

DISCUSSION PAPER No. 15

***MOTHERS, BOORAI AND SPECIAL CARE:
AN EXPLORATION OF INDIGENOUS
HEALTH CARE WORKERS' PERCEPTIONS
OF THE OBSTETRIC AND NEONATAL
NEEDS OF RURAL VICTORIAN
ABORIGINAL AND TORRES STRAIT
ISLANDER FAMILIES TRANSFERRED TO
THE MERCY HOSPITAL FOR WOMEN***

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Abbreviations

AHLO	Aboriginal Hospital Liaison Officer
DHS	Department of Human Services (Victoria)
Mercy or MHW	Mercy Hospital for Women
NETS	Neonatal Emergency Transport Service
NICU	Neonatal Intensive Care Unit
VPTAS	Victorian Patient Transport Assistance Scheme
WIES	Weighted Inlier Equivalent Separations

Onemda **VicHealth Koori Health Unit: Discussion Paper Series**

The *Onemda* VicHealth Koori Health Unit (formerly VicHealth Koori Health Research and Community Development Unit), launched in June 1999, has been developed in partnership with Aboriginal communities and organisations, in particular the Victorian Aboriginal Community Controlled Health Organisation. Core funding is provided by the Victorian Health Promotion Foundation, The University of Melbourne through the Centre for Health and Society where the Unit is located, and the Commonwealth Department of Health and Ageing.

At the core of the Unit's work is a commitment to undertaking, collaborating in and supporting research that directly benefits the Koori community. The work of the Unit spans academic and applied research, community development, and medical education. The combination of these activities is a central and innovative aspect of the Unit's function, as is the identification and use of mechanisms to link research with the improvement of health care practices and policy reform. Overall, these tasks are guided by a Strategic Oversight Committee.

In relation to the research program, five key areas govern the inquiry undertaken within the Unit. These comprise: historical research into Koori health policy and practice; historical and contemporary research into health research practice, ethics and capacity building; applied research on the social and cultural experience of Koori health, well-being and health care delivery; health economics research on the factors and processes that impact on the provision and use of Koori health care; and the evaluation of Koori primary health care and related health promotion programs.

The Discussion Paper Series (DPS) is directly linked to this diverse program of research and provides a forum for the Unit's work. The DPS also includes papers by researchers working outside the Unit or in collaboration with Unit staff. Individual papers aim to summarise current work and debate on key issues in Indigenous health, discuss aspects of Indigenous health research practice and process, or review interim findings of larger research projects. It is assumed that the readership for the series is a broad one, and each paper is closely edited for clarity and accessibility. Additionally, draft papers are 'refereed' so as to ensure a high standard of content.

More information on the series, on the preparation of draft papers, and on the work of the Unit can be obtained by directly contacting the Unit. Copies of all discussion papers are available from the Unit (T: +61 3 8344 0813), or can be downloaded as pdfs from the *Onemda* website (www.onemda.unimelb.edu.au).

Discussion Paper Titles

Discussion Paper No. 1: Ian Anderson, Harriet Young, Milica Markovic & Lenore Manderson, *Aboriginal Primary Health Care in Victoria: Issues for Policy and Regional Planning* (December 2000).

Discussion Paper No. 2: Kim Humphery, *Indigenous Health and 'Western Research'* (December 2000).

Discussion Paper No. 3: David Thomas, *The Beginnings of Aboriginal Health Research in Australia* (September 2001).

Discussion Paper No. 4: Michael Otim, *Indigenous Health Economics and Policy Research* (November 2001).

Discussion Paper No. 5: Daniel McAullay, Robert Griew & Ian Anderson, *The Ethics of Aboriginal Health Research: An Annotated Bibliography* (January 2002).

Discussion Paper No. 6: Ian Anderson, *National Strategy in Aboriginal and Torres Strait Islander Health: A Framework for Health Gain?* (March 2002).

Discussion Paper No. 7: Anke van der Sterren & Ian Anderson, *Building Responses to Blood-Borne Virus Infection among Kooris Using Injecting Drugs—Improving the Link between Policy and Service Delivery* (December 2002).

Discussion Paper No. 8: Kim Humphery, *The Development of the National Health and Medical Research Council Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research: A Brief Documentary and Oral History* (December 2002).

Discussion Paper No. 9: Michael Otim, Ian Anderson & Russell Renhard, *Aboriginal and Torres Strait Islander Hospital Accreditation Project: A Literature Review* (November 2002).

Discussion Paper No. 10: Nili Kaplan-Myrth, *Political Visions: Blindness Prevention Policy as a Case Study of Community–Government Relations in Aboriginal Health* (June 2004).

Discussion Paper No. 11: Gregory Phillips & the Project Steering Committee, Committee of Deans of Australian Medical Schools, *CDAMS Indigenous Health Curriculum Development Project: National Audit and Consultations Report* (August 2004).

Discussion Paper No. 12: Ian Anderson, Wendy Brabham, Bill Genat, Helen Keleher, Janice Jessen, Di Fitzgerald & Bernie Marshall, *National Indigenous Public Health Curriculum Audit and Workshop: Project Report* (October 2004).

Discussion Paper No. 13: Katrina Alford, *Comparing Australian with Canadian and New Zealand Primary Care Health Systems in Relation to Indigenous Populations: Literature Review and Analysis* (June 2005).

Discussion Paper No. 14: Terry Dunbar & Margaret Scrimgeour, *Ethical Assessment of Indigenous Health Research: A Review of the Literature* (December 2005).

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Executive Summary

This project is an exploratory study to obtain the views of rural Victorian Aboriginal Hospital Liaison Officers (AHLOs) and health care workers of their clients' cultural needs when they are transferred to the Mercy Hospital for Women for specialist obstetric or neonatal care, what the workers' perceptions of those families' experiences have been, and what information the health care workers would like to have available for future clients faced with the prospect of transfer to Melbourne.

The Mercy Hospital for Women has one of Victoria's four neonatal intensive care units (NICUs). Every year rural Aboriginal women who experience pregnancy complications, and babies born at the local rural hospital but who require NICU care, are transferred to the Mercy.

A review of the policy and research literature was carried out in order to better understand the historical and social context in which the issues of the poor state of Aboriginal health and the fear and mistrust of many Aboriginal people attending mainstream hospitals are embedded. Maternal and child health is especially important because of the long-term implications for the population as a whole. The establishment of the AHLO program was the first major step in Victoria towards making public hospitals more sensitive to the needs of Aboriginal people.

A qualitative approach was needed to meet the aims of this study. Great care was required in the choice of methodology, in order for a non-Indigenous public hospital social worker to conduct research in an ethical manner in the area of Aboriginal health. Rather than approaching patients directly, it was considered more appropriate to obtain the views of rural health care workers and AHLOs about their views of clients' needs. In-depth interviews were conducted with six rural Aboriginal health workers and AHLOs.

Rural Victorian hospitals and health services from areas where women or babies were transferred to the Mercy Hospital for Women during a two-year period were invited to participate in the study. Important client issues identified by rural AHLOs and health workers included communication with the metropolitan AHLO at the time of transfer, the cultural sensitivity of non-Indigenous hospital staff, the poor financial situation of virtually all clients and significant difficulties with transport and accommodation. Options to begin to address some of the problems identified by the rural health workers were considered.

Chapter 1 of this discussion paper incorporates a summary of the background and key focus of the study, a rationale of why this is an important area of research, and a review of the relevant research literature and government policy documents in order to understand past and current practices in the field of Aboriginal health care.

Chapter 2 describes the methodology of this study and includes a summary of the Mercy Hospital for Women's history of caring for Aboriginal women. The research design is outlined in terms of reasons for choices.

Chapter 3 provides a summary of the results of the data collection and discussion of the findings. The most significant themes were found to be the assistance and availability of AHLOs in metropolitan hospitals, the degree of sensitivity of hospital staff members to the cultural needs of Aboriginal families, the limited financial situation of virtually all clients and difficulties with transport and accommodation.

Chapter 4 describes the conclusions, strengths and limitations drawn from the researcher's interpretation of the data. Suggestions for future study are discussed, along with implications for practice and for education of social work students.

In this discussion paper, the terms 'Indigenous', 'Aboriginal' and 'Koori' are used to describe all people of Australian Aboriginal or Torres Strait Islander background. This project was conducted in 2004. Significant changes have occurred since then, and references are made to some of these.

Chapter 1: Australia's Biggest Health Challenge

This introduction focuses on reports of the health disadvantages experienced by Indigenous Australians, the identification of Aboriginal patients by hospitals, the obstetric status of Aboriginal women, issues of cultural sensitivity in the provision of health care, the roles of non-Indigenous staff caring for Aboriginal people in mainstream hospitals, the particular needs of rural patients transferred to metropolitan hospitals, and the establishment of the AHLO program in Victoria.

Despite enormous advances in health care over the last century, health outcomes for Aboriginal Australians remain far worse than for the general community; Golds *et al.* (1997) assert that it is Australia's biggest public health challenge.

Anderson and Loff (2004) have argued that recognition of Indigenous rights has gone backwards under the policies of the current federal government, exemplified by the decision to abolish the Aboriginal and Torres Strait Islander Commission without any alternative, democratically elected, political representative body to replace it. Unless the social context in which Aboriginal people are living is better understood and addressed by policy makers, it will be impossible to reduce the 'appalling disparities between the health of Indigenous and non-Indigenous Australians' (Anderson & Loff 2004:1282).

