people lashing out their frustrations and fear, because they don't understand what's going on.

The older women, however, were resolute in believing that health matters concerning women's bodies and their reproductive functions were the private domain of women and not for public display or involvement of the men. This resolve was evident in the Waratah community, where many of the women objected to the public displays of literature on breast health and sexual matters considering it inappropriate in their community. Instead they argued for this information to be presented in the privacy of the special women's health days held at the local centre. In the Coolabah community the women recalled how they needed to explain to health staff that reason for the poor uptake of the mobile breast screening service on its first visit there, was not due to a lack of understanding by the local women about the need for mammograms but because the van had been parked in a prominent part of the community 'where everyone could see it'.

The beliefs about what is or is not women's private business and the gender role influencing women's health behaviour as shown in the above narratives, are good examples of either a 'positive, existential or as negative' influence on health behaviour, according to the PEN-3 model. For example, the fact that some women were advocating for cancer to be a shared concern between women and men could be considered as positive perception and therefore to be encouraged because the men's involvement in this manner is congruent with the expectation of public health. In Western societies it varies as to whether women involve their husband in the cancer screening process. If women are diagnosed with cancer, then subsequent support services such as the 'Living with Cancer Program' generally assume that husbands or partners will be involved.

Alternatively the strongly held belief of the elders that health issues involving women's sexual bodies are 'women's private business' might also be regarded from the culture-centred paradigm, as an example of an existential perception because of its cultural significance and the values is not directly harmful to greater community. The task for public health is to work with women from that platform, by for example, supporting regular women's health groups where cancer information can be presented and discussion of female cancer facilitated. In this forum women can decide for themselves how to inform their husband or male partners. In other words public health strategies need to engage with women to determine the way forward, rather than impose 'outsider' strategies.

Women's faith and spirituality

An essential dimension of cultural identity demonstrated by the women's stories was the influence of religious faith and their spirituality. The Aboriginal Inland Mission (AIM) and other Christian based churches are important social institutions for many in both communities. Judy, from the Coolabah community is a strong advocate for the Christian teaching of the Aboriginal Inland Mission (AIM), as she believes her association with the church 'saved her life'. Part of the attraction of the AIM, that began under the administration of the Presbyterian Church (Hians 2003), is that it is not associated with negative events of colonialism history, unlike the imposition of other Christian missionaries. The original brief of the AIM under the Presbyterians was to integrate the social-cultural needs of Aboriginal people with the practices of a Christian religion (Nebel 2004).

Christian teaching prevailed in both communities in the colonial period. Many older women grew up in dormitories under the care of Lutheran or Catholic Church missionaries. Teachings from the Christian bible were obviously a source of solace for the women, their faith being evident by the displays of religious artefacts in their homes. Some also referred to the bible during interviews. An example was Aunty Nan, who attended the local AIM church and used her bible to gain inspiration and comfort from reading a daily devotion. Aunty Nan explained how passages from the bible had recently helped her deal with fears about travelling interstate to attend a reconciliation meeting. By referring to a passage from the Bible about her issues of fear, Aunty Nan felt affirmed that God's protection would ensure her safer return home. Aunty Nan showed me the bible passages from Romans 8:31:

> If God is for us who can be against us? (*Good News Bible* 1986 p. 1256).

And, Psalm 62: 2

> I depend on him alone,
>
> He alone protects and saves me;
> He is my defender and I shall never be defeated. (*Good News Bible* 1986 p. 633).

Aunty Rose, an elder who served on the local justice committee and had other important community positions, referred to the bible to guide her in these various roles. Aunty Rose's respect for the teaching of the bible was evident in this comment:

> This is what we use as our guide (showing me her Bible). Everything you want to know about life and law, even land rights it's there in the Bible. It's all there.

In addition to the influence of Christian teaching, it is however also apparent that the traditional values of Aboriginal spirituality are at the heart of women's faith and beliefs about the world. I was informed by several of women that Western Christian teachings are accepted 'fairly easily' because it is seen as just another view of what they already knew as their traditional religion. One young woman made the point when she said, 'They (Christians) talked about angels, we know these as spirits, and it's all the same'.

In an interview with the broadcaster Caroline Jones, Wadjularbinna, a national Aboriginal elder and social activist, expands on why 'her people' had accepted the Christian teaching of the missionaries. Wadjularbinna explained:

> Because we are spiritual people before the Western bible came…I learnt to pray and accepted the gospel, that Jesus

> Christ died and rose again, I accepted this as an addition to what I already know, because it speaks of the holy spirit, anything to do with the spirit has got to be connected with us (Wadjularbinna 1993).

Eddie Kneebone (cited in Mudrooroo 1995 p. 34) another Aboriginal elder defines Aboriginal spirituality:

> The belief and the feeling within yourself that allows you to become part of the whole environment around you–not the built environment, but the natural environment.
>
> Aboriginal spirituality is the belief that the soul or spirit will continue after the physical form has passed through death.

The women's belief in the spirit world also transcends to a fear of 'bad spirits' that cause sickness or harm, hence their anxiety about the lost spirits of the dead that can linger in hospital wards where they can affect the sick. One woman described this fear:

> Aboriginal women don't like hospitals; they associate that with serious illness and death. Another thing is the spirit remains. They always fear the spirits of people who have died in the hospital have remained and are there in the bed where they [the patient] are expected to sleep. And yes they do think people go to hospital to die.

A number of women expressed their belief that cancer is a manifestation of *payback* inflicted by 'bad spirits' as punishment for some misdemeanour or violation of a cultural lore by an individual or their family. In clarifying the significance of women's cultural beliefs over conventional knowledge Margaret, a non-Aboriginal nurse with many years experience with Aboriginal health care, knew that most Aboriginal women understood the biological causes of cancer but also needed a 'cultural explanation' of why cancer happened, and their belief in metaphysical forces of the spirit world often provided an answer. As Margaret explained:

> Yes some definitely believe in the supernatural causes… I don't know if these are beliefs or just an explanation. They need to be able to explain why it (cancer) has happened, why they got it.

> They believe in the holistic influences for all things, so that might sound like cultural beliefs, but it goes for all things.

Margaret's explanation reflects the holistic view that Aboriginal women hold about the manifestation of disease. In other words the cause of the life threatening disease of cancer needs to be understood as a biological entity influenced by spiritual forces aroused by a disharmony in the relationships of family, social groups and the community.

Community Identity

The concept of neighbourhood as defined in the Pen-3 model relates to a location or district shared by groups of people not necessarily bound as a community by a common understanding or ambitions (Airhihenbuwa 1995). The significance of considering neighbourhoods is in determining the capacity, in terms of economic status, location power structures and so forth, of a community to develop or support public health programs. The neighbourhood in which the community of Waratah is located is a rural setting comprising mostly farming country and a few homesteads. The neighbourhood of the Coolabah community is mostly undeveloped bushland and beaches with the residential areas centred in one small region. Both neighbourhoods have about 70% unemployment and no access to industry or trade work outside of the communities because there is no public transport system. The neighbourhoods that provided the context for this research are better defined as communities in that the Aboriginal residents hold a tacit bond of a shared history, common struggles and a common resolve to assert their Aboriginal culture, and retain traditions of their ancestors. Both communities have their share of complex social problems, and some residents are committed social activist advocating for more autonomy, better community resources for health, schools and employment, and aspire to what an elder of the Coolabah community described as: 'Getting the pride back into the people, getting them to respect their land in the traditional sense'. This particular elder, a member of the local Council, was planning with others, to redevelop the agriculture industry that had once been the pride of the community. And in Coolabah and Waratah communities there is an emerging craft-making business to supply the neighbouring tourist industry.

Community influence in health

The relatively small populations and the geographic isolation of the rural neighbourhoods increases the community's influence in determining the norms of behaviour in relation to health care and other aspects of community life. A negative aspect of community life is what the women called the *gold fish bowl* situation that made it difficult for people to keep their health matters and personal lives private. An Aboriginal nurse explained:

> Here in (name of community) it is like a *goldfish bowl*, everyone can see what everyone is doing, where they are going and who with.
>
> Imagine if they had been playing around with someone and they needed to see the gynae doctor. Everyone would be asking 'what she doing seeing that doctor, or coming to that clinic?'
>
> This is especially difficult for a woman who doesn't have a husband or whose partner had died or is away somewhere.

This situation causes difficulties for local Aboriginal health workers who are sometimes accused by antagonistic families of breeching confidentiality about a person's health problems or of showing favour to a particular family. According to the Aboriginal health workers, the situation persists despite assurance to the accusers that Aboriginal health workers are bound by a professional code of ethics. Margie, my research facilitator in the Waratah community, explained the antagonism between families originated from the early settlement of the community, when the white authorities herded different tribes together, without understanding the social, cultural and linguistic differences among different Aboriginal populations. Margie explained that these differences could result in conflict:

> There are plenty of fights between families. You see all these different tribes were put together in (Waratah).
>
> Some of those families never got on, they were always feuding and that goes on still. They don't forget, and pass on the bad feelings to the next generation.

The family influence

The family's influence on a woman's decision about cancer and health care generally, is significant because of the family's central position in a woman's identity as a mother, wife and nurturer. The influence of the family and the women's social network (that were in effect like an extended family), in shaping perceptions of cancer and treatment decision, was reiterated in many women stories.

The family's involvement in caring for the sick included giving emotional support and having significant input to the sick person's day-to-day care. In addition, as cancer was generally perceived to be a fatal disease, family involvement was paramount in supporting the sick person as they would need to prepare for death and family and friends should have the opportunity to 'pay their respects'. Phyllis and Joan who both had experiences of cancer in their families stressed the significance of this support:

> They (the sick person) need to have their family with them, give them strength to deal with it (cancer treatment). When they go over there to the hospital, those places don't have room for the family to stay, we can stay, but not the whole mob, there can be a lot of them.
>
> That's terrible for them (the sick person) they can't survive without that family support, giving them care.

In response to my question about the relative importance of family support to a patient progressing with treatment, Joan and Phyllis replied:

> Oh yes, without having the family close by they (the person with cancer) wouldn't go through with the treatment.

I then asked, 'Is that why some people won't finish their treatment?' To which they confirmed:

> Yes that would be it; they are no good without someone giving them support, caring for them especially when they are a long way from home.
>
> The family give care, show care, it's important to know people care about you, especially when you're sick; you need that (care) more.

From the Western perspective the family's influence on the individual's and community's perceptions of cancer could be viewed positive if the outcome is compliance with the prescribed treatment bur negative if a woman abandoned or refused medical advice. Carol, the Aboriginal cancer liaison officer, gave the example of how one family's resistance to cancer surgery had far reaching influence on the decision-making about cancer treatment throughout the community. Carol recalled the story of this family's unwavering belief that their mother's death was caused by surgery because they believed the surgery had 'let in the air', and this caused the cancer to spread. Their mother's exploratory surgery had revealed an inoperable bowel cancer with evidence of metastasis, so her prognosis was poor. But because this particular family had considerable status in their community, their views influenced the perceptions and opinions of the whole Aboriginal community in their region, as Carol explained:

> Because this lady (the mother with cancer) was a key member of her community, she had a big influence on other people in the community.
>
> Plus this family have a very strong influence especially because they have key positions in the community, in government, health and education. They are all educated,

> you'd think they'd work it out, but they insist on their belief that once cancer is exposed to the air, through surgery cutting the person open, that's what makes cancer spread.
>
> So that affects others (in the community) if a member of their family gets diagnosed with cancer that's it as far as the family is concerned, the person will die and they (the family) would not agree to surgery.

Another Aboriginal health worker confirmed this:

> If the family decided *no* to cancer treatment, then the woman may not come to her clinic appointment. I go and get them, because that's my job, but I have to deal with the family. Tell them how the treatment will help. I have to persuade them for my client's sake. But I can't guarantee that she will finish treatment. I may get them to start the treatment but getting them to complete it is hard.

Negative aspects of the family's involvement in decision-making are that a woman is deterred from having cancer diagnostic tests or reporting abnormal symptoms if she knows her family holds antagonistic views about conventional treatment. The Aboriginal health workers described the difficulty of their role as advocates of public health messages for cancer screening while trying to support a woman in the ambiguous position of knowing her family are against the procedure and would not consider treatment anyway. One Aboriginal health worker described this dilemma:

> If a member of the family gets diagnosed with cancer, that's *it* as far as some families are concerned, the person will die, they (the family) won't even accept treatment because they believe there is no point, it would only make the suffering worse.
>
> The person with cancer doesn't know which way to go, with pressure from the family and the expectation that they will die.
>
> Some (women with cancer) just want to give up when maybe their cancer is local and can be easily treated.
>
> The family expects them to die! It affects how the family are around the person, they wouldn't be sending out any positive message that's for sure.

In the Waratah community, the Aboriginal health workers knew of several women whose Pap smear tests showed abnormal cells or their mammograms had suspicious signs, but these women were unlikely to return for follow-up because their family lacked faith in biomedical treatment. As Amy explained:

> They (the woman with cancer) may not want to tell the family for fear of being rejected, or of putting stress on relationships, like with her partner or husband.

From my observation, the influence of the family in decision-making did not completely discount an individual woman's preferences for cancer treatment. The difference is that a woman's decision to proceed or disregard medical advice had been considered from the standpoint of her family's well being first rather than from an egocentric position of 'what's best for me'.

The Aboriginal health workers cautioned that it cannot be assumed families are automatically against cancer treatment as they pointed out decision against biomedical methods is in some cases made on the basis of outdate information as well as the influence of cultural beliefs. Aboriginal health workers experienced many families who sought all the current information about cancer treatments to help them weigh up the benefits in the context of their cultural values. An example is Carol's story of a family who wanted to know everything about their mother's cervical cancer, its prognosis, treatment options and the expected outcome, so they were positioned to make an informed decision about her progress. The family in this story were the woman's husband and two sons, which caused Carol some embarrassed initially because as an Aboriginal women she would not normally talk with men about women's anatomy. Carol recalled how she spoke with this family:

> I asked the patient what I should say to them, and asked her if I could talk to them (her husband and brothers) about her condition. She said they are her closest family and they must know about her condition.
>
> She had cancer of the cervix so I had to give all these details, and talk to them about the radium treatment, where the cancer was and how she would have surgery.
>
> At first I felt embarrassed talking to these guys about that sort of cancer and how the radium stick would be placed in the vagina.
>
> This was women's business; a lot of people think you shouldn't talk about this with the men. But she (the patient) was all right about it she wanted them to know so they understood what she was going through and what should happen.

The families that were cynical about cancer treatment based their opinions on experience of witnessing relatives and friends who died form cancer despite enduring debilitating treatment and the added distress of being away from home.

While there was consensus among the women about the family's central role in decision-making, the health care staff cautioned that the next of kin are not necessarily the best source of support when a woman is away from home undergoing cancer treatment. For example if there were pre-existing tensions the presence of the husband might add to the anxiety of the situation. Carol explained this further:

> Sometimes the woman comes with her partner or husband who beats her and here she is with just him sitting by her hospital bed. At home she might get away from him, or have the help and support of other women. But stuck down here in the hospital or one of the hostels, it's all a bit unnatural anyway to have your husband or partner sitting with you all day, he gets restless, and starts taking it out on her and she get stressed with him being there.

Carole stressed that it was important to the women's well-being that these family tensions were acknowledged and that the women needed to be consulted about who they wished to escort them, rather than making assumptions.

The colonial identity

In the Coolabah and Waratah communities it was apparent that an important constituent of the women's cultural identity was the effect of colonialism. Just about all the women interlaced some aspect of colonial history into their stories about cancer. The wounds of history continue to cause much them pain and grief. Both communities were former government run Aboriginal reserves that had church missionaries administering the schools, some health care services and residential dormitories for children.

The shared histories and tacit knowledge of the effects of history appeared in many ways to be a unifying construct of the Aboriginal participants (men and women) in this study. The axiom of Wilhelm Dilthey's (Dilthey, cited in Bulhof 1980 p. 38) philosophy on history explains this phenomenon of shared memories, both good and bad events that unite a society:

> A society's study of its past articulates its memory. This memory is 'productive for the social life of mankind': it causes a feeling of solidarity, a sense of shared values and a commitment to a common goal which in turn inspires its cultural leaders, its heroes, political founders and religious leaders.

The majority of participants in both communities are descendants of the original families who were forcibly relocated from their traditional land to these government Aboriginal reserves. Participants therefore, were united by a shared history and their cultural traditions. What was striking to an outsider was that the older women grew up under the oppressive regimes of what had been considered 'postcolonial'[16] policies to protect the Aboriginal people. The elders shared their memories of being segregated from the white people in their community and some were forced to live in communal

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[16] Bobby Sykes an Aboriginal activist/advocate questions the use of the term post-colonial, in saying. *What have they left?* Smith, L, 1999. *Decolonizing methodologies. Research and indigenous peoples*, Zed Books Ltd., London & New York. The postmodern view is that post-colonialism is a process in the decolonisation agenda that is yet to be achieved.

dormitories because the white authorities had judged their parents as unfit to care for them. Aunty Ruth, from the Waratah community, remembered the distress of being taken from her Mother and separated from her brothers because the white authorities decided her mother was 'mad' and therefore unfit to care for children. The older women shared reminiscence about their disciplined life in the dormitories where they trained to be subordinate to the *whiteman* rules. Aunty Ruth recalled:

> The children in the dormitories were disciplined and expected to work as domestic servants to the officials and their families.

Aunty Ruth shared her experience of growing up in a church run dormitory:

> We were controlled and everything we did was controlled by the *migloo-* the *whiteman.* We were like prisoners; we couldn't do anything without permission from some *whiteman.*

The older women were able to recall the days, when they had been separated from the 'white kids' at school and how Aboriginal children rarely had the opportunity to progress beyond grade three or four of the school curriculum. This history of restricting the education of Aboriginal children is remembered as another colonial act the *whiteman* used to maintain authority over Aboriginal people by limiting their opportunities. This perception continues to make some women feel resentful toward non-Aboriginal people.

In the Waratah community the older women showed me the geographical point of demarcation that in their childhood days, had separated the Aboriginal community from the white residents. Even today in this community the styles and conditions of houses and the separate location of the non-Aboriginal hospital and teaching staff residence from where most Aboriginal people lived perpetuates a sense of segregation in the minds of some. The elders in the Waratah community frequently prefaced their stories with: 'when we were living under the dog act'. 'Living under the dog act' is a pragmatic and derogatory colloquialism used by the women to emphasise their feelings about the living conditions they suffered as well as the generations of Aboriginal peoples before. When talking about their predecessors the women said they lived 'under the act' in reference the *Protectionist Act*, its full title being *The Aborigines Protection and Restriction of the Sale of Opium Act 1897.*

The protectionist legislation, proposed in 1895 by the then Commissioner for Aboriginal affairs Archibald Meston, was intended to protect the Aboriginal people from exploitation and allow the 'wild tribes', said to be uncontaminated by European invasions, to return to their land (Kidd 1997; Meston 1895 p. 3). But rather than benefiting the Aboriginal people, the legislation allowed punitive and denigrating acts against them. Under the protectionist legislation Aboriginal people from different tribes, language groups and life style were gathered together and placed in various government reserves that were often many miles from their traditional land. The combination of church missionaries and protectionist administrations ruled the Aboriginal people with the intention of what Elkin described as: 'to bring them the blessings of civilization and Christianity' (Elkin 1954 p. 322).

