2001

Aboriginal and Torres Strait Islander health at the end of the 20th century

Neil Thomson (Ed.)
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Aboriginal and Torres Strait Islander health at the end of the 20th century

Editor: Neil Thomson

Australian Indigenous HealthInfoNet
Perth
2001

www.healthinfonet.ecu.edu.au
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About the Australian Indigenous HealthInfoNet

The Australian Indigenous HealthInfoNet's mission is to contribute to improving the health of Australia's Indigenous people by facilitating the sharing and exchange of relevant, high-quality knowledge and information.

We address our mission by:

- undertaking research, including knowledge translation;
- disseminating relevant information;
- facilitating information exchange;
- providing Internet and related training; and
- developing Internet sites for Indigenous and other relevant agencies.

The HealthInfoNet takes a broad view of Indigenous health, along the lines of that promulgated by the National Aboriginal Health Strategy Working Party, and expanded by the National Aboriginal Community Controlled Health Organisation:

*health is not just the physical wellbeing of an individual, but the social, emotional, and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being thereby bringing about the total wellbeing of their community.*

As a result, we aim to facilitate the sharing of knowledge and information about a wide variety of issues of relevance to Indigenous health to the many potential users of this knowledge. The potential users include policy makers, health service providers, program managers, clinicians and other health professionals (including Indigenous health workers), researchers, academics and other teachers, students, and the general community.

In the ways we address these knowledge needs, the HealthInfoNet is an international model in knowledge management (KM) for the health sector. As such, we focus on people and organisational culture to stimulate and nurture the sharing and use of knowledge; on processes and methods to find, create, capture and share knowledge; and on technology to store and make knowledge accessible and to allow people to work together without being together.

Reflecting the diversity of the HealthInfoNet's target groups, an aspect of our KM functions which justifies special mention is our knowledge translation (KT) work - the branch of research which attempts to make the findings of pure and applied research available in a form that facilitates their translation into action. In addressing the knowledge needs of our various target groups, we research and develop specific knowledge for each of these groups.

Most of the knowledge generated by our research activities is made available on the HealthInfoNet's Internet site, which is the main means of dissemination. This knowledge includes detailed overviews of specific health topics, introductory material about specific conditions, regularly updated summaries of Indigenous health status, and brief answers to frequently asked questions. Knowledge of these types is complemented by useful information related to specific health areas.

Effective KM and KT require actions based on knowledge, so the HealthInfoNet also works directly with Indigenous people to improve their use of the Internet, and assists Indigenous and other relevant agencies in Internet site development - to make their knowledge and information accessible.

The work of the Australian Indigenous HealthInfoNet is undertaken currently by a small part-time team based at Edith Cowan University in Perth and an Indigenous Project Officer based in Brisbane. We are assisted in our work by an extensive Australia-wide network of HealthInfoNet Consultants.

The research functions of the HealthInfoNet are supported by funds from a variety of sources. The Internet-based functions of knowledge and information dissemination and exchange are made possible by a grant from the Commonwealth Department of Health and Ageing's Office for Aboriginal and Torres Strait Islander Health. The training functions are supported by external grants, and Internet site development work is undertaken largely on a cost-recovery basis. Edith Cowan University's Faculty of Communications, Health and Science and Centre for Public Health continue to support the HealthInfoNet.
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¹ Papers on a number of other major health problems, such as cardiovascular and ear disease, were presented at the ASM, but were not available for inclusion here.
Preface

I deeply regret that it has taken so long for these important papers to be published. The papers were presented originally at the 1999 Annual Scientific Meeting (ASM) of the Royal Australasian College of Physicians (RACP).

Reflecting the importance that the RACP attaches to the issue, Indigenous health was a major theme of the ASM. Six sessions over two days were devoted to various aspects of Indigenous health – the general policy context, lessons from the experiences of Indigenous peoples internationally, consideration of specific health services initiatives, and detailed examination of individual health topics.

Publication of the papers was delayed for two reasons. First, it had been hoped to include all papers presented at the ASM. The initial delay involved waiting for the ‘final’ papers. By the time that it was accepted that the final papers would, in fact, not be forthcoming, so much time had passed that it seemed hardly worthwhile proceeding with the publication. So, the second delay occurred when the publication was put ‘on hold’. It was decided eventually to proceed with the publication, largely because of requests for copies and in recognition of the considerable efforts that the authors had made in the preparation and editing of their papers.

Bearing in mind the audience at the ASM – mainly physicians – some of the papers in this publication have a definite medical and technical ‘flavour’. However, as Fred Chaney pointed out at the official opening of the ASM, physicians, as a group, are powerful in the formation of public opinion. As a result, it is important that they too are as informed as possible about Indigenous health issues.

Most of the papers still contain relevant and valuable material and lessons. I'm most grateful to all the authors who provided their excellent papers, and I apologise, again, for the delay in their publication.

Neil Thomson
Perth
November 2001
Good morning ladies and gentlemen.

My name is Richard Wilkes and I am a Darbarlyung Nyoongar of the Swan River and its plains and the Darling Ranges.

I am a Nyoongar elder in my tribal structure, as well in my own rights. I am also a descendent of the Beeliair which was led by Midgegooroo and Yagan. They are my tribal descendants from which I have descended, and through them my tribal connections are to the Mooro, Beelu, Weeriup, Waylo and Banyowlla tribes.

It is now my very pleasant task to welcome you people wherever you may come from all over the world to this great country Australia and into my part of this country of Western Australia for the Royal Australian College of Physicians 1999 Annual Scientific Meeting.

According to our oral history, Nyoongar people lived a quite reasonable level of good health over thousands of years before the coming of the whiteman and the early settlers.

To stop a headache, a wrapping of woven fur from koomal the possum or woven belts would be wrapped around the forehead.

Mother's milk would be used to clear congealed pussy eyes. Mother's milk was used to cure earaches as well as to stop a baby from crying.

Other cures were obtained from chewing herbs or mixtures of gum resin for stomach aches and fevers. The ultimate cure came from our very own doctors the Boylla gudjud huk, who knew all the cures I have mentioned and many more. They could tell what was ailing someone, and they would tell the patient or their carers or their leaders what was wrong with the person so that they could use the remedy.

The Boylla gudjud huk also used spiritual healing to heal ailing patients - sorcery or magic, call it what you like, but it is real way of healing our Nyoongar people. In the old days the land, our gnungyung bujora, was good to its Darbarlyung Nyoongar people.

Gnungung Bujora, our mother earth, looked after her people and our bidair Marmun Pannar, the father of seasons, copulated with our mother the earth to give her people six good seasons - not four but six seasons - which determined the health, food and the lifestyle of their people.

Then along came the invaders bringing with them a very unhealthy style of living. They were the carriers of many diseases and death for the river people, diseases that would kill more than their killer guns did.

After a period of time, the newcomers started to establish themselves here on the Swan River and the more land they took to develop the less safe it was for the Nyoongar people to live near them.

Massacres began to happen as the invader began to advance to take up more and more land. If the people did not obey, they were killed. Warriors, old men, women and children, the gun knew no age differences.

Warriors were rounded up and put onto Rottnest Island Jail - a jail that was built especially to hold Aboriginal men.

Many of our men died and they never returned to their homes or their families or their loved ones. If they died there and were buried there, then their spirits could not return to the mainland so therefore their spirits couldn't go into the dreamtime.

Women and you girls suffered as well. They were 'domesticated', and white seed was sown into black ground and the colour of our skin was changed forever.

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2 Mr Wilkes' address began in the Nyoongar language, but it has not been possible to confirm the written form of these words. So, rather than use possibly incorrect words, they have not been included here. Also, it was not possible to confirm the spelling of some of the Nyoongar words in this address. The Editor apologises to Mr Wilkes and the Nyoongar people for the omission of the initial part of the address and for any errors which may have gone uncorrected.
Many mixed-blood children were killed at or after birth by their mothers, sometimes by the mother and the black father and sometimes by the not so black father. The mothers' lives at this stage were pure hell but they had to do it.

Gradually mixed-blood offspring were accepted by the tribes. But not by the white authority, because round-up time of these offspring had begun, and they were placed in missions, foster homes and adopted out into white family homes as future servants or whatever they thought was best for the child at that time and place.

By this time, concentration camps were set up at Moore River north of Perth (called the Moore River Settlement) and down in the south in a place named Carrolup via the town of Katanning (called the Carrolup Native Settlement). These were the camps for the unwanted Aboriginal people of Western Australia - the refugees of this country. The only difference was that they didn't have another country to go to.

Bigger missions set up by the churches were the nurseries of the stolen and unwanted children. The churches also wanted to study and to convert the heathens into good, solid, god-fearing people. Smaller missions were set up in strategic places in the colonised country. These places were really slave labour camps. The new landowners at this stage controlled the destiny of the Nyoongar people at that time. The threat of punishment or death was the key to good behaviour.

The health of the new people flourished while that of the Nyoongar was just the opposite. The new landowners were able to use new hospitals, surgeries and medical outposts at will to check and keep their health in good order, while the Nyoongar people had nothing.

Nyoongar people could not get the same treatment and their land and resources were taken them. As people, they represented nothing, except human stock that could be had for as little as one meal a day.

Colds, flu, tuberculosis, consumption, measles, german measles, whooping cough, chickenpox and venereal diseases were rife in the deteriorating health of the oldest race of people on this earth. Penicillin was hard to find, especially when there was only a limited supply.

All these new diseases and sickness were blamed onto the magic powers of the Boylla gudjud huk, the Nyoongar doctor, so tribal groups blamed him and other tribes. Tribal revenge was sought and tribal clashes occurred quite frequently, because there were so many unexplained deaths.

All this happened from 1826 onwards and was still happening at the turn of the century. The 1905 Act was introduced and this law controlled the movements of all Nyoongar people throughout the State, especially the lower half.

Around September in 1953, a Nyoongar couple made local history by becoming the first Aboriginal husband and wife family to be granted permission to reside in a Western Australian State Housing rental home. Mr Richard Kickett and his wife Ruth were housed in Bishopsgate Street in Carlisle, a suburb of Perth.

Others followed. They all wanted to live like the white man, so the transition had begun. The State Government began to provide housing accommodation for them in towns. This was a sorry day for the Nyoongars, because what precious little land they had left they gave it to be housed in town and the promise of a better life. It would have been better to live the old way and then learn to live the new way before we made a decision.

Our people were still dying more and more into the 70s, 80s and 90s. More die a lot younger than other people living in this great country of ours. Men die in what should be the prime years of their lives and our women much the same, although they live ten to fifteen years longer than their male counterparts.

Suicide is happening too frequently among our children and teenagers, and a lot of black deaths in custody had been recorded. Professionals, family and ordinary people say that this is all due to alcohol and drugs, others say its sex abuse, others say its just plain suicide, but, at the end of the day, one can come to the conclusion that there are many menacing factors that are affecting our people to commit suicide.

For many years, mental health among our Nyoongar people was ignored. A lot of our people's health has been affected in some way by events that have happened to us in years gone by.

All these past histories of ill-treatment could be the foundation source of ill-health. What has happened to us could be the cause of sexual abuse, incest, family separation, drug and alcohol abuse, peer rejection, self rejection, etc, etc. However, we, as Nyoongar people, are aware of these problems and we are working hard with the Federal and State governments to develop strategies to improve
Nyoongar health in Western Australia. Organisations such as the State Office of Aboriginal Health and our own Derbarl Yerrigan Health Service and satellite Aboriginal Health Services are part of it.

I'm sure down the track our health will improve, but I also shudder at some of the empty promises made by our politicians. I remember one of the prime ministers saying that no Australian children should be living in poverty by the year 2000. I just wish this were true.

But some good things are happening, and, in welcoming you to Perth, I ask that your discussions and deliberations seek ways to improve the health and wellbeing of Nyoongar and other Aboriginal people. The wisdom and experience of the Fellows of the Royal Australasian College of Physicians should greatly assist the efforts being made by Aboriginal people throughout Australia to improve their own health. I wish you well in this important Annual Scientific Meeting.
Conference opening

Honourable Fred Chaney, AO

Introduction
My pleasure in having the opportunity to address you arises from three factors:

1. The fact that you are addressing issues of Aboriginal health at this conference
2. The way you have propagandised a link between health and socio-economic factors in your recent publication “For richer, for poorer, in sickness and in health ...” [1] and
3. The fact that tonight one of my sons is formally admitted as a Fellow into an organisation which reflects some of my own concerns and beliefs in its approaches to the first two matters mentioned.

Every parent would like to see his child in virtuous company. I address you in the belief that, given your concerns about the disadvantaged, you are such company.

My comments are those of a generalist to a group of specialists. If I can be of any service to you at all it would be to identify some of the issues which seem to me relevant to the difficulties in changing the unacceptable reality of widespread Aboriginal ill health. If they seem too obvious, I apologise, but you have my assurance however obvious they are inadequately addressed.

The need for stamina
One of the common features of involvement in Aboriginal issues is a sense of frustration at the seeming intractability of the problems. At the individual level this is particularly evident. Well-meaning newcomers to the field, properly conscious of historic and current injustice and under-provision, expect the application of their skill and goodwill in a new (ie. this year’s) enlightened era will soon make a difference. After a year or two of labour, the fact that there is little apparent change causes disillusion in some, resentment in others. I have seen plenty of examples of angry and even bitter responses to the “ingratitude” of those who are seen not to have responded to our “generosity”. Institutions can reflect the same impatience, turning attention to more responsive groups. The issues you are discussing are not intractable. They do require patient long-term effort rather than constant re-invention and useless searches for the golden key solution.

The political/economic barrier to environmental health conditions
One substantial, issue which is not intellectually contentious or difficult is the impact of the poor environmental health conditions of many Aboriginal people, particularly outside urban Australia. While there is formal governmental adherence to the notion that Aboriginal people are as entitled as other Australians to receive the range of services made available to other Australians [2], that formal adherence is not translated into action. Myths abound here. John Deeble and his colleagues laid to rest the myth that there is disproportionate expenditure on Aboriginal health [3]. The current Minister for Aboriginal Affairs in Western Australia, the Honourable Dr Kim Hames, may have performed his greatest services to the Aboriginal community when, prior to becoming Minister, he laid the ghost of another great myth urban myth, namely that there is over-provision of services for Aboriginal communities [4]. In fact, remote Aboriginal communities are the communities least likely to have proper water supplies, health services, essential services generally and – not of least importance – the normal enforcement of law and order. Good health, or indeed any other form of social progress, is unlikely to emerge from chaos and disorder. In all these areas there is clear and remediable discrimination against Aboriginal Australians which would not be tolerated for any other group. The cost of remedying these deficiencies would be large, but in no way beyond the capacity of the Australian economy. That we do not do so is a matter of political choice.

Poverty, inequality, demoralisation and health
A second area, more difficult to address, is the inter-relationship between health and other policy areas as well as factors, which might be thought to be outside the reach of government policy. Good health flows from more than a favourable genetic inheritance allied with good environmental health conditions. Wealthy English Lords die from drug abuse, an extreme demonstration of the reality that even in favourable economic circumstances without a satisfying life and adequate self-regard life can be nasty, brutish and short. When I read in the Australian Financial Review [5] of your report, For
Richer, for poorer, in sickness and in health... I cheered then rang the College for a copy. How important it is to have acknowledged

"Poverty and the Social Gradient"
The gap between rich and poor has increased in Australia over the past two decades. Research suggests that countries with a more egalitarian distribution of income have better health outcomes, and that policies which aim to reduce health inequalities must first address inequities in income distribution.

"Social Exclusion and Inclusion"
High levels of trust, feelings of belonging and community involvement are vital to the development of a positive and healthy society. Societies with high levels of economic and social inequity have less cohesion, more violent crime and higher mortality rates. Social support from family and friends and the existence of mutual trust and respect in the community have a protective health effect and assist people to recover from illness.

Certain groups within our society suffer disproportionately from social exclusion. These people include: the unemployed and work injured, people living with mental illness, migrants and refugees, sole parents, Aboriginal and Torres Strait Islander communities, the homeless, ex-prisoners, the chronically ill and older persons.

People who do not have access to social support die earlier, suffer more illness and are marginalised from society, making them emotionally and physically vulnerable.

These are part of the reality with which you have to deal, but which we hear too seldom debated. In the current drive for fiscal responsibility (which I support) and lower taxes (which I don't support at the cost of these sorts of remedies you advocate in that same publication), the political system is walking away from debating these issues. You are influential and must be prepared to join with journalists, academics, and churches—all the allies you can find—to promote debate.

You might ask 'why bother, what good will it do?' The answer is:

You are powerful in the formation of public opinion.