The gap in health measures, such as life expectancy for Aboriginal people, is approximately eighteen years lower than for other Victorian citizens (Koori Human Services Unit 2006:45) and is hardly narrowing. It contrasts with the gains over the past thirty years in the relative health status of Indigenous communities in other countries colonised by British settlers, such as the United States of America, Canada and New Zealand, where Nossal (in Ford 1998:111) noted that 'the gap between the native people of those countries, and other people, has been closing'.

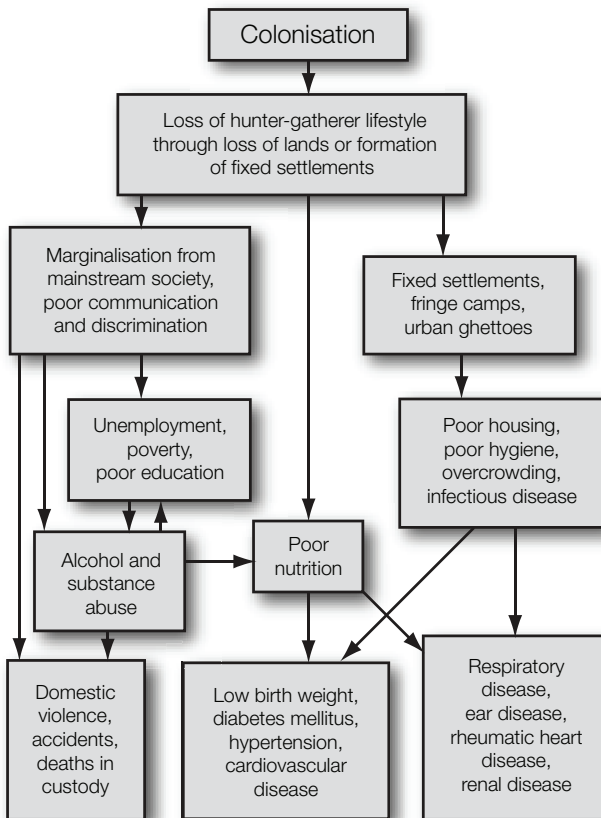
The *Aboriginal Services Key Plan Indicators Report to June 2003* from the Department of Human Services (DHS 2004) provides statistics about the major health and wellbeing indicators of Indigenous Victorians across the life-span, as compared with the general population. It notes the much higher rates of perinatal mortality, complications of pregnancy and babies of low birth weight, and lower rates of immunisation and engagement with maternal and child health services, as well as the higher rates of hospital admission for mental disorders (including alcohol- and drug-related admissions), injuries, diabetes, renal failure, and cardiovascular and respiratory diseases.

Government policy and Aboriginal health since colonisation

It is believed that, prior to European settlement, Indigenous Australians enjoyed better health than the first English settlers (Franklin & White in Reid & Trompf 1991). Wronski (1980:2) noted that ‘it is a matter of historical record that Aboriginal Australians were regarded as a remarkably healthy people by early European settlers’. However, the effects of colonisation on the health of the Aboriginal population have been recognised as disastrous and rapid, and included dispossession from traditional lands, violence at the hands of some Europeans, and exposure to exotic diseases from which Aboriginal people had been previously geographically isolated prior to colonisation.

Mathews (1998:626) has mapped the consequences of colonisation for Aboriginal people and the effects on their health, including infant health, in the diagram below.

Figure 1: Historical impacts of colonisation upon Aboriginal health



By the mid-nineteenth century, the decline in Indigenous health was obvious. A system of segregation onto reserves was established, initially in New South Wales and then in the other colonies, for the protection of Aboriginal people ‘from the excesses of the Europeans’ (Saggars & Gray 1991:122). The presumption was that the Indigenous population would gradually die out.

During the latter part of the nineteenth century and early years of the twentieth century, medical treatment for Aboriginal people was largely unavailable and hospital staff frequently refused to care for Aboriginal patients. When treatment was given, it was generally on the verandah or in the yard of a local hospital. Segregated medical treatment or refusal of treatment was common for Aboriginal people until the 1960s (Saggars & Gray 1991).

Some facilities for Aboriginal people (known as 'lock hospitals') were established in the early 1900s because of Europeans' fear of the spread of introduced diseases such as venereal disease—for which no effective treatment was available at the time—and then of leprosy. As noted by Saggars and Gray (1991:123): 'Small hospitals were established on uninhabited islands west of Carnarvon, Western Australia, and they received many of their "patients" in chains.'

However, by the 1930s it became clear that Aboriginal people were not dying out, and a government policy of assimilation was then pursued. The goal was absorption of Aboriginal people into the general Australian population and consequently their eventual extinction as an identifiable group: 'An important premise of the assimilation policy was that prejudice towards Aborigines was insoluble, and only through the gradual breeding out of Aboriginality would harmonious coexistence become possible' (Saggars & Gray 1991:124). The *Bringing Them Home* report by the Human Rights and Equal Opportunity Commission (1997:4) stated that, under the assimilation policy, 'between one in three and one in ten Indigenous children were forcibly removed from their families and communities between 1910 and 1970'. The removal of Aboriginal children from their families often occurred in the same public hospitals where almost all Aboriginal women continue to deliver their babies (Campbell 2000).

Prior to the 1967 Federal referendum, Aboriginal people were excluded from full Australian citizenship. Of course, many people living today have direct memory of growing up under these circumstances. It was only after the referendum that the 'widespread ill-health of Aboriginal communities came to non-Aboriginal Australia's public notice' (Egan in Schwenke 1988:21). During the following decade, politicians and policy makers began to discuss the complexity of reasons for the poor health of Indigenous Australians and to clarify that poverty, loss of land, poor standards of education and housing, high levels of unemployment and racism are central to the problem and to attempts to reduce the health disadvantage.

While the federal government has maintained a prominent role in the funding and regulation of health services, under Australia's Constitution the provision of services has largely been a State responsibility (Saggars & Gray 1991). The nationwide figure for overall spending on health care for Aboriginal people in 1998–99 was 22 per cent higher than for non-Indigenous Australians. Anderson and Loff (2004) asserted that the extra spending is inadequate considering the dimension and entrenched nature of the health disadvantage of Aboriginal people. Nossal (in Ford 1998) argued that the extra money spent is largely absorbed by the higher costs involved in delivering services to rural and remote communities.

Prior to the establishment of the Commonwealth Office of Aboriginal Affairs in 1968:

little recognition was given by the States to the special health needs of Aboriginals. In mid-1969 Ministers agreed that State Health Departments should pay special attention to the special health needs of Aboriginals, and each State (except Tasmania) established an Aboriginal health unit (House of Representatives Standing Committee on Aboriginal Affairs 1979:79).

There was a dawning recognition by governments that many Aboriginal people were deeply mistrustful of mainstream medical and hospital services:

Many... Aboriginals are reluctant to use conventional medical services. Factors involved in this are:

- Aboriginal apprehension of the strange surroundings and procedures found in doctors' surgeries and hospitals;
- European professionals' unfamiliarity with and lack of sensitivity to Aboriginal cultural beliefs and practices;
- Experience of Aboriginals of being misunderstood and discriminated against; and
- Distress arising from Aboriginals' poverty and inability to pay.

The result is that often Aboriginals do not present themselves for treatment and when they do present it is often very late (House of Representatives Standing Committee on Aboriginal Affairs 1979:97).

The wording and tone contained in some of the early policy documents illuminates the wide range of attitudes at the time within government towards Indigenous people and health. The Department of Aboriginal Affairs' *Report of Activities for the Period 19 December 1972–30 June 1974* described concerns about Aboriginal health as largely 'myth', despite acknowledging that no valid nationwide health statistics on which to make judgments existed. In a discussion of the treatment provided for leprosy sufferers, the report stated that:

Some unfortunates are, of course, retained in institutions for continuing treatment. It is believed that there are some other Aboriginals suffering from the disease who are avoiding treatment... The situation cannot be remedied overnight. Previous neglect and disregard, and inadequate social conditions, have resulted in Aboriginals falling easy prey to all varieties of ill-health. A major factor is the lack of knowledge among some Aboriginals about health matters (DAA 1974).

However, during the same year, 1974, Federal Health Minister Dr Everingham said in his remarks to the *Workshop on Aboriginal Medical Services* (1974:7):

We are very much aware that good health depends on social factors more than on medical treatment. The social factors include adequate nutrition, and diet, satisfactory housing, clean water supply, sanitary amenities, educational and employment opportunities and, of course, the absence of racial discrimination.

The Special Health Services Section (Aborigines) was established in May 1974 within the Victorian Department of Health, the mandate being to provide preventative medicine and community health to the State's Aboriginal people (Saggars & Gray 1991). In 1974, the community-controlled Victorian Aboriginal Health Service was also established. During the same year, in an effort to improve Indigenous health, the *Workshop on Aboriginal Medical Services* (1974:27) recommended that, 'Serious consideration should also be given to the training of Aboriginal health and field workers'.