In Queensland the more recent *Deed of Grant in Trust 1984* (that was an amendment of the *Land Act 1962 (Qld)* (Kidd 1997) and adaptation of *Land Right Act 1979-1983* of other Australian states and territories), were intended to give Aboriginal people land tenure and some degree of control over the administration of their communities (Kidd 1997; Tickner 2001). The acronym for the *Deed of Grant in Trust* is DOGIT, which Aboriginal people use as a metaphor and an analogy of 'living under-the-dog-act' because according to the elders it aptly reflects the living conditions provided to them by the state government. As Aunty Ruth told me: 'they treated their dogs better than us; at least they let the animals go where their own way'.

The intention of the DOGIT policy was to foster self-determination by transferring ownership and administration of former protectorates and reserves to the Aboriginal people. The principal of the DOGIT was that Aboriginal Councils should make the by-laws and govern their communities. The Council was to be responsible for the community's maintenance and infrastructure, and for the administration of the Community Development Employment Program (CDEP) and other government projects. The communities soon became disillusioned when it was realised that the Aboriginal Councils had no real authority because state cabinet could rescind local decisions or by-laws and thus ministerial control of the community was never relinquished [17] (Kidd 1997). From the perspective of the current residents in both communities, the DOGIT legislation failed to change anything, and only provided the legal framework for 'their possible creation' (Kidd 1997 p. 330). The apparent broken promise of the DOGIT is regarded with cynicism and regenerated old feelings of mistrust toward government officers and white authorities generally.

In matters of health care the dictatorial oppression of colonialism over Aboriginal people's lives was at its worst. In Queensland, for example, the colonial authority was exemplified in the *Contagious Disease Act 1868*, later amended to the *Health Act 1911*, legislating forcible confinement in 'lock-hospital' institutions of Aboriginal people with

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[17] Currently there is a paper under discussion with the Queensland Government on reforming the authority of Aboriginal Community Councils. *Making choice about Community Governance*, 2003. Queensland Government, Brisbane.

contagious diseases and other 'anti-social' conditions or behaviours, and a compulsory medical examination of all the 'patients' (Watson 1993). The colonial mentality justifying the lock-hospital system was evident in this paternalistic view of the then Chief Protector of Aborigines Dr. Cecil Cook who argued:

> The aboriginal had careless and irresponsible habits, which rendered it impossible to keep him under observation or to submit him to a course of treatment unless he was under restraint (Dr. Cecil Cook, cited in Watson 1993 p. 247)

Many Aboriginal people remember the lock-hospital as a punitive institution that not only forced 'white man's medicines' but also destroyed family relationships by segregating sick people from their community, often for an indefinite time (Watson 1993). Aunty Nan became quite emotional during our interview when recalling childhood memories of being separated from her mother who had leprosy and was therefore confined in a lock-hospital, which at the time was difficult to access from the general community especially for a child. Aunty Nan told how the white authorities deceived her when they removed her from her mother and placed in dormitory accommodation with other children. Aunty Nan recalled the experience:

> They told me I was going away for a holiday, then they put me in the dormitories with all the other girls, my brother he was put in the boy's dormitory. I was never allowed to see my Mother again, even when she died they didn't let me go to her funeral.

Aunty Nan concluded: 'I wasn't stolen I was taken'.

Although the particular lock-hospital related to in Aunty Nan's story is no longer in operation its location is visible from central areas of the Coolabah community and continues to cause feeling of grief for Aunty Nan and others who had similar experiences. These older residents still point to the site of the old lock-hospital calling it the Alcatraz - the *Punishment Island.*

The memories of the punitive system of lock-hospital influences the contemporary perception of hospitals as being places where people die, and where people risk losing control and therefore hospitals are best avoided. The women's ambivalence toward Western hospitals was summarised by Joan who described hospitals as: 'Another paternal institute, no one likes going to the white people for treatment for anything'.

The anxiety about hospitals can be further provoked when white hospital staff question Aboriginal women about personal or family details. An Aboriginal health worker said the older women felt vulnerable when asked about family business or were prompted to talk about feelings or to give opinions, because they basically mistrusted how the white authorities would use these details. This Aboriginal health worker explained:

> The *whiteman* knew all about the *blackman's* business and now they don't want to tell the *whiteman* anything, they don't want to lose themselves again.

Colonialism and hospitals

Cynicism and mistrust toward Western authority is often directed toward health care and welfare institutions. Franz Fanon (1965 p. 121) had argued that it is: 'the most tragic feature of the colonisation situation', because it underpins the cause of health disparities in the colonised Indigenous populations. Frantz Fanon (1965 p.121) attempted to explain the ambivalence of colonised people toward Western medicine in his book *A dying colonialism* in which he argued:

> Introduced...at the same time as racialism and humiliation, Western medical science, being part of the oppressive system has always provoked in the native an ambivalent attitude.

> The colonial situation is precisely such that it drives the colonized to appraise all the colonizer's contributions in a pejorative and absolute way.

The women attributed many of their health problems to the imposition of Western biomedical methods that not only marginalise but denigrate traditional medical practitioners as 'witch doctors', which implies they are evil or criminal (Trudgen 2000 p. 138). A popular belief in the communities is that the whiteman has brought in health problems. Some of the older women express their disappointment that biomedical methods of health care force traditional medicine and healing practices underground. They blame the imposition of Western methods for the destruction of Aboriginal people's security in the traditional medicines and the loss of rich cultural knowledge attributed to those referred to as 'Medicine men' and Healers. For this reason the use of what Aunty Ruth called 'traditional healing ways' is not freely disclosed to the *whitefella* 'for fear of being put down' and because this traditional knowledge now needs to be protected.

The women explain their ambivalence toward the Western health care system as being based on their fear of paternalistic attitudes of some staff; the incongruence of reductionist methods of biomedicine, as well as racism and hospital policies restricting family visiting. Furthermore, the women feel insecure in an environment where predominately non-Aboriginal Western hospital staff are often unaware or disrespectful toward Aboriginal cultural values. Adding to their anxiety is the women's fear of leaving the supportive care of family and the relative security of their community, to enter the culturally different environment of a Western hospital. These fears are intensified for women who believe their condition will be fatal regardless of treatment possibilities.

The women said they were less anxious about attending the primary health care centre in their community, because there they felt culturally more secure as many local Aboriginal people worked in the health centre and in the local hospital. Some of the women, however, had concerns that confidentiality was compromised in their local health care service where it was difficult not to be seen in a small community. A non-Aboriginal health professional who was perceptive to this difficulty explained:

> Some people get very concerned about confidentiality, you imagine how difficult it is to slip into the hospital or community clinics without seeing someone you know.
>
> I have had people come after hours with some minor complaint insisting they are seen by Dr. M, then it slips out that they really want to have a pap smear done, but didn't want to come when a particular worker was on duty.

Women, who were particularly concerned about confidentiality, attended other hospitals outside of their community if this was possible. Of course a suspicious or abnormal cancer screening result made it inevitable that a woman must leave the community in order to attend a city or regional hospital for further investigation. If a woman required cancer treatment it was necessary for her to live some distance from her community for maybe weeks or even months while undergoing treatment. May, a woman from the Coolabah community, felt the worst aspect of her breast cancer treatment had been the separation from her family and male partner because she felt unsupported and alone. Phyllis, a friend of May's stressed the point:

> It's hard enough when they have to leave their family and leave the community to go over to the mainland to get treatment. It's really hard if they have to go to Brisbane.

The journey to Brisbane from May's home involves a thirty-minute flight, which is often delayed by bad weather, then another hour and half flight. For a number of women the possibility of having to leave the community is enough to deter them from pursuing any type of cancer screening that could reveal the need for treatment or further tests.

A further stressor for rural women living away from their home community arises when they have to navigate the unfamiliar geography of a large city or town. The experience of Carol, an Aboriginal cancer liaison officer, was that rural women felt lost and lonely in a city, so much bigger and crowded than what they were used to. Carol explained:

> They (women with cancer) don't know where they are. Brisbane is so different to their communities where they know everyone, and there are not many places in their community to go anyway.
>
> Just imagine people coming from (Coolabah or Waratah) even to get around Brisbane is hard, they can't manage the bus system or the trains.

The experience of Jay, an Aboriginal cancer health worker was that the relatively poor education of some rural women meant they were ill equipped to navigate the hierarchical system of large central hospitals. Jay explained:

> Here in (Waratah community) a lot of the women don't have much education they are very shy. I think they feel conscious they don't know how to ask.
>
> But a lot of these women here get too frightened, they don't know how to work the system, like how to make an appointment or ask someone for directions. They feel shy, intimidated, because they don't have the education.

Reductionism

The biomedical mind/body split in health care is incongruent with the conceptualisation of holism valued in Aboriginal culture. Carol made this point:

> Aboriginal women don't just talk about the physical disease, to them its much more holistic, it embraces all elements of their lives.

Vital aspects of holism for Aboriginal people include their relationships and interdependence with family and social networks; and the inter-relationship of people-land-spirit (NATSIHC 2003;, 2004; Reid 1982). Health is valued as an holistic condition of harmony between and within these relationships, and health issues implicate all of life elements. Therefore an imbalance in the physical body resonates in the social, spiritual and cultural identity of a woman (NATSIHC 2004). This notion of holism is compromised by the reductionist methods of biomedicine as in the example of physical examinations that focuses on a single body part, such as the breasts. The women said in this situation they felt *shame* because the focus on their breast or other body parts, detaches them from their complete identity as Aboriginal women.

The concept of *shame* described by the women was in terms of the embarrassment, vulnerability and shyness experienced when having the medical gaze on their body in a manner perceived to be disrespectful of cultural mores about modesty and discourteous of the relationship with and the role of their husband or male partner. The women explained to me that *shame* to Aboriginal women is more than just the embarrassment common to most women in similar circumstances; it is a deeper cultural construct as one woman described:

> Yes, *shame* is a big thing, and embarrassment. Knowing people when you have that done is too embarrassing. But *shame* is more than that. Aboriginal women don't show off their bodies like the white people, they are not used to baring their bodies.

The cultural context of *shame* is about a woman's social position, her place in the community. Amy, a non-Aboriginal health care professional with considerable experience in Aboriginal health, explained the concern:

> This (shame) is also a big barrier to services, like doing cervical screening and mammograms, which exposes the woman's body. If the staff (doing the screening tests) doesn't show respect for the sacredness of being a woman

> they cause *shame*, the woman being examined feels *shame*.

Disrespect, according to the women's perception, is shown when hospital staff ignore people or left them to wait unnecessarily; talking with other staff during a clinical examinations instead of focusing on the person; using paternalistic terms such as 'luv or dearie', to address them, which is particularly offensive to the elders; and any communication perceived by the women and others as patronising or racist.

Other situations that cause *shame,* according to Marion, an Aboriginal health worker, are associated with cultural mores about women's interaction with other men who were neither their husband nor partner. If a woman is examined in the presence of another man, who could be a member of the health care staff, it causes *shame* for the women as well as for her husband or partner.

Self-surveillance methods advocated by biomedicine particularly in the interest of cancer prevention or early detection is further source of *shame*. The women reported feeling uncomfortable about touching their bodies in the manner suggested for breast self-examination for example. Furthermore from an holistic perspective the recommended techniques of breast-self examination is not easy to practice for many of the women because they share their home with immediate and extended family members and therefore lack the necessary privacy for self-surveillance. Bill, an Aboriginal mental health worker, related the problem to the context of primary health:

> Most health promotion programs missed the point because Aboriginal communities lack even basic health knowledge or the expected health related living conditions to do health promotion.

Bill continued:

> You have to consider what their homes are like; who is living there what their life is like.

Feelings of *shame* are intensified by other medical advice related to cancer treatment. An example given was the procedure of vaginal dilatation, a practice necessary for preventing vaginal constriction that is a side effect of radiation therapy for cervical cancer. Carol's experience is that Aboriginal women have difficulty complying with this procedure because it is not usual practice for them to handle their genitals in this manner, and the older women who were not sexually active saw the procedure as unnecessary. As Carol explained:

> They hate that vaginal dilatations. Some of the women don't see the need for it because they are not sexually active. It is not something they consider relevant to them.
>
> Others just don't like doing it to themselves, some just don't do it, then they get adhesions and intercourse would be painful and difficult.

Health workers who worked with cancer patients, expressed their dismay that the women who had difficulties following this and other medical treatment advice, were often labelled as non-compliant by the non-Aboriginal staff, who did not consider the problem from a cultural perspective associated with *shame*. Clearly interventions to correct or change the problem of adherence to medical treatment should focus on the meaning of this procedure from the Aboriginal woman's perspective and negotiate a culturally appropriate alternative method.

Racism

> The doctrine of the congenital inferiority and worthlessness of a people (Luther King 1968 p. 48)

Martin Luther King's (1968) sentiment on racism, shown above, is the embodiment of colonialism that continues to plague those who were or continue to be oppressed by the authority of others. The women's stories convince me that the affliction of racism is deeply ingrained in the consciousness of the contemporary Aboriginal populations. The wounds of racism inflicted by over 200 years of the doctrine of 'inferiority' and subjugation, have not healed but have been transposed from generation to generation. The roots of racism are grounded in the architecture of both rural communities because these were established as a consequence of colonial policies of supposedly 'post colonial' governments.

Racism is not only in the history of ancestors as the Aboriginal women reported they frequently encounter racist attitudes of white people in hospitals and elsewhere. Hearing the women's experience of racism reflected to me the emotions aroused by the rhetoric of Martin Luther King Jr. (Luther King 1987 p. 17) on being a Negro in white America in which he epitomised what racism means to the afflicted:

> It means trying to hold onto physical life amid psychological death...it means seeing your mother and father spiritually murdered then being condemned for being an orphan...
>
> It means being harried by day and haunted by night by a nagging sense of nobodiness and constantly fighting to be saved from the poison of bitterness.
>
> It means the ache and anguish of living in so many situations where hopes unborn have died.

The effect of ongoing racism makes Aboriginal women very aware of people's attitudes and actions, and some are quite defensive toward non-Aboriginal hospital staff as Carol explained:

> Whenever I do those cultural awareness classes with hospital staff, someone always asks me why Aboriginal people are so aggressive, and so defensive. I explain they have to be, and most often that aggression is to protect themselves, it is a defence against all the racism they have experienced, and their families (have experienced).
>
> Indigenous people have lived all their lives with racism. The white people, those non-aboriginal people, really don't know what that feels like, they just don't understand racism, they have never felt the discrimination, of being looked down on because you're black, or getting ignored in places

Carol was frequently asked to advocate for the Aboriginal women because they had been subjected to racist attitudes of staff in the city hospitals in particular:

> I would say that 2 or 3 times a week I hear from clients (Aboriginal women) about a staff member that treated them bad, you know, a bad comment or an attitude, yes 2-3 times a week. Someone will react or say something that triggers off a defensive response (from the client).
>
> You know Aboriginal people are very sensitive to racism and prejudice. They have had so much of it they can spot it even if the person (hospital staff) thinks they are being open.

The women believe that although overt racism is more subdued because of anti-discrimination policies, racism toward Aboriginal people remains deeply ingrained in many non-Aboriginal societies. For this reason, Aboriginal people are very sensitive to even subtle signs of racism when interacting with non-Aboriginal people. Another concern of women, who have to live away from their community because of cancer treatment, is that in the city or regional towns they are exposed to a simmering pot of ingrained racism in the general community. An Aboriginal health worker described the situation:

> If they (the women) are staying at the hostel, they feel trapped because they can't get around the town, and the locals and even the police push them around. Well, the police would just be watching them like they suspect them, expecting them to do something wrong.

Carol told the story of a rural woman whom the city police had stopped because she appeared be acting 'suspiciously', when her real problems were the befuddling effects of her cancer treatment and the fact that she was trying to find the way to another suburb where her relatives lived. Carol concluded this story by asking: 'would they (the police) have stopped a white woman?'

Pat abandoned her cancer treatment at one city hospital, which was actually nearer her home than the hospital she was currently attending, because of racist staff. Pat's view was:

> The staff at (name of hospital) looks down on Aboriginal people, and treat us bad. I don't want to go back there.

Pat attributed the late diagnosis of her breast cancer to the attitude of racist staff. When she initially presented for aspiration tissue sampling of a breast lump Pat believes this was not examined thoroughly and so the cancer was missed. There was no way for me to verify Pat's cancer history, but what is important is Pat's perception that attitudes of racist staff had compromised her chance of being cured. Pat said her current hospital experience was positive and she felt cared for. Pat had been touched by the staff's kindness toward her:

> They (the hospital staff) are all really lovely to me. Up in the ward they made a fuss of me. When I was in there having the lump drained the staff gave me a present. I was so surprised they gave me two books and some low sugar chocolate. I can't have the other (chocolate) because of the diabetes.

Aunty Em stories suggest she believed racial prejudice and cultural stereotyping were reason why her sister's breast cancer had been 'overlooked' until the disease was too advanced for treatment. Aunty Em recalled the story of her sister's experience:

> My sister got breast cancer, there was just a sore and they (the hospital staff) didn't take it seriously they were dressing it like it was a wound probably thought she'd been kicked, got it (the wound) in a fight or something.
>
> Then she felt these lumps under her arm and when she picked the scab (of the breast wound) it started to bleed. Then they did a biopsy and found the cancer. It was too far-gone. They couldn't do much for her then.

May shared her story of 'racist staff', whom she perceived were responsible for causing unnecessary distress when her sister was receiving treatment for advanced ovarian cancer:

> She (May's sister) had a lot of pain and they (hospital staff) kept wanting to give her tablets. We came in one day and it made me cry to see her trying to swallow. She couldn't swallow nothing it was drooling down her chin. She looked terrible no dignity, yet they kept giving her these tablets. They (hospital staff) weren't listening to her.

Beth's experience of racism occurred while visiting her husband during his hospitalisation for palliative treatment for a lung cancer:

> When I got to the ward where he was they ignored me, just like I wasn't there. Then this sister (nurse) treated me badly, like I wasn't important. She wanted to know who I was and said I can't see him because I'm not next of kin. I said I'm his defacto you got no business talking to me like that. I want to know what's wrong with him.

The non-Aboriginal health care staff working in the local health centre in the rural communities, reported how they are at times accused of racist acts, when for example they have to refuse entry to an intoxicated person, or if there is an unfavourable action to be taken such as dismissing or reprimanding a member of staff. A senior nurse in one community recalled the extreme reactions of a local family when their mother died in the hospital. Some members of this family became very angry and aggressive toward this staff member, projecting the accusation of racism as causing their mother's death, although from the medical perspective the women's death was expected. In this case the cry of racism seems more likely a projection of the family's extreme and acute grief in the same way that others might use blame and anger to avenge their loss.

Institutional racism

Institutional racism is inherent in the standard methods, rules or policies that govern Western biomedical practices (D'Souza 1995; Henry, Houston & Mooney 2004). Institutional racism in the form of intrusive questioning, policies restricting cultural practices, or the written information only in English for example, are said to be as much a barrier to Aboriginal people access to health care services as is the racism based on the ideology of biological superiority (Henry, Houston & Mooney 2004).