Politicians act when ideas are in good currency. That is how democracies work. Only a limited number of issues remain important in the public mind at any one time. Usually, health is one of them as we all have a personal interest in our present and future health. It was not only Paul Keating quoting Jack Lang, his mentor, who said, "In the race of life always back self-interest, at least you know it's trying." Tocqueville, using arguably more elegant phrasing, suggested that you must link the idea of rights to personal interest "which provides the only stable point in the human heart ..." [6]

In these post-80s but still greedy and self-interested times—we are driven to self-interest by being thrown onto the market in our working lives, as much as we create a market through self-interest. As was pointed out by Hamish McRae, there is a big discrepancy between GNP per head and welfare and that difference explains why between 1970 and 1990, when in the United States GNP per head climbed by about 30%, living standards in the United States hardly rose [7].

You can help engage the community's self-interest with these wider issues. You engage intimately with the public at an individual level. You are trusted and have influence. You are engaging the public, keep it up. If you can interest the community enough, governments will act.

The daily task
My next point is that in dealing with the Aboriginal community a pastoral approach may be vital. There may well be issues of the spirit which are central to what you are trying to remedy. If "spirit" is too daunting most would agree that "anxiety, helplessness and confusion" may well be elements of Aboriginal patients' circumstances when faced with illness and the need for medical attention [8]. The intensive work with Aboriginal mothers by the Nguntju Tjitji Pirni Corporation in Kalgoorlie, is an example of an attempt to connect with Aboriginal mothers in a way which gave them a network of social support and a forum for their empowerment, which helped those mothers make informed choices about their own and their families' health [8]. Such efforts are hard to maintain—at the individual level I have already referred to the possibility of disillusion and burnout. Bureaucracies of their nature do not lend themselves to consistent personal warmth or community development approaches, yet surely such approaches are at the heart of any chance to progress.
It is my intuitive belief that caring about people enough to take an active interest in them is likely to enhance their confidence and capabilities. That pre-existing belief led me to attach significance to the long-term follow-up of the late Dr Kevin Cullen’s work of 25 years ago with his regular counselling of Busselton mothers (non-Aboriginal mothers, I assume) about their children’s behaviour.

The Journal commentary on Dr Cullen’s initial report, is in terms which are relevant, I believe, to this issue of pastoral care, “... any paediatrician who deals with children and parents believes innately that his counsel and guidance makes some difference in parent-child relationships and in the behaviour of the child, even if so subtle as to be immeasurable. If he did not believe so, he would not be a paediatrician.” [9]

What I found even more interesting was the follow up to that research 20 years after the event which suggested significant beneficial differences among the group of children whose mothers had received Dr Cullen’s counselling and encouragement. The note on the follow up article says, in part, “It appears that the initial benefit obtained from active counselling of mothers about their pre-school children’s behaviour may be long lasting, favourably affecting the individuals’ psychological well-being, educational achievements, and social habits as adults.” [10]

Confidence building and encouraging positive rather than negative attitudes seem obvious beneficial things to do. Do we need further research to establish the notion that such things can enhance quality of life and health outcomes? After all, in industrial relations there are examples of doing no more than taking an interest in workers to enhance their productivity and in education a teacher’s belief that students are clever and can learn, can enhance both teaching effectiveness and educational outcomes – even measured I.Q.

What attitudes are brought to treating Aboriginals, and what efforts are made to overcome difficulties in communication and attitudes among the patients themselves are all part of the agenda of matters needing attention. These are matters which are directly in the control of the profession. I think that is well known to this audience, but do we face up to the challenge of acting on that knowledge, or do we go on recycling patients without regard to their capacity to benefit from treatment or your capacity to give the treatment which is beneficial?

That brings me to my final point, which unlike the last mentioned issue you do not control but which, again, you can influence. In all the complexity of issues – all the plethora of reports [11] 3 on what needs to be done to deal with established government priority areas of health, employment and education, what of the great symbolic issues?

Aboriginals as our First Nation

There is a major issue unaddressed, or at least inadequately addressed. It is my view that addressing it is fundamental to having a secure starting point from which to go forward in a way which will gain the commitment of Aboriginal people. I have expressed it elsewhere as follows:

“The unease in the relationship between Aborigines and the rest of us is not yet widely understood in the community. The task of reconciliation is more fundamental than achieving more equal social outcomes for Aborigines. There is a deeper issue that so far we have been unwilling to face. What we fail to acknowledge is that Aboriginal involvement in post-European settlement was involuntary and remains involuntary.

From their perspective, there is, and was, no choice. There was no consent. But that is not how the rest of us see it.

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3 Report on the Task Force on Aboriginal Social Justice, Volume 1, Government of Western Australia, April 1994, page 7 – “A further important context is the long history of efforts to benefit Aboriginal people, and to resolve their problems either in isolation or as part of programs directed towards the wider community. We refer to these later: at this point we wish to stress that we are very well aware of this work. When the Task Force commenced its work, one benevolent if sceptical observer noted that there must be 8,000 similar reports. The AAPA library in fact contains 800 reports on Aboriginal affairs produced since 1985, although there are certainly many more reports on specific aspects of Aboriginal affairs. It may be fair to comment that many of these reports have provided broad analysis rather than specific recommendations. This is understandable, given the magnitude of the problems they cover. The experience of the Task Force is also that it is difficult to move away from the ever more demanding investigation and description of problems to developing strategies and recommendations.”[11]
At present, our acceptance of Aboriginal Australia appears to depend on Aborigines accepting that they are part of Australia like other minority migrant communities. Like other minorities, they enjoy all the rights of citizenship but no more.

There is powerful resistance to any notion of inherent rights flowing from Aboriginality. The idea of a special status for the First Nation, which is part of the fabric of the United States, Canada and New Zealand, is not yet part of the Australian self-image. That is why Mabo has proved so hard to accept and why the notion of achieving agreed outcomes, on which the Native Title Act is based, has proved so hard to implement.

That is the tough core debate we have yet to have and must have. Long-term reconciliation means coming out of that debate with a common acceptance of the legal and moral basis on which we live together and would live and work together in the future.” [12]

The notion of recognition of Aboriginal people as our First Nations may seem very remote from your concerns. But the sessions later today on the comparative position in countries such as the United States and New Zealand may suggest that the different attitude and approaches, including the quite different degree of Constitutional recognition, in those countries are worthy of our consideration. I think that the unease in our relationship is something which has to be dealt with if we are to deal with the most difficult issue of all, namely obtaining Aboriginal commitment at the individual level. A notable contributor to Aboriginal health services in eastern Australia, Barbara Flick, dealt with what I have described elsewhere as the most important and most difficult issue which is in the area of Aboriginal responsibility. In the context of commending the current Federal health department’s work with State health departments, and the adoption of benchmarking (under the admirable leadership of the Hon Dr Michael Wooldridge), she was reported as saying, “Meeting … targets will also require our own people to take responsibility for implementing some life-style changes if the problems of obesity, diabetes and substance abuse are to be improved.” [13]

It is very hard to urge the leaders of the Aboriginal community to promote this vital element of the equation, in the absence of an honest and realistic attempt by governments to meet the service deficiencies referred to earlier, and where there is no attempt to rectify the lack of consensual basis to our ongoing relationship. Noel Pearson recently tackled the subject in a way, which for most of us would be impossible. Our own lives are so comparatively fortunate we would feel it was out of place to do so in the same manner. But it is also very difficult for Aboriginal leaders to lecture their fellow victims of dispossession and dispersal on the virtues of personal responsibility in the absence of an honest commitment by governments to play their part by providing equally for their Aboriginal citizens.

**Action is required on all fronts**

There is no single golden key to improving Aboriginal health. Your skills and your dedication are an important part of what is needed. So too the provision of basic services is essential. Engagement of Aboriginal communities, families and individuals is essential. A determination on the part of mainstream services to look after Aboriginals as effectively as the rest of the community is looked after is essential. But I don’t think that any of this will work as we would like until the unique status of Aboriginal people in Australia is recognised and our ongoing relationship is regularised. The High Court did away with the myth of terra nullius in 1992. That should have demonstrated to all of us that it is a myth the Aboriginal people are just another ethnic minority in Australia. The thought I want to leave with you is that until there is a political settlement we are not going to achieve all the results you seek. We need your best efforts if we are not to be lamenting the same problems in a generation.

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2. National commitment to improved outcomes in the delivery of programs and services for Aboriginal peoples and Torres Strait Islanders. COAG, 1992. 7 December.


5. For richer, for poorer, in sickness and in health, in Australian Financial Review. 1999.


Recent national initiatives in Indigenous health

Ian Anderson

It may seem like stating the obvious, but I want to preface this account by saying that I believe health care reform is critical if Australian governments are to effectively address the challenge of Aboriginal and Torres Strait Islander health. This is particularly the case given the demonstrably poorer health status of Aboriginal and Torres Strait Islander people. However, despite the fact that the Commonwealth commenced funding Aboriginal health programs soon after this was enabled by the constitutional changes of 1967 [1], the Commonwealth health portfolio did not begin to provide sustained national leadership in Indigenous health policy reform until the 1990s.

The significance of this historical failure in the provision of policy leadership is underscored by a comparative analysis of Indigenous health trends in North America and New Zealand. In documenting the relative institutional failure of the Australian health system to provide an effective infrastructure for Indigenous health care, Stephen Kunitz makes the point that the:

- different forms of federalism have had important implications both for the way that central and state governments deal with Indigenous people and for their health. These differences have tended to be more observable in regard to infectious than to non-infectious diseases, because health services that have been created have been better equipped to deal with infectious conditions. In general, where treaties have been signed and where the central government has assumed responsibility for relationship with Indigenous people, their general health and welfare are better than where state governments have assumed responsibilities (page 6) [2].

Arguably, within federal health systems central governments can play a strategic role in the development of mechanisms to compensate people, such as Aboriginal and Torres Strait Islanders, for whom existing State government or market driven health care services are ineffective, difficult to access or otherwise inappropriate. Within the structure of the Australian health care system, the Commonwealth health portfolio plays a lead role in negotiating and strategically developing the nations health care financing system. This occurs through negotiation with central Commonwealth agencies such as the Department of Finance, and Prime Minister and Cabinet in addition to a complex array of governmental, provider and consumer interests. Without Commonwealth health portfolio leadership in Indigenous health, it is difficult to envision how the link between improved service delivery and the financing of health care could be strategically consolidated. Further, such policy leadership would be a necessary pre-condition to the adoption of a needs-based approach to Indigenous health services development, and the possibility of supporting such services through the development of appropriate and effective linkages with related mainstream components of the health system.

The first attempt to develop a national framework to coordinate planning and Indigenous community participation in health policy development occurred in context of the implementation of the National Aboriginal Health Strategy (NAHS). However, the implementation of the NAHS had limited success in securing institutional reform within the health sector [3, 4]. As a consequence, following the evaluation of the NAHS, the administrative responsibility for the Commonwealth Aboriginal health program was transferred from the Aboriginal and Torres Strait Islander Commission to the Commonwealth Health portfolio in July 1995. This strategic move has subtly transformed the development and implementation of national Aboriginal and Torres Strait Islander health policy and strategy. In particular, there has been a greater focus on the development and utilisation of health portfolio mechanisms, structures and policy levers to achieve Aboriginal health outcomes through improved capacity and performance in the health sector. Other sectors of government, such as housing, environmental and public health infrastructure and education, are acknowledged to play an essential role in achieving outcomes in Indigenous health, but they are drawn into this health focussed framework through a number of formal and informal inter-sectoral structures.

In this paper, I wish to describe some of the current key current issues in national Aboriginal and Torres Strait Islander health policy. In order to do this I first wish to outline the strategic framework, or the set of institutional structures, providers and mechanisms developed by the Commonwealth Health portfolio in order to progress reform in the health sector. It is not possible to comprehensively survey all the issues relevant to national policy so the focus here will be on those priorities related to reforms in health service delivery. Detailed consideration of current risk and disease specific strategies will not
be possible. Using this examination of identified national priorities, I intend to identify the factors critical to the further implementation of the strategic approach that the Commonwealth has fostered.

The Framework Agreements in Aboriginal and Torres Strait Islander health

In the period following the transfer of administrative responsibility in Aboriginal health, priority was given to the development of Aboriginal Health Framework Agreements that commit signing parties to specific structures and processes as mechanisms to give effect to the national strategy in Indigenous health. These multi-sectoral agreements involve a joint commitment to improving Indigenous health outcomes by: the Commonwealth Minister for Health; State and Territory Health Ministers; the Chairperson of the Aboriginal and Torres Strait Islander Commission (ATSIC) and representatives of Aboriginal community-controlled health organisations [5]. They provide for agreement on:

• the development of national and state/territory level forums, involving all stakeholders to provide advice and input to policy and planning processes;
• the introduction of planning processes at the regional level with a focus on improving the capacity and effectiveness of primary health care services, and reducing access barriers to mainstream services by making these services more appropriate and sensitive to the needs of Indigenous people and establishing standards and quality assurance processes;
• the need to increase the level of health sector resources allocated to reflect the level of need; and
• the need to give priority to improving data collection and evaluation mechanisms.

As such, the Framework Agreements reflect the view that roles and responsibilities in Indigenous health are not clearly separated between the Commonwealth and the State/Territories. The principle being that both levels of government are 'jointly responsible for responding to the needs of all Australians including Aboriginal and Torres Strait Islander peoples' (page 222) [5]. Further, the Agreements consolidate the coordinating role provided by the Commonwealth health portfolio in the development of national health policy and the key role played by States/Territories in managing, coordinating and planning health care services.

Aboriginal Health Framework Agreements have now been signed for all jurisdictions (most of them in 1996) [6]. Progress in the development of regional plans is at various stages nationally, and it is probably too early to make clear evaluative comments about the success of this approach. Concerns continue to raised by the Aboriginal peak bodies representing the Aboriginal community sector, such as the National Aboriginal Community Controlled Health Organisation, about barriers to the maintenance of effective and equal partnerships in policy and planning [7]. The development of partnerships between Australian governments and Aboriginal and Torres Strait Islander communities is a central plank in current health strategy, so clearly this issue will require close monitoring and further development. Achievements to date, under the Framework Agreements, include the establishment of regional planning forums in all States and Territories (including the national forum: the Aboriginal and Torres Strait Islander Health Council); and the completion of regional plans for South Australia, central Australia (Northern Territory) and Queensland [6]. In facilitating the development of joint planning, the Commonwealth allocated $6.8 million, from the 1999-2000 financial year, to priorities identified within these completed regional plans [6]. Another important outcome of the Framework Agreements has been the development of the first National Performance Indicators and Targets for Aboriginal and Torres Strait Islander Health, to which all health Ministers agreed in August 1997 [6].

Within the current national policy framework there are core domains of policy and strategy development that constitute developmental themes. These are:

• developing the infrastructure and resources necessary to achieve comprehensive and effective primary health care for Indigenous peoples;
• addressing some of the specific health issues and risk factors affecting the health status of Indigenous peoples;
• improving the evidence base which underpins the health interventions; and
• improving communication with primary health care services, Aboriginal and Torres Strait Islander peoples and the general population [6].

Here I will focus on those component strategies that are critical to the development of primary health care capacity.