Aboriginal Hospital Liaison Officer program

The AHLO program in Victoria originated from a report by I. Wronski—*The Growth and Development of under-5 Aboriginal Children in Shepparton/Mooroopna* (1980). In order to begin to address the health disadvantages of Aboriginal children, Wronski made several recommendations among which was the 'encouragement of the development of Aboriginal Health workers by the Aboriginal Co-operatives' (1980:8). The Working Party on Aboriginal Health reported on this matter to the Victorian Health Minister in 1981.

The poor health status of Indigenous people, their particular cultural needs in accessing public hospital care and the historical insensitivity of hospitals to those needs were acknowledged, and the AHLO program was established within the Health Commission of Victoria in 1982 by the Koori Health Unit. According to *The Aboriginal and Torres Strait Islander Hospital Accreditation Community Report* (VKHRCU 2004:2), 'This was to be the first major step in changing the hospital environment to meet the cultural needs of the Koori community'.

An Aboriginal health worker (hospital liaison officer) was located in each of sixteen public hospitals in Victoria to provide emotional, social and practical support to Aboriginal patients and their families, and to advise hospital staff members about the needs of their clients. According to Saggars and Gray (1991:160), one of their chief roles was to act as 'cultural brokers'.

The number of hospitals with AHLOs grew to eighteen—fourteen in rural Victoria and four in Melbourne—but never reached the recommended figure of forty-three positions. Atkinson (1990:49) noted in his review of the service:

The 1981 Working Party on Aboriginal Health recommended the establishment of 43 Liaison Officer positions. This suggests that the scheme is presently understaffed with its 18 positions, which could be adding to the existing work pressures of officers.

This gentle understatement was indicative of the difficulties in achieving greater acceptance of the need for meeting the agreed target workforce placements. (Since the late 1990s a number of public hospitals in Victoria, which were not included in the AHLO program but identified the need for a similar service for their Aboriginal patients, have employed Indigenous health workers from their own hospital budgets.)

The Koori Health Unit of the DHS reviewed the AHLO program in 1994, and program guidelines were developed in 1996. However, little has been published about the program by the liaison officers themselves or by the hospitals in which they work, or about the care

the hospitals provide for their Aboriginal clients. A notable exception to this is *Lookin' after Our Own*, a major study conducted by Clarke, Andrews and Austin (2000) of the Aboriginal Family Support Unit at the Royal Children's Hospital in Melbourne. The study examined the history of Aboriginal health and the experiences of Indigenous families whose children needed to attend the Royal Children's Hospital for medical care. Members of the Aboriginal Family Support Unit also conducted interviews with children's family members for the study. The results confirmed the crucial role of the Unit for Support of Indigenous Families at the hospital, and the importance of cross-cultural education for non-Indigenous staff members. It also highlighted the great difficulties for some families—especially those from rural areas—in getting their children to the hospital to attend medical appointments.

There is insufficient research exploring the needs of rural Aboriginal women, particularly those needing transfer to metropolitan public hospitals for specialist obstetric care. There is little examination of the working conditions of AHLOs and, therefore, of their ability to care for their clients adequately. Some literature has indicated that they are overworked and under-resourced. Atkinson (1990) found that the Working Party on Aboriginal Health's recommendation for forty-three Aboriginal hospital liaison positions was considered not only to be a minimum but also an interim measure.

What is known is that most of the AHLOs are attached to the social work departments of the hospitals in which they work, and that this has been so since the start of the program, as 'it seems that Liaison Officer work is related or overlaps with the operations of these (Social Work) sections' (Atkinson 1990:12).

Notwithstanding this important development in Victoria, and the establishment of programs in other States to assist Indigenous patients in mainstream hospitals, Atkinson (1990:1) argued that, 'It is abundantly clear that we can ill afford to take comfort in the assumption that conditions have significantly improved in the broader picture of Aboriginal health care'. In view of some recent indices of Aboriginal health, it is apparent that sixteen years later this statement remains just as valid.

The causal connection between health status and the social and political context in which it is embedded is clearly articulated in the recent literature examining Indigenous health patterns. The most dominant feature is that of inequity in outcome due to 'dispossession of land rights, poverty, discrimination, poor housing, unemployment and racism, which is observed in Aboriginal communities throughout Australia' (Borthwick 1981:40). Henry, Houston and Mooney (2004) argued that Australian health care is racist, and that the consequences of this include a lack of trust in the health system by Aboriginal people and a lack of confidence in their own culture.

Obstetric status of Aboriginal women

It has been argued by Dugdale and Watlemaro (2001), in a study of a rural community in Queensland with a large Aboriginal population, that the range of health outcomes for Aboriginal people is just as diverse as for any other cultural group, and that blanket stereotypes need to be avoided. Statistically, however, obstetric outcomes for Aboriginal

mothers and their babies are much poorer than for other Australians, based on several criteria:

- The proportion of low birth weight (less than 2500 grams) babies of Aboriginal mothers is twice that of babies of non-Aboriginal mothers; that is 15 per cent in the Aboriginal group, compared with 7 per cent in the non-Aboriginal group (DHS:2004).
- The difference appears strongly related to socio-economic status. Townsend, Davidson and Whitehead (1992), in a major British study examining inequalities of health based on occupational class and dividing people into five categories, found that people in the poorest occupational class were three times as likely to have a baby under 2500 grams as those in the richest group. The detrimental long-term health effects of low birth weight have been well documented.
- The perinatal mortality rate (which measures stillbirths and neonatal deaths within twenty-eight days of birth) among Aboriginal babies (2.37 per cent) is more than twice the rate (0.97 per cent) of all Victorian babies (DHS 2004). Loughran was quoted in a newspaper article by Nader in the *Melbourne Age* (2004:4) as arguing that the significantly higher rate of infant mortality within the Indigenous community is related to the 'lack of cultural understanding between patients and health-care providers'.

For all these reasons, Campbell (2000) considered Aboriginality *in itself* to place a pregnant woman in the 'high-risk' category. Her report, *From Her to Maternity*, examined different models of obstetric care available to Aboriginal women in Victoria, and included interviews with health workers and Aboriginal women. A significant proportion of outpatient obstetric care for Victorian Aboriginal women now takes place in Aboriginal-controlled health services, such as the Victorian Aboriginal Health Service in inner-city Fitzroy and the Rumbalara Aboriginal Co-operative in Shepparton; however, almost all reported births (98 per cent) to Aboriginal mothers in Victoria occur in mainstream public hospitals (ABS 2000). While acknowledging that some individual mainstream health workers provided excellent and sensitive care to Aboriginal women, Campbell (2000:24) argued that

consistency in appropriate service provision does not exist within institutions. Story after story maintains that contact with hospitals is regularly a traumatic experience for Aboriginal people. This trauma is in addition to that caused by their immediate medical needs.

The health status of Indigenous mothers and their babies has been nominated as a priority action area of the Koori Human Services Unit of the DHS because of its long-term implications for the health of Aboriginal people in general. It is now well documented that babies of low birth weight:

are at higher risk of illness and death as infants, and also at higher risk of developing cardiac disease and kidney disease as adults... Aboriginal women are more likely than other women to give birth when aged less than 20 years. Young mothers are more likely to have low birth weight babies and complications of pregnancy (DHS 2004:iv).

Since future health is known to be largely determined by the quality and appropriateness of obstetric and neonatal care, it is clear that this is an area of health care where there is significant potential for direct improvement in health outcomes for Aboriginal mothers

and babies, and therefore for Indigenous Australians in general. Importantly for this study, in Victoria a higher proportion of Aboriginal people than the general population live in rural areas. Every year, women and babies living in rural Victoria are transferred to hospitals in Melbourne for specialist obstetric and neonatal care.

Aboriginal people have no realistic choice but to attend mainstream services when hospital admission is required. Despite the widespread fear of hospitals, a consequence of their much worse health status is that they need hospitalisation more often than non-Indigenous Australians, and more often require specialist services, which, in Victoria, are concentrated in Melbourne.

Identification of Aboriginal people using health services

To draw meaningful conclusions about the health of Aboriginal people and their engagement with health services, it is necessary to know the Aboriginality of patients using mainstream medical services.

Accurate identification of Aboriginality when people attend public hospitals for care has been a long-standing problem throughout Australia, and has only been seriously addressed in Victoria during the past ten years. Correspondence to the Health Minister in 1984 commented that for Victorian Aboriginal people there was a total lack of reliable statistics to permit even the simplest measurement of health status. 'In 1982–83, only six Aboriginal patients were recorded admitted to Melbourne hospitals and in 1983–84, a mere seventeen were recorded. Both these totals are obviously grossly inaccurate' (Bollard & Jennings 1985:8). Twenty years later, although the data collected still varies—between States, between different health service providers in each State and even within each health service—the possibility for measuring health status in a meaningful way has improved enormously.

Since 1 July 1993, the Victorian government has required that all Australian-born persons being admitted to hospitals be asked whether they are of Aboriginal or Torres Strait Islander origin. (A patient's Aboriginality is determined simply by the response given to this question.)