The public health policies advocating cultural appropriateness or cultural sensitivity and cultural safety in health care for Aboriginal people (NATSIHC 2004), have not been realised in practice according the women in this study. However, the cultural heterogeneity of Aboriginal people means that not all the women were affected by institutional racism to the same degree. Nevertheless, many experienced common issues of discrimination against their culture in hospitals, including having to complete bureaucratic forms or other documentation that are only written in English without an interpreters[18] and when medical terms are not explained. Although all the women in this study spoke English it was not necessarily their first language and some had limited literacy and could not understand hospital jargon.

Other experiences of institutional racism according to the women included the hospital policies that limited their visitors and visiting times. It is culturally important for the Aboriginal women to involve family and friends in supporting and providing care for the sick person, and to be there to pay their respects especially when the person was in the palliative phase of treatment and near the end of life.

The discriminatory factor from the women's perspective is the hospital appointment system and time-lines that do not fit with their way of using time. Generally Aboriginal people view time in terms of non-linear events and the daily activities would be organised according to priorities of social and family responsibilities (Smith 1999;

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[18] There are a few interpreters service for Aboriginal languages, for example the Kimberly region of Western Australia and in the Northern Territory where there are more traditional cultures because the tribes had been not as devastated by policy of colonialism and thus traditional languages have been retained. In the Queensland communities, there is no official Aboriginal language interpreter services, thus if interpretation are required it is left to a family member, otherwise the person remains uninformed.

Trudgen 2000). Consequently an assumption by non-Aboriginal health care staff is often that Aboriginal people lack the ethic of responsibility because they fail to keep a clinic appointment time or to follow medical orders, a situations that cause tension and misunderstanding between health care staff and Aboriginal people (Jacka 2000). A concern of Aboriginal and non-Aboriginal health care staff is that while women missed clinic appointments because they prioritised family business, they are also ignoring their own health problems until the condition is too advanced for corrective treatment. Jay, an Aboriginal cancer health worker, identified the hospital system of appointments schedules for cancer screening and mammograms as a barrier to Aboriginal women access to these services. Jay explained:

> But this set up here (appointment system) with the breast screening; they don't understand that Aboriginal women don't keep time; you can't rely on them to keep appointments. They (the screening service) should be more opportunistic, do the women as they come, when they get here.

Jay gave an example:

> Like Aunty Amy here, her appointment is for this afternoon, but she's here now, but they (the radiographer and receptionist) say they can't do her now. She's got to come back at her appointment time at 2.30. But she won't come back.
>
> That's it once they leave here they get onto other things. They're not likely to come back for that. Then, where do they go? The van (mobile breast-screen) only comes every second year. That can be too late, if they got a problem, maybe cancer it can grow by then.

Another manifestation of institutional racism is the hospital policies that place the sole responsibility for care of the sick with hospital staff, which according to some women prevented family involvement thus compromising an important cultural element of holistic healthcare. An Aboriginal health worker summed this up: 'Treatment should be a partnership between the medical team and the patient and their family'.

Norman, an Aboriginal paramedic, believed strongly that being separated from family involvement in direct care is detrimental to a sick person's healing. He said:

> They don't want treatment anyway, it takes them away from home, from here (name of community), and then if the family are not involved that makes them even more sick.

Karen relied on having family involvement and support during her cancer treatment. Karen was living away from her home, while she attended for palliative radiotherapy treatment for lung cancer. She was adamant that her treatment would be 'unbearable' without the companionship of her sister who stayed with her in the hostel. It was critical to Karen's treatment regime that her sister and other family members were in attendance, to provide not just emotional support, but to maintain a cultural link with her home community, without which Karen asserted she would not have agreed to start the treatment:

> I couldn't get through all this without my family. I feel so bad, sometimes I feel like chucking it in, if it wasn't for them, my sister and my children. But they keep me going.

Karen's sister Emily adds:

> Yes I know how to cheer her up I know what she's thinking and can say something that makes her laugh or distracts her.

The cultural link was evident when Emily continued saying:

> Sometime we talk *language*[19] especially when she's feeling bad or the staff are making her feel angry or something, then we talk *language* so they don't know what we're saying.

Karen then said: That's why I need family with me. They understand how I am feeling.

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[19] *Language* used in this context is a colloquialism for an Aboriginal dialect orf tribal language.

The outcome of Karen's story was that she abandoned radiotherapy treatment knowing it was palliative anyway and decided her need to prepare for death in her own community was much more important.

Barriers

Aspects of institutional racism in the hospitals can be seen in the rules and polices that prohibit cultural ceremonies and rituals considered important particularly at a time dying or death. Many women spoke of their fear of hospitals because these were places where people died and therefore spirits of the dead could linger to cause harm. This fear of death is compounded when proper cultural ceremonies for freeing the spirit of the dead are not performed or facilitated in anyway. Ray, an elder and councillor in his community, spoke of his anxiety when visiting his wife in the regional hospital where she was seriously ill at the time of our interview. Ray described his fears:

> I don't like hospitals because people die there. You don't know if you are going in a bed where someone died.
>
> It frightens me. I can smell death. Sometimes I can see the spirit still in that room (the ward). You can see the people are frightened of being in hospital for that reason.

Ray then described a cultural practice of *smoking-out* the room where someone had died to help release the spirit:

> If we know there has been a death there (in a room or building), then we would smoke it out. We use sandalwood sticks wrapped in papaya leaves, light it up and blow it around the room and leave it there to smoke out the spirit. I would be all right then and might stay in the room.
>
> I don't think your hospitals would be happy with that; they might get worried if some *black fella* starts putting the smoke around.

The accounts of the fear surrounding death in hospitals explains why Aboriginal people might be reluctant to prolong their stay in hospital and also suggests they remain powerless to implement important cultural practices that could avert the situation. But as Ray suggests in his comment shown above, Aboriginal people believe their cultural practices are still regarded with suspicions and assumed to be inferior to the Western ways.

Summary

Cultural identity cannot be separated from health behaviours and perceptions. This discussion has focused on the following component of identity: the regional identifications of being *Murri* Aborigines born in Queensland, women's social roles as mothers, grandmothers and wives and their role as a spiritual beings (which are expressed through Christian religious practice and/or by traditional ways of ceremonies and rituals to mark spiritual events of birth and death, for example).

By far the greatest influence is the relationship and expectation of families in health care decision-making, which can either encourage or deter women from seeking participating in cancer screening or treatment. There was no consistency in adherence to traditional beliefs about the privacy of women's business with men as well as women advocating for cancer to be considered as a family affair. Nevertheless many of the women in this study considered their role responsibilities to their families as a priority to their personal needs for health care.

A distinguishing feature of the identity of the rural Aboriginal communities was the shared history of being constructed under the oppressive administration of government reserves and church missions. Aboriginal people's disappointment in successive 'post-colonial' policies is that many such as the DOGIT, were paternalistic and reminiscent of colonial mentality of missionaries and government officers who controlled every aspect of Aboriginal society.

Moreover the women's ambivalence about entering the biomedical system of cancer treatment is also related to their fear of disempowerment because of racism.

CHAPTER SEVEN

COLONIALISM AND CANCER

From the perspective of the Aboriginal women in this study cancer was analogous to the imposition of European colonialism. For just as the European coloniser's invasion in the 1770s, spread through the Aboriginal tribes, claiming the land and destroying cultural traditions and life styles, so cancer cells invade and spread through the human body, colonizing and eventually destroying its host, the healthy body. The women considered a diagnosis of cancer an invasion that made them vulnerable and similarly subservient to another type of colonialism, this time it was the authority of Western biomedicine.

The analogy of cancer and colonialism was compounded by a belief held by many of the women that the increasing incidence of cancer in their community was attributed to the *whiteman,* who was the perpetrator. The women generally viewed cancer as a fatal disease caused by the *white-man* but not as an introduced disease like tuberculosis, smallpox and other infectious diseases, but as a consequence of the subjugation of their cultural ways through the process of colonialism. The older women in particular were adamant in blaming the *whiteman* for cancer, believing their vulnerability to cancer increased as a result of the *whiteman*'s denigration of cultural beliefs and traditions.

Aunty Nan, one of the older resident of the Coolabah community, expressed the common view in reply to my question, 'What do you think causes cancer?' Aunty Nan replied:

> It (cancer) wasn't here before the *whiteman*. In the old days we were healthy, never had any problems. We eat bush food, possum, kangaroo meats, bush berries all that. We didn't know about cancer, didn't know what it was. No one had it... they might have done (had cancer) but we didn't know about it, no one talked about cancer.

Maria, a resident of the Waratah community, agreed with the view:

> Cancer wasn't heard of in the old days, when our people first came here no one got cancer.
>
> Before they would get their own food, good hunting possum, kangaroo, lizard eggs, the food was good they never really got sick. Cancer is a disease brought in by the white-man. It must be if there was no cancer before that.

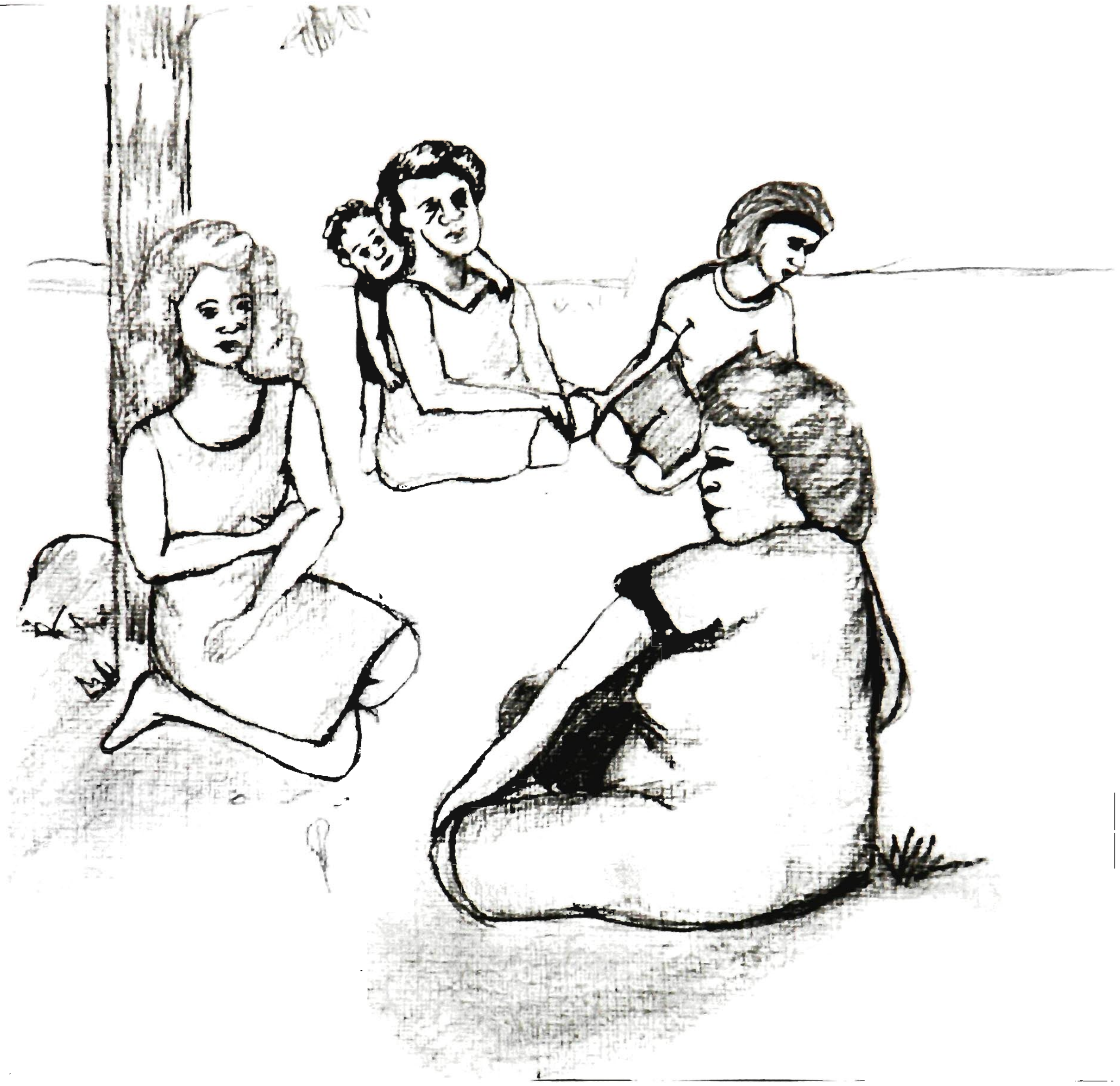
When I explored these thoughts with Maria and Aunty Vera, another elder and long serving Aboriginal health worker, about the association of cancer with the loss of traditional foods since colonisation, Aunty Vera replied:

> It (cancer) was rarely heard of there were a few, but nothing like today. It's the diet; they don't have the good diet they used to have. In the old days they could go hunting, cook kangaroo and possum and get the bush fruit.
>
> Today they might get an echidna but that's all. They just grow up with that Western junk food they don't live healthily, with grog and the smokes.

Constructing the meaning of cancer

The meaning of cancer explored here is the result of a social process. Interactions within each community included a process of sharing stories about cancer, interpreting and evaluating public health information, reframing beliefs based on experiences and appraising the experience of others. Julie highlighted the importance of this interaction process for shaping meaning, in figure 2 that follows, in which she illustrated a typical social network of rural community.

Figure 2: The community network where meanings are formed



Other sources of cancer information available through the women's clinics included public health literature and audio-visual material some of which was designed to be culturally appropriate. Examples include the audio-video production *Hey Tidda* (Kirk & Barney 1996), described previously in the introduction chapter, was well received because the women related to the rural context presented in the video and also to the narrators who are Aboriginal women with personal histories of cancer. The cultural mores against the public displays of women's health information meant that unless women attended the clinic or other women's health promotion days where cancer was discussed, their only source of knowledge about the disease would be through social networks and their own observations. One health worker alluded to the limitations of this:

> So if the knowledge isn't accurate or facts are somehow distorted, then that's what people get told. It's hard to change those views, those attitudes. If a family has an experience (with cancer) then that's their source of knowledge.

The women potentially had access to other sources of information on cancer through the popular media's health promotion messages on television and celebrities stories of their 'courageous battles' as published in women's magazines. However, the images portrayed of women with cancer and those used to promote awareness of cancer screening in the popular media are rarely women of colour let alone an Aboriginal woman. Consequently the women in this study did not relate naturally to the role models presented in the media and health-promoting messages.

Fear of the invader

The most common image of cancer that these rural Aboriginal women were exposed to is most often a negative one. This is because of their experience with a family member, friend or neighbour with cancer who were more likely to have had an advanced disease when they were diagnosed and thus beyond the stage of corrective treatment. Consequently in the community networks pessimistic and fatalistic perceptions of cancer are perpetuated. Carol, the Aboriginal cancer liaison officer, had the view that some women form their perception of cancer and their pessimism about treatment from family stories of 'the old days' when biomedical management of cancer was less sophisticated and palliative methods for control of symptoms were rudimentary.

As Carol explained:

> They remember seeing someone in the family get sick with cancer, maybe they were cut up from surgery like mastectomy scars, and then when they (the cancer patients) get really sick

> and waste away, that scares people they don't want to be like that.
>
> Then other people only rememberer seeing the bad cancer, you know fungating wounds, bad smells that sort of thing. It would be like the body rotting that would make anyone feel scared about cancer.

During my fieldwork, the Waratah community were in an acute state of grief after the recent distressing death of Mary, a local woman who everyone had known. Mary had very advanced cervical cancer when diagnosed just seven months before her death. The entry in Mary's medical chart described the finding at diagnosis as 'a massive erosion; the cervix is not visible', which indicated she had suffered visible symptoms, pain and bleeding from the erosion for many months before presenting for diagnosis. Mary abandoned a course of palliative radiotherapy at the city hospital and left without warning to return to her community and to her family. Mary was reported to have said: 'what's the use of going down there (the city) there's nothing more that can be done for me now'. The women telling the story remembered Mary's dying as a 'whole community business' because her life-story had been a concern for many and was well known for its tragic trajectory of events. Mary's medical and social history included traumas, abuse, aggression, infections and alcohol related health problems plus complex family dysfunctions, spanning the whole forty-nine years of her life. I learnt from reading her hospital records that despite her frequent visits to hospitals for traumas and infections, Mary had never volunteered or agreed to have any type of cancer screening tests despite the obvious efforts of many health workers and her friends.

On returning to her community after abandoning palliative treatment, Mary's physical symptoms of pain, gastrointestinal disorders, hallucinations and other distressing problems were eventually fairly well controlled with consultative support from the regional palliative care team. However, the perception of her close friends and family was that Mary died in pain suffering emotional and spiritual turmoil, which left the community with an image of another bad cancer death.

To encourage other women to participate in cancer screening the health workers used Mary's cancer story to emphasise how bad the disease can get if not detected early. Aunty Vera, the senior health worker explained:

> I always tell them about Mary I tell them, she left it too late, every month when we have the women's clinic I'd go round and tell her to come to the clinic, but she never came always saying *I'm all right nothing wrong with me.* When all the time she must be having some symptoms, bleeding or something, it (cancer) doesn't get that bad overnight.
>
> When she was here (in hospital) and real sick she said to me I should have listened to you Vera I should have got checked out sooner.

At this point in our interview Aunty Vera became overwhelmed with emotion. Upon recovering she continued:

> But they (other local women) know about Mary and others like her, like June here with ovarian cancer, and still they won't come for the check up.

There was anecdotal evidence in both communities that women's participation in cancer screening programs had increased since the introduction of culturally designed public health information and the employment of Aboriginal cancer liaison health workers. In the Waratah community, for example, health care staff observed at least a fifty percent increase in the number of local women having mammograms since the previous visit of the mobile breast screening service two year ago. The improved uptake was also attributed to the breast screening van being parked in a less conspicuous place in the community in respect of cultural mores related to privacy of women's health business. In the Coolabah community the health workers noted that of the eighty-six local women eligible for a mammogram, fifty or maybe sixty had a mammogram during the three-day visit of the mobile breast screening service[20]. There was, however, no published record of a corresponding improvement, in attendance for follow-up of abnormal findings, cancer survival rates or a reduction in cancer mortality rates in this population. Aunty Vera confirmed that many of the women who had abnormal Pap smears results did not return for follow-up investigations and expressed her frustration about this situation:

> They (the women) won't come back for the follow-up. I told one woman who had an abnormal test result, I think it was CIN III, anyway she needed to have a follow-up appointment for treatment. I told her it's up to her it's her F..... body it's her F...... health. I'm just telling her to see Dr. Michael to get sorted out. It's nothing to me. She (a patient) said I'm not coming up, I don't want Dr M look up my C... That's the attitude lots of them think like that, some of them are so stupid, ignorant really.

Dr Michael a gynaecologist who conducts a monthly clinic in the Waratah community talks about the difficulty of convincing the local women that an abnormal Pap smear test does not necessarily mean they have cancer, he said:

> The big problem is they (the local women) view findings from mammograms and Pap smear as having the same significance.
>
> If they are told the mammogram shows a lump or an abnormality then that means cancer, which it usually is. So when we say they have to have a follow up appointment because of an abnormal Pap smear test, then they immediately think that means they have cancer.
>
> I think that's why a lot of them don't come back for their follow up appointment.
>
> They all go into denial here (name of community). The health workers go out looking for the patients to come to the clinic, but even if they come they might not agree to be examined.