Primary health care services

Aboriginal and Torres Strait Islander primary health care services are currently seen to play a pivotal role in the implementation of a strategy for improving Aboriginal and Torres Strait Islander health outcomes. It seems obvious to say that primary health care usually constitutes a person’s first point of
contact with the health care system involving general practitioners, community nurses, community-based allied health professionals and Aboriginal and Torres Strait health workers. However, it is worth keeping in mind the complexity of the functional definitions of primary health care. For instance, according to the World Health Organization (WHO) primary health care is (page 16):

...essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individual and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country’s overall health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first elements of a continuing health care process.[8]

The conceptual approach advocated by the WHO to primary health care was consolidated in the National Aboriginal Health Strategy [9]. In broad terms, this functional definition continues to frame Commonwealth approaches to the reform of primary health care services, which are, for instance, defined as:

those health services which involve continuity of care, integration of prevention with sick care, a concern for population as well as individual health, community involvement and the use of appropriate technology. It will encompass those socially organised practices and programs which aim to protect, promote and restore people’s health through disease prevention and health promotion [10]

Currently Aboriginal and Torres Strait Islander people access an array of distinct types of primary health care service, including: Aboriginal community-controlled health services (ACCHS), State/Territory funded primary health clinics and mainstream community health services and private general practice. The Commonwealth Health department has argued that if health strategies are to be implemented in a way that takes account of the capacity of Indigenous communities, and their priorities and concerns, such strategies will require effective structures and mechanisms for Aboriginal Torres Strait Islander participation (pp222-223) [5]. There is a broad consensus that ACCHSs build such operational principles into primary health care delivery, and as such play a critical role in national Indigenous health strategy. However, it is fair to say that there continues to be disagreement between stakeholders about how to provide for, from a national level, an appropriate and effective mix of primary health care services. Further, there are difficulties in translating agreed principles of effective primary health care delivery into funding models that can be used to develop planning principles. For instance, one operational framework for the WHO model of primary health care identified its core components as:

- education concerning prevailing health problems and method of preventing and controlling them;
- promotion of food supply and proper nutrition;
- an adequate supply of safe water and basic sanitation
- maternal and child health, including family planning, prenatal care, qualified birth attendance, care of newborns, and monitoring child growth
- immunisation against the major infectious diseases;
- prevention and control of locally endemic (vector borne) diseases
- appropriate treatment of common disease and injuries; and
- the provision of essential drugs [11]

To this original list, other commentators have also added:

- basic oral health care
- mental health care;
- care of the physically disabled; and
- the use of effective traditional medicines [11]

However, the development of primary health care services needs to be closely attuned to the particular health needs and institutional context for health care delivery. Some components of this WHO operational framework are therefore less relevant to Indigenous health in Australia. For instance, the
prevention and treatment of locally endemic (vector borne) diseases is a component of Indigenous primary health care only relevant to particular regions. On the other hand, arguably one could identify chronic illness management as a critical operational element of primary health care service provision in Indigenous health contexts. The WHO operational model, to a certain extent, reflects the particular developmental context of the third world. Some work has been progressed that identifies the core components of primary health care service models for Indigenous Australians in remote area contexts [12]. However, not enough attention has been given to date to the development of operational models of primary health care for Indigenous Australians in rural and urban Australia. It is not possible to build financing models for primary health care services without some clarity on the different operational elements that need to be supported. Such clarity is particularly critical if there is to be effective negotiation between levels of government on the coordination of the resource inputs into Aboriginal primary health care services.

Health outcomes may also depend on how the different components of primary health care are operationally linked. For example, it has been argued that Aboriginal and Torres Strait Islander health outcomes require the development of primary health care services that integrate at a local and regional level clinical care, population health and health education/promotion activities (pp 222-223) [5]. Such primary care services also play a pivotal role in facilitating and organising inter-sectoral actions in health (such as with local housing programs or the development of community infrastructure) [5]. In other words, an effective approach to reform for Indigenous primary health care should provide for the development of components of service, as per health need, and integrate the delivery of such components.

There is not the space to review existing evidence to support the current national priority given to the development of Aboriginal and Torres Strait Islander primary health care capacity. However, it is worth noting that while there is broad consensus that this priority is defensible - the evidence framework that might enable an informed judgement of the likely impacts of improved Indigenous primary health care capacity and effectiveness is patchy. This issue will be returned to below.

In the delivery of primary health care services to Indigenous Australians, Aboriginal health workers play a key role, and are supported by a range of primary health care workers such as doctors, nurses. An appropriately skilled multi-disciplinary team is ideal to ensure the primary health service is effective. The critical issues in developing an approach to sustaining the development of such a system of care would entail a focus on the development of more effective strategies in health financing and workforce development.

**Health care financing**

Data that provide a comprehensive analysis of national expenditure in Aboriginal health have only recently become available. In their national expenditure study, the Australian Institute of Health and Welfare and the National Centre for Epidemiology and Population Health (AIHW/NCEPH) used the 1995-96 financial year as the base year, and took into account health funding provided to Aboriginal and Torres Strait Islanders through both 'mainstream' and specialised programs and from all funding sources (Commonwealth, State/Territory governments and the private sector). This study estimated that recurrent expenditures for and by Aboriginal and Torres Strait Islander people for all services and all source of funds was 8 per cent higher than for other Australians at $2,320 per person [13]. Taking into account income – the expenditure on the health of Aboriginal and Torres Strait Islander people was similar for Australians in the same income category – despite marked health differentials [14].

The expenditure analysis determined that, in terms of gross expenditure, $822 million was provided through government programs, with state/territory and local government accounting for 80 per cent of all government expenditure. The relatively smaller Commonwealth investment is directed through Aboriginal specific programs, such as the funding provided to the ACCHSs, and specific strategies in diabetes, sexual health, emotional and social health. In addition, the Commonwealth provides funding for health care through its mainstream Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS). Indigenous Australians had access to only 24 per cent of the per capita allocation of the MBS and PBS relative to that provided to non-Indigenous Australians in 1995-96. In another study of Aboriginal and Torres Strait Islander access to the MBS and PBS, it was reported that Aboriginal and Torres Strait Islander people everywhere encountered significant barriers to the effective utilisation of the resources provided through both these schemes. For instance, between 15-38 per cent of Aboriginal and Torres Strait Islander people were found to have no effective Medicare number or card. In urban areas, between 15-20 per cent of Indigenous people do not have access to current Medicare numbers [15]. According to the AIHW/NCEPH study, if all Commonwealth expenditure is considered, the per
capita expenditure for and by Indigenous Australians was 63 per cent of that of non-Indigenous Australians [13].

On the other hand, gross expenditures through state and local government programs are relatively higher with respect to Aboriginal and Torres Strait Islanders at a ratio of 2.19:1. This is a consequence of a number of factors. States and Territories provide, in some jurisdictions, Indigenous specific primary care services. Use of acute care hospital services is relatively higher, reflecting patterns of morbidity and, in some instances, poorer access to comprehensive primary health care service. The costs of providing health services to geographically remote regions are also a factor in the relatively higher expenditures at this level of government.

These studies of health financing point to some significant problems in the ways in which Aboriginal health care is provided for. All in all, given the level of morbidity in Indigenous communities, the global level of expenditure would seem to be too low. Further, the spread of investment does not appear as yet to provide the basis for the development of an effective and efficient comprehensive primary health care for Aboriginal and Torres Strait Islander people.

Since the Commonwealth health portfolio assumed responsibility for the Aboriginal health program, there has been consistent growth in expenditure provided through the Office for Aboriginal and Torres Strait Islander Health (from $116.0 million in 1996/97 to $155.0 million in 1998/99) [6]. This growth has resulted from a range of initiatives including: the allocation of new resources to the Aboriginal and Torres Strait Islander primary health care program; specific initiatives in sexual health, diabetes and eye health and appropriations that provide for collaborative environmental health initiatives with ATSIC. Further, some reforms of existing health financing mechanisms for the MBS and PBS have been developed (such as the provision of Section 100 arrangements for pharmaceutical programs in remote communities, or the provision for alternative funding mechanisms so that doctors employed by the ACCHSs are able to bill Medicare as an additional source of income for services) [6]. The Health Insurance Commission is also currently testing innovative approaches to enrolment on to the MBS in some regions [6]. Some of these reforms in health financing have established the conceptual grounds and consensus about the development of needs-based funding mechanisms. However, it remains to be seen whether such principles become consolidated in future funding structures. The performance audit of the Aboriginal and Torres Strait Islander Health Program also recommended, with respect the Indigenous specific program, greater emphasis on the development of needs-based planning mechanisms [16].

It is a fairly straightforward proposition – that the provision of health financing should support the development of effective and efficient health care services for Aboriginal and Torres Strait Islander Australians. However, while significant steps in the reform of health financing arrangements have been made, this requires further development and linkage with the planning processes in order to provide for a comprehensive, needs-based system of primary health care.

**Workforce development**

A critical issue for the development of effective health care for Indigenous Australians, is the development of an appropriate health workforce. It is possible to qualitatively characterise the mix of skills necessary for effective Aboriginal primary health care. This mix includes competencies in: cross cultural practice; chronic illness management; integrated population and clinical care service delivery; the provision of emotional and social health services; and an understanding of the relationship between health care provision, community development and self-determination. There is of course a spectrum of workforce development needs, ranging from the needs of the primary health care workforce as employed within the ACCHSs and other Indigenous specific programs, and the generic needs of the mainstream Australian primary care health workforce.

Increasing national workforce development initiatives in Indigenous health have strategically focussed on the primary care workforce. For instance, recent national initiatives include the development of regional workforce recruitment services, which have a particular focus on improving the recruitment and retention issues for Indigenous-specific primary health care focus. Also, the recent reviews of General Practice in Australia highlighted the need to develop the capacity of Indigenous specific and mainstream general practice [17, 18]. Professional health colleges and associations have focussed on developing their role in Aboriginal health, particularly with regard to health workforce development. For instance, the Royal Australian College of General Practitioners (RAGCP) has developed core curricula in Indigenous health for its general practice training program [6]. The RAGCP is also working in collaboration with the Commonwealth Department of Health and Aged Care to increase the number of general practice registrars seeking training placements in ACCHSs [6].
A strategic approach to workforce development in Indigenous health will require the development of a more detailed quantitative understanding of workforce requirements. In particular this would aid cross-portfolio negotiations on these matters, and might provide the needed additional leverage to align the institutional stakeholders in Aboriginal health workforce development within a shared strategy. In part, the processes of regional planning in Aboriginal health may provide some baseline data to these ends. Further, the agreement by Australian Health Ministers Advisory Council in October 1998 to support a National Aboriginal and Torres Strait Islander Health Workforce Modelling Project indicates the broad support for strategic action in this priority area [6].

There are now some longitudinal data available to assess trends in Indigenous participation in health sciences education training [19, 20]. According to this analysis, there is some doubt about the sustainability of current growth of Indigenous graduates in health sciences. Overall growth in these fields of study has been slow and has lagged behind other outcomes in Indigenous higher education. For the higher education sector, course graduations have continued to grow, but the numbers of people commencing new courses in health sciences has shown some signs of decline. Clearly this issue will require further attention in Indigenous health policy. Actions taken to date by the Commonwealth have aimed to strengthen developing networks of Indigenous people with health sciences training through, for example, the provision of funding for the Australian Indigenous Doctors and Association and the Council for Aboriginal and Torres Strait Islander Nurses.

A slightly different picture emerges with regard to trends in Indigenous participation in health sciences education in the vocational education and training sector (within which Aboriginal health workers are mostly trained). Here, in parallel with trends in the mainstream vocational education and training sector there continues to be strong growth in outcomes [20]. This is encouraging given that the health care practice provided by Aboriginal health workers is critical to the delivery of effective primary health care within a community development framework. It is critical to assess the sustainability of such trends, the comprehensiveness of current access to training for health workers, and the whether such training in the vocational education sector provides pathways into higher education for graduates. The Australian Health Ministers Advisory Council agreed in 1998 to endorse a National Review of Aboriginal and Torres Strait Islander Health Worker Training, agreeing that 'priority is for the development of a national framework for progressing the development of Aboriginal Health Worker training including mutual recognition arrangements to ensure the mobility and career progression across regions and States and Territories' [6].

These developments in Aboriginal and Torres Strait Islander health workforce strategy are encouraging - given the findings of the review of the National Aboriginal Health Strategy which highlighted the failure of the Commonwealth Education portfolio to strategically align Indigenous education strategy with national policy development processes in Indigenous health [3]. However, in the absence of a clearly articulated, and agreed strategy, in this area, it is difficult to assess the extent to which the current Commonwealth strategic framework has succeeded in creating sufficiently robust policy linkages with national Aboriginal education strategy. This issue will require attention if the development of the Aboriginal health workforce is to be sustained beyond discrete workforce initiatives.

Evidence and health policy reform

Throughout this paper the current priorities in national Aboriginal and Torres Strait Islander health policy and strategy have been described. The Aboriginal and Torres Strait Islander health disadvantage has been well documented and characterised over the last thirty years. However, the focus of investigation has only more recently begun to shift towards the type of research agenda that leads to the evaluation of interventions. With a focus on notions of effectiveness and efficiency in health sector reform, and the strategic priority given to the development of Indigenous primary health care capacity — it is clear that some attention needs to be given to the development of evidence to guide such Indigenous policy reform. However, such knowledge needs to be also developed in a way that it makes an impact on policy development and health care practice. This has been a particularly critical issue in Indigenous health where institutional relationships between the research and evaluation sector and Indigenous health community structures have not been conducive to the development of collaborative working relationships. There are a number of inter-related strategies that will only be flagged at this point. These include strategies to improve the quality of Indigenous data produced from health information systems and to strengthen the link between research and reform in health policy and practice. Over the last triennium, the National Health and Medical Research Council (NHMRC) has worked to develop a framework and methodology for priority driven research in Aboriginal health [21]. Emphasis has been given to reform in the development of research priorities to strategies that build
collaborations between the research sector, ACCHSs and communities, and those involved in Aboriginal and Torres Strait Islander health policy. The Australian Bureau of Statistics has concurrently been developing a more strategic and integrated approach to the development of data relevant to Aboriginal health within its health survey program [6]. The development of the National Aboriginal and Torres Strait Islander Health Information Plan, as a strategy in reform of data collected within health information systems, received endorsement from the Australian Health Ministers Advisory Council in 1997 [22].

These strategies will take time to be consolidated and evaluated. However, clearly the development of evidence to guide action will continue to be a critical element in national Aboriginal and Torres Strait Islander health strategy.

Conclusion
There has been quite a subtle, yet significant, transformation in national Aboriginal and Torres Strait Islander health strategy since the transfer of administrative responsibility in Aboriginal health from ATSIC to the Commonwealth health portfolio. In particular the development of partnerships in policy that build collaborations between government and the community sector, and between levels of government, has been a key outcome of this period. Given the structure of the Australian health system, it is clear that such partnerships need to be maintained and will require ongoing developmental attention. The focus in current national health strategy on health sector reform, and particularly on the development of Indigenous primary care capacity would seem to be both strategic and defensible. The evidence base in Indigenous health needs further development in order to ensure such strategies are focussed on providing for effective systems of health care delivery. A critical element in this approach will be the development of reform in health financing, and the consolidation of an Indigenous health workforce strategy. These policy issues will require some conceptual and technical development. Now that some of the foundations for reform have been laid, the task for the Commonwealth health portfolio is to maintain leadership in Indigenous health and consolidate some of gains achieved to date laying the groundwork for future reform.

References
10 Aboriginal and Torres Strait Islander Commission and Department of Health and Human Services (1995) Memorandum of Understanding between the Department of Health and Human Services and the Aboriginal and Torres Strait Islander Commission (ATSIC), Schedule 1, Definitions.
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Aboriginal health: reform through community control

Puggy Hunter

Introduction
This presentation is about reform and how Aboriginal health issues are not being addressed. Hopefully my presentation will provide you with some thoughts to take away and maybe there are some people here today who have opportunities to make changes or who will actually take the concerns of the National Aboriginal Community Controlled Health Organisation (NACCHO) on board.

Aboriginal community-controlled health services (ACCHSs) embody the principles of community development, from the establishment of the first service in Redfern in 1971. There are over 100 services Australia-wide. They are organised around State affiliates of NACCHO as the umbrella-body for these services. NACCHO is the peak national body in Aboriginal health in Australia.

ACCHSs are primary health care services initiated, planned and managed by local Aboriginal communities, aiming to deliver high quality, holistic, and culturally appropriate health care. They are also often known as Aboriginal Medical Services (AMSs). They range from large multi-functional services employing several general practitioners (GPs) and providing a wide range of services, to small services without GPs, which rely on Aboriginal health workers and/or nurse practitioners to provide the bulk of primary care services. The services form a network, but each is autonomous and independent both of one another and of government.

Status of Aboriginal health
The poor health of Aboriginal people is well known. Everybody feels a bit sad and sorry for the status of Aboriginal health, and it’s like a trophy that you pull down once a year and polish it up and then you put it back in a glass cabinet because you don’t want to do anything with it but you own it. And that’s what we hear government say ‘what are we going to do about “our” Aboriginal health, and “our” Indigenous health’. It is not ‘their’ Aboriginal health - it is ours, and now we are looking at it ourselves.

Life expectancy of Aboriginal people is 20 years less than that of non-Aboriginal people (1994). Aboriginal people are overall 4 times more likely to die in a given period than non-Aboriginal people (1994). Aboriginal men aged 35-44 years have over 10 times the non-Aboriginal rate of death (1985) and women 6 times (WA 1990-94).

Over 65% of Aboriginal people had attended a funeral in the preceding 12 months (1994). This is something that Aboriginal people are very familiar with. Honestly, I’m tired of burying my mob. I can tell you, we plan all our lives around funerals.

Diseases
Over 60% of excess mortality in the Aboriginal and Torres Strait Islander population is due to circulatory conditions (26%), injury and poisoning (16%), respiratory conditions (15%), and diabetes (8%). There is a significant burden of ‘diseases of poverty’ such as child malnutrition, rheumatic fever, trachoma, skin disease, and ear diseases - as seen in developing nations.