However, a Victorian survey published by the Koori Health Unit of the DHS in 2000 (*Koori Health Counts—Counting Koori Births in 1998*) indicated that hospital admissions staff identified only 412 (that is, 48 per cent) of an estimated 860 Indigenous women who gave birth in Victoria to 870 babies, including multiple births, during 1998. Estimates were derived by comparing statistics from hospitals, the State Registry of Births, Deaths and Marriages, and the maternal and child health nurses in each local government area. Hospitals have, until recently, generally ascribed a mother's Aboriginal and Torres Strait Islander status to her child, and therefore have not correctly recorded the birth of a baby whose father is Aboriginal but whose mother is not. (This issue has been now been addressed at the Mercy Hospital for Women by asking obstetric patients about the Aboriginal and Torres Strait Islander status of their babies' fathers.)

Accurate identification of Aboriginal patients in public obstetric hospitals relies on hospital staff members:

- being aware of the importance of identification and the reasons for asking a woman if she is of Aboriginal or Torres Strait Islander origin on admission: the reason is to appropriately direct resources and to formulate policies and programs that can begin to reduce the disadvantage, and 'to assist in the development of policies aimed to redress disadvantages in Aboriginal health' (Clarke, Andrews & Austin 2000:55) and
- feeling comfortable about asking the question, thus maximising the likelihood that the question will be asked and in a manner that does not discomfort the patient.

It has been asserted that there has historically been reluctance on the part of admissions staff in Victorian hospitals to ask if patients are Aboriginal, particularly in metropolitan hospitals. However, Bollard and Jennings (1985:10) argued that 'such difficulties are more perceived than actual. Thorough explanation of the reasons for collecting the data, together with the advice that the Aboriginal community was seeking the information, were found to be highly persuasive factors.'

Of course, for accurate identification to occur a person must also be willing to acknowledge Aboriginal or Torres Strait Islander status when asked at admission. This in turn depends upon a patient being confident that he or she will not be discriminated against, but will receive care that is sensitive to, and affirming of, individual cultural needs. For the reasons of history and policy argued above, such confidence and trust is often missing when Aboriginal people attend hospitals.

Cultural respect

Betancourt (2004:953) noted that 'cultural competence is necessary for the effective practice of medicine'. The World Health Organization has defined health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (Townsend, Davidson & Whitehead 1992:42). For most Aboriginal people, the concept of health also relates to communal rather than just individual wellbeing, and their relationship to the land is also integral. Rather than owning land, people are '*owned by*' the land (Goold 2002). Culture is defined by the *Macquarie Dictionary* (Macquarie Library 1999) as 'the sum total of ways of living built up by a group of human beings, which is transmitted from one generation to another'.

In the context of health care Parsons, in Reid and Trompf (1990:108), asserted that 'culture involves the transmission of norms or patterned ideas and behaviours that become habitual ways of responding to health and illness, including therapeutic decision-making'. It may not be possible for non-Indigenous hospital staff members who are involved in the care of Aboriginal women to possess detailed knowledge of their many different beliefs and traditions. It is argued here that what *is* necessary, and possible, is for those staff members to be aware of the reality and the degree of the health disadvantages suffered by Aboriginal people, while also having an appreciation that the root causes of the disadvantage are both enormously complex and inextricably linked to the poor socio-economic, educational and employment status of the majority of their Aboriginal patients.

The reality of the plurality of cultural beliefs and traditions must be understood, and the valuing and affirming of cultural respect should be conveyed from staff member to patient through the episode of care.

Feedback from clients of public hospitals

If public hospitals believe they need to become more responsive to the needs of their clients, Draper (1997:7) argued, in her study of projects undertaken in hospitals around Australia, that ‘hearing the voices of consumers is the most effective way for hospitals to get good information about what needs to be done’. She also included patients’ carers in her definition of consumers.

Careful consideration of methodology is essential if useful feedback is to be obtained, especially from ‘vulnerable’ client groups, and direct contact (for example, by questionnaire or survey) is not always the most effective method. Draper (1997:38) also asserted that ‘written surveys appear to be inappropriate for patients of Aboriginal and Torres Strait Islander descent’, although no direct supporting evidence of this was given. Consumer organisations were considered able to advocate and provide information about the needs and experiences of the people they represent. However, Draper argued that there is little point in hospitals obtaining information unless there is also a commitment to implement study results, and to be clear about this in advance. Such a commitment involves a philosophical readiness for change and openness to criticism in order to improve services, and in most cases it also requires the allocation of extra resources. Commitment, therefore, needs to be accepted at a senior management level and at appropriate clinical levels.

Rural patients in need of specialist medical care in metropolitan hospitals

When a country patient is transferred to a metropolitan hospital for specialist care, a medical emergency—either existing or potential—is implied. This scenario, as well as the practical difficulties of having to travel a long distance from home to receive medical care, means that this group of patients and families has extra and particular needs.

Keleher and Ellis (1996), in a study focusing on the needs of rural Victorian patients (and their families) who required specialist metropolitan hospital care, found important factors in reducing the inherent distress: those factors were the level of available family support in Melbourne; socio-economic status; quality of *care* (as distinct from *treatment*); and information about services for rural families received from hospital staff. Family support and socio-economic status are directly linked, because the cost of travelling to Melbourne to visit and provide emotional support for a relative in hospital is prohibitive for many families. Egan in Schwenke (1988) argued that the single best indicator of the health of a community is its socio-economic status. The World Health Organization (2000) concurred, also noting that poverty is concentrated in rural areas.

The study conducted by Keleher and Ellis did not differentiate between cultural groups; however, given the low socio-economic status of most Aboriginal families, it can be inferred on this criterion alone that rural Aboriginal patients needing to transfer to Melbourne for specialist care will be among the most disadvantaged.

Indigenous women transferred for specialist obstetric care

De Costa and Child (1996) studied the types and rates of ante-natal complications suffered by Aboriginal and non-Aboriginal women admitted to King George V Hospital in Sydney. They found that during the study period 6.7 per cent of Aboriginal women were transferred from other hospitals, compared with 3.1 per cent in the non-Aboriginal group. Further, in the Aboriginal group, 38 per cent of pre-term births were to mothers transferred from other hospitals, compared with 27 per cent in the non-Aboriginal group (probability<0.001). This report did not distinguish between transfers from other metropolitan hospitals and those from rural areas. However, it appears that Aboriginal women and babies are more likely than other rural patients to need transfer for specialist care.

The research questions in this current study were:

- From the perspectives of rural health care workers, what aspects of hospital-based obstetric models of care are considered the most important for ensuring culturally sensitive care for Aboriginal clients?
- What, according to health care workers, have been the experiences of rural Aboriginal women, and their families, who were transferred to the Mercy Hospital for Women for specialist obstetric and/or neonatal care during the period from 1 April 2001 to 31 March 2003?
- What information about the Mercy Hospital for Women would rural Aboriginal health care workers like to have available to give to their clients who are faced with the prospect of transfer and in what format would they find the information most useful?

It is hoped that the study has contributed to improved care practices for staff members of mainstream public hospitals providing obstetric care for Aboriginal and Torres Strait Islander women, and to improved health by providing better information on clients' perceived needs as recognised by Indigenous health workers.

Chapter 2: The Research Approach

To conduct this study, it was necessary to produce a design that could answer the research questions in a manner that accorded with guidelines for working with Indigenous communities as provided by the National Health and Medical Research Council. The most fitting and congruent research design involved qualitative data collection and analysis methods. Given the wealth of objective data that is now collected about the socio-economic and health status of Indigenous women, and which can be understood in the context of history and social policy in Australia over the past 200 years, there is ample evidence of negative outcomes for Indigenous women accessing the mainstream health system.

Indigenous people and research

Aboriginal people's experience with research has generally been that 'it gets done to you—rather than by you or with you' (VKHRCDU 2000:25), and that the motivation for research by non-Aboriginal researchers has often been to satisfy their own needs more than any commitment to attempt to achieve an improvement in the health outcomes for Aboriginal people.

The belief of some Koori people is that non-Indigenous-controlled research has been used 'in producing information which is used *against* [my italics] Koori communities (Native title cases etc.)' (VKHRCDU 2000:24). Aboriginal people have been the subject of a great deal of research over many years, which has been concentrated too much on description of the problem, rather than focusing on achievable positive outcomes. Some Aboriginal people believe they have been 'the most highly researched people in the world' (VKHRCDU 2000:24). Mak *et al.* (1998:647), in a study of community health surveys in Aboriginal communities, observed that obtaining informed consent is a complex matter 'given the cultural, linguistic and power differentials which exist between non-Aboriginal health professionals and many Aboriginal people'. Humphery (2001:197) argued that research 'is intimately bound up with histories of colonisation'. Not surprisingly, there is great scepticism in the Aboriginal community about the value of research unless it is community-controlled or conducted jointly with Aboriginal people.

Despite the volume of research that has been undertaken, Aboriginal women continue to suffer a 'fourth world' standard of health (Sutherland 1998:3). Great care, therefore, must be taken in the choice of appropriate methodology when undertaking more research involving these women.

In addition to the ethical issues described above, the principal researcher in this study—a non-Indigenous hospital social worker—needed to be mindful of the particular mistrust within the Aboriginal community that often surrounds the social worker’s role. Families interviewed by the Aboriginal Family Support Unit at the Royal Children’s Hospital in 2000 were asked if they would see a social worker if no Aboriginal liaison officer was available: two-thirds responded that they would ‘definitely not’ (Clarke, Andrews & Austin 200:119). Although requesting to see a hospital social worker to discuss a personal issue is clearly different from agreeing to be interviewed about hospital experiences, some parallels remain.