I observed the doctor's concerns during a consultation with Jean, a young Aboriginal woman who the local health workers had eventually persuaded to come for a follow-up of an abnormal Pap smear test. Jean arrived looking very sullen and avoiding eye contact with anyone in the clinic. The nursing staff were anxious for Dr. Michael to see Jean before she

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[20] In the interest of women's privacy and cultural mores about women's private business, the mobile breast screening van was parked at the back of the health care centre where it is less visible to the main thoroughfare of the community.

changed her mind again. Jean made no verbal response to Dr. Michael or to Frances the health worker when they explained why the abnormal Pap smear test indicated that a colposcopy examination and possibly treatment was required. Jean's only response to Dr. Michael's explanation was an 'ugh' sound, shaking her head slightly indicating her refusal of his request to examine her. Jean did agree to the health workers suggestion that the examination could be done at the regional hospital where a female doctor was available. Jean remained silent throughout the consultation until outside of the clinic when she obviously questioned Frances about the abnormal Pap smear test as I heard her say: 'Well ask the doctor, go back in and ask him'. Jean came back into the clinic and blurted out: 'What does abnormal test mean?' Following this outburst Dr. Michael carefully explained to Jean about CIN I and II and the risk of this developing into cancer, stressing the need for the colposcopy. Jean listened to Dr. Michael but did not ask any further questions. Frances predicted that like many young women, Jean would worry that she had cancer, but her fear of having a diagnosis confirmed was enough to prevent her from returning for the colposcopy. Avoiding a diagnosis of cancer was also linked to what Frances described as Jean's 'other domestic problems' that could be made worse if her male partner believed, as many others did that cervical cancer was a sexually transmitted disease.

Other participants offered examples of how misunderstanding about medical terminology perpetuated negative perceptions and unnecessary anxiety, as was evident in the stories of Josie and Mavis. Both Josie and Mavis, who worked in different areas of Aboriginal health care services, were participating in a focus group discussion on women's cancer issues. Initially Josie appeared unusually anxious asking for the door to be left open because she felt 'an anxiety attack coming'. During the discussion Josie explained the basis of her anxiety was 'just talking about cancer' she continued to tell her story. Seven year ago Josie had the first of two abnormal Pap smear tests results. Her second test showed CIN III changes for which she had a cone biopsy, which Josie was convinced meant a cancer had been removed and the disease will always be as she said: 'somewhere in her body'. Her intense anxiety was based on the assumption that she had cervical cancer. This affected Josie profoundly as she attributed any physical discomfort to be another symptom of cancer. Josie shared with the group what she called her 'worst fear' on discovering sore and tender breast lumps that hurt more with movement. Her general practitioner undertook various tests including urine analysis for pregnancy despite Josie's protest that this was impossible after a cone biopsy. Consequently when hearing the urine test was positive Josie immediately heard this to mean she had breast cancer and reacted with much distress before the doctor convinced her that the positive urine test meant she was pregnant. Josie in her role as an administrator with an Aboriginal health cancer service, witnessed many other women with similar fears of cancer and hesitant about undergoing cancer screening or following up test results. Josie concluded: 'They don't want to find the cancer…they didn't want to know'. Mavis's story was similar to Josie's in that she also had a cone biopsy for a CIN III cervical dysplasia and remained unconvinced that she did not have cancer, despite her knowledge as an experienced health worker. Mavis explained:

> I didn't really know what CIN meant, or if the cone biopsy would cut out cancer or what. I am still not convinced I'm free of cancer but I get regular check ups.

Mavis and Josie's experience of receiving abnormal Pap smear tests plus their professional work in Aboriginal primary health centre positioned them as potential role models who could encourage others. However, both these women were uncomfortable about sharing their personal experience with others or talking about cancer out of the context of their work role.

Cancer is a deadly disease

A dichotomy was apparent where the women underwent Pap smear tests and mammograms despite having a fatalist view of cancer and professing a lack of faith in biomedical treatment options. Maria and others demonstrated this dichotomy in our interviews. Maria, like most of the women was quite well informed about the need for cancer screening and underwent two mammograms during the past three years. Yet Maria's response confirmed her fatalistic view of cancer:

> What can be done about it (cancer)? It can't be cured can it? No one can stop it.

And another woman added:

> Well cancer is terminal... it is a terminal disease. I've got liver cancer. I know it's terminal they can't do anything about that.

A group of five other women gave very assured responses to my question about their knowledge of cancer. The immediate response from one woman was:

> I'd kill myself if I got cancer. I couldn't have all that pain and suffering. I'd kill myself and get it done with.

Someone else in the same group added:

> Well they can't cure it, there's no cure. It's a bad disease.

Again all the women in this group reported they had regular Pap smear tests and some had had a mammogram when the mobile service visited the community. Similar fatalistic attitudes were apparent in another group of women who invited me to talk about cancer. Following a brief introduction about my research I asked the group: 'So what do you think about cancer?' To which different members replied:

> It's a killer.' (Everyone in the group nodded as if in agreement).
>
> Ye it kills all right.
>
> It spreads.
>
> It's a deadly disease.

Aunty Pam, a member of this group who had experienced four members of her family die with cancer in the recent months. This experience caused Aunty Pam to be cynical about the benefits of cancer screening and efficacy of treatment considering this was futile because the disease was 'always fatal'. Aunty Pam justified her antagonism toward cancer treatment in recalling her family's experience:

> My brother, he just had a spot on his hip, that's all. No sooner they found it was a cancer, he died all in a month.
>
> Chemo was no good for him or any of my family it doesn't work. If I ever get cancer, it's heredity isn't it? It I get it, I definitely won't have chemo or anything, it makes them more sick so why go through all that and then there're going to die anyway.

Then in response to my statement that cancer was treatable when detected early enough, Aunty Pam replied:

> Yes well all my family had their check-ups, they didn't leave it, but it was still no good. When they found the cancer it was too late, the chemo didn't help.

Not all participants shared Aunty Pam's cynicism but many still conveyed a note of resigned acceptance in their comments about cancer. For example, a group of older women viewed cancer as synonymous with pain and death, despite evidence to the contrary as one of the women in this particular group was a cancer survivor. The groups' opinion was that their friend survived cancer because as they said: 'They found it early'. Interestingly, the woman in question indicated her unwillingness to be interviewed by walking away from the group when I started asking questions. The women's negative perception of cancer as a killer disease was understandable when they witnessed sad cancer stories of others like Mary that everyone in the community talks about. While successful stories of cancer survivor were rarely told or even known about, consequently there was little sense of cancer survivorship in either of the communities.

Don't talk about the invader

Cultural beliefs that discouraged public health teaching about cancer were that 'talking about it might make it happen'. The women often prefaced our interview with a caveat that they did not like talking about *it* (cancer) because it made 'them feel sad', or that talking could 'tempt fate' and 'make it happen'. Margie who had cared for her sister and very recently a close friend when they were dying from cancer, explained:

> People don't like to talk about cancer it makes them feel bad. If someone gets it people stay away, there're afraid of it, they might think you can catch it or something, but mostly they don't like to talk about it.

And another participant said:

> Well no one wants to talk about cancer, they shy away from the topic. You get frightened... I think talking (about cancer) can bring it on.

A health worker added:

> I think people are just afraid of cancer, don't like to talk about it. (It) brings bad feeling, makes them feel sad. I don't like to talk about it really, but it's my job, to get the women especially, to talk about it, to get them checked out.

The perception of Norman an Aboriginal paramedic was:

> People don't want to talk about cancer, don't want to say the word. They all leave it 'till its too late; they think cancer means death because they only know people who have died from cancer.

In the early days of fieldwork an entry in my reflective journal revealed the dilemma and anxiety I had about how to raise the topic of cancer in my interview with two women. My entry was as follows:

> *Reflection,* I was getting concerned about whether to mention cancer as neither Karen or Emily had said the word. I could assume that they knew Karen's diagnosis as she was here having radiation therapy.
>
> But Emily seemed to stress the lung infection issues as if that was what they wanted to believe or even what Karen believed. They just seemed reluctant to actually say the word cancer.

Later in our interview Karen's expressed the common fear of talking about cancer when she said:

> When I hear that word (cancer) I feel fear. It is the big *C*, you know, frightening, means you're going to die.

The women's reluctance to discuss cancer at a personal level meant that our initial interviews had to focus on safer topics of cancer screening and health services generally. If a participant was willing to talk about cancer, at first there was always at least two degrees of separation between the participants and the people they spoke of in relation to cancer stories. It was not until our second or third interview during my subsequent field visits that the same women revealed their own stories of having cancer.

A social consequence of keeping quiet about cancer was that people diagnosed with the disease felt isolated in their experience as there was no obvious support network of others dealing with the disease or who had history of cancer. Local health care staff knew of women in the community who had survived cancer but were not willing to talk about their experience to the general community. A nurse summarised this situation:

> Mostly people think cancer is a death sentence and that not many people recover from cancer. They don't talk about it anyway so maybe no one knows who's got it.
>
> There are a few women come to think of it who have cancer. Aunty L she had cervical cancer and had a hysterectomy a couple of year ago, she's okay. Then there's Mona, who I think had a mastectomy or lumpectomy, anyway she was put on Tamoxifen and that was a few year ago, she's fine and still out there.
>
> There are probably more people who have had successful treatment but keep it to themselves.

When Karen was having palliative radiotherapy for lung cancer at the city hospital she had been surprised to encounter other people from her community who were having cancer treatment. Karen had no idea there were others from her community also dealing with cancer.

Cancer is a dirty disease

The health care staff's perspective of why the women were reluctant to talk about cancer was that cervical cancer, in particular, was considered to be a social disease. Lynn explained:

> Some don't want to talk about cancer because of what other people will think. They might think it is a *dirty disease* or they caught it (cancer) from mucking around, you know not having a clean life.
>
> So they don't want to get a bad reputation, they keep it to themselves until its too late like Mary when they found her cancer, it was too late, it was dreadful, she must have had problems before then.

The public health methods of surveillance and monitoring of women's compliance in terms of the call-recall system for cancer screening ironically added to the perception of cancer as a social disease. This was evident from my interview with a group of women, who said they felt embarrassed when the sexual health care staff came to their homes to remind them to go for Pap smear tests. One of the women, Mandy asserted:

> We would be out, we don't like the staff coming round when everyone knows where they're from. All the neighbours would be *dorying*[21] nagging saying look they come for her, she been messing around, she got the *pox*[22] don't go with her...

Another contributor to the negative perception of cancer as a social disease was the acronym CIN for Cervical Intraepithelial Neoplasia the biomedical classification of cervical cells dysplasia. Some heard the term CIN as *sin* implying immoral behaviour. The women explained a reason for this connection was because they had been informed that sexually

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[21] *Dorying* is a colloquialism of Aboriginal people that means being nosey, prying into other people business. I am informed by an Aboriginal person that the origin of the term is the name of an Australian soap opera character, whose persona had been the nosey neighbour.

[22] *Pox* is used here as a term for venereal disease

transmitted diseases caused cervical cancer. Consequently when some women heard that their Pap smear test identified CIN as abnormal cells, firstly the woman assumed she had cancer and then got concerned that others, in particular her husband or male partner, would assume she had been 'messing around'. I asked an Aboriginal nurse who coordinated the women's clinics how staff talked with the women about abnormal Pap smears:

> The women always think the Pap smear is a cancer test, doesn't matter what I tell them. So they reason that any abnormal results from their Pap smear must mean they have cancer. But no one (in the clinic) likes to talk about cancer. If they have an abnormal pap smear, we don't mention cancer, the doctor might say the smear showed CIN 1 or 2, or the test showed some abnormal cells, so this is why the doctor needs to do more tests.

Many women shared a common misunderstanding about cervical cancer being a sexually transmitted infection, consequently they attached the same social stigma to cervical cancer as to STDs like syphilis or gonorrheae. Another concern was that older women who were unmarried or widowed were particularly hesitant about having Pap smear tests or seeking medical advice for sexual problems. These older women were more concerned about the judgement of their social network or community that they had been 'messing about' if they were seen to attend the women's clinics. Even if they had troubling gynaecological symptoms they chose to ignore these rather than risk social *'shame'*. Health workers believed that older women generally did not even consider themself at risk of cervical cancer, as they were no longer sexually active. On the other hand, the health workers believed some younger women also avoided having Pap smear tests or attending the sexual health clinic because they feared being judged as promiscuous or that they were victims of sexual abuse. As one health care worker explained:

> That's why they won't go for the Pap smear; because it's likely they got STDs from bad sex, rape, being bashed up.

Colin another health worker concluded:

> They've (young women) got no pride in themselves; they don't care about their health. They give up on themselves.

Cancer is just another problem

Several health care staff offered the theory that some local women viewed cancer as 'a way out, a release from a troubled life', and they accepted the disease as just another problem in a difficult life. Sally, a health care professional with many years of specialising in an Aboriginal mental health program, shared her views on this theory:

> Cancer is part of all other problems, like mental health, it is not just drugs or petrol sniffing, there are many other problems, they (the people) can't see a way out.
>
> A lot of Aboriginal people here in (name of community) follow the Christian doctrine. They belong to the AIM (Aboriginal Inland Mission) and believe that if they suicide they will go to hell. That's why cancer may be seen as a way to die, a way out of their problems. So if they think they have cancer, they will leave it, even with symptoms, or they might go to the doctor and get diagnosed, but then not go on with the prescribed treatment. Cancer is a way out.

And Bill, an Aboriginal mental health worker added:

> Something like cancer is a way out, like a self-destruct attitude. Some women could think, cancer will give them the way-out, they want to die.

My review of participant's medical records revealed how complex and difficult some women's lives were. The records identified a chronology of diseases, infections and injuries, domestic abuse and other traumas, which occurred since their infancy and continued throughout their life. Typical health problems in infancy recorded in the medical charts included scabies, otitis media and gastritis and the syndrome of illnesses recorded as *failure to thrive*. In later childhood, repeated episodes of bronchitis, perforated eardrums, urinary tract infections, sinusitis, injuries and bites were prominent. In adolescence, pregnancies and miscarriages dominated. In adulthood, medical records showed injuries from fights, drunkenness, self-inflicted physical abuse, domestic violence and infections. The most common systemic diseases recorded for adults were diabetes, cardiovascular disease and renal failure.

The accumulated problems of some women's lives were exemplified by Lillian's story. Lillian was a young Aboriginal woman in her mid twenties. Her medical records revealed a pattern of regular hospital visits during her adult years for; domestic violence injuries, accidents, self-inflicted injuries, as well as lacerations from fights, infections, gynaecological problems and other illnesses. When I spoke with Lillian she was waiting to be seen for chest injuries sustained from being kicked by her male partner a few days before. Hospital staff asked me to talk with Lillian because they wanted to encourage her to return for a follow-up of an abnormal Pap smear test taken a few weeks previously. In our interview Lillian rationalised that an infection on her ovary accounted for the abnormal Pap smear test. Her medical record confirmed the presence of a urinary tract infection some months before that was treated with antibiotics. In reply to my question about her understanding of the Pap smear, Lillian replied that she knew it was a cancer test but did not know 'what cancer did'. Lillian's hospital record showed the last Pap smear identified CIN II changes and a follow up examination of colposcopy was necessary. The prophecy of the health workers that Lillian would not return for the examination was proven correct. The health care staff lamented that there were many young women like Lillian who adopted a self-destruct attitude in denying any symptoms other than acute health problems because as the health workers stated, 'they suffer so much grief and anger' and cancer then becomes just another burden or alternatively 'a way out'.

It could be surmised that those women who had endured a lifetime of hospital attendance for injuries, infections and trauma might be conditioned to associate medical attention and hospitals only with acute health problems, rather than considering them as primary health care facilities for health promotion. In addition some might be more reluctant to attend hospitals voluntarily for non-urgent condition or when they were asymptomatic. I observed such a situation in a general clinic, where a woman presented with a recurring urinary tract infection that she refused to have investigated and asked only for the antibiotics and painkillers. Lillian attended the hospital for treatment of injuries at least once a week but nevertheless did not return for a follow-up appointment of an abnormal test of a potentially life threatening disease. This apparently incongruent behaviour fits with Franz Fanon's (1995) notion of ambivalent behaviour of colonised people toward health care. Colonised people avoid getting entrapped by the system of their oppressors or prolonging the encounter with Western biomedicine. In short, they may only want to deal with the immediate problem and then 'get out' (Fanon 1965).

Blotting out the enemy

The situation of social and domestic violence was another deterrent to the women's health seeking behaviour. The health workers shared their concerns about the dissenting way of life of some social networks that prevented women from taking advantage of local cancer screening services and clinics. This conundrum was summarised in the words of one health worker:

> Some (women) feel *shame*, awkward, because maybe there's domestic violence or alcohol problems, and they feel embarrassed for people (at the hospitals) to think that.

The feeling of *shame* in this context referred not only to the modesty associated with the body, but the fear of being judged about their dissenting life-styles or social misbehaviour, by other members of the Aboriginal community as well as by non-Aboriginal people.

The women acknowledge that alcohol was damaging their culture as well as their health but at the same time internalised the 'inevitability' of this behaviour in their small community. As one elder explained, 'There is nothing else to do, when we get together that's part of socialising'. The introduction of alcohol to Aboriginal communities by Europeans was regarded by some as another insult of colonisation that contributed to the current tensions between Aboriginal and non-Aboriginal people. Although a local elder of the Waratah Community Council reminded us that throughout history humans had ingested or inhaled hallucinogens and other mind-altering substances extracted from plants, and that currently alcohol was just easer to obtain.[23] The elders blamed alcohol for many of the social and health problems in their respective community as one summarised:

> There is all this shit about culture and getting the culture back will make the difference. But with those people (dissenting groups) there is no Aboriginal culture in (name of community). (Name of community) culture is about drinking; fighting; beating up; drugs; petrol sniffing, that's their culture.

Several participants told their stories of using alcohol to 'blot out their troubles' including health worries. Judy believed alcohol prevented people from seeking health care firstly because being drunk meant not thinking about their symptoms and secondly hospital staff could not perform cancer screening or other tests on a woman who was intoxicated because legal consent was not possible. Judy believed that some women used alcohol intentionally to help them forget their illness:

> Alcohol just makes people forget or ignore their health problems. If you get them when they're sober they know what to do and then they get concerned about their health. But as soon as they get back on the *grog*[24], they let it all go again.

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[23] In 2002, the Aboriginal Community Council introduced by-laws to control the sale and consumption of alcohol in their respective communities. The local canteens have been closed and the sale of alcohol is restricted to products in non-glass containers to reduce the injuries caused by broken glass littering the communities. These by-laws apply to visitors as well as the residents.

[24] *Grog*, is an Australian colloquialism for Alcohol

> That is one of the big reasons why Aboriginal people don't get their cancer found until it is too far-gone. They know something is wrong but ignore it, block it out with *grog*.

A senior nurse confirmed Judy's concerns when recalling her experience of women presenting at the hospital for a clinical examination, in an intoxicated state. This participant referred to the staff's dilemma of having to refuse an intoxicated woman's request for a Pap smear when the staff knew she had symptoms or was at risk:

> We get some women who only present when they are drunk, as if this gives them courage to have the examination or maybe just stand up to their husbands. But we can't do it (the Pap smear test) if they're drunk, because we can't get proper informed consent.
>
> But I think they know they have problems, maybe they are having pain or bleeding, but have to be drunk to lose their inhibitions.