The thing about the disease is that it is all tied up with poverty. Living in poor conditions is all part of the sickness. What I want to know is, how do I get my mob on that side? – the same level as the non-Aboriginal person on the other side. How do we actually get Aboriginal health on the same par as the non-Aboriginal person? The Australian thought of giving a ‘fair go’ to everybody seems to fall away when we’re talking about Aboriginal people. So, the basic human rights of the individual constantly are left behind when we talk about Aboriginals. We have human rights to things like housing, rights to public health, Medicare, social security, social services and all these so-called international programs that Australia prides itself on signing off on but not fulfilling – makes you wonder.

Basic human rights
The International Convention on the Elimination of All Forms of Racial Discrimination, article 5 was ratified by Australia at the United Nations in 1975. It reads:

... State Parties undertake to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone ... to equality before the law, notably in the enjoyment of the following rights: (e) economic, social and cultural rights in
and this means the rate of young people dying, and more so Aboriginal men, has to mean 54,000 below the poverty line, thinking that something is going to change and waiting...always waiting. Fewer Aboriginal families have more than one member employed than other families. Fewer Aboriginal people have skilled vocational qualifications – 4.5% compared with 11% for non-Aboriginal people.

Look at our housing rights. In all States and Territories, Aboriginal people are more likely to live in overcrowded houses. 90% of total Australian households classified as 'severely over-crowded' in the 1996 Census were Aboriginal households (from only 2% of the population). It just makes you wonder why we have to live like this when we've got one Australia.

Fewer Aboriginal people own their own homes (31% of 71%). Our home ownership – another dream – was supposed to be an Australian dream – now we're flat out trying to get a house, let alone owning one.

We talk about water – 54,000 Aboriginal people in Australia are served by reticulated water systems capable of supplying less than 1,000. Some of our mob are living out there under conditions that no one in their right mind would tolerate. You would have to have had a laugh when they had the Sydney scare about all those bad things floating around in their water – our mob live with that daily and no one seems to bother about that. As Aboriginals, we have to laugh because of the amount of money and the concerns of the government getting chucked out and all these sorts of bad things going to happen to them and we think – why don’t they look at us and see where they’ve got us living and working and living?

Look at our rights to health access. There is considerable inequitable health expenditure for Aboriginal people. While the average Australian sees a GP five times a year, Aboriginal and Torres Strait Islander people average fewer than two GP consultations per year.

For every $1 spent per head out of the national Pharmaceutical Benefits Scheme on the general population, only 22 cents is spent per head on Aboriginal people. For each Medicare dollar spent per head on the rest of the community, only 27 cents is spent on an Aboriginal or Torres Strait Islander person. How can Aboriginal communities access healthy food when the proportion of family income required to purchase a healthy basket of foods is 2-3 times higher in rural and remote communities than those living in main centres? A 10% Goods and Services Tax on food will worsen the crippling disparity in food access which is a basic human right. (Government benefits will go up by only 4%.)

Now as we all know, the governments and the States and Territories love to talk about the amount of money they spend on Aboriginal health. In the real world I can tell you what we think about it as Aboriginals because we think - 'that’s a lot of money you said you spent' - then you would think ‘that’s the misinformation that goes out', (because you honestly think that all us Aboriginal people that live around the place are living at the Ponderosa or High Chaparral out there.

Current feature of health activity

One of the problems for delivering health care is that funding allocation and program structures are defined by body parts. So you have the dollars for the ears, the dollars for the eyes, dollars for the heart, the kidney. Well, its alright if you’re in a system where you can actually go off and have the opportunity of seeing all these things in one place but, as we all know out there, this is not the case. The holistic framework that NACCHO works under doesn't fit within the body parts. Health dollars go to the body part with the best argument. They are not linked to holistic health care- health promotion, primary health care, and preventive health care. This also denies that social inequalities are the leading underlying cause of disease.

As if breaking up the body in little parts was not enough, the brain has now been cut into pieces. We now have a confusing array of mental health program structures and strategies that don't talk to each
other. We have injury prevention programs that deal with self-harm before people kill themselves that don’t talk to the programs that deal with issues after people kill themselves or to prevent people killing themselves. It’s so confusing for the individual person, for anybody to make any sense out of it. Maybe that’s the plan, but I don’t know.

What’s wrong with this approach?
In Aboriginal health, the ‘organised’ approach – not the ‘organ’ approach – is needed. The organ approach often fails to reach the most disadvantaged and rarely addresses more than one risk factor. It ignores the socio-economic antecedents of disease. Consequently, it may be irrelevant to people’s real concerns and because of this it increases powerlessness by failing to consider the communities’ real concerns. Importantly it diverts attention of community groups away from structural challenges to short-term unsustainable programs (Labonte, 1998). You’ve got someone sitting in the city who wouldn’t have an idea what’s going on in my area, but they wake up every morning with a great idea for us Aboriginals and they want to give it to us and they sure do, I can tell you! Then they come back and give us more. So I’d say to them if you wake up with something early in the morning, keep it!

The right approach – community control
Community development is the right approach. It is essential to integration, efficiency, and ownership of health problems. It is a mediator for social change. Because of this it is empowering, overcomes local obstacles to health access and best practice and Aboriginal community groups are able to negotiate the terms of their interdependence with external organisations.

Framework Agreements
An obligation for the development of health services, and social and economic issues exists in Australia though the Aboriginal and Torres Strait Islander Framework Agreements signed off by each State and Territory Government, the Commonwealth, ATSIC and State affiliate of NACCHO. The National Aboriginal Health Strategy (NAHS, 1989) was endorsed by the Heads of State and Commonwealth governments in 1990 and the Framework Agreements are underpinned by the NAHS. The Framework Agreements are about:

- improving access to health programs, in line with need;
- increasing the resources available for Aboriginal health, to reflect the higher level of need of Aboriginal and Torres Strait Islander people;
- transparent and regular reporting for all services and programs;
- joint planning processes to inform resource allocation, allow for full Aboriginal participation in decision making and priority setting; and
- improve cooperation and coordination of current service delivery.

Framework Agreements – what is their status?
In some areas, the level of joint planning, and inter-sectoral communication and collaboration has reached an all-time high (such as in the NT). Other States have paid little more than lip-service to consultation with the Aboriginal community-controlled health sector. The Commonwealth needs to bring much more accountability to bear on the States to meet their responsibilities under the Framework Agreements, as they are the key to collaboration, partnership and accountability to the Aboriginal community.

Other structural reform issues
NACCHO is active in a range of other structural reform issues – such as workforce needs to improve Aboriginal and Torres Strait Islander health, best practice in Aboriginal health care delivery, and public health law.

The Workforce Modelling Project (which assesses the current and future health workforce requirements for Aboriginal people and Torres Strait Islanders across the State government and the community sectors) is currently in progress. NACCHO has established recruitment and promotion services in each state and the Northern Territory. NACCHO is active in Ministerially appointed general practice bodies such as the GPETC and GPPAC. Member services have developed important resources for training of health professionals such as the Information Resource kit from the Aboriginal Health and Medical Research Cooperative in NSW and the Aboriginal Health Worker Training CD-ROM by the Kimberley Aboriginal Medical Services Council.

We need to educate Aboriginal children across the whole range of the education continuum from primary school to university to such a standard such that bridging courses are not necessary. We have university courses coming down the line, picking up bridging courses to make them look good. I don’t
say that you should discredit this process, but the reality is the universities need to say to the high
schools – ‘hey, hold on a minute, these kids you’re sending me are not up to scratch’.

Our member services have been leaders in best practice in Aboriginal health care. Best practice means
that:
- services are confident;
- that health service decisions will lead to better health outcomes; and
- that one investment is preferable to another (because the direction of effort to one alternative
means that another is denied).

The Kimberley Aboriginal Medical Services Council has developed a textbook in *Aboriginal Primary
should help to reduce clinical practice uncertainty and variation, to organise PHC activity (for example,
by using information technology) and supplement gaps in knowledge with strategic research and
Aboriginal identified research priorities. Everybody thinks that things can only be done in the city –
things can happen in the bush and I think people should get used to that idea, that people in the bush do
have some good ideas, disregarding what colour you are. There are things happening out there and that
sort of stuff is on the top shelf as far as we’re concerned because there’s been a lot of documents
written for us.

‘National conscience’ reports

This is what they do when they’re feeling a bit sad – they always think ‘oh those poor bastards, we
better do something’. So they do, they write these great reports: the Royal Commission into Aboriginal
Deaths in Custody, social justice reports, and the *Bringing them home* report on the stolen generations,
the National Aboriginal and Torres Strait Islander Health Strategy.

What do they do with them? Jack up their bed, put them on the cupboards so that it looks! These things
have to be implemented and until they do it’s no good talking to us Aboriginals about another plan
because they haven’t actually implemented all these things along the line. We’re talking about ‘it’s time
for our conscience to get another prick again – we better go and do another report’ – and that’s the sad
part about it.

Public health law

There appears to be a systematic exclusion of the application of public health legislation to Aboriginal
communities. They make these laws that some of my mob were living in. Some of these conditions out
there, you wouldn’t dare put your own dog out there. Yet our mob is expected to live in there because
the law was not enforced.

There is often a continuing requirement to demonstrate health gain from government provision of basic
citizenship rights in Aboriginal service and infrastructure projects. When Aboriginal communities
attempt to make local and state government responsible for health standards, they have been met with
frustration and finger pointing.

The ‘Madiwah Loop’ example illustrates this. A local shire brought an action in the Western Australian
Supreme Court against the state over substandard living conditions on state-owned Aboriginal reserve
land, claiming a breach of the 1911 Health Act.

The shire (and community) lost the case, not for want of evidence of a breach, but on a legal
technicality - that the Crown did not bind the Crown. So they get off the hook, so the people can just
stay where they are and, in the meantime, the States get the money for those Aboriginal people, the
shire gets the money for the Aboriginal people as well - the so-called disability allowance – that’s what
we are.

So the question I ask here is, who’s bloody responsible, because every time you go to one mob they tell
you it's the other mob – ‘oh, it's the State, it's a State problem’ – ‘oh, it's the Commonwealth’. And this
is where Aboriginal health has been – it's been in this sort of vacuum of finger pointing and so we
constantly go on waiting for someone to one day (for the finger to turn around) to say 'oh, it must be
me'.

NACCHO has argued that a public health law review is needed. Basic health hardware appears to be
denied for Aboriginal communities on the basis that responsible State government departments are not
bound by their own public health laws.

This is unlikely to survive serious legal challenge (Barker, 1994). The application of public health law
and enforcement of the common law 'duty-of-care' remains an important and largely unexplored means
of improving Aboriginal health status by mandating discharge of government responsibility. The States and Territories, who have been receiving this money for all these years, should be held accountable for what’s out there. They should be made to answer the questions that we always put on the table, but they don’t.

Conclusions
Community-control in Aboriginal health care is required for community development and structural reform. It is the process whereby structural reforms can address socio-economic and health inequality. Public health legislation can advance Aboriginal health. We need a review to determine whether a lack of enforcement/penalties is responsible for the health determinants being ignored.

Finally – if you want to be involved in Aboriginal health, my best advice honestly is to involve Aboriginal people in a true partnership. And when I say true partnership, I tell people don’t come to us about what colour the car is, after you bought it. Come to us when we talk about what sort of vehicle we need to actually get to where we want to go, and then let’s sit down and talk from there because we can work that out with you.
Indigenous health: lessons from the United States

Stephen Kunitz

Abstract

Despite high per capita income, the population of the United States does not have life expectancy that is significantly different from that of Australia, Canada, and New Zealand. It has been proposed that this is due to the fact that in the United States income inequality is greater than in any other advanced industrial nation, whereas it is substantially more equitable in the three Commonwealth countries. On the other hand, the life expectancy of Native Americans is substantially higher than that of Australian Aborigines, and slightly higher than that of New Zealand Maoris, despite the fact that in each country Indigenous people are significantly poorer than the rest of the population.

The argument is made that the surprising pattern is due to the existence of a unique health care system for American Indians which has provided a full range of preventive and curative public and personal services. Because of its success, there has been interest in implementing something like it in other countries which have Indigenous populations.

This paper discusses the differences in political cultures between the Commonwealth countries on the one hand and the United States on the other. I argue that the conditions which have led to the existence of universal entitlement to health care in the Commonwealth countries make it unlikely that a targeted categorical program for a particular group would be created. Conversely, the increasingly powerful entrenchment of interest groups in the United States makes it unlikely that universal entitlement to health care will be implemented, but also has made possible the existence of categorical programs such as the one for American Indians.

Introduction

The implication of the title is that there are lessons to be learned from the United States with regard to the provision of health care for Indigenous people. I believe there are lessons to be learned, and I have described them at length elsewhere [1]. Simply stated they are as follows:

1. The Commonwealth should have primary authority for the financing and provision of comprehensive, regionalized health services for Aborigines;
2. Health services should be kept separate from highly politicised issues such as land rights, natural resources, and economic development;
3. Professional experts must have a secure place in the system, even as mechanisms are created to assure sensitivity and responsiveness to community concerns; and
4. The existence of treaties between the Commonwealth and Indigenous groups is fundamental for a sustained commitment to the provision of health services as well as the protection of rights to land and resources [1].

In this paper I shall not repeat in any detail the reasons for these conclusions, which are as relevant now as when they were written several years ago. Instead I shall argue that the American system of providing comprehensive, regional health services to Indians living on and adjacent to reservations has been generally successful but is the product of a political culture so unique that many of its lessons are unlikely to be implemented elsewhere.

Background

The United States is an enormously rich country, richer indeed than all but a small handful of countries. It is also a highly unequal country. Income distribution is more unequal in the United States than in any other highly developed nation. This is important because a lot has been written about the impact of inequality on health [2], [3], [4]. It has been argued, for example, that in countries which have passed through the epidemiologic transition to a regime of high life expectancy and very prevalent non-infectious and man-made diseases, inequality is a better predictor of life expectancy than is per capita income.

Some relevant national data on income, life expectancy and inequality are displayed in Table 1. Although inequality may well have increased in the decade since these figures were calculated, the relative ranking of countries is still probably very much as it was. The four countries included are all English-speaking, economically advanced, liberal democracies with significant Indigenous populations. Among them, the United States has the highest per capita income and is the most unequal with regard
to its distribution. The poorest 25 per cent of the U.S. population has income which is only slightly more than a third of the median per capita income of the entire population. Of the other three countries, New Zealand has the lowest per capita income but the most equitable income distribution. The poorest 25 per cent of the population has income that is more than half the median income of the entire population. Australia and Canada occupy intermediate positions with regard to both the size and distribution of income. Neither the great differences in income nor income inequality is associated with a significant difference in life expectancy among the four countries. The range of two years in life expectancy is relatively unimpressive contrasted with the range in both per capita income and income inequality.

### Table 1

<table>
<thead>
<tr>
<th>Country</th>
<th>LE (1994)</th>
<th>GNP/per capita US$ (1994)</th>
<th>Income per adult in the poorest 25% of the population as a per cent of the median income per adult year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>77</td>
<td>18,000</td>
<td>46.5 (1985)</td>
</tr>
<tr>
<td>Canada</td>
<td>78</td>
<td>19,510</td>
<td>45.8 (1987)</td>
</tr>
<tr>
<td>New Zealand</td>
<td>76</td>
<td>13,350</td>
<td>53.6 (1978-88)</td>
</tr>
<tr>
<td>USA</td>
<td>77</td>
<td>25,880</td>
<td>34.7 (1986)</td>
</tr>
</tbody>
</table>

Source: 1994 data are from [5]. Data on income inequality are from [6], p40.

Similarly, there is no obvious association between income, income inequality, and life expectancy of Indigenous people in these countries either. Among Indians in 1989, median household income was 66 per cent of the U.S. figure (IHS 1996), and mean income of Indian men 15-64 years was 55 per cent, and of women 70 per cent, that of their counterparts in the general population [7]. Among Aborigines in 1991 and 1996 mean per capita income was 61 and 64 per cent respectively of the income of the Australian population [8], [9]. Among Maoris in 1996, annual median household income was 79.5 per cent that of non-Maoris, and average weekly income of people 15 years of age and above was 77 per cent (New Zealand Income Survey 1996). While the measures are not precisely comparable across countries, they do indicate that the income of Indigenous people is substantially less than that of non-Indigenous people in their respective countries, and that Maoris are relatively less deprived than either Indians or Aborigines. (I have no recent data for Canadian native peoples.) Table 2 indicates that Native Americans and Maoris, in the richest and poorest countries respectively, have virtually identical life expectancies. They are followed in distant third place by the Indigenous people in Australia, the intermediate country with regard to both per capita income and income inequality.