Rather than requesting to interview patients directly, it was proposed to interview workers from the women’s local health services about their perceptions of their clients’ experiences and needs. In the context of Aboriginal women, who have no practical choice but to attend mainstream public hospitals when they need specialist obstetric and neonatal care, this was considered to be just as valid and more appropriate than approaching patients directly.

Research aim

Victoria has four neonatal intensive care units: one at the Royal Children’s Hospital (where no babies are born) and the other three in hospitals that have specialist obstetric services—the Mercy Hospital for Women, the Royal Women’s Hospital and the Monash Medical Centre. In 2002, just over 5000 babies were born at the Mercy, thirty-six to women who identified themselves to hospital staff as being of Aboriginal or Torres Strait Islander background. As noted in Chapter 1, the true figure is likely to be higher. During the period 1 April 2001 to 31 March 2003, Aboriginal obstetric patients were transferred from nine regions in rural Victoria to the Mercy—involving (usually) trips by ambulance to an unfamiliar hospital in a large city (which may itself be unfamiliar and seem overwhelming), as well as the inherent stress of the medical emergencies that necessitated the transfers.

The stated vision of the Mercy Hospital for Women in its annual report (2000) is ‘to build an enduring capacity and passion to serve those with special needs’. The hospital has, over many years, undertaken numerous activities aimed at enhancing the cultural sensitivity of the care provided to its Aboriginal clients, including those from rural areas. These activities have included the establishment of a full-time AHLO; cross-cultural training of admissions staff, who are responsible for asking women whether they are of Aboriginal or Torres Strait Islander origin; the establishment of a Koori Community Consultation Reference group to provide advice and feedback to the hospital regarding policies and practices; a Koori ‘Open Day’ in 2000; a permanent display in public areas of the hospital of Aboriginal artwork and posters; the development of outreach gynaecology service to the Echuca Aboriginal community; and the establishment of the ‘Transitions’ ante-natal clinic, which provides continuity of care in medical, midwifery and Aboriginal health

However, it was apparent that some staff, including senior clinicians in key positions, remained unaware that accurate identification of Aboriginal patients is important or why it is important. Comments from some senior staff can be generalised as, ‘why would I need to know which of my patients are Aboriginal, when we treat everyone equally?’ Most accept the explanation that it is crucial for delivering appropriate care, both at an individual level

during hospitalisation (for example, informing the Aboriginal Women and Family Support Unit of admission and for optimal discharge planning and timely referral to post-discharge support services) and at a program level (to target service delivery effectively, to begin reducing the disparity in health status between Aboriginal and non-Aboriginal Australians, and for the efficient use of public money).

This project aimed to inform non-Indigenous staff about the needs of Aboriginal women and babies transferred to the Mercy for specialist care, as perceived by rural health workers.

Research design

In order to explore the health care workers' views of issues relevant to rural Aboriginal women and babies who were transferred to the Mercy for specialist obstetric or neonatal care, and those of their families or carers, a qualitative approach was indicated. It was proposed to invite Aboriginal staff from the hospital or health service in each local area from where one or more women or babies were transferred to the Mercy during a defined two-year period to participate in a semi-structured interview, using questions to initiate discussion about their views of families' experiences. Questions drew on the literature and practice experience. Some important aspects of care for rural patients could be anticipated and these were included in the interview guide (see Appendix).¹ However, the major focus was on the extra, or particular, needs that Aboriginal women's health workers believed their clients had when faced with a medical situation requiring transfer.

A letter of invitation was sent to the chief executive officer and health worker at each rural hospital or Aboriginal health service in Victoria from whose area at least one patient was transferred to the Mercy for obstetric or neonatal care between 1 April 2001 and 31 March 2003. Prior to contacting the chief executive officers, the AHLO at the Mercy was requested to identify those areas from where Aboriginal patients came during the two-year period. She did this by checking data routinely provided by the hospital's Health Information Service. 'Rural' was defined as having a home address in an area with a non-metropolitan STD telephone code. No information identifying individual patients was requested or recorded.

Approval for the study was obtained from the Research Ethics Committee—Mercy Health and Aged Care and from the Human Ethics Committee, Faculty of Health Sciences, La Trobe University—and the Aboriginal Liaison Unit at La Trobe was consulted. A senior staff member at the *Onemda* VicHealth Koori Health Unit at The University of Melbourne, who also has extensive public hospital experience (including several years as an AHLO at the Royal Children's Hospital and as a member of the Aboriginal and Torres Strait Islander Hospital Accreditation Project team), agreed to co-supervise the project. A commitment to seriously consider and implement recommendations resulting from the study was sought from the hospital executive prior to it being undertaken.

¹ This research was conducted as part of a La Trobe University postgraduate degree, so all data is stored as per the requirements of La Trobe University, Faculty of Health Sciences Human Ethics Committee.

Before the study commenced, extensive consultation occurred within the Social Work Department and with the AHLO and Aboriginal health worker at the Mercy. Further consultation was undertaken with health professionals and researchers from outside the hospital who are involved in Aboriginal health care.

Of the seven rural hospitals and two health services that were invited to participate, four hospitals and two health services agreed to do so. One hospital replied that its AHLO position was vacant, one replied that its AHLO is male and therefore was not an appropriate person to interview regarding the needs of obstetric women, and one hospital did not respond.

Semi-structured interviews were undertaken with the nominated staff member(s) of the rural hospitals and health services that agreed to participate. The interview guide was used to remind the interviewer about broad topics to be covered. However, it allowed for inclusion of information that the interviewer may not have previously considered, but which was potentially very valuable.

Five of the six interviews were conducted in the rural towns where the Aboriginal health workers are employed, and one was conducted at the Mercy (at the request of the health worker, who was coming to Melbourne for a conference).

Most participants had previously met or had some contact with the Mercy Aboriginal health workers, one of whom was present on each of the rural visits. AHLOs and workers at Aboriginal health services are part of a relatively small group; most of them have worked in their jobs for a number of years and know each other.

Notes were taken during each interview and then, soon after the interview, detailed case notes and a written summary made. The summary was returned to the participant, both for confirmation of accuracy and to give participants the opportunity to add, elaborate or withdraw any remarks. Printed information about resources that had been requested by the participant during the interview was provided with the returned summary.

Chapter 3: Themes and Implications of the Findings

This chapter presents the findings from the six interviews conducted with rural AHLOs and health workers. It discusses themes that emerged from categorising and analysing the case notes, as well as the implications for the Mercy Hospital for Women and other Melbourne Level 3 obstetric hospitals (i.e. those with Neonatal Intensive Care Units) in providing culturally sensitive care for rural Aboriginal clients.

All participants considered their *contact* with the AHLO or health worker at the Level 3 hospital as essential. Contact is required both to ensure appropriate support for the woman and her family, and also for the rural worker, herself, to discuss with her counterpart at the metropolitan hospital the extent and nature of contact she had with the client prior to transfer and to communicate her perceptions of the client's and family's particular needs. All Victorian hospitals with NICUs now have Aboriginal health positions. Every worker interviewed stated that she always makes telephone contact with her metropolitan colleague as soon as she becomes aware that transfer will occur.

Therefore the *timing of contact*, at the point of transfer, was believed to be crucially important. As well as the cultural and emotional support derived for the client from meeting a helpful Aboriginal person at the metropolitan hospital, the most commonly identified practical needs were for assistance with transport and accommodation. As one rural health care worker said, 'there are three main issues: transport, accommodation and communication'. In the event of the AHLO at the metropolitan hospital not being available at the time of transfer, some participants stated that they would ring the Aboriginal community agency nearest to the hospital so as to provide a client with an essential link to an Aboriginal support worker. Communication at the time of a mother or baby's transfer back to the rural hospital, or discharge home, was also seen as vitally important. No research literature regarding contact between liaison officers at different hospitals was found.

Severe financial hardship was identified by each rural health worker as a major problem for clients—almost *all* of whom, along with their networks of family and friends, are solely reliant on Centrelink payments for their incomes, and consequently have no reserves of money on which to draw. Transfer to a Level 3 hospital therefore represents a financial, as well as medical, crisis for the overwhelming majority of clients of rural Victorian Aboriginal health workers.

The main purposes identified for which money is needed (immediately) are to meet the needs of transport, (relatively) low-cost accommodation and the basic requirements of patients being admitted to hospital, such as pyjamas and toiletries. Because obstetric transfer very often occurs in the context of extreme prematurity, and therefore many weeks or months

earlier than expected, women can be 'caught' unprepared and cannot ask family or friends (who are mostly in a similar financial situation) to simply go shopping on their behalf. One AHLO commented that the lack of such basic necessities is often a source of severe embarrassment for Aboriginal patients in mainstream hospitals. There is overwhelming evidence of the low socio-economic status of most Aboriginal people (ABS 2006:72).

Most rural AHLOs did not have a budget beyond their own salaries, and therefore had no capacity to assist financially with such emergencies. Some refer clients to local mainstream aid agencies or Aboriginal co-operatives. However, in the situation of emergency hospital transfer, there is usually insufficient time or ability to access these services. A perceived lack of confidentiality in rural agencies was also a concern to one health worker. Another reported that she regularly provides small amounts of money from her own pocket to assist clients with expenses.