Inhibitions referred to by this senior nurse quoted above related to the feeling of *shame* the women experienced when expected to expose their private body to a stranger especially if a non-Aboriginal person was in attendance.

The women I interviewed were aware that drinking alcohol negatively affected their health and hindered their access to primary cancer services. Mandy along with others in her social group, seemed well aware that alcohol restricted access to health care services:

> I get the Pap smear done and had the mammogram when they came here. But I have to wait 'till I'm sober, they (hospital staff) don't like it if you've been drinking. She's the same (nodding towards her friend May) she's got to get a lump seen to; she won't if she's been drinking.

Aunty Shelia shared the experience of how her relative's alcohol dependency had marred the symptoms, which eventually was diagnosed as liver cancer. The problem according to Aunty Shelia was that her Aunt's history of alcoholism was well known to local hospital staff and, from Aunty Shelia's perspective, they assumed that alcohol was the cause of her symptoms rather than looking for new problems. Sandra had a similar story of how her husband's alcohol addiction and his other drug use prevented him from seeking medical advice until his lung cancer became too advanced for corrective treatment. Sandra recalled that for some months before his diagnosis her husband had a troubling cough and was spitting out blood, both obvious symptoms of lung disease:

> His problem was alcohol, because that made him feel all right, he could ignore his symptoms, that's the problem of the grog it makes people block out there troubles. And he was smoking a pack-a-day of *shag*[25] (raw tobacco) and he got the *yandi* [26] had all of them three, the *grog,* the smokes the *yandi.*

The way of life associated with alcohol presents a dilemma for a culture-centred approach to public health, because there were both positive and negative aspects of this behaviour. The negative perception is that alcohol, that usually involved smoking as well, is known to be detrimental to health. But the social interaction associated with the behaviour is an important, 'normal' part of community life and the focal point of forming meaning about health issues. This dilemma is illustrated by Marilyn's story of living with cancer. Less than a year ago Marilyn underwent surgery to resect a bowel cancer. During our interview Marilyn asked my advice about her continuing problems of bowel cramps, diarrhoea and rectal bleeding. At the same time Marilyn shared jokes with other people in the house, about their previous day's card game and drinking session. Then Marilyn explained to me that although she knew it was harmful to her condition, she was unable to 'give up that life' because that was all she knew and it was her life, which she described as: 'smoking, drinking and being with the mob'.

Aunty Susan, who was having treatment for breast cancer and lymphoedema, had made adjustments to her life style but admitted she continued to smoke cigarettes and enjoy a 'beer or two':

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[25] *Shag* is an Australian colloquialism for raw tobacco that is either rolled into cigarettes or chewed

[26] *Yandi* is the term used by some Aboriginal people when referring to Marihuana

> Yes I still smoke, can't give that up, but I try to eat fruit and drink plenty of water.
>
> And the *grog*, I still like a beer or two, but not so much as before... I see how the alcohol messes people up; makes them ignore their health. Some of them know they have lumps in their breast, but they go drinking and forget their health.

Marilyn and Aunty Susan's stories demonstrate how the cultural enclave of their social network is a greater influence on their everyday lives than the advice from health care professionals. Compliance with biomedical expectations of cancer patients requires them to give up the negative behaviours of smoking and drinking but by complying, the women risk being marginalised from their social network. Douglas (1992) offers an explanation for this dilemma. Douglas (1992) argues that individual's autonomy in rational decision-making about public health issues is really an incongruous notion when the influence of social network predominates. Douglas (1992) offers the example of how risk-taking behaviour of individuals in the homosexual community is determined by the consensus views of the social network rather than an individual's moral or cognitive stance. An individual member of a dissident homosexual community that upheld for example, fatalist views about human immunodeficiency virus (HIV) infection, or alternatively chose to maintain a risk-taking way of life, was unlikely to comply with sound medical advice about changing certain life style practices (Douglas 1992). As Douglas asserts refusal to accept sound, as in scientific, advice should not be attributed to weakness of understanding. It is a preference' (ibid, p. 103).

Similar pressures to comply with the social norms and values of ones cultural group were demonstrated in a study of an African American heterosexual community. The study showed that gender based social roles and relationships of African American men and women defined their risk taking and health care behaviour in relation to HIV prevention (Airhihenbuwa et al. 1992). African American women for example, chose to risk exposure to HIV infection rather than asking their male partner to use a condom because they were concerned that to do so would jeopardising their relationship with the risk of his rejection and possibly his support in chid care (1992).

Other health care professionals concurred with the view that cancer was a manifestation of 'a stressful life' but suggested that some women denied their cancer diagnosis because they were afraid not only of the disease but also of dying from cancer. No doubt this fear was based on the general perception that cancer was synonymous with 'pain and suffering'. This was summarised by a health care worker:

> What some of these women go through in their lives, it is no wonder that they get sick. Cancer is a manifestation of all their troubles.
>
> But they still don't want to admit it [having cancer] they keep it to themselves. Admitting you have cancer is admitting you're dying.
>
> ... That's how they see it, so if you don't have to find out then that's okay you can go on denying it.

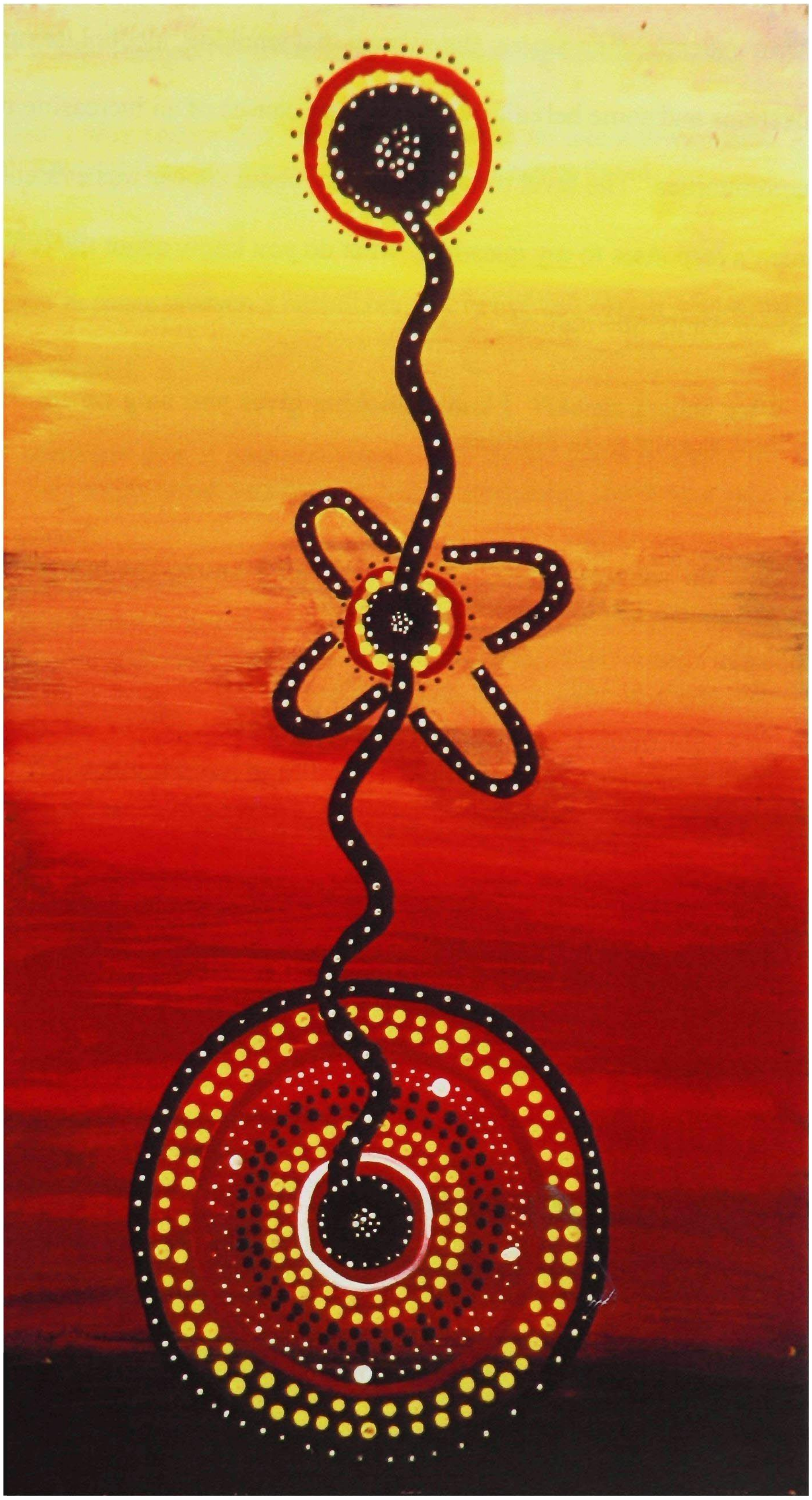
June's story verified what the health care professionals were saying. June had recently been diagnosed with poorly differentiated adenocarcinoma of the ovary and was referred for further treatment to a surgical cancer specialist at a city hospital. A local health care worker accompanied June during the diagnostic procedure and therefore witnessed what the doctor said about the diagnosis. Despite having a witness, June stayed firm in her denial of the cancer diagnosis. According to the health care staff, June would not engage in any conversation about cancer despite being given detailed explanation by medical and nursing staff at both regional and local hospitals. June persisted with the denial telling her family that she had an appendicectomy and would recover with tablets. The health care worker recalled June's story:

> June went to (name of hospital) to have her appendix out, but they found this tumour on the ovary. It can be fixed if she goes

> to Brisbane for more surgery. But she really doesn't want to go. When Dr M told her it was a tumour she didn't react, I was with her, but when Dr M said it was cancer then she (June) broke down had a good cry, it hit her then.
>
> But she is still afraid to go to Brisbane away from here; it is such a big thing. The family can't help if they don't know what it is. I'm seeing her tomorrow, I talk her through it, get her to go.

June's story demonstrated the common anxiety about leaving the community to undergo cancer treatment because this added stress was too much to bear for many women. Julie explained that it was critical for Aboriginal women to feel connected and supported spiritually and emotionally by their family throughout their journey of dealing with cancer. Julie portrayed this spiritual connection in her painting shown in figure 3. In this painting the woman's family in the community are symbolised by the small concentric circles connected like an umbilical cord to a larger more complex system of circles. This larger circle configuration represents the layers of a Western hospital system as a community in which the woman with cancer could be lost without maintaining connection with her community.

Figure 3. Spiritual connection between communities



Beliefs about cancer

There was general understanding among the women that smoking, alcohol, sexually transmitted infections and some hereditary factors were causes of an increasing prevalence of cancer in the communities. The level of understanding about cancer was evident in the sample of women's responses to my question, 'what do you know about the causes of cancer?' To which Aunty Sue replied:

> What causes cancer? I know smoking gives you lung cancer. I think it must go in families.

And Isabel and May answered:

> How do you get cancer? It's in families I know, but how can you get it? I know smoking is no good.

Sophie responded:

> The only thing I know about cancer is lung cancer, because I smoke. Everyone smokes here, I want to give up but how can I it's all around.

Aunty Shelia said:

> Smoking. I don't smoke now, gave it up long time ago. I wish these young ones would stop smoking. Smoking-that will give you cancer.

Aunty Shelia encouraged her daughters to have regular cancer screening tests, because she believed ' cancer was in the family'. Aunty Sheila's had lost one sister to cancer and another was currently undergoing treatment for breast cancer.

And Aunty Ann told me:

> I lost my son, a sister and my father through throat cancer... of course they all smoked.

Lisa, a relatively young woman expressed her dissonance about smoking:

> I know that smoking causes cancer of the lungs, I smoke because of the worries there is nothing else to do round here. What is there for young people?

Aunty Em, offered a metaphor of a tree to explain her understanding that cancer was like a tree, rooted deep within the body with its branches spreading throughout, she concluded:

> That's why cancer can't be cured, because no one knows where all the branches have gone, and the root is never found.

Cancer is contagious

There was evidence in some women's narratives of a belief that cancer was contagious as Margi's statement showed:

> If someone gets it (cancer) people stay away, there're afraid of it, they might think you can catch it or something.

A health worker added:

> It is a strong belief that cancer can be caught it is not something said outright, but I've seen husbands wash their hands after touching their wives, or some people don't want to come too near the cancer patient because they fear they can catch the disease.

Aunty Susan shared her story of having chemotherapy following a mastectomy and how she felt her children shy away from her:

> I lost my hair; it happened quickly, just brushing it and I found great clumps on the floor.
>
> One of the kids called me and said look Aunty all your hair is coming out on the floor, but they wouldn't pick it up they didn't want to touch it. I think maybe they thought they'd get cancer from it. So I asked them to cut off all my hair, but they wouldn't do that either, same thing (fear of catching cancer) so I had to do it myself.

Young women and cancer

The public health messages about cancer did not appear to influence the younger women. The few I interviewed were less informed and considered cancer to be a problem for older women. While many younger women were cognisant of the need for cancer screening and early detection practice, they seemed not to relate this to themselves. Few had attended for Pap smear tests or clinical examination unless they had specific problems after giving birth.

Debra and Jenny, for example, who were 25 and 30 years old respectively, knew about the effects of cancer from being with their Aunt who died from breast cancer. Debra said she 'got checked out' after the birth of her daughter, but Jenny said she knew cancer made people very sick, but she was unsure of what cancer actually was. Her questions demonstrated a similar level of understanding to the other young women , Jenny asked:

> How do you get cancer? How do you know if you've got it? What does cancer do?

Another two young women, Betty and Alice recalled Mary's 'awful death' from cancer a few weeks previously saying how the experience left them with the impression that 'she had lots of pain and suffering'. Nevertheless neither Betty who was 35 years old nor Alice who was 28 years old, had presented for a Pap smear test and both women were below the eligible age for free mammograms. Betty gave one reason for not dwelling on her own health issues at the moment in terms of the more important priority of focusing on her 15-year-old nephew who had recently been diagnosed with a sarcoma. The family's distress was compounded because as Alice said, 'no one knew kids got cancer' and so his symptoms had not been considered as a threat and the condition was undiagnosed until too late for curative treatment to be an option. Betty explained:

> No one in the family knew anything about cancer; they had heard of it but not that it could affect children. The first sign was when he broke his shoulder after a fall, and then the cancer was found. By then it was too far-gone.

Alice added:

> We don't know anything about cancer, is it in families, should we get the other kids checked? What should we look for? We don't know what causes it, or what to look for.

The older women were unanimous in their concerns about the young women's risk taking life styles. Aunty Rose's view was that young women related the information about sexual health and cancer risk to being a problem only for older women. Colin a young health worker gave his view:

> They (young men and women) have no self-respect; they don't bother to take care of their bodies. They are all right to go around having sex everywhere, with everyone, but when they get infections they let it go, that can lead to cancer can't it?

Aunty Vera shares her concerns about increasing incidents of sexually transmitted diseases and infection among the young women:

> We are seeing a lot of young girls lately, children really some 13-14 years old, with abnormal pap smears. They start with sex so early, soon as they can some of them only 12 years old. And they have lots of partners they don't know what it is really, they don't use condoms or anything, some aren't too clean either. And the boys, men some of them, they're just as bad, don't use condoms and go with any girl.

Another health worker added:

> These young girls don't ever think they will get sick or even get the STDs, they are too young to know what it's all about. Yet I see many of them are getting STDs and HPV. They should know they are at risk of getting cervical cancer too.

Spiritual forces and cancer

Although the women clearly knew about environmental and biological causes of cancer, a traditional belief in the power of metaphysical forces regarded, as 'bad spirits aroused as payback', remained strong. Margie, attributed payback to the history of feuds between different families and tribes from the days when they were forced to live together in the government reserves:

> Some of those families never got on, they were always feuding and that goes on still. They don't forget...and then pass on the bad feelings to the next generation. So if there has been some recent troubles, maybe someone has gone off with another woman or man or stolen something and that's enough to get them looking for *payback*. It is an evil thing, I've seen people just fade to nothing and die. Or get really sick, they can't work on or do anything.

Another Aboriginal nurse added:

> Payback is always a fear; some really believe this and will get someone to help find who's got the curse on the person who is sick.

Some women like Aunty Em were dissonant about accepting conventional knowledge about cancer and being faithful to cultural beliefs. The dilemma was evident in her comment:

> Smoking, that will give you cancer, don't know, maybe bad spirits, when people get into trouble, get stressed up, they make bad things happen.

I reflect on Aunty Em's metaphor of a tree to define the cancer, and wonder if this related also to the external forces of 'bad spirits' that could feed the growing cancer in the body, but I was not able to clarify this with her.

Further evidence of the endurance of traditional beliefs about external forces causing cancer was Beth's story. Her story also gave another reason for the general reluctance to speak about cancer in a personal sense. Beth, a middle aged women, persisted with a belief that she was the cause of her husband's lung cancer because she had wished it upon him. Beth was provoked into wishing harm to her husband after many years of domestic abuse by his hand that caused her much emotional and physical suffering, and continued to compromise her health. Beth recalled: 'I said I hope you get cancer and die, and he got it'.

Beth's experience was an example of different cultural paradigms that could be the basis of inappropriate intervention. For example, from a biomedical perspective Beth's grief response of self-recrimination could be considered irrational and categorised as an abnormal grief response requiring professional intervention to alter her perception of the issue. Beth's grief, though was embedded within a cultural belief about 'payback', which Western theories of grief would not consider or accommodate.

Summary

In this chapter I described participants' views of cancer as being connected to colonisation because the disease is seen as an unwanted invader and an affliction of the dominant culture of the *whiteman*. Furthermore, having cancer means women are vulnerable to the paternalistic authority of biomedicine. Cancer is a social construct incorporating women's popular knowledge, as well as their experiential perception formed from witnessing the demise of others. Although there is common knowledge about the biological causes of cancer, traditional beliefs of spiritual forces often prevail as well as the need to attribute the disease to the scourge of the colonisers. Some women choose to ignore their symptoms to avoid adding to the complexity of their difficult lives. Women who undergo cancer treatment have difficulty following medical advice and maintaining their usual social patterns of interactions.

The women's perception of cancer as a 'killer disease' and their ambivalence toward medical advice on abnormal cancer tests or their denial of the problem, might suggest a passive resistance, or resigned helplessness to the inevitable. On the contrary, in the next chapter I present the stories of how women resist the colonial mentality of biomedicine and advocate instead for cultural values and traditional practices that are culturally important when someone is dealing with the life threatening disease of cancer.

CHAPTER EIGHT

CULTURAL EMPOWERMENT

In this final chapter of data analysis I use the concept of *cultural empowerment* from the PEN-3 model as a framework for presenting the cultural values and practices that came to prominence when the Aboriginal woman in this study confronted cancer. Cultural empowerment is considered the most critical domain of the PEN-3 model because its tenet is to affirm cultural strengths that should be integral to public health strategies or interventions rather than view culture only as a barrier (Airhihenbuwa 1995; Airhihenbuwa & De Witt Webster 2004).