### Table 2

<table>
<thead>
<tr>
<th>Country</th>
<th>Years</th>
<th>Life expectancy at birth</th>
<th>Indigenous as a percentage of non-Indigenous</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Indigenous</td>
<td>Non-Indigenous</td>
</tr>
<tr>
<td>Australia</td>
<td>1991-96</td>
<td>60.4</td>
<td>77.7</td>
</tr>
<tr>
<td>New Zealand</td>
<td>1990-92</td>
<td>70.5</td>
<td>76.3</td>
</tr>
<tr>
<td>USA</td>
<td>1992-94</td>
<td>71.1</td>
<td>75.5</td>
</tr>
</tbody>
</table>

Sources: Australia - [10], New Zealand - [11], United States - [12], corrected for misclassification of race.

The high life expectancy of Native Americans seems unlikely to be explainable entirely as a result of high per capita income. After all, life expectancy of the entire U.S. population is, if anything, lower than that of the populations of the poorer countries. Thus, income by itself is unlikely to be an adequate explanation. I will suggest that the Indigenous people of the United States and New Zealand have reached similar points via different pathways. In New Zealand equality of income and integration into the national society is in general greater than in the United States and Australia. In the United States, a unique health care system for Indians has made up for many other inequalities. In Australia neither equality nor a highly effective comprehensive health care system for native peoples exist.
The significance of health services

A significant body of work over the past 20 years has been devoted to minimising the medical contribution to the health of populations [13], [14]. In this tradition 'medical contribution' has generally meant the personal physician system, not the public health system involving such things as for example the protection of water supplies, the safe disposal of sewage, and the passage of legislation requiring the wearing of seat belts.

On the other hand, an equally significant body of work over the same 20 years has been devoted to the assessment of the medical contribution to the improvement of the health of populations [15]. Most of the studies in this tradition classify causes of death as either amenable or resistant to medical care. Here medical care is defined in its broadest sense, that is prevention, cure and care, including the application of all relevant medical knowledge, the services of all medical and allied personnel, the resources of governmental, voluntary, and social agencies, and the cooperation of the individual himself. An excessive number of such unnecessary events serves as a warning signal of possible shortcomings in the health care system, and should be investigated further [16] (emphasis added).

Avoidable deaths may thus occur for a variety of reasons, including inadequate funding, inaccessible services and/or populations, incompetent staff, and non-compliant patients.

In Table 3 I have listed the ratios of age adjusted rates of avoidable deaths, comparing Indigenous to non-indigenous people in Australia, New Zealand, and the United States. The avoidable causes of death I have used are a few of those agreed upon by the European Community (EC) consensus conferences, with the exception of diabetes, which I have added. Unfortunately, I have been unable to replicate the EC categories precisely because the EC has put age boundaries around many of the causes, and the published data to which I have had access do not include that level of detail.

Table 3

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(total) ratio</td>
<td>Male ratio</td>
<td>Female ratio</td>
</tr>
<tr>
<td>Infant mortality</td>
<td>1.0</td>
<td>2.7</td>
<td>1.8</td>
</tr>
<tr>
<td>Tuberculosis</td>
<td>6.2</td>
<td>11.1</td>
<td>47.8&lt;sup&gt;5&lt;/sup&gt;</td>
</tr>
<tr>
<td>Cerebrovascular accident</td>
<td>1.0</td>
<td>3.6</td>
<td>3.7</td>
</tr>
<tr>
<td>Hypertension</td>
<td>0.9</td>
<td>10.6</td>
<td>10.6</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>0.5</td>
<td>0.5</td>
<td>0.8&lt;sup&gt;6&lt;/sup&gt;</td>
</tr>
<tr>
<td>Cervical cancer</td>
<td>1.9</td>
<td>8.3</td>
<td>4.2</td>
</tr>
<tr>
<td>Motor vehicle accident</td>
<td>3.0</td>
<td>4.1</td>
<td>3.6</td>
</tr>
<tr>
<td>Chronic liver disease/cirrhosis</td>
<td>3.8</td>
<td>8.5</td>
<td>23.0</td>
</tr>
<tr>
<td>Ischaemic heart disease&lt;sup&gt;7&lt;/sup&gt;</td>
<td></td>
<td>2.9</td>
<td>2.9</td>
</tr>
<tr>
<td>Diseases of the heart</td>
<td>1.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>3.0</td>
<td>12.1</td>
<td>17.5</td>
</tr>
</tbody>
</table>

Sources: United States - [18] and [19], Australia - [10], New Zealand - [11]

The results show a gradient in the ratios of Indigenous to non-Indigenous avoidable causes of death from lowest in the United States, to intermediate in New Zealand, to highest in Australia. The

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<sup>4</sup> I have not found current data for Canada, and it is not included.

<sup>5</sup> The difference between men and women is not statistically significant

<sup>6</sup> The figures for breast and cervical cancer in New Zealand are averages of the ratios of women 45-65 years and 65 years and above

<sup>7</sup> The published Australian data include only ischaemic heart disease. The published U.S. data include in addition to ischaemic heart disease, rheumatic and hypertensive heart disease. For more precise U.S. data which suggest higher cardiovascular disease risks in some Native American populations than in the general population, see Lee et al. [17].
important exceptions are motor vehicle accidents and cirrhosis of the liver, for which the ratio is lower in New Zealand. Although this pattern does not prove that health care contributed significantly to the differences, it is consistent with that explanation (see also [20]).

The provision of health services for American Indians

Elsewhere I have described, and tried to explain, the differences in the way health care services are provided to Native American and Indigenous peoples in Australia, Canada, and New Zealand [21, 22]; [1]. The point I should like to make here is this. For the past forty years in the United States, both personal health care and public health services for American Indians, particularly those living on reservations, have been provided by a federal service dedicated exclusively to those functions. The reasons are complicated, but have to do with the existence of treaties between many Indian tribes and the federal government. Though often honoured more in the breach than in the observance, treaties have meant that tribes have the status of domestic sovereign nations and deal directly with the federal rather than state governments for many purposes. This special relationship has been reaffirmed by the courts on many occasions, though congressional from states with large Indian reservations, and with non-Indian constituents who covet Indian resources, have often tried with varying degrees of success to weaken or terminate the relationship.

The Indian Health Service (IHS) is a branch of the U.S. Public Health Service, which is one of the four uniformed services, along with the Army, the Navy, and the Air Force. In addition to Indian health, the Public Health Service is responsible for the Centers for Disease Control, the National Institutes of Health, and a variety of other functions. It in turn is located within the Department of Health and Human Services, a part of the Executive branch of the federal government, whose secretary is a political appointee and a member of the President’s cabinet. Like all government agencies, the policies of the Indian Health Service are shaped by the President’s budget, Congressional appropriations, and political choices and government policies.

The creation of the I.H.S. and its location within the Public Health Service was the seemingly paradoxical result of the policy of termination and abrogation of treaties pursued by the Eisenhower administration in the 1950s [22]. Previously it had been an inadequately funded, haphazard program located within the Bureau of Indian Affairs, part of the Department of the Interior. Transfer to the Department of Health and Human Services (at that time Health, Education and Welfare) came about as a result of attempts to weaken and destroy the Bureau, to devolve federal Indian programs to states and counties, and to integrate Indians into the mainstream of American life. When it became clear that those lower levels of government did not want the responsibility, and that in any event Indian health status was so inferior to that of the rest of the population that it would be a disaster to leave them without services, transfer was decided upon. The original idea was that, once the health status of Indians had been raised to that of the rest of the population, termination could proceed and Indians would be able to be assimilated into the mainstream where they could compete on an equal footing with their fellow citizens.

The system of health care that was created was unique in the United States. The Indian Health Service has been a regional, integrated system which includes: personal care at the primary, secondary, and tertiary level; and public services such as the protection of water supplies, safe disposal of sewage, epidemic investigations, public health and school nursing, immunisation clinics, and so on. All of this has been provided at a remarkably low cost.

Since the 1950s when the policy of termination led to the transfer of Indian health programs to the U.S. Public Health Service, Indian policy in general has undergone major transformations. Indians benefited from the civil rights movement of the 1960s, for federal programs were developed which created the possibility for both new careers in, and community control of, human service organisations. Since then, legal, medical, educational, and social service programs have increasingly been managed by tribal agencies and have employed local people. Then in the early 1970s, in a momentous reversal, President Nixon formally abandoned the policy of termination which had been pursued while he was Vice-President in the Eisenhower administration in the 1950s. Two important pieces of legislation were soon passed, one of which allowed Indians to use federal funds to administer programs previously managed by the Bureau of Indian Affairs and the Indian Health Service. The other provided more money for health care for Indians and education of Indians in the health professions. Together this legislation encouraged greater control by Indian tribes of their own affairs, primarily in the area of human and social services. While funding levels remained high, this was a policy widely applauded by most Indian leaders. Beginning in the late 1970s and early 1980s as government spending on Indian health has failed to keep up with costs, however, the situation has become less hopeful.
With regard to health services in particular, a number of problems have become increasingly visible [1]; [22]. First, Indian Health Service hospitals provide a more limited range of services, both diagnostic and therapeutic, than community hospitals in general and have shorter average lengths of stay and lower occupancy rates. Because a full range of services is not provided, even at the major referral centres, an increasing proportion of services must be provided by personnel paid for by contract funds. They tend to be more expensive than I.H.S. personnel and services. Thus relatively less money is available to pay for more expensive services.

Second, because services are increasingly being paid for by contracts managed by Indian tribes, maintaining an integrated service is less likely. Among other things, uniform data collection suffers. This is problematic when presentations must be made at congressional budget hearings, and it diminishes the chances for an equitable distribution of limited resources based on knowledge of differing needs.

Third, recruitment and retention of professional staff have become increasingly difficult. For about twenty years, from the Korean War to the early 1970s, there was a universal military draft of physicians. Since the U.S. Public Health Service is one of the four uniformed services, two years' duty in the Indian Health Service could satisfy a physician's military obligation. The result was that recruitment of physicians, and of many other professional staff who also qualified for military commissions, was not a problem. Since 1973 when the military draft for physicians ended, recruitment has become increasingly difficult. The problem is exacerbated by the inadequate facilities, which do not compare favourably with those available elsewhere, and which make practice less attractive than in non-IHS facilities.

Fourth, the result of devolution and limited budgets has been, since the 1970s, increasing competition between tribes. I can only speculate, but it appears that the weakening of the federal agencies which have been advocates for Indians (the Bureau of Indian Affairs and the Indian Health Service), has not resulted in the emergence of an equally persuasive and influential non-governmental interest group representing all or most Indian tribes.

Thus, while the Clinton administration continues to affirm the special government-to-government relationship that the federal government has with Indian tribes, the ability of tribes to develop and maintain their own high quality programs has been weakened.

**Categorical and universal entitlements to health services**

Despite the problems, the Indian Health Service has had a remarkable record of achievement, for I believe the data indicate that much of the improved health experienced by Indians over the past forty years is attributable to it. That view is widely shared, both in the United States and abroad. Indeed, the Indian Health Service has been regarded by various observers in Australia, Canada, and New Zealand as a model of how personal and public health programs ought to be delivered to Indigenous people.

Why then have such programs not been implemented in countries with similar minority populations? After all, there is evidence that organisations that do the same sorts of work tend to organise themselves in increasingly similar ways, what has been called institutional isomorphism. Armies, schools, hospitals, and airports all look reasonably similar in developed countries [23]. The answer, I believe, is that the existence of universal entitlements to health care in the commonwealth countries makes it virtually impossible to create a categorical program like the Indian Health Service. For in a universal system there is likely to be great resistance to singling out some categories of people for special treatment.

In all three of the Commonwealth countries, as in the U.K. itself, Labor parties have been an important part of the political landscape for most of this century and have had a profound impact on the creation of systems of universal entitlement to health care. While there are undoubtedly important differences among them, for present purposes their similarities are more noteworthy, especially in contrast to the situation in the United States, where there is nothing comparable [24] [25] [26] [27]. Without a Labor party and a tradition of social democracy, the redistributive policies implicit in universal entitlement to health care have been difficult to implement. Arguably, it is the redistributive nature of universal entitlement schemes which has led to the failure to create such a system in the United States [28].

The creation of universal entitlement to health care in the Commonwealth countries has meant that government agencies must negotiate with peak associations of health care providers in order to both make and implement policies. This may be considered a form of corporatism, or neo-corporatism. The applicability of the idea of corporatism to Commonwealth countries has been a subject of some debate (eg. [29], [30]). It has various definitions, but common to them all is the notion that certain associations
assume a formal and intervening position between individuals and the state [31]. It may be of two
types: 'interest intermediation' and 'policy formation' [31]. 'Interest intermediation' refers to the quasi-
governmental functions undertaken by certain peak associations, which involves the actual
implementation of policies. 'Policy formation' refers to formal involvement in policy-making but may
not involve actual implementation of policy. The two are often found together, but the connection is not
inevitable.

On the Continent quasi-governmental bodies engage in both functions: policy-making and
implementation. For example, in Germany and a few other countries sickness insurance funds are
responsible for managing health care budgets on behalf of the government. This has been called the
Bismarckian system. In England and in other Commonwealth countries the policy-making function has
been predominant. Thus with regard to health care, services are paid for out of general revenues and
governments may negotiate with professional associations but manage the budgets directly [32], [33],
[34], [35], [36] [37]. This has been called the Beveridge system [38].

Thus in the Commonwealth countries and on the Continent certain privileged groups are routinely
involved in formal consultations with regard to the making and/or implementation of government
policy. Conversely certain groups, or nascent groups, have little or no access to the policy-making
process. In New Zealand, Maori representation in the equivalent of peak associations carrying out both
policy-making and implementation functions is well established. This is not so in Australia, where
there is great fragmentation of authority over the system between the state and Commonwealth
governments. Only Aboriginal Medical Services, supported largely by Commonwealth funds and
providing only primary care, are under Aboriginal control. And the peak association speaking for
Aboriginal health care, the National Aboriginal Community Controlled Health Organisation
(NACCHO), represents mainly the interests of primary care providers and consumers and influences
and implements policies relevant mainly to primary care. Other sectors of the health care system are
represented by other groups, or not at all. A system that is at once fragmented in administration and
universal in coverage is not one that can respond to the special needs of particular populations.

In the United States, where the system is generally considered more pluralist than in the commonwealth
countries and on the Continent, interest groups tend to have a less formalised place in policy-making
and in carrying out government functions. Moreover, interest group access tends more often to be via
Congress (the legislative branch) and the Judiciary (through law suits) than the Executive branch,
which is the more common route in parliamentary systems [36]. And the proliferation of interest groups
in the United States has meant that the ubiquity and strength of consumer groups is greater than it is in
less pluralistic systems. In the latter, producer groups, whether of goods or services, tend to be
predominant [39].

The result is that instead of universal entitlements based upon the idea of solidarity, in the U.S. there
are particularistic programs, each with its own history, that arose for a variety of very different reasons,
but generally as a result of interest group bargaining. Medicaid is a program for the poor which derives
from traditions of charity, is supported by a combination of federal and state funds, is administered at
the state level, and requires a means test. Medicare is the program for people over 65. Along with
Medicaid, it is what remains of the failed attempt to create a universal national health insurance scheme
in the 1960s. The End Stage Renal Disease Program provides treatment for people with that condition;
it is also paid for by Medicare funds; and resulted from the very effective lobbying efforts of several
special interest groups, including consumers and producers of services and appliances. Likewise federal
prisoners and military veterans are beneficiaries of special programs. And of course so are Native
Americans who are members of federally recognised tribes.

All of these are categorical programs for people with particular attributes, whether age, disease
condition, income level, legal status, or ethnicity. Citizenship by itself is not sufficient to qualify for
government sponsored services. The result is great variation in rights to care. Most people have private
coverage through their employers and have very different benefits depending upon the plan in which
they are enrolled. People in categorical government programs may have private coverage as well. And
an estimated 15 per cent of the population has no coverage whatsoever.

8 An exception is the role the organised medical profession plays in disciplining its own members in the United
States [32].

9 While there seems to be little disagreement that the two forms of corporatism, the liberal and the authoritarian,
are very different, there is considerable disagreement over the degree of difference between the liberal
commonwealth type and pluralism. Rather than radically different, they are considered by some to lie along a
continuum [29].

27
Thus in the United States we have created a remarkably effective health care system for a relatively small population of Native Americans. It is both narrow and deep, and it has helped reduce the impact of income inequality. Almost certainly it would not have been established had there been universal entitlement to health care. This assertion is supported by the fact that when President Clinton introduced his ill-fated health insurance scheme in 1993, major budget cuts for the IHS were also proposed. They were rationalised by claims that universal coverage would make up the difference [22]. Just as certainly, in systems with universal entitlement, there is likely to be great resistance to this sort of special categorical program due to concerns about equity on the part of large sections of the public, as well as on the part of managers of the system. There are always exceptions, but in general I believe the distinction to be valid.10

These observations suggest several lessons in addition to those I asserted at the outset. First, it seems clear that categorical programs like the I.H.S., that are both narrow and deep, can have a significant impact on a population’s health, even in the presence of inequality and in the absence of major economic advance. It is also clear, however, that income (and presumably other forms of equality) can have profoundly beneficial effects as well.