Transport was identified as another major issue. When a baby is delivered at the local rural hospital, and transfer to a Level 3 nursery (NICU) is required, transport is arranged via the Neonatal Emergency Transport Service (NETS). This means that the baby, and not the mother, is the client. The mother has to make her own way to Melbourne, often following delivery by caesarean section, in order to be with her baby. She generally has to discharge herself 'against medical advice' from the local hospital, yet she is not eligible for ambulance transport. In this situation, most rural Aboriginal women rely on the assistance of the AHLO, or public transport, to get to Melbourne. (Rural health workers reported that their clients' families often do not have access to a reliable private car.) The destination Level 3 hospital sometimes changes during ambulance transport, between the time of the patient's departure from the rural hospital and arrival in Melbourne, because of a change in the bed-state at the receiving hospital. This, of course, adds to an already extremely stressful situation, depending on arrangements made prior to departure between the client, her family and health workers at both the rural and metropolitan hospitals.

The ability of the health workers to assist with transport varied markedly between services, and depended upon the availability of a car, the distance from Melbourne and other work commitments. Given the importance placed by health workers on transport as an issue, it was surprising to find that not all workers were familiar with the Victorian Patient Transport Assistance Scheme (VPTAS), which is operated by the DHS to provide assistance with transport and accommodation costs for people needing to travel more than 100 kilometres (one way) for specialist medical care. Additionally, one AHLO, although she knew of the scheme, commented that she doesn't advise clients to use it because there is 'too much paperwork' involved.

Transport difficulties for families attending appointments at the Royal Children's Hospital were documented by Clarke, Andrews and Austin (2000) and the expectation on AHLOs to assist with transport was discussed by Atkinson (1990); however, no literature was found about the transport difficulties for women whose babies had been transferred by NETS from rural to specialist hospitals.

Low-cost suitable *accommodation* for mothers (who are usually discharged from hospital while the baby is still in NICU) and family members was perceived by rural health workers as a major problem for their clients in Melbourne. The availability of appropriate accommodation varies across hospitals. At East Melbourne, prior to relocating to Heidelberg in 2005, the Mercy had two parents' bedrooms adjacent to the special care nurseries, which were intended for short-term stays and were not able to accommodate older children (there are four such rooms at Heidelberg).

Vizard House, located close to the Mercy at East Melbourne and operated by the Lions Club on a non-profit basis, was not familiar to all health workers interviewed but was well regarded by those whose clients have stayed there. Similarly, Indigenous Hospitality House located in Carlton, while not known to all participants, was considered to be an important resource by those health workers who did know of it. However, some people commented that its usefulness is significantly limited by its closure during school holidays. Information pamphlets about both these services were sent to participants who had not previously known about them. Clarke, Andrews and Austin (2000) highlighted the problem for rural Aboriginal families whose children need hospital care in Melbourne, and noted that families usually feel more comfortable if accommodation is available within the hospital.

Hospital identity did not emerge as a major theme because rural Aboriginal health workers did not distinguish greatly between the care received by their clients at the Mercy and Melbourne's other Level 3 obstetric hospitals. Two main reasons for this appear to be:

- the chronic shortage of maternal and NICU beds, which means there is almost never a choice of hospital, so women or babies are transferred to whichever hospital has a bed (although, whenever possible, families from Gippsland are transferred to the Monash Medical Centre, while families from northern and western Victoria access the Mercy or Royal Women's Hospital); and
- the names of individual patients transferred to the Mercy during the chosen two-year period were not obtained. Therefore, health workers usually did not have particular 'Mercy' clients in mind when they were interviewed, but generally spoke about their perceptions of a *number* of clients' experiences of being transferred to Melbourne for Level 3 care, regardless of which hospital happened to be involved. This was simultaneously a limitation of the study (less information than expected was obtained specific to the Mercy Hospital for Women) and a strength, since many of the findings are likely to be also applicable to other Level 3 hospitals in Melbourne caring for rural Aboriginal families.

One worker commented that, because of the shortage of maternal and NICU beds, rural Victorian women and babies are quite often transferred to Adelaide; this does not receive the publicity that occurs on the less frequent occasion when a mother or baby from Melbourne has to be transferred interstate owing to a lack of suitable beds.

Consistent with the finding by Atkinson (1990) that acceptance of, and engagement with, hospital services by Aboriginal people is higher in hospitals with AHLs, rural health workers expressed a general satisfaction with the *appropriateness of care* received by their

clients in Melbourne's Level 3 hospitals, so long as the AHLO was available (none reported any specific problems or complaints about non-Indigenous staff caring for their obstetric clients). However, the particular needs of Aboriginal patients are not always recognised. One health worker stated that Aboriginal women's cultural needs ought to be given respect by hospital staff members equal to that accorded the religious beliefs and requirements of other patients; this level of respect was not perceived to be consistently demonstrated in mainstream hospitals, either specialist or local.

Several health workers commented that their *clients' need to return home*, often quite soon after a baby's birth and while the baby is still in the NICU section of the special care nursery, is often misinterpreted by metropolitan hospital staff as 'poor maternal bonding'. However, health workers reported there is nearly always a more practical problem, such as nobody to care for older children at home (one health worker commented that Aboriginal women usually do have 'a mob') or that they desperately miss other family members, who may not be able to come to Melbourne to give support. The difficulties for rural Aboriginal women remaining in Melbourne while their babies are in hospital therefore appear to result from a combination of lack of support, money and suitable accommodation.

One AHLO commented that she believes that when women return home, possibly travelling back and forth to visit their babies, there is a high rate of undiagnosed postnatal depression, possibly in part due to being caught 'half-way' between the support systems of the Level 3 hospital and that of the local community, for example the maternal and child health nurse. (There is known to be a high rate of clinical depression among mothers generally of babies in NICU; in some cases this is postnatal depression, while other mothers suffer from a reactive depression to what went 'wrong', feelings of guilt and grief over the loss of the expected normal pregnancy and healthy baby.)

All health workers interviewed considered that a network of Melbourne-based, 'ex-NICU' Aboriginal families could provide valuable informal support to rural families whose babies are inpatients of special care nurseries in metropolitan hospitals.

One health worker spoke of the particular importance that many Aboriginal people place on a person's birthplace, and that the family of a baby transferred in utero to a metropolitan hospital might therefore consider him or her to have been born in the 'wrong' place. This can lead to a sense of disconnectedness from country, which may continue long after mother and baby have returned home. She suggested that a simple yet powerful way to alleviate this problem would be for the birthing suite staff to offer an Aboriginal woman her placenta to take home for burial, thus creating a physical and symbolic link between mother, baby and the land.

One question in the interview guide asked about the worker's perception of any link between clients' satisfaction with their care at the Mercy and the medical outcomes for their babies. The first person interviewed replied that the number of her clients to whom this could apply was too small for her to make any meaningful comment. Upon reflection, the interviewer believed this would also apply to other participants, and so this question was not asked during later interviews.

Some of the problems experienced by rural Aboriginal women, such as problems with transport, accommodation and the costs associated with being away from home, will also be familiar to rural non-Indigenous patients of low socio-economic status. Other specific issues, such as the widespread fear of hospitals and discrimination, are much less likely to be shared by non-Aboriginal patients.

Issues for local hospitals was an important (although unforeseen) theme to emerge from the interviews and case notes. Some of the hospitals and health services visited have very large catchment areas, and raised issues of access, transport and accommodation even for women attending the 'local' hospital, which may still be a long distance from home. Workers at hospitals close to State borders also contend with significant anomalies affecting their clients, depending on which side of the border they happen to live. Some examples given of this were that women living on one side of the border are entitled to free antenatal education at the local hospital, while those on the other are charged for the service, and the differences in the State-administered schemes to assist rural patients financially with transport and accommodation costs. While the VPTAS can assist Victorian women living more than 100 kilometres from suitable medical care, women from New South Wales have to travel more than 200 kilometres to qualify for their assistance scheme. No literature was found discussing these issues.

The perceptions of AHLOs and health workers about levels of sensitivity of care at the local hospitals varied widely and emerged as a significant theme. It was considered that participants may have felt comfortable discussing this with people not connected in any way to the local hospital. Also, local issues are experienced on a daily basis for workers and their clients, whereas dealing with any of the metropolitan hospitals and staff will only occur occasionally when a client is transferred for specialist care.

There was marked variation between the information about hospitals that the interviewed health workers had available for clients. One AHLO had current printed information on all Level 3 hospitals, but several people had very little information and relied on verbal information from the metropolitan hospitals' AHLOs. Printed pamphlets, or information that can be downloaded from the Internet, were considered to be useful to give to clients. One health worker suggested that she would like to have a fridge magnet with the contact details of metropolitan hospitals' AHLOs.

All health workers interviewed were aware of the Mercy's pending move to Heidelberg. It was generally considered that access by car would be easier, either from the east or via the Western Ring Road, than the East Melbourne location. Access by public transport may be more difficult for rural families, as the hospital is now further from the city, but its location immediately adjacent to the Heidelberg train station was considered an advantage. The provision of low-cost accommodation in the vicinity of the new hospital was seen as very important. There was discussion of the Lions House accommodation project, which is proposed to be built on the site of the Repatriation Hospital for the use of rural families attending either the Mercy or the Austin Hospital, with a connecting shuttle bus.²

² The State government has allocated land for the Lions House accommodation project, however permission for construction to begin has not yet been given. In the meantime, the Lions House Foundation has leased a 4-bedroom unit close to MHW, with priority given to rural families with babies in the special care nurseries. For low-income families with VPTAS eligibility, there is no out-of-pocket expense.