Resistance in the name of culture

The significance of culturally different perceptions of cancer became most evident when a woman and her family dealt with choices about cancer treatment. As had been shown in chapter six and seven, many of the women of eligible age, complied with cancer screening and were cognisant of the benefits of early detection practices. When diagnosed with cancer, however, the woman's decisions about managing the disease were made from a cultural perspective of beliefs, values and traditions rather than solely on biomedical advice. Several reasons for this emerged. Firstly, the perceptions that cancer was a fatal disease meant the woman and her family considered the physical distress associated with side effects of treatment were not justified. Secondly, the perception that cancer was a single disease, therefore outcomes would be the same regardless of sites or stage of growth. Thirdly, biomedical methods of treatment contravened fundamental cultural values about a woman's body and her social position.

As previously demonstrated in chapter seven, being separated from family and the social support of the community to undergo treatment in a distant hospital, increases woman's feelings of vulnerability to the authority of Western biomedicine. Also the feeling of 'shame' is heightened for women when they are expected to expose their body to the *whiteman's* medical gaze or divulge information about sexual practices usually considered women's private business. Amy explained how the women felt:

> People think it is the procedures that make them feel *shame.* But it's not just that. Most women understand that's how it has to be done. It's when the procedure violates the essences of the woman, her inner sacredness of being a woman.

'Shame' in this context relates to what could be viewed as a type of cultural embarrassment where fundamental cultural values are violated or compromised by biomedical methods. The 'inner sacredness of being a woman' is associated with the interconnection of the physical and emotional body that is always considered in terms of relationship with the spiritual body. When being examined in the sterile environment of a hospital clinic the women deal with feeling of 'shame' by imaging themselves to be invisible and detached from what was happening, a situation captured by another of Julie's paintings which she called 'A surreal experience', shown here as figure 4.

Figure 4: The sterile clinical examination – a surreal experience:

Julie presents a stark comparison to the sterile clinical environment represented in figure 4 shown above, in the next painting shown as figure 5 in which the significance of women's body-spirit relationship is symbolised. This painting is of a woman doing breast self-examination while surrounded by the colour yellow that embodies life and hope with the serpent coiled in the left upper section of the painting symbolising 'the creator' connecting physical and spiritual bodies.

Figure 5: The body-spirit connection of breast self-examination.

Take away the cancer but leave me whole

The threat to a woman's spiritual and physical integrity is amplified by the invasive treatment of cancer surgery. The dissection of the physical body necessary to remove a cancer violates her cultural identity. This ultimate threat to a woman's identity is an important reason why many choose not to start the process of detecting cancer, refuse or modify surgical treatment. Here the risk to cultural identity is seen to be a greater concern than the surgery per se. Annette a non-Aboriginal health professional, shared her perspective gained from many years experience in rural Aboriginal health:

> For Aboriginal women cancer or any disease affecting the female parts, the females biological functions, also threatens to undermine their place in society.

The women in this study were unanimous in their fear of being 'cut up' and having body parts amputated or removed through surgery. Surgery for breast cancer was the most dreaded because of its assault on the female body and its threat to the relationship between a woman and her husband or male partner. Karen an Aboriginal women from the Waratah community, refused medical advice to have a mastectomy choosing instead the conservative treatment of a lumpectomy. Karen summed up the feelings of many of the women:

> I don't want them cutting me up leaving me to be half a women.
> My breast are my *womanness.*

In our interview the persistence of Karen's apprehension about the consequence of 'going under the knife' was evident in her story of a recent event. The hospital ward staff had asked Karen to sign a consent form for a local anaesthetic in order that her pleural effusion could be aspirated. Karen jumped to the conclusion that she was signing consent for surgery, and consequently reacted by disconnecting her intravenous infusion and walking out of the ward. Fortunately her sister Emily arrived in time to see Karen striding off in the hospital grounds in a rage, and was able to placate her and clear up the misunderstanding.

Many of the women said they would make the same choice of refusing radical surgery of a mastectomy to preserve the intactness of their body and integrity of spousal relationships. Aunty Ruth's response was typical of many. Aunty Ruth had breast cancer:

> I was frightened, when I got to hospital and saw those other women with their breast off and there was one woman she was moaning and crying with pain. I didn't want that, I didn't want my breast off and all that pain. So I asked them to just take out the lump. Then I had the chemo and some rays.

Aunty Shelia shared the story of her sister who 'feared the knife' and refused to have her breast 'cut off'. She had agreed to an excision of some axillary lymph nodules and chemotherapy, which she later abandoned because as Aunty Shelia recalled, her sister believed the treatment was 'killing her'. Another women decided to forgo surgery for a bowel cancer choosing instead to 'take her chances' as she explained:

> It's too late for this bowel cancer, I said no to surgery. I don't want them cutting me inside, leaving me in a mess. I'm better off without that. So I came here to end my days back where my family live, this is where my parents lived.

It transpired the 'mess' this woman feared was having a colostomy bag that she perceived would damage the relationship with her husband as well as her self-image as a woman, something she was not prepared to risk.

Carol gave a particularly profound example of how surgical cancer treatment compromised a woman's cultural identify and thus her position in society. The story was about a rural woman who had surgical treatment to remove an oral cancer. Carol continued the story:

> I had one lady last year who had her tongue removed and some glands, she couldn't talk or eat properly, it was terrible. I mean talking is part of the *Murri* culture. We shouldn't have let that happen it was awful for her.
>
> So when she went back to her community she couldn't be part of it. She died anyway so how did the so-called treatment help? It just took away something important and took her away from her family and community when she needed them most.

From the perspective of biomedicine, glossectomy would be the surgical treatment of choice to remove a cancerous tumour of the tongue but clearly from a cultural perspective this procedure was a devastating insult to the women's social functions and as Carol suggested, the surgery in effect resulted in this woman's 'social death' before her physical death. A culture-centred approach to this woman's situation would prioritise the existential cultural values of being with family and the community where the women in question might also have had access to traditional medicine or healers, as well as conventional palliative treatment.

I was aware of interviewing only two women, Fay and Aunty Susan, who had undergone radical mastectomies for treatment of breast cancer. When interviewing Fay, our focus was the recurrent cancer for which she was receiving palliative treatment, as she indicated unwillingness to 'dwell' on her previous mastectomy. Aunty Susan on the other hand was unusual in that she willingly talked about having a mastectomy and also about an earlier hysterectomy, (although she was unsure why the later surgery had been necessary). Aunty Susan said she rejected suggestions offered by the 'white women' from the cancer support service about bra padding to cover the mastectomy site. Aunty Susan reasoned that she was 'past sex' and there was no one to see her body anyway, and it was too hot to wear a bra. At the time of our interview it was late summer when the average daytime temperature was around 33 degrees Celsius. Consequently Aunty Susan experienced the discomfort of heat rash from wearing the elasticised lymphedema bandage on her arm and on both legs. Aunty Susan was unclear about the cause of the lymphedema but it seemed most likely associated with her previous hysterectomy treatment.

The discomfort of wearing extensive elasticised bandages in the tropical heat seemed ground enough for not complying with this particular biomedical advice, which related to a context that was different to Aunty Susan's situation. This reinforced a point made by Carol:

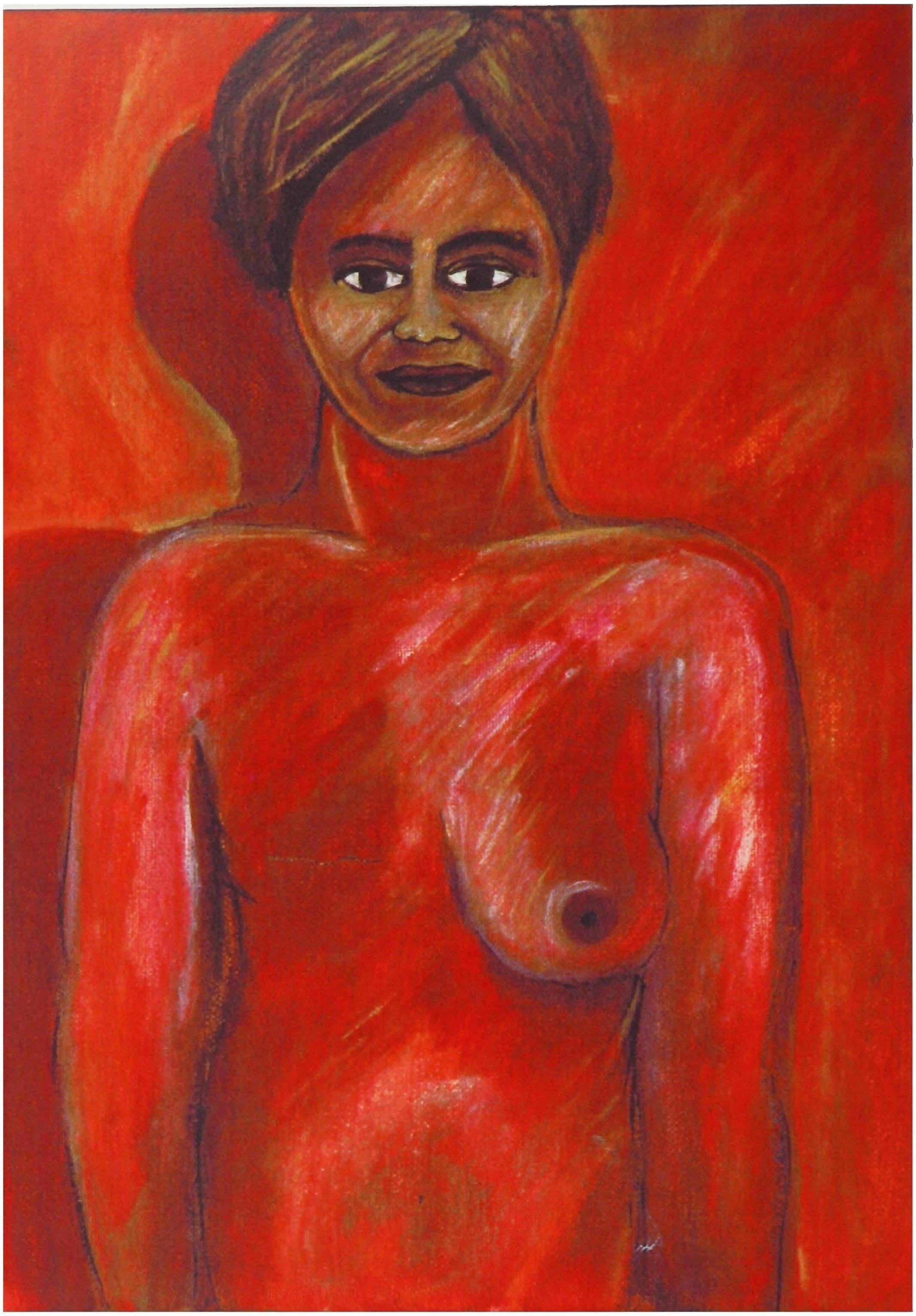
> It's like the support services and information about cancer is all written for the white woman, living in their suburban houses, having nice things and family, Aboriginal women can't relate to that.

Other health care workers confirmed that generally Aboriginal women rejected using any type of breast prosthesis or enhancements that may be offered post mastectomy, as one woman concluded:

> Bra staffing is only for white women, us Aboriginal women don't want to use those things.

The impact of a mastectomy on an Aboriginal woman's cultural identity was an important issue for Julie who portrayed the violation of this surgery in the painting shown as figure 6 in which she used a vivid red image of a woman confronting her physical self after, as Julie described it, 'a breast amputation'. Julie explained her use of the colour red in the painting was to portray the woman's anger toward the biomedical mutilation of the very core of her self as a woman. But at the same the dark shadow appearing behind the woman, embodies the presence of a spiritual guardian giving support and strength to help the woman overcome this crisis.

Figure 6: Take away the cancer but leave me whole



The spiritual Christian belief about the sacredness of the body was another important reason why some women rejected surgical treatment for cancer. Judy, my research facilitator confirmed this point in saying: 'Our body was a creation of God that we should not interfere with, no matter what happens'. Other women in this interview group agreed and one reiterated Judy's statement saying: 'we have to respect God's work our bodies are sacred'. The Christian teaching that influenced the women's belief about the sacred body is evident in several sections of the New Testaments Bible. One example is in 1-Corinthians 3:17:

> So if anyone destroys God's temple or destroys it, God will destroy him. For God's temple is holy, and you yourselves are his temple (*Good News Bible* 1986 p. 1269)

The influence of earlier Christian church teaching also attributed to women's shyness, or 'shame' when asked to focus on their physical body. Interestingly none of the Aboriginal women in this study ascribed blame to God for their cancer, in contrast to some African American women with similar strong Christian faith and spiritual beliefs. Research suggests African American women are more likely to understand the biological causes of cancer but also attribute to the disease to the 'will of God' or as a punishment from God (Bailey, Erwin & Belin 2000; Gregg & Curry 1994). The implication of God in explaining cancer varies from the Aboriginal cultural notion of 'payback' that implies the actions of 'bad spirits' inflicting harm, rather than the fatalism of God's will.

The cultural significance of religious and spiritual beliefs and the Church's central place in the African American community is the basis of *The Witness Project*, a culture-centred program. *The Witness Project* was designed by a medical anthropologist who recognised that for the majority of African American women the church is the central place for social interaction, worship, education, networks and companionship and therefore an ideal focal point to address health issues (Bailey, Erwin & Belin2000; Erwin et al., 1999). The public health aim of *The Witness Project®* is to encourage African American women to have mammograms as well as to develop a culture of support and cancer survivorship. *The Witness*

Project epitomizes a model of cultural empowerment because every aspect of the program reflects spiritual and faith components that are vital aspects of African American culture. The potential for similar faith based approach or other culture-centred programs that could support Aboriginal women with cancer would be worth exploring in a future project.

Going our own way

The dominate position of biomedicine's authority is evident where non-compliance is defined as a deviation from medical advice or prescribed drug regime (Humphery, Weeramanthri & Fitz 2001) and is expressed as a concern for both Aboriginal and non-Aboriginal health care staff. Leslie, an Aboriginal social worker lamented the problem:

> We may get them (women with cancer) to Brisbane to start their cancer treatment but because they are so far from home they don't want to continue it and will go home before the treatment is completed.

Carol shared her experience:

> I have to persuade them to have treatment, that's my job, but I can't guarantee the she'll finish it. I may get them to start treatment but getting them to complete it is the hard part.

It seems incongruous that Carol and Leslie as Aboriginal woman had to persuade others to comply with Western methods even if these conflicted with their cultural beliefs or values. Carol had many examples from her clinical practice, of rural Aboriginal women who were persuaded to start radiotherapy, or chemotherapy only to abandon the treatment before completing the course, and left sometimes without notice to Carol or other staff. The non-Aboriginal hospital staff expressed their distress and bewilderment that these women did not share their concerns or worries, which maybe could be addressed, as one radiotherapy nurse said:

> If we knew they had to get home, we could plan their treatment around this. But when they just get up and leave, it negates all the treatment they have had so far, why do they do that, just go?

Carol's concern was that the women who abandon treatment risked having unnecessary suffering because cancer health care services were limited or non-existent in the rural communities:

> I just worry about them and how they get on, some of these women have terrible disease, very advanced. I don't know how they manage. It must be terrible for them without proper treatment being available. Some of them live in remote or rural communities that don't have medical facilities and certainly no oncology service.

Accepting Western medicines

Most of the women said they accepted the benefit of conventional medication, for example, morphine that was often prescribed for palliative treatment of pain. However, the women's priority was to remain alert in order that they could be part of community life for as long as possible. Stoicism was another reason evident in women's account of why some rejected Western medications. Aunty Alice gave an example of her relative who refused morphine despite obviously suffering pain. Aunty Alice recalled:

> I could see my Aunty had pain the way she held her mouth like chewing (Aunty Alice demonstrated). I could tell she was chewing away the pain. But she wouldn't have the morphine.

In response to my questions about whether her Aunt was concerned about losing control if given a narcotic, Aunty Alice said:

> It's not that so much, they just don't want a fuss made of them, they don't want people to see they can't manage the pain, they think they should manage it.

The health care staff felt concerned about compliance with medication and agreed that generally Aboriginal people were not good at keeping to drug regimes or treatment schedules. One difficulty was that some people required multiple drugs for other health problems, so it was easy to be confused about dosages and medication times. The medication dosage problem was overcome to an extent by the introduction of the Webster pack system where pharmacists prepared and packaged the drugs into the daily doses that could then be delivered to patients by the health workers at the appropriate times.

There was also the concern of the security of drugs in homes where it was not unusual for several family members to live together in the same house, and for friends to stay or visit at any hour of the day. The health workers confirmed that a characteristic of *Murri* culture was to share everything, including medications, not just the morphine but any drugs or treatments that they believed could help another member of the family. The *Murri* way of sharing is a good example of what Airhihenbuwa (2004) identified as an existential cultural value because it is enduring and therefore in the context of public health needs to be accommodated.

Sandra's perspective of her husband's cancer treatment echoed the opinions of many other participants about the grief and cultural rift felt when a sick person underwent cancer treatment and was away from home. Sandra's husband neglected early symptoms of lung cancer and thus palliative treatment was prescribed. Sandra continued her story:

> They took him to (name of town). When they told him it was cancer they wanted to cut him up, go under the knife, but he wouldn't have that, so settled for radium treatment.
>
> He went down to Brisbane for that, seven weeks he was there. He started to get awful thin, down to bone on his chest they said the cancer had spread. They let him come home here (name of community). They brought him here to the hospital he was dead in three week.
>
> All that time away and all that radium and he still died, it wasn't worth it. If the treatment wasn't going to work, why put him through all that? He could have stayed here been with his family and with his people.

Margie's grief over Mary's death appeared to be aggravated by her resolve that Mary's palliative radiotherapy in a city hospital had taken her away from the care and support of family and friends at an important time. Margi believed the treatment deprived Mary and those concerned for her of: 'the last good weeks of her life'. The health workers acknowledged that the desire to be at home or choose one's place of death was not unique to Aboriginal people, but the difference was that non-Aboriginal people were unlikely to be as distant culturally or geographically from their homes if they needed to be hospitalised.

An important cultural consideration is the significance of the place of death for Aboriginal peoples, as Leslie, an Aboriginal social worker explains:

> It is important to have open honest commination as the patient and their family will want to be at home to die, home being in their community, the community of their birth. This is very important for the passing of their spirit.

The women's distress of learning they had cancer was intensified by deceptive or ambiguous information about the prognosis. Regardless of whether a woman's cancer prognosis was, from the biomedical perspective, good or bad she and her family needed the truth so they could choose where they wanted to be. An Aboriginal health worker explained:

> In the terminal stages of a disease, when death is imminent, it is very important for Aboriginal women to be with their people and in their own home. Being home does not necessarily mean at home but just in the community where the person was born.

A serious concern of health care staff, including the local health workers is the lack of resources to provide health care to the terminally ill in the rural communities. Many homes cannot accommodate a sick or dying person either because of overcrowding or because of poor household infrastructure such as an indoor bath or reliable hot water supply. I visited many homes during my fieldwork that lacked basic facilities such as hot water tanks, working refrigerators and even telephones. I had a humbling experience when visiting an elderly woman's home, which had been condemned some years before because of 'borers'. I recorded my observations and reflections of the experience:

> [Name] house is clean, very tidy and decorated with pictures and ornaments. There is a large pot of water boiling on the stove for her bath. Judy offers to turn it off to avoid wasting gas, [name] said she had a bath outback in the outhouse and put a towel on the floor because the concrete is cold.
>
> I could see the fridge door was held partially closed with a brick but not very well because the fridge light could be seen.
>
> [Name] told us she had the telephone installed only two weeks ago, and is still getting used it, she said, 'it makes me jump every time it rings'.
>
> This was her first home telephone. This made my frustration about not having mobile phone access seem pathetic.