Second, even successful categorical programs like the IHS are vulnerable to erosion as budgets are constrained, costs rise, and political commitments weaken and change. The same is of course true with regard to other commitments, for example to equality in New Zealand.

Third, in a system with universal entitlement to health care, it is particularly important which groups are able to shape government policy-making and implementation. For several reasons, Maori representation is much greater in New Zealand than is Aboriginal representation in Australia.

Finally and perhaps most important, because resources for health care are limited in all countries, there appears to be a trade-off between broad but shallow coverage and narrow but deep coverage of populations. It seems to be almost impossible except in very unusual circumstances to combine both broad and deep coverage. The virtual inevitability of these constraints is why I believe it would be well nigh impossible to implement elsewhere the kind of program that for a time has worked so well in the United States. It may also be why in the United States it is unlikely that we will develop a universal entitlement to health care any time soon.

Acknowledgments
Linda Bryder and Neil Pearce provided helpful references.

References

10 New Zealand seems to be a partial exception to this observation, for Maoris have been given a large voice in policies that affect them.


27. Richards, R., Closing the door to destination: the shaping of the social security acts of the United States and New Zealand. 1994, University Park: The Pennsylvania State University Press.


Indigenous health: lessons from New Zealand

Colin Mantell

E nga mana, e nga iwi, e nga reo
Tena koutou katoa
E nga mate kua hingahinga atu
Huri noa, huri noa
Haere, haere, haere

Ninety years separated the writings of Maui Pomare as he travelled around New Zealand as Minister for Maori Health and his grandson, the late Eru Pomare, whose poignant and often painful observations in Hauora III pointed the difference that existed in health conditions of Maori in New Zealand and their non-Maori counterparts. The passage of 90 years had seen some of the expected improvements, but for all the gap was very slow to close. Life expectancy for Maori males lagged five years behind non-Maori and, in many conditions, the relative risk ratio remained at three or four times non-Maori. Of special concern was that the least progress toward equity was in those conditions where efficient preventative measures already existed. The Australian Aboriginal people have fared much worse and this paper speculates as to why this may be and lists New Zealand initiatives that are aimed at generating equity in health for Maori.

The first difference is that New Zealand has a Treaty signed at Waitangi in 1840 affirming the contract established then between the Crown, Queen Victoria, and Maori from throughout New Zealand. Treaties between colonising nations and Indigenous peoples were not unusual but the Treaty of Waitangi embodies three separate concepts.

The first (Article 1) was that Maori ceded rights to the Crown to govern. The second is about rangatiratanga – the right of self-determination over the use of lands and waters of New Zealand. Hence there is a separate set of rules (rights) for Maori in terms of access to fishing, etc.

The third article is about human rights and guarantees equal rights for all New Zealanders – Maori and European. Embodied in this article is equity of access to all New Zealand has to offer. Latterly this has come to include equal opportunity to good health.

For the first 130 years the Treaty was largely ignored, certainly Maori saw precious little benefit in the existence of the Treaty. However, the Labour Government in the late 1970s awakened the nation and established the Waitangi Tribunal for the specific purpose of hearing grievances against the implications of the Treaty by the Crown. These began with land claims for large tracts of land confiscated from Maori under all kinds of guises. Soon followed the political implications of this effect on the national conscience. Considerations of the second and third articles became a requirement by law for all government organisations. Now, 160 years after its signing, the Treaty is a cornerstone of all New Zealand activity.

Some examples of the influences on Maori health and development are listed below.

Maori providers

The Health Funding Authority distributes all government health and disability funds and, as part of its move to allow more self-determination, has established more than 200 contracts for service with Maori providers. For the larger providers (for example, Raukura Hauora o Tainui), this includes health clinics, general practitioners, accident and emergency centres, health prevention programs, etc.

This type of contract is an important recognition that, for some services, the Maori providers are the preferred provider.

Cultural units within mainstream services

Typically hospitals have established units that both oversee and facilitate the treatment of Maori patients within the service. A marked reduction in patients failing to attend for elective surgery or outpatient appointments is a direct beneficial effect (both fiscally and health-wise). To improve the
effectiveness of group managers (for example, the manager of surgical services), they are expected to have some specific cultural requirements in their annual strategic plans. Examples may be:
- a requirement to have an employment policy for Maori staff with targets for success;
- to include a program of education in cultural matters for all staff dealing with patients; and
- success in these indicators is included in the annual appraisal of the Manager.

Educational institutes
Most tertiary education centres have developed charters with targets for the involvement of Maori in their programs. For example, the University of Auckland has a list of Equity Performance Indicators for all departments including
- access;
- participation;
- success (for Maori students in courses);
- retention; and
- completion.

Educational opportunity
The School of Medicine, University of Auckland has an affirmative action program – Maori and Pacific Admission Scheme (MAPAS). The number of admissions has increased from a single student in the initial year, 1972, to 23 students in 1999 (see Figure). Overall, there have been 213 admissions (140 Maori and 73 Pacific Islanders). There have been 97 graduates, 81 are studying now, and only 35 students have been lost to the program. Importantly these 178 students and graduates would not have had any opportunity to study medicine without MAPAS.

Vision 2020
In 1997, the objective of 10% of all New Zealand’s doctors being Maori by the year 2020 was set. There were not enough Maori secondary school students reaching the minimal standard to contemplate careers in medicine or any other health care profession. The Faculty of Medical and Health Sciences at the University of Auckland established a bridging course, the Certificate in Health Science, to allow students to attain the entry requirements for medicine and a wide variety of other health courses – 36 students are enrolled in the first year.

Medical research
Since 1994, the Health Research Council (HRC) has had a separate Maori Committee considering training programs and research projects for Maori Health Research. Currently it has a budget of $2.1
million and funds four Maori Research Centres throughout New Zealand. A higher proportion of its budget is spent on workforce development than the more traditional biomedical, public health or clinical committees.

**Department of Maori and Pacific Health**

If one wishes to impact an area of health care where deficiencies are obvious, first one needs to focus specifically on the problem area. In Auckland, the health plight of Maori and Pacific people are similar and so, in June 1996, the Department of Maori and Pacific Health was established in the University of Auckland, together with a Maori and Pacific HRC-funded research centre.

The Department has the usual roles in teaching, research and community involvement, but also adds support of Maori and Pacific students within the School’s program, to its role.

**Conclusion**

Of these initiatives, the most important is the value of the Treaty of Waitangi for it establishes the right of Maori patients to aspire to good health and Maori students to aspire to careers in the health professions.

We still have a way to move and sometimes it is depressingly slow.

Australia in 1999 has a lot of similarities to the New Zealand of 20 years ago:

- little involvement of Indigenous people in their health system;
- lot of activity, but little giving up of power;
- words not actions in priority setting;
- little workforce development; and
- slow acceptance that Aboriginal people are becoming increasingly urban.
Indigenous health: what needs to be done in Australia

Ian Ring and Jacinta Elston

Introduction
There have been four key recent developments in Indigenous health. They are:
1. publication of clearer evidence of the lack of improvement in the mortality in Australia’s Indigenous population – in contrast to much more rapid improvements and much lower levels of mortality in Indigenous populations in comparable countries;
2. publication of the Expenditures on health services for Aboriginal and Torres Strait Islander people [1], providing information on expenditure levels for the Indigenous and non-Indigenous populations;
3. clearer documentation of the pervasive control by governments over fundamental aspects of the lives of Indigenous people until very recently, and the deleterious effects of this lack of control on health; and
4. the Prime Minister’s commitment to reconciliation providing a unique opportunity to address these interrelated issues.

Lack of improvement in Australian Indigenous mortality in contrast with the Indigenous populations of New Zealand and the United States of America
There is no evidence of a significant fall in the overall mortality of Australia’s Indigenous population for the last two decades. By contrast, mortality rates for New Zealand Maoris and Native Americans have fallen substantially since the early 1970s. Current mortality rates for Australian Aboriginals and Torres Strait Islanders are at or above rates observed 20 years ago for Indigenous populations in comparable countries, being 1.9 times the rate in Maoris, 2.4 times the rate in Native Americans and 3.2 times the rate for all Australians [2].

Expenditure levels for health services for the Indigenous and non-Indigenous populations
The key findings of Expenditures on health services for Aboriginal and Torres Strait Islander people [1] are that:
• for all sources of expenditure, public and private, Australia spends $1.08 on the Indigenous population for every $1.00 spent on the population as a whole. That might be appropriate if the Indigenous population was only 8% sicker, but, by most measures, the health status of the Indigenous population is at least three times as bad as the population as a whole;
• State governments spend $2.19 on the Indigenous population for every $1.00 spent on the non-Indigenous population. This higher level of spending by State governments largely reflects the higher admission rates to hospital for Indigenous people because of their higher level of illness. While the level of spending by State governments is not fully in line with the higher level of need of the Indigenous population, it is a lot closer to being based on need than is expenditure by the Commonwealth; and
• the Commonwealth spends 63c per capita on the Indigenous population for every $1.00 it spends on the population as a whole.

Adverse health consequences of recent government control over the lives of Indigenous people
For Indigenous people, control has been exercised over freedom of movement, place of residence, private savings, marriage, whether parents could keep and raise their own children, employment and location of employment, and whether married couples and their children could live as family units [3].The last of such policies persisted until the 1970s and form part of the life experience of many of today’s Indigenous population
The effects of these policies have been extensive, continuing and disabling. Separation trauma has been found in many cases to damage self-esteem and adversely affect well being, relationships and parenting skills and the damage may consequently be passed from one generation to the next. Separation can also lead to depression, suicide, delinquency, violence and alcohol and drug abuse [4]. The effects on
children raised in dormitories/institutions in terms of family life and the acquisition of parenting skills may be profound.

More specifically, the 1994 National Health Survey found that people who were forcibly removed in childhood were twice as likely to assess their health status as poor or only fair, compared with people who were not removed. Forcibly removed people were not better educated, nor were they more likely to be employed or to be receiving higher incomes than those who remained in the communities. However, they were twice as likely to have been arrested more than once in the last five years [4].

Many forcibly removed children and their subsequent children and grandchildren have lost their cultures, their languages, their heritage and their lands, as well as their families and communities. Government actions interfering with family life affected the health and morale of many Indigenous communities. Indigenous men and women lost some of their purpose in raising families and building communities, and individual responses to this loss could result in drinking binges, hospitalisation following accidents, or assaults or behaviour which led to incarceration or premature death [4].

There is increasing evidence that lack of control in one’s working life can have profound consequences for health – with a substantial increase in mental health problems and a 2-3 fold increase in the risk of heart disease. These findings are based on extensive studies of the British civil service [5]. The lack of control, which many current Indigenous adults have actually experienced over fundamental aspects of their lives, is on a different scale entirely to the lack of control experienced by public servants in their working lives. Far greater health consequences for the Indigenous population should cause no surprise.

Reconciliation

The Prime Minister’s call for reconciliation has evoked ambivalence and uncertainty – hope that it might mean Government commitment to move national Indigenous issues forward, but hope is tinged with a degree of cynicism. This cynicism has been exacerbated by what is seen as token actions taken at the bicentennial. As a result, there is concern that reconciliation associated with the millennium might also be largely token and aimed more at cosmetic changes for the consumption of the foreign media, than action which would constitute the kind of significant and enduring change required for genuine reconciliation. The new millennium and the Sydney 2000 Olympic Games and the Prime Minister’s call for reconciliation provide a unique and timely opportunity for Australia to make the kinds of gains experienced in New Zealand and North America, but reconciliation can only occur if it is to be a reconciliation of substance.

If there were no issues to be addressed there would be no need for reconciliation, and if there is to be reconciliation there needs to be a recognition of what the issues are, how they arose and what now needs to be done in both practical and symbolic ways so that Australia even if somewhat belatedly, attracts international respect and a sense of national pride for its efforts.

A way forward

Creating a climate for change

Even those closely involved in Indigenous efforts are not fully aware of the persuasive influence of government control over fundamental aspects of Indigenous life and the continuing thread linking past policies with current circumstances. While there is widespread knowledge about the Stolen Generation, many are not aware of government control over family life through the dormitory system, control over whether families could live together as a family unit, marriage, savings and employment. Those from the general population who are unaware of the past and have themselves grown up in far more favourable circumstances, are perhaps understandably inclined to blame the Indigenous population for their current circumstances and to resent measures required to deal with disadvantage. No government can take the action required without public support and there is, therefore, a need to launch a public information campaign to inform the public as to why there is a need for reconciliation and why it is both a matter of common humanity and in Australia’s national interest for genuine reconciliation to occur. It is necessary to deal with the fact that the minority view that Indigenous people enjoy preferential treatment is based, not on fundamental prejudice, but on misinformation. A former coalition government was responsible for the 1967 referendum on Indigenous issues. The task for today’s government is to engender similar popular support for the current reconciliation process.

Harnessing a national effort

The issues that need to be dealt with to remove the inequalities in the lives of Australia’s Indigenous people cover virtually all fields of government administration – including housing, education, law and justice, land, environmental issues, business and economic development, family and community affairs, local government and health. All three layers of government are involved. A way needs to be found of
harnessing a national effort for a very complex range of issues in a very complex system of government. In the circumstances, only the Commonwealth can provide the necessary leadership and coordination. Perhaps the nearest parallel, and it is by no means an exact parallel, is Australia’s effort in the control of HIV/AIDS. This is a highly complex issue and Australia’s record in this field is as good as anywhere in the world. In the current context of discussion on reconciliation, the Commonwealth should discuss with the Indigenous community proposals such as the formation of a National Council of Indigenous Affairs – a Council which might meet twice a year to stimulate and coordinate necessary activity across issues such as those listed above, and across all three layers of government. The purpose of this Council would not be to usurp the roles and responsibilities of individual agencies, quite the reverse. The nearest actual parallel might be the report commissioned by the Western Australian Government [6], except that the Council would need to be an ongoing, rather than a one-off exercise, to ensure that progress is being made.

Such a Council could help to ensure that health, while important as an issue, is not the only issue to be addressed. Health is a consequence of other more fundamental issues, land and legal social political changes, which all need to be the subject of coordinated national effort as part of a genuine reconciliation.

Health

Health ought to be seen as a fundamental right, rather than something that has to be tackled as part of a reconciliation process. Nonetheless, given the lack of progress so far, it may be that reconciliation may provide the best opportunity to do the things that should have been done previously.

Too much has been made of the complexities of tackling the health issues. The fundamental point is that not only have the Indigenous populations in comparable countries made much more headway in the pace and extent of improvement in health status, but so has virtually every population in the world [7]. The difficulty, does not lie in the concepts but in the execution. There are five key issues which need to be addressed [2], [7] [8] [9].

1. Community control of health services.

One of the pioneering developments in Indigenous health services in Australia has been the struggle to develop, maintain and enhance community-controlled Aboriginal health services. Those services are still struggling to get the necessary resources to provide a comprehensive set of services, particularly for prevention and public health, but their real strength has been the relationship between such services and their communities. This relationship is fundamental, because no health service can function adequately, let alone optimally, without a satisfactory relationship with the community it is there to serve. While this point has long been recognised by Commonwealth governments of both persuasions, State and Territory governments have had far more difficulty with the concepts, perhaps because of a concern of potential political embarrassment from financial or other maladministration. Of course, the answer to this lies in the decades of successful administration by community-controlled health services, but there are two key steps that State and Territory governments could take to alleviate their concerns. The first is to take steps to train staff so that they can take on the technical and managerial aspects of health service administration. The second step is to follow the lead of the Canadian Government and implement a three-stage process of preparing communities for taking over responsibility for health service administration. [10]. In the end, the relationship between State governments and community-controlled Aboriginal health services needs to be one based on agreements for specified amounts of money to be provided for specified services in terms of the nature, volume and quality of the services provided, with appropriate mechanisms for monitoring and review.

2. Comprehensive health service provision.

There are some services that all Indigenous communities will need to provide – treatment services, antenatal, immunisation, health promotion, chronic disease control, environmental health, mental health, substance abuse, communicable disease control, dental, sense organ, aged care, community development etc. There is no need to ask whether these services are required for any particular community or setting as there is no population in Australia, Indigenous or non-Indigenous, or for that matter for most of the world, that does not require such services. The relative priority of such services may vary somewhat from place to place, and individual communities may have additional priorities, but there is no place that does not need to have such a set of services. That said, there are few health centres that can be said to be in a position to offer such a comprehensive set of services at an adequate level for the Indigenous population – particularly for the prevention and community services that are required to break the cycle of ill health. Few communities are in a position, for example, to offer even such basic services as those required for alcohol, tobacco and nutrition, or for an adequate approach to
diabetes prevention and control. It is firstly a question of a change in mindset so that funding agencies recognise that where need is greatest, then the highest quality is required. Australia has set itself a set of targets for improvements in Indigenous health, but not specified the services, policies and programs required to achieve the targets. This is a major need, together with the provision of adequate funds for such services, if communities are to be in a position to deliver services to meet community needs. This is not a question of imposing a set of services on communities — rather it is seeing priority setting as a community responsibility but ensuring that the necessary resources are there for basic services.