Chapter 4: Putting the Findings into Practice

This study sought to examine:

- the aspects of care considered by rural Aboriginal health workers to be most important for culturally sensitive hospital care for their clients;
- clients' experiences—from the perspectives of the health care workers—of being transferred to the Mercy Hospital for Women for specialist obstetric or neonatal care; and
- the information the health care workers would like to have available for clients who are faced with the prospect of transfer.

From analysis of the interview case notes, the most significant themes were found to be:

- the assistance and availability of AHLOs in metropolitan hospitals for communication and support;
- the sensitivity of hospital staff members to the cultural needs of Aboriginal women and families;
- the extremely difficult financial situation of almost all clients; and
- the implications of difficult financial situations, especially regarding transport and accommodation.

Most AHLOs and Aboriginal health workers employed across the State's public health system are in sole positions. The implications of this are that since no person can be on duty around the clock, each hospital or health service that employs only one person will inevitably have significant amounts of time when that person is unavailable. Consequently, there was a high level of reported stress and perceived lack of support on the part of solo workers. A number of participants commented on this and said that their best sources of support are their AHLO colleagues at other hospitals. Non-Indigenous hospital staff members were often perceived to have unrealistic expectations that the health worker would have expert knowledge of, and responsibility for, all issues relating to all Aboriginal patients attending the hospital. One rural AHLO, whose hospital does not have a full-time security guard, commented that she is expected to fulfil this function in relation to Aboriginal families.

In the context of maternal transfer following delivery by caesarean section at the local hospital, the expectation on AHLOs to provide transport raises occupational health and safety issues and the questions of legal responsibility and duty of care for the client's safety.

The serious health disadvantage suffered by Aboriginal Australians, and the great importance rural health workers attach to timely access to metropolitan hospital AHLOs, has implications for *all* large metropolitan public hospitals. At the time this study was conducted, only six public hospitals in Melbourne employed (either directly or through the DHS) AHLOs or health workers. This included the Mercy and the other three hospitals with NICUs; however, there are many other public hospitals providing specialist State-wide services to which rural patients are transferred that have no Aboriginal health workers to provide patient support.

From January 1999 until 30 June 2004, the Victorian State government paid a 10 per cent supplement to the Weighted Inlier Equivalent Separations (WIES) payment to public hospitals for providing inpatient care to Aboriginal patients. In 2001, the DHS commissioned the Australian Institute for Primary Care at La Trobe University and the VicHealth Koori Health Research and Community Development Unit (now *Onewda* VicHealth Koori Health Unit) at The University of Melbourne to conduct the Aboriginal and Torres Strait Islander Hospital Accreditation Project. Eight Victorian public hospitals, including the Mercy, were studied in regard to their practices around the identification of Aboriginal and Torres Strait Islander patients and the provision of services to those patients. A direct outcome of the accreditation project was the decision to increase the WIES supplement from 10 per cent to 30 per cent, from 1 July 2004.

In order to receive the supplement, each hospital has to account for the money it receives, and demonstrate that it is being used effectively to provide appropriate care to Aboriginal patients. For hospitals with a sufficient number of identified Aboriginal patients, and therefore with WIES payments to cover a salary, employment of an Indigenous health worker is now required along with other measures to demonstrate better care.

All interviewed Aboriginal health workers identified the extreme financial hardship of clients facing transfer for specialist obstetric or neonatal care: given the implications of this financial hardship for issues such as transport, accommodation and basic personal needs such as toiletries, it is argued here that it should be possible for such expenses to be covered by hospitals (either individually or collectively) within the increased WIES money received for care of Aboriginal patients. The WIES payments for the care of some babies can be high, for example around \$200,000 in the case of an extremely premature baby. The 30 per cent WIES loading for a single Aboriginal baby is, therefore, potentially around \$60,000. The majority of rural babies return to their local hospitals prior to being discharged home, so the WIES payment is shared between the hospitals, but most of the money goes to the metropolitan hospital providing the Level 3 (intensive) care.³

This study, therefore, occurred at a time when the Victorian government had resolved to allocate significant extra resources to public hospitals for their care of Aboriginal and Torres Strait Islander patients, in return for much-improved accountability. It also coincided with a commitment from all of Australia's medical schools to include cultural competence as a compulsory aspect of student training. It is important that university schools responsible

³ Hospital administrators have argued that when they are 'over their WIES targets', as they frequently are, and get no more money for treating the 'extra' patients, then the 30 per cent loading becomes meaningless. At the time of writing, this remains an issue of contention between hospitals and the DHS.

for the training of other health professionals—including nurses, social workers and other allied health disciplines—also pay serious attention to the inclusion of appropriate cultural training in the core competencies for students.⁴

As argued by Oldenburg, McGuffog and Turrell (2000:492):

Health professionals can play an important role in recognising that the determinants of health are rooted in factors ‘upstream’ from the healthcare system (broadly, the economic, social and cultural fabric of our society) and in promoting strategies that will influence these upstream factors. However, they also have a contribution to make through their own professional and clinical practice as part of a whole-of-society effort.

Within hospitals, *ongoing* cross-cultural training is vital to ensure that staff members (who are, of course, not all university educated) coming into contact with Indigenous patients have at least a broad knowledge of the reasons for the poor health status of Aboriginal Australians since white settlement, and an understanding that, before then, ‘Indigenous Australians were healthy and maintained physical, emotional, mental and spiritual wellness’ (CDAMS 2004:7). Hospital staff also need to know about and respect the traditional importance ascribed to ‘men’s business, women’s business’ in the appropriate delivery of public hospital health care for Aboriginal people.

Hospitals must recognise that the delivery of culturally sensitive care for Aboriginal clients also means actively supporting the employment of Indigenous staff members, and training and apprenticeships for Indigenous students, and providing a physical environment that is welcoming for Aboriginal patients and families. Effective, ongoing consultation with the local Indigenous community and agencies is integral to the provision of culturally sensitive care.

Limitations of this study

The constraint of ‘outsider mistrust’ is always a reality for a non-Indigenous person (and especially a social worker) involved in research in this area, even when the study is conducted with Indigenous supervision and in conjunction with Aboriginal people. This study did not reach saturation, owing to the limitations of time and funding. Each interview added some new and different insights. It would have been valuable to invite liaison officers and health workers in *all* rural areas of Victoria to participate—owing to the scarcity of Level 3 obstetric beds and NICU cots, and the consequent lack of choice of hospital, the next woman to be transferred to the Mercy could come from any of these areas.

⁴ In 2005, the Australian Research Council awarded a linkage grant—From Colonisation to Conciliation: A Collaborative Examination of Social Work Practice with Indigenous Populations—to The University of Melbourne’s School of Social Work and Centre for Health and Society, the School of Social Work at Michigan State University, the Royal Children’s Hospital (Melbourne) and the Mercy Hospital for Women (Melbourne). The aim of the project, which commenced in March 2006, has been summarised thus: ‘The social work profession, along with many other human service professions, has a complex history of working with Indigenous populations. One of the significant factors in the maintenance of this problematic relationship is the marginalisation of Indigenous issues within mainstream social work practice. This project, in collaborating with Indigenous communities, social work practitioners and academics in Australia and the United States, will examine current practice needs and their interrelationship with current social work pedagogy. This analysis will identify ways in which social work practice can enhance, rather than inhibit, Indigenous well-being, and how social work education can be reframed so as to engender such practice.’ (See www.c2c.unimelb.edu.au)

Benefits of the study

Benefits of the study to date have included the establishment of personal links with rural hospital staff, such as AHLOs caring specifically for Aboriginal clients, and others including midwives and social workers with responsibility for working with clients from all cultural backgrounds. Contact has continued with some of the people met during the rural visits. Rural health workers were appreciative of the time involved in making the visits, as reflected in comments such as, 'nobody ever comes to us—we're always the ones doing the travelling'.

The gaining of first-hand knowledge of some of the rural towns, hospitals and health services from which clients are transferred and to which they return will be of continuing importance for the researcher and the accompanying Mercy health worker, and hence clients.

Through an increased knowledge of the issues gained during this study, and through meeting with Indigenous and non-Indigenous people who are working in the field and who are committed to improving Aboriginal health outcomes, the author was invited to join the ARC Linkage Grant application (see last footnote) as a partner investigator.

Discussion has begun between the DHS, the Mercy, the Royal Children's Hospital, Monash Medical Centre and St Vincent's Hospital with the aim of making VPTAS more easily accessible to Aboriginal families, and recognising that a scheme based primarily on a reimbursement model does not effectively meet the needs of families who are unable to afford the up-front expenses of travel and accommodation. A pilot study, known as the 'VPTAS Quality Improvement Project for Aboriginal Patients', that has seen the establishment of a VPTAS 'float' to provide immediate financial assistance to rural Aboriginal families attending these hospitals began on 1 August 2006.

The results of the present study have helped to inform the Mercy Hospital for Women's strategic planning for improving the services provided to Aboriginal women and families, and may also be of some use to other hospitals when considering similar issues.