Judy confirmed that many homes in this community are in a similar state of disrepair though a major new building project is underway and most residents including this elderly lady are to be rehoused.

Cultural empowerment

As previously discussed some women defied biomedical treatment advice by either denying their cancer diagnosis, abandoning treatment, or not complying with medical advice opting instead to stay in the community with their families. There is general agreement among the women that staying at home allows them to access traditional medicine. The 'medicine-man' or healer is often sought in preference to or sometimes in addition to conventional treatment. The women's faith in traditional health care practices was consistent in both communities and health workers confirmed that the traditional healers and 'medicine man' remained vital to a sick person's treatment and care. As Margie confirmed:

> The medicine man, the traditional healers are very important. They help save the person; they (the medicine man) don't go for the physical illness but start with the spiritual life, healing the people that way.
>
> They (medicine man) make the person feel fulfilled and satisfied in their mind, they can have a good death. Sounds funny, I don't mean they help them to die, nothing like that, but I mean they don't have to suffer in themselves, they can work thing through, deal with their issues, their grief, that sort of thing.

Miss Lilly[27] recalled numerous incidences from her experience as the hospital matron, when the 'clever man or witch doctor' (sic.) had been called in to 'break the power of bad spirits' on a sick person, or to undo a curse imposed by another 'medicine man' from a different tribe. In the days when Miss Lilly was the matron, she and the hospital staff understood the need to work together with the traditional medicine man and healer because she had accepted what a patient's family once told her:

> A white man can take a white man's sickness out of a *black fella,* but only a black man could take *black fella's* sickness out.

Fay shared her experience of attending a traditional healer at the same time as having conventional palliative treatment:

> I know the chemo and other treatment can't help me, my disease is too far-gone. I hate going to the clinic when I know they can't tell me anything good.
>
> But now I can go for some healing, my family found a traditional man at (name of community). I can be with my people there.
>
> The healing has given me so much strength, I don't feel angry now, and I have dealt with my grief, freed up the anger. I am stronger now.

Fay cautioned, as other women had done, that the identity and work of the traditional healers and medicine man was 'sacred knowledge' to Aboriginal people and not for outsiders to know about. Fay reasoned that Aboriginal women who abandoned conventional cancer treatment did so because they could not access traditional healers or medicine while in the city hospitals.

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[27] Miss Lilly has remained in the community after her retirement in 1968 and was in the care of the local hospital staff at the time of our interview.

Karen had used a traditional *Murri* medicine called *Gumbi Gumbi*[28] as a wound dressing to help heal her wound following lumpectomy to remove a breast cancer. A nurse in one local health care centre confirmed that it was not unusual for plugs of *Gumbi Gumbi* and other substances to be found in a patient's wound. From the appearance of Karen's breast wound, which she showed me, it was evident that the *Murri* medicine had been effective in the healing process.

Leslie confirmed that Aboriginal people commonly used some type of traditional medicine in combination with conventional treatments. In her practice in a regional hospital, Leslie found the medical doctors generally accept that traditional medicines are used and just ask that they be informed to ensure there is no contraindication for conventional treatments The experience of others is that Western trained health care staff in city hospitals are not as accommodating of Aboriginal cultural practices in general. Traditional healing practices are considered sacred knowledge. '*Murri* medicines' are not willingly disclosed to non-Aboriginal people because as one woman explained, she fears being ridiculed for her beliefs. The palliative care staff in the regional hospital where Leslie worked accommodates some traditional practices for Aboriginal patients but is limited by the boundaries of hospital policies, which prohibits ceremonies like smoking out a room to clear the spirits of the dead, as the procedure could set off fire alarms.

Julie illustrated the significance of traditional healers to the holistic care of the sick, in several paintings. In figure 7 Julie symbolises the traditional healers as the hands surrounding the sick person and their family, which buffers them from the invasion of cancer cells, illustrated as the white circle surrounded by yellow dots that are outside the healing circle.

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[28] I was informed that the ingredients of *Gumbi Gumbi* is traditional knowledge which Aboriginal people preferred to keep to themselves.

sick person and their family, which buffers them from the invasion of cancer cells, illustrated as the white circle surrounded by yellow dots that are outside the healing circle.

Figure 7. The Traditional Healer protecting and nurturing

The next painting in figure 8, called 'The many paths to healing' illustrates the central focus of a woman in a healing environment that involves many forces, including traditional and conventional medicines and the ancestor spirits portrayed as small dots in the background and purple energies surrounding the woman's image. Each path represents the communities and the families that women need to support their cancer journey.

Figure 8: The many paths of healing

The local women explained that the identity of traditional healers was not common knowledge to all the community and some 'medicine men' lived in remote regions, which meant not everyone had access to them. Margie explained there were different types of medicine man that were specific to a tribe:

> They were special people but depending on which tribe they were from they (the medicine man) each had different things they did, so you didn't call in just any *medicine man* they had to be from the right tribe.

The significance of the location of traditional medicine men and healers was that if a family did not have sufficient resource to undertaken the necessary travel, their choice would be limited to conventional biomedical treatment or whatever traditional medicine is available in their community.

The majority of women lamented how they felt spiritually weakened and more vulnerable to the invasion of the cancer because of being separated from their usual cultural basis of security. Julie symbolised the disempowerment of a woman spiritually disconnected from her cultural supports in the painting shown as figure 9. The painting called 'Overpowered by cancer - a body without spirit' is of a lone female figure being progressively engulfed by cancer cells. Julie symbolized the spiritual effects of disempowerment by the use of colour; the purple background in the first image to the left of the paining represents the spiritual strength surrounding the women that keeps the cancer at bay, this declines to the black background in the third image showing the woman alone and spiritually weakened and overwhelmed by the cancer cells.

Figure 9. Overpowered by cancer: A body without spirit (Rogers, 2000).

When cancer takes over, does the palliative approach empower?

Palliative care is a biomedical approach of providing symptom control and holistic, compassionate care for people with an incurable cancer or other terminal conditions. Palliative Care Australia (PCA) define the aims of palliative care:

> …to make the person feel in control of their treatment and their quality of life. It involves family and friends, recognising that they, too, need to be prepared for the death of someone they love, as well as being there to offer help and support during the grieving process (*What is palliative care* 2002)

The holistic parameters of this Western model are expressed as: Patient and family centred care (*Standards of palliative care provision* 1999 p. v)[29] which does not completely align with Aboriginal women's notion of holism as the inter-relationship of people as well as relationships between people and the 'land, sea and spirit' (NATSIHC 2004 p. 4). Only very recently have Aboriginal people's cultural perspective been considered in palliative care services. This oversight is partly due to the cycle of under-representation, where Aboriginal people have not accessed palliative care services and thus there has been no opportunity to develop an understanding of their cultural perspectives. Pat a health worker with a government department, offered another explanation:

> Palliative care has no meaning to our people. Looking after the sick is a concern of all the community. Our people don't want to be sent away for their dying.

Richard Trudgen (2000 p.154-5) in his important book *Why warriors lie down and die*, about the culture and health of the Yolŋu people, described how different cultural views of end of life situations caused emotional trauma that intensified the family's grief:

> Yolŋu families are traumatised because the dominant culture lacks understanding of death and dying as Yolŋu see it…

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[29] The National standards for palliative care provision are currently being rewritten to include the domain of cultural context and criteria that relate to cultural difference to be considered when offering service to Indigenous people (Nightingale, E 2004, Standards for providing palliative care for all Australians. Work in progress, Version 1.3.)

> Yolŋu believe- the health system 'steals' their elders and sick countrymen from them at the point of death.
>
> What was seen as compassionate and humane treatment by the hospital staff was seen as something akin to being imprisoned by the patient and their family.

The women in this study were mostly positive about their experience of palliative care services, with some reservations about the number of health care professionals involved. The women explained how they felt uncomfortable with the excessive attention of the multidisciplinary team, which were integral to the Western approach of most palliative care services. Carol explained that it was uncharacteristic for Aboriginal women to attract attention to themselves and those from rural communities in particular were more shy in the presence of white professional people, especially those in a large city hospital.

Karen shared her experience of feeling angry and violated by the constant gaze of numerous health care staff including students wanting to ask her questions, when she was in hospital for cancer treatment. On some occasions, when Karen felt particularly unwell she just wanted to be left alone and given some privacy to be with her sister and other family visitors. Karen was however, positive about her experience in the regional palliative care unit that was nearer to her community and particularly appreciated the alternative therapies:

> You get massages and nice music and it is all so nice. Everyone is just lovely and nothing is too much trouble. They don't force you to do anything. I love it there.

Another attribute of this regional palliative care unit was that Karen could be admitted directly, thus by-passing the usual arduous admission routines and avoid the risk of encountering staff unfamiliar with her condition and wanting to undertake further clinical examinations or tests.

Carol had successfully introduced some Aboriginal families to the facilities of a main palliative care service in the city. However, Carol needed to negotiate with the staff on behalf of the various families to ensure the palliative care providers did not bombard them with what was described as: 'too many questions and having too many people coming into the patient's home'. She recalled a recent good experience with a palliative care unit that was well received by the patient and family concerned:

> I introduced one family (to palliative care) early on and this time they (the staff) just provided counselling and some volunteers to come in and help out nothing much, but the family really appreciated that.

And another family who benefited from a palliative care service:

> I found one family had a really great experience with the palliative care staff. When their mother was dying no one wanted to talk to the children about it. The family asked me ([to talk to the children) but I couldn't do it. So the counsellor from (name of palliative care service) came in and she talked to the children and answered their questions, it was so good. Made such a difference to everyone, I'm sure it helped the children's grieving.

The *Murri way* to care

The *Murri way* refers to the cultural traditions, beliefs, values and practices that inform how families support and care for people with cancer and during the final days of their journey. In relating this to the concepts of cultural empowerment of the PEN-3 model, the *Murri way* is akin to the positive and existential nurturers and therefore should be central in culturally appropriate palliative care for Aboriginal people and the associated supportive care for their families.

Aunty Alice, an ancillary staff member at the Coolabah community's hospital had the view that the most important approach in caring for cancer patients especially those in the terminal stage, was that their desires and needs were heard:

> You have to listen to the people, and find out what they want
>
> We can't push them (people with cancer) into treatment and hospital ways if they don't want it. They should have what they want. It is their life that matters now.
>
> I tell the family to put their worries and upsets aside, it is the sick person that needs them to concentrate on them now, give them some dignity.

Aunty Alice described how she and other hospital staff placed the 'cancer patients, those that were dying' in a special area of the hospital where they could view the beauty of the environment with rainforest and sunshine shimmering on the sea:

> We look after the cancer patients give them special care. Like when I'm cleaning their room, I won't use any chemicals, because it will upset them some feel sick and some get breathing problems from that smell.

Other staff described the family's involvement in caring:

> All the family want to be there, and they will do shifts so the patient is never on their own, no one should die alone.
>
> Someone will cook the meals and bring this up to the hospital and everyone will carry on laughing and joking like normal. We all get to talk about the good times, also do some remembering about those good times, they like that.

And Aunty Shelia added

> They (the sick person) like the family to come, to give their feet a massage, helps them to relax, just having the family there doing something, is comforting.

And Beth said:

> We (the staff) will always cook for the cancer patients we don't serve them up the same as everyone else. We ask them what they feel like, if they want fish soup we make that, but leave out the onion because that taste is too strong for them and spoils the fish taste.

From these accounts the importance of the social network and family support was once again emphasised. The social needs of the sick was summarised by two young health workers in response to my question: 'what would be most important to you as an Aboriginal person if you were really sick? One health worker replied:

> Have plenty of tea, sugar & milk they sit and talk for hours.
>
> To have family and friends around, and maybe a couple of good funny kids, not too many though.

And the other health worker's reply alluded to the struggles evident in many of women's stories:

> Not to be too far away from home, or you'll be homesick as well. (To have) friends, family, pets if hospitalised, and staff that are willing to give you 110% and not make life harder for you, because life is already hard enough.

Let me die in my place

Spirituality was a significant aspect of the women's cultural identity, as previously discussed in chapter six, which some expressed through the practice of religion, 'going bush', attending cultural gatherings, and conducting ceremonies to honour births, deaths and burials.

In both communities I heard several stories, from Aboriginal women, health workers and non-Aboriginal staff about the spiritual experiences of people dying. Aunty Alice told the story of how her sister died following breast cancer surgery:

> She had been a thin woman, so felt the lump easily; she had some radiotherapy in (name of city). After about three months, she seemed to be strong and getting her health back. She was joining in with family events and keeping busy until one day she was sitting with the family and said: 'well I'm tired now and ready to go.
>
> The family thought she just wanted to go to for a sleep, so didn't worry when she got up and said 'I'm gone now', then went to bed and died. I don't think she had pain though she just died.

Beth shared the profound spiritual experience of her husband's death from lung cancer:

> It was lucky, I was going home after work and thought I would just look in on him (in the local hospital). When I saw him I knew he was going. He was dying, so I told the staff I was staying. One of the Sisters was saying prayers with him and then went.
>
> Then a miracle happened. I was holding his hand, he was sick then and so thin, all bone. I was holding his hand and I saw he started to fill out, his arms first then his whole body filled out like he was a young man...(Beth became overwhelmed with emotion and cried at that point).

> He died a young man it was a miracle. He was beautiful when he died, peaceful and young.

Aunty Shelia and Judy shared the experience of their uncle's recent death in the local hospital. Judy had been walking home from work when she heard him calling and Aunty Shelia also heard their uncle 'singing'. Their Uncle Mike had heard music that he described as spiritual voices of the ancestors. Just before Uncle Mike died more of the family arrived because they too had heard the music and the call, which they referred to as 'singing'. Judy remembered that nearly all the family were with Uncle Mike by the time he passed away.

As Uncle Mike's death was a recent event, I was able to ask how one of the non-Aboriginal nurses perceived the experience his death. His nurse had provided care for Uncle Mike and was on duty when he died, he described Uncle Mike's death as a 'bit spiritual' and added:

> First he (Uncle Mike) was diagnosed, had a bit of treatment, and then came back here (name of community).
>
> Then he got sick again and just decided that's it, no more treatment, I'm packing it up now and then he died a few days later, all the family were with him. They must have known.

The significance of this next and final story is that it best represents the goal of cultural empowerment where the culture of a sick person had been central, thus allowing - in this case - Uncle Nathan to negotiate how and where to conclude his journey of physical life, regardless of his cancer diagnosis. I had been uncertain whether the numerous people who told Uncle Nathan's story were also aspiring for a similar end or just wanted to inform me that this was how it could be, this was the *Murri* way.

The story belonged to Uncle Nathan who when diagnosed with some type of gastrointestinal cancer needed to remain in the city hospital to undergo palliative treatment. However, after only a few days at the hospital Uncle Nathan discharged himself and asked the family to take him home because he wanted to be in his country in 'the bush' to prepare for his passing. Uncle Nathan knew his prognosis was poor and stated he did not want to have any 'fuss' from either hospital staff or from his family. Other participants confirmed Uncle Nathan's desire to go into the bush was not an unusual event in this particular community. I was informed that many others had chosen to live the traditional way in the bush, although the sick often attend the local hospital for treatment or received visits from the health workers. The location of the particular area where Uncle Nathan had chosen was protected and thus out of bounds to all outsiders. Aunty Alice continued the story:

> So one of his sons went out with him and they set up camp. His son was there to look after him. And they (the hospital staff) kept a watch, kept a lookout for him from here (at the hospital).

Aunty Alice explained further, that the hospital doctor and nurses knew about Uncle Nathan's condition and of his choice to camp in the bush to end his days. According to his sons Uncle Nathan did well out there and was very happy when he passed away. Uncle Nathan's son liaised with the hospital staff and with other members of his family keeping them informed about his condition and a health worker visited him if required to check if any medication or other supplies were needed. When he died Uncle Nathan's son notified the hospital in order to complete legal formalities.

Aunty Alice said Uncle Nathan died in 'tune with his spirituality'. He chose to prepare for his final days being in harmony with his culture and his identity, which Aunty Alice described as: 'always a very private man, very dignified, didn't like fuss or people knowing his business'. In choosing his way of dying, Uncle Nathan had not completely dismissed the options offered by biomedicine, according to hospital staff medications and supplies were sent to him. But he was not dominated by conventional methods; instead he was able to take control of his life and his cultural needs rather than just the disease. Although this final narrative is of an

Aboriginal man's story, it was given to me by the women, (several times) to emphasise their expression of what was really meant by culture-centred holistic care and the *Murri way*, which was aspired to by rural Aboriginal people at the end of their journey with cancer.

Summary

In this chapter I have demonstrated how a diagnosis of cancer motivated the women to assert their cultural values and needs over biomedical advice about treatment. The concept of *cultural empowerment* of the PEN-3 model (Airhihenbuwa and De Witt Webster, 2004 p 486) provided a frame for presenting the women's stories that highlighted the positive and existential cultural practices. Examples of the 'positive' values were the family's involvement in providing care, and in protecting the cultural integrity of the sick by negotiating decisions about treatment, and the environment of care, strategies that become paramount in the final days of the sick person's life.