3. Funding

No one would argue that additional funds can or should be given without clear specification of the additional benefits to be provided from additional resources. That said, the funding issues, which have been the subject of a lot of misinformation, must be addressed if an adequate set of services is finally to be provided. The prevailing view, among both politicians and the public at large, is that huge amounts of money have been thrown at Indigenous health, and that, since health has not improved, the money must have been wasted, eaten up by a bloated bureaucracy, or corruptly or incompetently used and that, in short, providing any additional funds would throw good money after bad.

Fortunately, we now know what the situation really is [1]. As outlined above, Australia is probably spending about a third of what it needs to spend on a needs basis. That is, we spend approximately the same on the Indigenous population as is spent on the non-Indigenous population – despite the fact that the Indigenous population is three times as sick! The higher levels of illness mean a higher use of hospitals, and a higher need for medical, nursing and other services — and particularly for prevention and community services required to stop people getting sick in the first place. Current funding levels mean that the necessary services can not be provided at adequate levels.

While the States and Territories are still not spending enough, they are probably spending about two-thirds of what is required on a needs basis. The main issue is spending by the Commonwealth on funds under its own direct control. The chief issue here is one of happenstance rather than explicit policy. The fact that that the Commonwealth actually spends less per capita on the Indigenous population (63 cents) than it does on the non-Indigenous population ($1) is because of the lower level of access that the Indigenous population has to the main funding schemes – Medical Benefit Scheme and Pharmaceutical Benefit Scheme. However the position is not as extreme as it may seem, as the Commonwealth also funds some schemes administered by the States. Nonetheless, the fact remains of an enormous inequity in funding through schemes under the Commonwealth’s direct control. On a needs basis, the Commonwealth is spending perhaps a fifth of what is required. Australia cannot go on being the one developed country in the world making little or no headway with the health of its Indigenous population while the national government actually spends less on the Indigenous population than it does on the non-Indigenous population. Now, of course, the Commonwealth recognises the importance of the issue and is working on it, but it is important that there be a speedy and satisfactory outcome on this issue, and an outcome which appropriately recognises the higher level of illness (need) in the Indigenous population.

4. Training

The need for a skilled workforce is basic. Australia has approximately 30 Indigenous doctors (when on a per capita basis it should have hundreds), nursing is probably going backwards because of the more stringent entry requirements for the new graduate programs, there are perhaps one or two Indigenous dentists, and hardly any allied health workers. There is a major need to provide an upgrade path for the key field workers, Aboriginal Health Workers, in to the tertiary scheme. For an interim period of say 10-15 years, there will be a continuing reliance on non-Indigenous doctors, nurses etc, whose training does not specifically equip them to work in Indigenous health. There is also a major need for short courses for non-Indigenous staff working in Indigenous health.

Many countries have adopted the concept of teaching health centres, which provide model health services, and train the different categories of health staff in such services as a practical way of both advancing health service delivery issues, and of providing training in a very practical setting.

The needs are so great that simply providing a few extra places in training institutions here and there will not make any appreciable difference. A National Indigenous Health Training Strategy, modelled on the success stories in Australia (for example, the Newcastle medical school), and overseas for example the NZ Vision 2020 [11] and the US 9 Project 3000 by 2000 [12] is required.

The point is that a major coordinated national effort is required to tackle the training requirements and to bring about substantial improvements in the next 10-15 years.
5. New models of health service delivery

Because of the complex interaction between health, environmental, educational, economic and social issues, there is a need for new models of health service delivery. Maori health services are often embedded in a wider range of services encompassing community processes, preschools to preserve language and culture, pensioner accommodation, and, on occasion, employment and other social and economic services. There is no necessary translation of overseas models to Australia, and Australia must forge its own approaches, but it would clearly be worthwhile to learn wherever possible from other countries, which appear to have made much more headway. Within Australia there are promising developments at, say, Palm Island, and such efforts are worth further support and encouragement.

An incremental approach will not do it

It is sometimes argued that we are on the right track, that there are lots of good things happening, and that it takes generations to bring about improvements in health. Of course there are lots of good local initiatives scattered throughout the country. The reality, however, is that Australia has adopted an incremental approach to Indigenous health rather than a break-through approach. While rapid improvements in health are possible (they have happened all around the world and, most tellingly, the death rates for the Maori population dropped by a third in the 1970s), we are not seeing significant improvements in the health of Australia’s Indigenous population at a national level because Australia has yet to implement the kinds of health, social and political changes that are required for such improvements to occur.

In these circumstances, a little bit more of the same, an incremental approach, is really not going to make much difference. Australia is not doing what it needs to in order to achieve the national Indigenous health targets, and a continuation of the present scale and direction of health services will mean that current problems will continue for as far ahead as we can see. A determined national health approach to provide the necessary services is required. We should bite the bullet, decide to do what is required to achieve the targets, and thereby make the gains experienced by comparable countries [9].

Recommendations

That in the year preceding the millennium and the 2000 Olympic Games, the opportunity be taken to build a reconciliation not just of words but of real substance which recognises and effectively addresses the key circumstances affecting Australia’s Indigenous population and which includes the following six components:

1. A major information program is required to build the climate required for national reconciliation, to confront our history, and to inform the public of the link between that history and the health of Australia’s Indigenous population, and of the action now required to make the changes achieved in comparable countries. The point of such a program is not to engender guilt, but to aid in understanding of what needs to be done and why.

2. Discussion with the Indigenous community of mechanisms such as a National Council of Indigenous Affairs to help to harness a national effort from the three layers of government and the Indigenous community across a complex range of health, education, environmental, legal, political, social and economic issues.

3. Endorse the principle of community-control of health service delivery.

4. State and Commonwealth governments to institute needs-based funding formulae, with additional funding being provided with clear specification of additional benefits to be provided and on an agreement basis specifying the additional services and outcomes to be provided in terms of price, volume and quality.

5. Institute a comprehensive National Indigenous Health Training Strategy with 10-year targets for graduates to be produced across the full range of health professional, upgrade paths for Aboriginal Health Workers to the tertiary sector, and short courses for non-Indigenous staff working in Indigenous health.

6. Provide support for new models of health service delivery, which combine health service development with other social, economic, educational and economic services in Indigenous community-controlled processes.

Note: Information from this paper has been incorporated into a Submission to the House of Representatives Standing Committee, Family and Community Affairs Inquiry into Indigenous Health.
References:
4. National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from their Families (Australia), Bringing them home: report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from their Families. 1997, Sydney: Human Rights and Equal Opportunities Commission.
The role of the Royal Australasian College of Physicians in Indigenous health

Dale Fisher

Introduction

The substandard level of health of Indigenous Australians has been well documented and remains a seemingly endless source of clinical, academic and political reports. Any improvements to health are measured in terms of anecdotes rather than fundamental reform. All organisations involved in Aboriginal and Torres Strait Islander health issues are well intended and generally made up of hardworking individuals who impart a personal vigour not seen in most sections of the work force. For this reason, most individuals and organisations suffer considerable frustration at the lack of progress. Why are there such barriers from sound ideals and policies to effective implementation of initiatives targeting the health of individual Aboriginal and Torres Strait Islander people?

Blame is directed at times to government, Indigenous health organisations, health service providers and the Indigenous population itself.

This paper addresses possible explanations for the lack of progress. It discusses the importance of establishing partnerships and the need to devolve implementation to a regional level. The Royal Australasian College of Physicians (RACP) can play a fundamental role in reform, but we need to accept that we are not in a position to form policy or to fund or provide services. The College is a repository of knowledge and expertise that can be used by Indigenous organisations and government.

Organisations involved in Indigenous health issues

Countless organisations have a stake in the health problems of Indigenous Australians. Many of these groups, including Commonwealth and State health bodies, have a responsibility for the health of all Australians whereas other groups have been established for the sole purpose of addressing Indigenous health issues (Table 1).

Each organisation has 'Terms of Reference' and, necessarily, areas of business will often overlap. In fact, in most specific areas addressing health service delivery and reform there will be several organisations with a legitimate interest. This frequently leads to disharmony between groups. Such difficulties must be overcome when considering the raison d'être for the organisations, and so, in recent years and out of a respect for each organisation's expertise and commitment, partnerships between groups have evolved. An example of this is Aboriginal health forums. These are made up of Commonwealth health representatives, State government representatives, the Aboriginal and Torres Strait Islander Commission (ATSIC) and the State affiliate of the National Aboriginal Community Controlled Health Organisation (NACCHO). The aim of these groups is to formulate joint planning and policy.

Traditionally the RACP has not formally sought such partnerships. There are many examples of input to policy and service provision from individual Fellows, but they have needed to abandon conventional College committee structures to be effective.

11 Dr Dale Fisher has lived in Darwin since 1992. He became a fellow of the College in 1993 and works as an infectious diseases physician at Royal Darwin Hospital. A significant portion of this work involves delivery of outreach general physician services to Top End communities. He has been the NT representative on College Council for 3 years.
**Table 1: Organisations involved in Indigenous health**

<table>
<thead>
<tr>
<th>Organisations specifically involved in Indigenous health</th>
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<tr>
<td>Commonwealth Department of Health and Aged Care</td>
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<tr>
<td>State health departments</td>
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<td>Primary care service providers</td>
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<tr>
<td>Specialists</td>
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<tr>
<td>Hospitals</td>
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<tr>
<td>Others, including education, housing departments, etc.</td>
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<tr>
<td>National Aboriginal Community Controlled Health Organisation (NACCHO)</td>
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<td>The Office of Aboriginal and Torres Strait Islander Health (OATSIH)</td>
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<td>Aboriginal Torres Strait Islander Commission (ATSIC)</td>
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<td>Aboriginal Health Units (State and Territory based)</td>
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<td>Aboriginal and Torres Strait Islander Health Council</td>
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**The Royal Australasian College of Physicians**

If one is to consider the role of the College in Indigenous health, one must consider the overall Charter of the College. What is the College? and does it have a role at all in such a sensitive area? Moreover, do the RACP Fellows want their College involved?

The Association of Physicians was formed in 1930 from which the Royal Australasian College of Physicians with 231 foundation Fellows was incorporated in 1938. The motto *Hominum servire saluti* adopted for the coat of arms at the time means 'To serve the health of our people'. By 1992, the Faculties of Occupational Health, Rehabilitation Medicine and Public Health had been incorporated. In 1997, the College established a Health Policy Unit (HPU) and in 1998 the College of Physicians amalgamated with the Australian College of Paediatricians (ACP).

The Health Policy Unit was formed with a view to better coordinating a variety of health issues important to the RACP and Australian society. It works in close collaboration with the Social Policy Committee but calls on numerous expert Fellows within the College at various times. In fact, all Fellows have a stake in the HPU and have the potential to be called on for expert advice. The College's current social priorities include:

- social and economic determinates of ill health;
- Aboriginal and Torres Strait Islander health;
- passive smoking;
- nutrition and physical activity;
- injury;
- illicit drugs; and
- aged care.

The focus of activity is in the development of partnerships with implementation bodies, funders and policy makers. In fact, successful initiatives are founded on an acknowledgment that the RACP is not a service provider, funder or policy-maker. It is, however, a body of excellence. No single Fellow could claim to be an expert in any more than one of those priority areas. However, within the realms of the College we have the top experts in Australia and New Zealand.

Furthermore, the College sets and maintains the standard of service delivery and ethics in internal medicine. It is fundamentally involved in the training of ‘experts’ and in their continuing education. Most particularly, its core business is chronic disease in all its aspects. It is chronic disease which is the major burden affecting the wellbeing of Indigenous Australians.
Mission statement

The Royal Australasian College of Physicians (RACP) comprises a Fellowship of medical specialists who are committed to providing the highest quality of care in internal medicine, paediatrics and their sub-specialties for the people of Australia and New Zealand. The College is in the forefront of medical research and health education and through its Faculties has particular expertise in public health medicine, occupational medicine and rehabilitation medicine. It espouses the highest ethical standards in the care of individual patients and involvement in health and wider social issues. The College joins with other health bodies throughout the world, particularly in Asia and the Pacific region, and with government and other communities to advance the health of all people.

The need for partnerships and devolution

History as well as day-to-day practice tells us that the most well intended efforts by the most influential national health bodies have little impact at a community or individual level. The focus must be on how resources can be used in an effective way to provide patient service. While partnerships must exist at a Federal and State level, they will possibly be most advantageous at a community level. The establishment of community controlled health organisations or local area health bodies gives service providers the opportunity to form a local partnerships. Functional examples of such groups exist in the Tiwi Islands and Maningrida in the Northern Territory.

The providers' knowledge can be imparted to the local health board, which is in the best position to prioritise and implement reform. Furthermore, such partnerships can facilitate a multidisciplinary approach to include education and environmental infrastructure including housing and sanitation. Currently most Indigenous communities do not have (effective) health management boards forcing health service providers (mostly non-Indigenous) to attempt their own prioritising and implementation. Most of these individuals are not in a position of introducing a sustained and prioritised service. If their successor has a different priority then all the efforts are lost.

Sustainable reform can only be created by empowering the reform to the community itself. Any initiatives need to be institutionalised by the health board or health worker so that, as doctors and nurses turnover, the reform remains. The only health service provider that will remain in the community (be it remote, rural or urban) for the long-term is the local Indigenous health care worker. A massive injection of resources and effort needs to be made to establish area health boards and to improve the expertise, respect and rewards of health workers.

The delivery of specialist services to remote Aboriginal and Torres Strait Islander communities

In November 1997, Professor Alan Walker convened a Cottrell Conference inviting practising clinicians, paediatricians, surgeons, obstetricians, psychiatrists, primary care medical officers and nurses, and Aboriginal Health Workers to a three-day workshop on the Tiwi Islands and later in Darwin. Participants were asked to formulate recommendations, which if implemented would result in the improvement in the delivery of specialist services remotely.

It was acknowledged that the value of specialist service provision was severely hampered in an environment with inadequate primary care. Notwithstanding the need for increased numbers of health workers as well as medical and nursing primary care practitioners, the Conference produced twelve recommendations representing the needs of Fellows delivering specialist services to remote and rural regions.

1. Increase the number of specialist training positions suitable for and/or located in rural and remote Australia.
2. Develop flexible and innovative supervisory arrangements for trainees in rural and remote areas.
3. Develop cross cultural training programs for specialists and those in training.
4. Support the continuing training of specialists with 'generalist' skills (for example, general physicians, general paediatricians and general surgeons).
5. Encourage senior Consultants to take up work with Aboriginal and Torres Strait Islander people in rural and remote Australia.
6. Support continuing medical education, particularly distance support for both specialists and primary care practitioners.
7. Support regional hospitals as places of training, particularly for 'generalists'.
8. Provide mechanisms for re-entry into mainstream specialist practice, including the tertiary referral hospitals, for specialists who have worked in remote and rural areas.
9. Support on an ongoing basis, face to face interaction and information sharing between specialists from different Colleges serving in rural and remote areas.

10. Provide technical advice for remote area standard treatment guidelines on request.

11. Involve rural and remote practitioners in the development of any national clinical practice guidelines, so that the rural and remote perspective is included.

12. Lobby the Government to set up language centres and co-unity education teams to improve the communicative and cross-cultural aspects of health service delivery.

The Cottrell Conference is not a blue print for Indigenous health reform. It is, however, a message from a diverse group of specialists practising medicine in remote areas of Australia to the Council of the various specialist Colleges outlining their needs. Implementation of reform remains dependent on the establishment of partnerships.

The RACP Aboriginal and Torres Strait Islander Health Committee

The College has recently established this new committee. It is hoped that, through collaborative efforts with Indigenous organisations and facilitated by the HPU, we can, as a College, make a useful contribution toward the reform of Indigenous health. As well as its advocacy role, it will work within established College mechanisms to develop any areas including training, education and workforce which can have an impact on Aboriginal and Torres Strait Islander health.

Conclusions

The Royal Australasian College of Physicians, as an expert resource, has an obligation to play a fundamental role in reforms to improve Indigenous health levels. The emphasis needs to be on the formation of partnerships at all levels but particularly to devolve implementation to a community level. The College at a national level needs to be facilitating those partnerships, but also needs to be proactively addressing the needs of its Fellowship. Furthermore, there needs to be an emphasis upon learning lessons and recognising and discontinuing ineffective activity.