Lowitja O'Donoghue (1998:5), in an address to graduating nurses in New South Wales, stated that:

The process of redressing the mistakes of the past will inevitably be long and slow and painful. But we must not be defeated by the enormity, or the long-standing nature of the problem. It is only by acknowledging causes, and understanding the impact of them, that we can begin to find solutions.

References

- Anderson, I. & Loff, B. 2004, 'Voices Lost: Indigenous health and human rights in Australia', *The Lancet*, vol. 364, pp. 1281–2.
- Atkinson, G. 1990, *Report of the Review of the Aboriginal Hospital Liaison Officer Scheme*, Health Department of Victoria, Melbourne.
- Australian Bureau of Statistics (ABS) 2000, *Occasional Paper—Hospital Statistics—Aboriginal and Torres Strait Islander Australians 1997–98*, Cat. No. 4711.0, ABS, Canberra
- ABS 2006, *Measuring Australia's Progress*, Cat. No. 1370.0, ABS, Canberra.
- Australian Department of Health 1974, *Workshop on Aboriginal Medical Services—Albury, NSW 5–7 July 1974*, Australian Government Publishing Service (AGPS), Canberra.
- Betancourt, J. R. 2004, 'Cultural Competence—Marginal or mainstream movement?', *New England Journal of Medicine*, vol. 351, no. 10, pp. 953–5.
- Bollard, P. & Jennings, G. 1985, *Victorian Aboriginal Health Statistics*, Health Commission of Victoria, Melbourne.
- Borthwick, W. 1981, *The Working Party on Aboriginal Health*, Health Commission of Victoria, Melbourne.
- Campbell, S. 2000, *From Her to Maternity*, Department of Human Services (DHS), Melbourne.
- Clarke, A., Andrews, S. & Austin, N. 2000, *Lookin' after Our Own*, VicHealth Promotion Foundation, Melbourne.
- Committee of Deans of Australian Medical Schools (CDAMS) 2004, *Indigenous Health Curriculum Framework*, VicHealth Koori Health Research & Community Development Unit, The University of Melbourne.
- de Costa, C. & Child, A. 1996, 'Pregnancy Outcomes in Urban Aboriginal Women', *Medical Journal of Australia*, vol. 164, no. 9, pp. 516–17.
- Department of Aboriginal Affairs (DAA) 1974, *Report of Activities for the Period 19 December 1972–30 June 1974*, AGPS, Canberra.
- Department of Human Services 2004, *Aboriginal Services Key Plan Indicators Report to June 2003*, DHS, Melbourne.
- Draper, M. 1997, *Involving Consumers in Improving Hospital Care: Lessons from Australian Hospitals*, Department of Health and Family Services, Canberra.

- Dugdale, A. & Watlemaro, I. 2001, 'Aboriginal Health: A sick minority skews statistics', *Aust J Rural Health*, vol. 28, no. 5, pp. 111–15.
- Ford, N. (ed.) 1998, *Aboriginal Health: The Ethical Challenges*, Caroline Chisholm Centre for Health Ethics, East Melbourne.
- Golds, M., King, R., Meiklejohn, B., Campion, S. & Wise, M. 1997, 'Healthy Aboriginal Communities', *Aust NZ J Public Health*, vol. 21, pp. 386–9.
- Goold, S. 2002, Indigenous Health: Political Will and Social Responsibility, Seminar presented at RMIT School of Nursing and Midwifery, RMIT, Melbourne, 9 May.
- Henry, B., Houston, S. & Mooney, H. 2004, 'Institutional Racism in Australian Healthcare: A plea for decency', *Medical Journal of Australia*, vol. 180, pp. 517–19.
- House of Representatives Standing Committee on Aboriginal Affairs 1979, *Aboriginal Health*, AGPS, Canberra.
- Human Rights and Equal Opportunity Commission (HREOC) 1997, *Bringing Them Home*, HREOC, Canberra.
- Humphery, K. 2001, 'Dirty Questions: Indigenous health and Western research', *Aust NZ J Public Health*, vol. 25, pp. 197–202.
- Keleher, H. & Ellis, J. 1996, 'Rural People Utilising City Hospitals: Issues for service provision', *Aust J Rural Health*, vol. 4, pp. 144–50.
- Koori Human Services Unit 2006, *Aboriginal Services Plan Key Indicators 2004–05*, DHS, Melbourne.
- Mak, D., McDermott, R., Plant, A. & Scrimgeour, D. 1998, 'The Contribution of Community Health Surveys to Aboriginal Health in the 1990s', *Aust NZ J Public Health*, vol. 22, no. 6, pp. 645–7.
- Mathews, J. 1998, 'The Menzies School of Health Research Offers a New Paradigm of Cooperative Research', *Medical Journal of Australia*, vol. 169, pp. 625–9.
- Mercy Hospital for Women (MHW) 2000, *Annual Report 2000*, MHW, Melbourne.
- Nader, C. 2004, 'Baby Death Rate Low, but Still a Worry', *The Age*, Melbourne, 16 September.
- O'Donoghue, L. 1998, *Healing Australia's Wounds: An Agenda for Nursing towards 2000*, NSW College of Nursing, Sydney.
- Oldenburg, B., McGuffog, I. & Turrell, G. 2000, 'Socioeconomic Determinants of Health in Australia', *Medical Journal of Australia*, vol. 172, pp. 489–92.
- Reid, J. & Trompf, P. (eds) 1990, *The Health of Immigrant Australia: A Social Perspective*, Harcourt Brace Jovanovich, Sydney.
- Reid, J. & Trompf, P. (eds) 1991, *The Health of Aboriginal Australia*, Harcourt Brace Jovanovich, Sydney.

- Saggars, S. & Gray, D. 1991, *Aboriginal Health and Society*, Allen & Unwin, Sydney.
- Schwenke, J. (ed.) 1988, *Aboriginal Health in Aboriginal Hands*, University of Newcastle, Newcastle, NSW.
- Sutherland, N. 1998, *Right of Ways: Working towards Improving Access and Equity for Indigenous Women in Mainstream Health Services*, Royal Women's Hospital, Melbourne.
- Townsend, P., Davidson, N. & Whitehead, M. (eds) 1992, *Inequalities in Health: The Black Report and the Health Divide*, Penguin, London.
- VicHealth Koori Health Research and Community Development Unit (VKHRCDU) 2000, *We Don't Like Research ... But in Koori Hands it Could Make a Difference*, VKHRCDU, The University of Melbourne, Melbourne.
- VKHRCDU 2004, *The Aboriginal and Torres Strait Islander Hospital Accreditation Community Report*, VKHRCDU, The University of Melbourne, Melbourne.
- World Health Organization (WHO) 2000, *World Health Report—Health Systems: Improving Performance*, WHO, Geneva.
- Wronski, I. 1980, *The Growth and Development of Under-5 Aboriginal Children in Shepparton/Mooroopna*, Health Commission of Victoria, Melbourne.

Appendix

Interview Guide

Please note that these questions are intended to initiate discussion, and are not fixed or rigid.

- Please tell me how you became an Aboriginal health worker—how long have you been doing this work, what does it involve, what kind of workload do you have, what sort of training have you had, are you a local person?
- Please tell me the story of what happens when one of ‘your’ women or babies has to come to the Mercy Hospital for Women for specialist care?
- Is there often a choice of hospitals or is it usually a matter of which Level 3 hospital has a bed or cot?
- How do the women feel about identifying themselves or their babies to Mercy staff as being of Aboriginal and Torres Strait Islander origin? What do you think are the most important factors in this?
- What sort of information and assistance do women and families need about travel to and from Melbourne and accommodation near the hospital? How adequate do you think is the assistance usually received?
- How do you usually advise the hospital of your involvement? e.g., via the patient, by referral letter or telephone call?
- What information about the hospital do you have to pass on to families? What would you ideally like to have, and in what format, e.g., brochure, website which could be downloaded?
- Do the women often have much contact with other Aboriginal people (e.g., Mercy staff, family or friends) during their stay in Melbourne? How important does this seem to be? What could Mercy staff do to help a patient who seems to be socially isolated if the AHLO is not immediately available when she is admitted?
- To what extent do women and families perceive that non-Aboriginal and Torres Strait Islander staff at the Mercy understand or respect their cultural needs? What do you believe are the most important of these?
- It is usually very stressful for families to visit NICU, especially for the first time. At this time of crisis, do most of your clients feel that appropriate support and information is received? Would some contact with other ‘ex-NICU’ Aboriginal families be helpful?

- What, if any, extra needs do you think your clients have being transferred to the Mercy from rural Victoria compared with those of non-Aboriginal and Torres Strait Islander women being transferred from metropolitan hospitals or health services?
- Do you usually receive adequate and timely information back from the Mercy when a woman or baby is discharged home or transferred back to the local hospital? What suggestions would you have for improved feedback?
- How closely do you think your clients' perceptions of care are related to the medical outcome, e.g., healthy baby, baby with some ongoing needs, stillbirth or neonatal death? When the outcome is not what they had hoped, how well supported do women and families feel at the Mercy? What different care needs do you think your clients have compared with other (non-Aboriginal) families at such times?
- The Mercy Hospital for Women will be moving to Heidelberg in 2005 and is reviewing all of its services as part of the preparation for the move. What suggestions would you make regarding the needs of your client group?