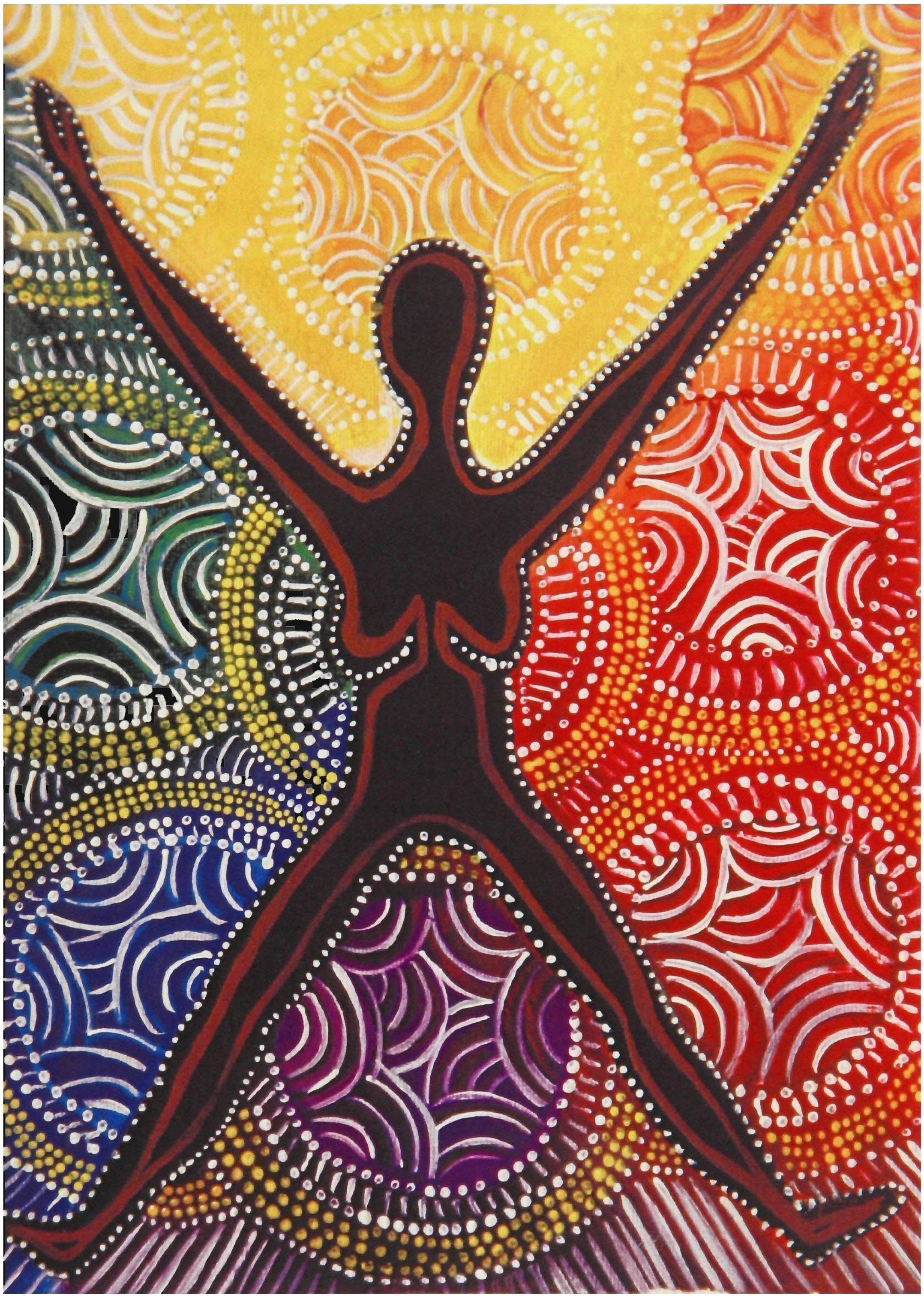
Existential values and beliefs about a woman's body are important influences on decisions about cancer treatment. The reductionist methods of surgical treatment arouse feelings of 'shame' for the women because the procedure violates the sacredness of the body as well as compromising social roles and relationships. Many of the women reject the radical surgery of mastectomy; opting instead for breast conserving procedures, also on the basis of religious and spiritual beliefs that a woman's body should be preserved in its wholeness.

When cancer treatment necessitates the women leaving the community, their apprehension increases because of the culturally disempowering effect of being separated not only from family support but also the opportunity to access a traditional healer or 'medicine man'. Traditional approaches to health care and healing are very important existential practices, which the women privilege over any biomedical advice.

Strong underlying beliefs that cancer is a manifestation of a spiritual force or bad spirit aroused by 'payback' supports the belief of some that control of the disease requires mediation by traditional healers. Predominantly, traditional healers and the 'medicine men' are valued for helping the sick gain spiritual strength and resolve issues that would otherwise hinder their transition to the spiritual world after death.

The *Murri way* of caring for the sick and the dying cancer patients is really only possible within the community. The essence of the *Murri way* of holistic caring is that cultural and thus spiritual matters take precedence over the disease and conventional methods of treatment. The sick person could be supported in their choice about whether they wanted to be in the bush living out their final days in a more traditional manner, or in the local hospital where the community could coordinate their care wishes and ensure they were never alone. The culture centred approach of the *Murri way* is to help the dying person be whole despite their cancer, and to find spiritual harmony during the final journey. This state of ultimate harmony and wholeness is beautifully portrayed in the final painting from Julie's story. Figure 10 is called 'Harmony and Wholeness: Body-Spirit'. The different coloured circles that surround the female figure represent different spiritual energies, which in Eastern cultures are called Charkas. The woman is physically 'whole' and her body is harmonious with the spiritual world where she will transcend.

Figure 10: Harmony and Wholeness: Body-Spirit



CONCLUSION

Cancer is a universally feared disease that shows no discrimination against race, gender, social position or wealth and to date the promise of medical science to defeat the delinquent disease remains mostly unfulfilled. Cancer is an adversary of double proportion for rural Aboriginal women because they perceive that having cancer is another form of being colonised. Not only does cancer threaten to control their body but also in the domain of biomedical cancer institutions, Aboriginal women fear again being vulnerable to the old adversary of the *whiteman's* authority. Of course the Aboriginal women want to take advantage of biomedical knowledge and treatment technology available for controlling cancer, but they question why their cultural values for holistic health care and healing should be compromised in the process.

What the women seek is an approach to cancer treatment that respects their cultural differences and integrates Aboriginal practices of healing and health care, which preserve their 'wholeness' as women, hence the lament I have chosen as the subtitle of this thesis: 'Take away the cancer but leave me whole'. Currently it is unlikely that Aboriginal women will find an harmonious relationship between their cultural values for 'wholeness' and the biomedical paradigm that informs cancer care services. In this study I demonstrate that Aboriginal women's fear and fatalistic perception of cancer manifests as an unwillingness to take on the passive compliant role of being cancer patients. On the contrary, a diagnosis of cancer appeared to inspire the women to position their cultural values and aspirations central to decision making about treatment and in determining their future health care needs. So while the women were not totally averse to receiving conventional cancer treatment, many chose to forgo biomedical options, opting instead for the cultural security of being with family and social networks and in their 'own country' where spiritual connectedness through healing and traditional practices could be assured.

It would be misleading for me to conclude, however, that Aboriginal women's ambivalence toward biomedical cancer treatment is only on the basis of different health care practices, or a fear of hospitals that represent *whiteman's* authority and places of death, or because of the distancing from the protection of family and community, or because of concerns about racism. While all these are facets of the context in which decisions about cancer treatment are made, at the heart of this psyche are the cultural losses associated with colonisation, which are perpetuated by the colonial mentality of biomedicine and health policies that impose a 'top down' or paternalistic system of health care.

The success of public health cancer screening strategies has drawn Aboriginal women into the primary level of biomedical cancer services, but has been less successful in attracting the women beyond this investigative stage. This is evidenced by the fact that there is an increased participation in cancer screening programs which subsequently leads to higher incidence rates being recorded, however, there is no record of a corresponding decline in cancer morbidity or mortality in this population. The Aboriginal women in this study generally participated in early detection and cancer screening as if obeying an authority. Cancer screening is an overt act of compliance so once the women have been 'checked out', many see that as the end of their obligation. The women can choose whether to return for follow-up of tests results or to ignore the whole situation until tracked down by some diligent health professional. Compliance is a revealing term in biomedicine in that it represents the hegemonic authority of the institution. Many of the women view their participation in medical cancer programs in just such terms: as an act of obedience. Because there is no middle ground for connecting the cultural space of Aboriginal women with the biomedical paradigm, the women's choice is to passively comply or defiantly reject Western medicine. A negative consequence of defying medical advice is that the health care options for rural Aboriginal women in their community are limited to primary health care facilities which are not adequately resourced to provide cancer treatment or palliative care.

The 'culturally appropriate' mantra of public health misses the point unless there is a deeper engagement of women in the care of their own health so that real choices are possible and the significance of culture and history is understood and respected. At the primary level, cancer services are more easily adapted to suit the culture of the local community, whereas in the cancer treatment arena of a city hospital Aboriginal culture is considered more as a barrier or a problem to be overcome. Rather than viewing culture as a problem to work around or attempt to acknowledge with displays of cultural artefacts or images, public health programs and cancer institutions should be based on the cultural strengths of a community. In contrast to the top-down method of designing 'culturally appropriate' health care which expects the Aboriginal population to 'fit in', a ground-up approach affirms cultural values and practices and acknowledges that these are the starting point for developing programs or services.

Identifying cultural strengths cannot be assessed by formulaic methods but instead requires the anthropological approach of learning from the people and being in 'their place' to understand the context of the community. Such an approach was used by Brough et al. (2004) in developing a 'strength-based' health promotion in an urban Aboriginal community. Brough et. al (2004) reported the shock of some members of the community at being asked to identify their 'cultural strengths' when usually researcher's inquiries were about the problems. The faith-based approach of *The Witness Project* for African American women (Erwin et al. 1999) is another example of a public health program that builds on the cultural strengths of a community. At the heart of this culture-centred philosophy is what Airhihenbuwa PEN-3 model promotes as 'cultural empowerment', which essentially values what already happens including the traditions and the unique cultural values influencing health care behaviours of particular cultural groups. In table 2 that follows, I use concepts of the PEN-3 model as a frame to present the cultural strengths as well as the negative elements there were apparent in the Waratah and Coolabah Aboriginal communities. The negative elements relate to long held health belief patterns, attitudes or structural barriers that are detrimental influences on health care for individuals and the community. Therefore in developing health care programs these negative elements are the primary focus for intervention, to change perceptions, inform or reframe structural policies for example, for the good of the collective.

Table 2: Cultural strengths and social needs

PEN-3 → COMPONENTS ↓	POSITIVE Cultural empowerment	EXISTENTIAL Cultural strength	NEGATIVE Detrimental influences
PERCEPTIONS: knowledge, beliefs, values attitudes, meanings.	Cultural identity and value differences of rural Aboriginal peoples Collective construction of meaning, involves family/social networks Capacity of communication between family and social networks The family has primary responsibility for supportive and practical care of the sick Holistic approach to health care that promotes harmony between physical-spiritual, family/kin and ecological relationships Beliefs that cancer is the manifestation of external forces as well as physical agents Meaning of cancer as a threat to individual and cultural integrity	Enduring influence of cultural heritage in the reconstruction of contemporary Aboriginal identity Tacit bond of a shared history and a resolve to uphold traditions of the ancestors Family support networks in decision making Family participation in care of the sick Women's defined social roles/responsibilities as carers/nurtures and health care providers Privacy of women's health business Faith and spiritual beliefs Cultural knowledge of healing practices and 'traditional' medicines	Resistance/ ambivalence toward Western medicine perpetuating 'colonial mentality' in public health, e.g. expectation for compliance with medical advice, Antagonism toward colonialist mentality of non-Aboriginal population including the authority of biomedical institutions Rejection/fear of surgical intervention and other biomedical treatment which is seen as a violation of the 'sacred body' Husband's supportive role is compromised by lack of understanding about women's health issues. A husband may deter his wife from undergoing cancer screening or medical treatment

PEN-3 → COMPONETS	POSITIVE Cultural empowerment	EXISTENTIAL Cultural strengths	NEGATIVE Detrimental influences
ENABLERS: resources, institutional support, socio-economic status availability of services	Rural location of community enabling public health changes to be disseminated relatively easily Good access for home-community based health care Predominance of Aboriginal Health care staff Culturally competent, sympathetic non-Aboriginal health care personnel Primary health care resources, comprehensive ambulatory services Established women's centres and health clinics Aboriginal Council promoting/ protecting the cultural integrity of the community	Access to Aboriginal healers, medicines and specific cultural ways of providing health care for the sick and dying Central role of AHW as mediators and cultural brokers Paramount importance of home-community based care Cultural practices for the end-of-life transitions	Protectiveness of Aboriginal healing/medicine and covert use of these, which prohibits integration with conventional western medicine Limited opportunity for non-Aboriginal patients to benefit from Aboriginal healing/health care methods. Lack of resources/health care professionals to support home- community based care in rural settings Colonialism and racism in hospitals, reflected in policies and routines which marginalise or prohibit important cultural practices

PEN-3 → COMPONENTS ↓	POSITIVE Cultural empowerment	EXISTENTIAL Cultural strengths	NEGATIVE Detrimental influences
NURTURES: supportive or discouraging influences, traditions, behaviour of family/social networks	Family / community participation in health matters AHW advocacy for cancer programs as a shared concern for women and men Shared concerns for young women's health Women's social networks	The seriously ill and dying people are the shared concern of the whole community. Healing and spiritual practices A whole community experience of grief when someone dies Intimate communication between family and social networks Defined cultural ceremonies and rituals associated with dying and the transition from life to death and passing to the spirit world	Blocking/rejecting all biomedical treatment and Western cancer support services Fear and fatalism toward cancer prohibits cancer patients and survivors from sharing their story Hospital policy which prevents important ceremonies to help spirits of the dead to pass on

I propose that public health programs or services can only be considered culturally appropriate when these programs acknowledge and build on the 'cultural strengths' rather than only focusing on the negative elements or 'barriers' that may influence health decision-making in a particular population. In table two shown above, I used concepts of the PEN-3 model (Airhihenbuwa 2004) to present the culturally based attitudes, values and beliefs of the Aboriginal communities in this study and identified these as 'cultural strengths'. When these 'strengths' are used to inform public health planning or service delivery the culture is empowered meaning it is valued not only within the Aboriginal community but also within the Western health care sectors. The role of the family in decision-making and health care for example, is clearly a positive attribute as are the family values relating to collective decision-making. Therefore any cancer related education or health care program should address the collective that is the family and other influencing social networks, rather than targeting only individuals. Furthermore, in a culture-centred model the central role of the family in health and welfare matters would be incorporated into a 'share-care' approach for those with cancer especially when treatment is palliative and end-of-life care is the focus.

In the final chapter of this thesis I presented several aspects of what the women called the *Murri way* of health care, which I suggest epitomise the cultural strength of the communities. The primary cultural strengths are: the family and social networks that provide support and counsel in health care decision-making; the extended family that are the advocates and primary carers of the sick; the culture of traditions including healing, medicines, spiritual beliefs that are vital in the milieu of the sick and dying and for giving solace to bereaved families. There is an irony in the Australian palliative care movement in that through most if its evolution this sector of the health care has looked to Eastern cultures and esoteric Western alternative therapies for ways to provide spiritual comfort and healing for the dying. Yet to my knowledge the epistemology of Aboriginal healing has not been considered. This is clearly an area for future research.

Promoting cultural strengths as the central focus of public health and cancer care services has implications for health policy and organization and may even challenge the structural elements of health care facilities. Hospital policies for example, as well as acknowledging the place of family involvement in the care of the sick would need to consider ways to accommodate the family's cultural need for ceremony and being in 'their country', particularly at the end-of-life stage. A culture-centred approach means working with the women and other key members of the rural community to engage them in defining cultural strengths and needs and determining their own agenda for future health care programs. I propose that palliative care for Aboriginal women with end-stage disease should promote cultural empowerment by supporting what the communities already do so well in caring for sick, and that the aim of this support should be to complement 'traditional' methods of health care and healing rather than imposing the Western methods of biomedicine as the only way. I suggest there are reciprocal benefits from understanding the ways of Aboriginal healing for the Aboriginal and for non-Aboriginal facilities, which make development of a trusting relationship between the cultures an imperative. I offer several recommendations and suggestions for future research that could build on the findings of my study and its contribution to the promotion of culture centre approach in public health and cancer-palliative care programs.

Recommendations

Recommendations for the development of a culture-centred approach in public health and cancer-palliative care are considered in three broad arenas. These are i) social ii) educational and iii) organisational policy:

i) Social

Recommendations to reduce cancer morbidity and mortality of rural Aboriginal women and to better support their health care needs in the treatment and palliative arenas are that:

Public health programs engage the local women's network to disseminate cancer information and encourage stories of cancer survivors as a means of shifting the fatalistic perceptions of cancer to a more hopeful outlook.

Aboriginal and non-Aboriginal health care professionals in cancer and palliative care services develop support networks between and within rural, remote and urban centres.

Cancer treatment services, such as radiotherapy units and chemotherapy services are located into regional areas more accessible to rural women who wish to remain at home while undergoing treatment as day patients.

Continuity of social and spiritual support for the sick and the dying is maintained through appropriate family and social network connections during times away from the home community.

ii) Educational

Recommendations to develop a more culturally secure health care environment for Aboriginal women with cancer and to enhance the cultural focus of cancer health educational resources include:

The workforce of AHWs, Registered Nurses and others with competencies in cancer education and palliative care provision is increased in the rural and central health care services.

Cultural competency relevant to Aboriginal health care is a mandatory requirement for non-Aboriginal health care staff.

Integration of Aboriginal culture and history and health care issues is mandatory in professional health care curricula.

Culturally attuned services or programs are developed. This could take the form of health education booklets, cancer public health resources, specific culture-centred cancer-palliative care information, which are designed with appropriate images, artwork and language; or simply a community based 'walk and talk' health education service as had been proposed by several participants of my research.

Cancer and palliative care education for AHW is designed as a career development opportunity that leads to specialists practice and articulates with higher levels of study.

Community based health education is flexible and mobile so that all sectors of rural communities have access.

iii) Organisational and policy

Recommendations for organisational and policy adjustment to promote the cultural strengths and address the social needs of rural Aboriginal women with cancer are that:

Collaborative relationships between Aboriginal and non-Aboriginal health care providers are fostered to remodel existing cancer- palliative care organizations so that these can better integrate Aboriginal approach to healing and health care. This collaborative work may also extend to redesigning the décor and structural layout of inpatient facilities so that these accommodate cultural needs for example, the need to interact with the natural external world and to have unrestricted access for family and friends.

Review existing policies to identify those that are incongruent with or restrictive of Aboriginal cultural practices or compromise cultural values such as communication mores

Expand rural communities Primary Health Care resources to accommodate palliative care services, for example psychosocial support and inpatient facilities for symptom control

Facilitate Aboriginal healing methods and cultural ceremonies in hospitals and community centres as far as is possible

Promote a 'shared care' approach whereby families are an integral part of the health care team in providing direct care and support for the sick

Develop home-based models of palliative care with rural Aboriginal communities this could be based on the 'hospitals without boundaries' philosophy.

Future Research

While it is hoped that my research will make an important contribution to public health policy and development of culture-centred cancer- palliative programs, further research is needed to explore other aspects of Aboriginal people's experience of cancer and to understand their attitudes toward biomedical treatment. Furthermore future research is needed to uncover the colonising elements of conventional health care and research methodology in order to progress the decolonising agenda. Research questions for future projects include:

What is the perception and cancer experience of Aboriginal men?

Are Aboriginal women's concerns about cancer surgery the same for cancer effecting non-sexual organs or body structures?

Are current procedures for assessment and management of symptoms congruent with Aboriginal cultural values?

How do Aboriginal women manage pain and other physical symptoms?

What are the psychosocial-spiritual support needs of the bereaved?

To what extent does the Aboriginal population use 'traditional' healing and medicines?

What is the epistemology and methodology of Aboriginal healing?
How do other Indigenous populations perceive and deal with cancer?

In this thesis I have attempted to contribute to the discourse of medical anthropology on decolonisation by advocating for a culture-centred approach that privileges Aboriginal culture in public health and cancer related health care. In the interest of balance I should conclude by noting that decolonisation is a cathartic and collective process that should engage all parties, that is the colonised and the colonisers, the dominant and the marginalised. Elements of colonial mentality can be so deeply imbedded in the psyche of both cultures that learnt defences become impermeable barrier to change. It is imperative therefore that Aboriginal and non-Aboriginal people work together to decolonise mind sets that have obstructed past effort for reform in health care. This can be achieved through shared scholarship, social and intellectual dialogue, imagination, sharing dreams and building respectful companionships.

The 'life commitment' I made to Aboriginal peoples who supported this study will be honoured in several ways which includes: presenting a report on my thesis to the Aboriginal Councils and the health care centres in both communities; disseminating the research findings and conclusions through professional publications and conferences; submitting a report to the relevant government departments including the NHMRC; and most importantly, building on the professional relationships with the Aboriginal community that began through the journey of my thesis and which will hopefully generate future shared endeavours.

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