Fellows involved with Indigenous health issues need to communicate their needs to state and federal College groups. At a local level, Fellows need to identify influential Indigenous groups and work in collaboration with them. We should also be lobbying local and state administration to facilitate the development of local area health boards to allow use of our 'expert' information. Perhaps most importantly we should be recognising the value of the Aboriginal health worker and acting as a consultant to that health worker, promoting their respect in the community and using their skills at prioritisation and implementation.

The College most certainly has a role in Indigenous health. We can be most effective if we appreciate the role of Indigenous organisations at all levels as well as Commonwealth and State administrators and work in complementary partnerships.

Acknowledgments

This paper describes my personal opinions as to the role of the RACP in Aboriginal and Torres Strait Islander health. It is not necessarily 'policy'. I would like to acknowledge individuals who have helped me form my opinions. These include such colleagues as Bart Currie, Paul Torzillo, Trish Angus, David Brewster, Diane Howard, Paul Bauert, Tarun Weeramanthri, Richard Larkins, Don Cameron, Don Swinbourne, Craig Patterson, Gary Disher and the RACP Aboriginal and Torres Strait Islander Health Committee.
Review of specialist medical services to rural and remote Aboriginal communities in Western Australia

Bill Musk and Catherine Rhys-Hearn

Abstract
This study was commissioned by the Health Department of Western Australia to review and document the services provided to Aboriginal people living in remote communities in Western Australia in 1995. The task was to investigate and comment on perceived problems, shortages and service delivery mechanisms and make recommendations for action with a view to improving and enhancing access to and utilisation of specialist medical services by people in remote Aboriginal communities in the state.

The requirement was to consult with the Aboriginal people in their communities and with their service providers in the communities, their regions and in Perth. Hospital admission data pertaining to hospital inpatient episodes for Aboriginal people were also examined. As a result it was recommended that; action is required to encourage services in the local communities and regional centres in preference to the capital city; health provider appointments meet cultural expectations; travel and accommodation for patients be upgraded and made more appropriate; improved communication between primary, secondary and tertiary health care providers be encouraged; and specialist diagnostic equipment be made more readily accessible (including the development of telemedicine).

Ways of encouraging suitable specialists to practise in rural areas should be sought and steps be taken to promote Aboriginal health as a discipline in undergraduate and postgraduate training for health professionals. It was also recommended that further work be encouraged to investigate the causes and patterns of disease and associated problems prevalent in Aboriginal communities in order to assist the development of appropriate preventive and management protocols.

Introduction
Hospitalisation and mortality rates among Aboriginal people in Western Australia are much higher than in the rest of the community [1] [2] [3]. There are particular problems in the delivery of health services in this State because its size is so great and the population is widely dispersed in rural and remote areas. Even rural centres are small towns by international standards.

Access by Aboriginal people to adequate and appropriate specialist medical care is very important, given their high levels of morbidity and mortality, their special cultural, traditional, and demographical circumstances and the failure to date of preventive strategies to improve their health status. The causes of chronic morbidity and premature mortality among Aboriginal people are frequently potentially preventable by lifestyle modification or early diagnosis and intervention with appropriate management to prevent the onset of advanced disease or complications of chronic disease. However, given that primary preventive strategies are being put in place but have not yet achieved their potential there are compelling needs to provide services which will prevent and encourage the diagnosis of many chronic diseases and provide and promote appropriate, effective intervention to prevent their progression. Particular programs for the prevention, identification and treatment of disease complications before they become irreversible are needed. Furthermore, the management of advanced chronic disease is often beyond the capacity of primary health care providers without specialist assistance.

Apart from the special needs of Aboriginal people, specialist medical (including surgical, obstetric, paediatric, etc.) care is also needed for other people from rural and remote areas for acute conditions and emergencies for the same medical conditions that people from urban centres require. This need is often more readily apparent than the need for specialist care for chronic conditions and the State has a tradition of attempting to meet these needs with the provision of highly developed services (such as the Royal Flying Doctor Service) bringing equipment and skilled care to people in remote areas and providing a means for rapid evacuation to centres where appropriately sophisticated specialist care can be provided.

The roles of specialists in providing medical care to remote and rural communities are seen as:
1. clinical diagnosis and treatment of individually referred patient;
2. direction and support of community medical and nursing staff;
3. development, supervision and evaluation of protocols for management; and
4. development, supervision and evaluation of protocols for screening.

Currently specialists appear to contribute most to clinical diagnosis and treatment of individually referred patients, but could do much more for their other potential roles.

In 1995 we successfully tendered to the Health Department of Western Australia to carry out a review of specialist medical services to rural and remote Aboriginal communities in Western Australia. The review commenced in October and we reported to the Health Department in May, 1996.

Aims
To review, document and suggest ways to enhance access to and utilisation of specialist medical services provided to rural and remote Aboriginal communities, including the role of the Patient Assisted Travel Scheme (PATS) in Western Australia.

Methods
The agreed research plan required:
1. Consultation with Aboriginal people living in remote communities.
2. Consultation with key stakeholders (major health service providers, the Rural Health Development Unit, the Western Australian Centre for Rural and Remote Medicine, the specialist medical colleges, the Australian Medical Association, country health authorities, individual medical specialists, and representatives of specialist organisations including learned colleges.)
3. Analysis of distances travelled for hospital admission.
4. Canvass opinions of:
   - medical directors;
   - general practitioners;
   - community nurses;
   - directors of regional health services;
   - medical specialists;
   - Aboriginal medical services;
   - Royal Flying Doctor Service; and
   - Australian Medical Association.

The review plan required that we ensured the views of Aboriginal people were incorporated into the final recommendation (that is, that we visit rural and remote Aboriginal communities to promote discussion of access to specialist medical services, the community elders, the community committees, community clinic staff and patients). This therefore involved visiting at least four rural and remote Aboriginal communities in at least three different geographical areas in Western Australia. Regional hospitals were also visited to gather the views of the staff treating people from rural and remote areas. These visits occupied the month of October 1995. In order to investigate the patterns of hospital admission of Aboriginal clients from remote rural areas, an analysis of the Health Department of Western Australian Hospital inpatient data files was undertaken. The data consisted of unit records for all Aboriginal people discharged from hospitals in Western Australia in 1994. These records included information on address, postcode, area, date of birth, sex, diagnosis, dates of admission and discharge, hospital morbidity code and a number of other data-related items. An analysis was undertaken to determine the distances people from remote communities were obliged to travel to be admitted to hospital. In order to do this, the addresses were coded to enable each remote community to be uniquely identified. The coding system was also designed to relate the community to an 'area' as defined by postal authorities and used by the Health Department of Western Australia and the Australian Bureau of Statistics. These areas were then linked to the Valuer General’s Office file of 'Northings' and 'Eastings' which relate to longitude and latitude. They were very convenient to use because it is then possible to use Pythagoras' theorem to calculate the straight line distance between two points. In a similar way, 'Northings' and 'Eastings' were also attached to the file of all hospitals in the State, again based on the 'area' of the hospital. A file was compiled of the records of people admitted to hospital who lived outside the Perth metropolitan area. Calculations were then made to determine the distance travelled by each inpatient from the address area in the hospital to which the patient was admitted. (These distances may be considerably less than 'road distances'.) Where a patient was admitted to hospital within the area in which the address was accorded this distance was assumed to be zero because 'sub areas' were not defined by our coding system.
Results

Travel
It was found that about one-third of all Aboriginal people living outside the Perth metropolitan area who required hospitalisation had to travel to a hospital outside their own area for inpatient treatment. It was further observed that, from these data, even ignoring distances travelled within areas, Aboriginal people from outside the Perth metropolitan area travel on average a distance of at least 323km ('as the crow flies') for any inpatient hospital episode.

In further analysis, it was observed that the most frequently recorded diagnosis for Aboriginal children being referred to Princess Margaret Hospital from remote and rural areas were acute bronchitis and bronchiolitis, and otitis media, and the most frequently recorded procedures were operations on the skin and subcutaneous tissues, intubations and radiological procedures. These findings raise the issue that at least some of these procedures could be reasonably readily made available in regional centres.

Information from interviews and surveys

Medical directors
A survey of nine medical directors of regional hospitals resulted in the following suggestions:
1. ensure that the doctors in the region as a group are consulted on the need for additional specialists;
2. ensure that the specialists appointed will provide the services required; and
3. ensure that the specialists are able to communicate with Aboriginal people.

General Practitioners
A survey of 306 general practitioners practising outside the Perth metropolitan area and 21 Aboriginal Medical Service practitioners and the three Royal Flying Doctor Service practitioners indicated:
1. distance seems to be the main problem;
2. the most needy regions appear to be the central area and the Pilbara;
3. the most needed additional specialist services are perceived to be ENT, ophthalmology and psychiatry, followed by orthopaedics;
4. ENT services are perceived as deficient in all regions;
5. additional ophthalmology services are most in demand in the north of the State; and
6. psychiatry is most in demand in the south of the State.

Additional comments from doctors were summarised as being:
• 'we are used to making do!';
• continuity of services is unsatisfactory;
• frequency of visits by specialists to rural areas is inadequate;
• rural GPs with procedural skills should be encouraged;
• telephone access to consultant physicians would be helpful;
• better still – telemedicine should be developed for the remote areas of Australia;
• similarly, quick answers to difficult queries would be very helpful;
• better accommodation for patients in regional centres and Perth is required;
• provision of transport for patients is a serious problem;
• better liaison services are required in Perth;
• one telephone call to a Perth hospital should generate an appointment with a specialist;
• more reliable appointment-keeping services need to be established;
• unnecessary follow-up appointments with specialists should be avoided; and
• 'social problems' are a major issue with aboriginal patients.

Community nurses
Letters sent to 31 community nurses working in Aboriginal communities resulted in 24 replies and indicated that the Kimberley area appeared to have fewer resident medical services available than other regions, that only 39% of the community surveyed had resident doctors and 57% had some visiting specialists. Paediatric specialist services were available in 79% of the communities but ophthalmology, the next most commonly available service was available in only 39% of communities.

Community nurses’ comments indicated:
1. only 39% of the communities surveyed have resident doctors;
2. 57% of the communities have visiting doctors; and
3. paediatric specialist services are generally available to the communities (79%).
Directors of regional health services

Directors of regional health services stated:
1. there are not enough specialists resident in country areas and the visits from Perth are all too infrequent and too short in duration to allow the specialists to visit remote communities;
2. transport difficulties for Aboriginal people from remote communities are a major problem;
3. specialists are reluctant to provide services in some areas because of lack of equipment, suitable consultation rooms and clerical support; and
4. financial incentives to specialists are poor.

Medical specialists

Only 28 replies were received from 63 letters to medical specialists. These indicated the following perceived problems:
1. transport deficiencies;
2. accommodation shortages;
3. shortage of equipment and support from nurses and other staff; and
4. resources and time are wasted by appointments not being kept.

Aboriginal Medical Services;

The Aboriginal Medical Services were seen to be moving towards providing specialist services separately from the general community because of the following issues:
1. inappropriateness of the appointment-making processes;
2. problems of access of Aboriginal people to general practitioners to obtain specialist referrals and a sense that the threshold for referral to a specialist is different for Aboriginal people and white people;
3. escorts are frequently needed;
4. insufficient Aboriginal liaison people exist in hospitals and accommodation hostels;
5. the frequency of visits by specialists to regional centres and remote communities is generally inadequate;
6. problems exist in seeking remuneration for medical services;
7. there is a need for greater cross-cultural training for specialists;
8. Aboriginal people would like a greater say in whom they consult;
9. there is inequality of opportunity to be seen by a specialist; and
10. specialist colleges need to recognise the needs of Aboriginal people and possibly provide diploma courses for general practitioners.

Royal Flying Doctor Service

Responses indicated that culturally appropriate medicine for Aboriginal people means taking more doctors to the communities rather than transporting Aboriginal people into regional centres or to Perth, and there is a lack of emphasis on preventive programs and poor compliance with treatment.

The Australian Medical Association

The AMA indicated that it supports decentralisation of medical services and recognises the need for specialists in regional centres to be multi-skilled. The Association supported a specialist rural locum system, but has a philosophical affinity with a ‘fee for service’. Grants may be needed to attract specialists to rural areas.

Discussion

The threshold for referral of Aboriginal patients to specialists appears to be very variable and appears to be dependent on:
1. presence of a doctor in the community;
2. distance to the nearest specialist;
3. modes of transport available;
4. cost of transport and who meets the cost; and
5. cost and adequacy of accommodation in Perth and regional centres.

Summary

Aboriginal people from rural and remote Aboriginal communities are unhappy when they leave their communities.
1. Travel and accommodation are expensive.
2. Escorts are also expensive.

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3. Keeping specialist appointments is frequently difficult.
4. Missed appointments may cause protracted delays.
5. Professional demarcations cause problems.
6. There is reduced choice of specialists by non-Aboriginal people.

Recommendations
1. Take some action immediately.
2. Services should be provided in the local communities.
3. Ensure that management conforms with cultural expectations.
4. Arrange appropriate escort services and accommodation at regional centres and Perth.
5. Good, reliable communication is essential.
6. Specialist diagnostic equipment should be available.
7. Telemedicine should be investigated.
8. There should be no financial disincentives to the care recipients.
9. Find ways of encouraging suitable specialists to practise in rural areas.
10. Aboriginal health should be designated as a medical specialty.
11. Commission further work to investigate the causes and patterns of diseases and associated health problems prevalent in Aboriginal communities.

References
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The development of clinical care guidelines for Aboriginal and Torres Strait Islander health

Sophia Couzos and Richard Murray

Introduction

Significant clinical practice uncertainty exists when managing the health problems faced by Aboriginal people and Torres Strait Islanders. Not only is the burden of disease greater with significant morbidity, but the spectrum of disease also includes skin infections, suppurative ear infections, trachoma and rheumatic fever, which are common in developing nations but still predominate as important health problems in the Australian Aboriginal and Torres Strait Islander population. The optimal management of these diseases of poverty is often not clear to many health professionals.

Health professionals are also generally unfamiliar with disease causes, the role of Aboriginal community-controlled health services (a community development model), how to practise within them, what constitutes 'best practice', disease prevention principles within the context of a consultation, and population approaches to health.

The frequent turnover of medical staff also introduces much inefficiency and compounds the difficulties in doctor recruitment widely recognised in rural and remote Australia. Aboriginal Health Workers in the Kimberley region of Western Australia have referred to this frustration and termed it 're-educating garriya fatigue syndrome'.

In the face of a high turnover of staff, community councils from the Kimberley have been very cognisant of the need for consistent, organised, and high quality care, and have been leaders in promoting such standards for Aboriginal health care. A culmination of this approach, taken to encourage best practice and overcome clinical practice uncertainty, was a systematic review of the evidence-base to act as a template for clinical practice guideline (CPG) development for many interventions in Aboriginal health that were unfamiliar to health professionals [1].

Aboriginal community controlled health services

The process of self-determination in matters of health is best embodied by and illustrated through Aboriginal community-controlled health services (ACCHSs). Primary health care delivered within these services is defined not merely by the cure or treatment of disease, but by community development approaches which are empowering to Aboriginal communities and mediators for social change. This contrasts with purely biomedical-focussed primary care approaches to treatment. Community-development approaches to health are essential for integration, efficiency, and ownership of health problems. They overcome obstacles to health access and best practice and provide a holistic focus that integrates biomedical, socio-environmental and population approaches to health that can prevent disease as well as treat. Through such structures, Aboriginal community groups are able to negotiate the terms of their interdependence with external organisations and direct attention away from short-term unsustainable programs to address structural health challenges.

Unfortunately, although health professionals have a mandate in matters of health, they do not in general have a good understanding of the history and socio-political background to the poor health of Aboriginal people [2] that lead to the grass roots establishment of the ACCHSs.

Take, for example, confusion regarding what 'culturally appropriate' care means. 'Culturally appropriate care in any setting anywhere involves presenting... what modern medicine has to offer...(but in a way that Aboriginal communities can understand).' [3] This unfortunately describes a process where the power relationship favours the health profession, not the community. Is this really what 'culturally appropriate' care is - as reported in an Editorial in the most prestigious medical journal in the world in 1998?

Culturally-appropriate care can only truly be delivered through a process of explicit community ownership or control, so that health care delivery and outcomes are accountable to the population served.
Poverty
The majority of the health problems faced by Aboriginal people have their origins in poverty.

Box 1. Poverty and overcrowding- key determinants of poor health in Aboriginal people.

<table>
<thead>
<tr>
<th>Poverty</th>
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<tbody>
<tr>
<td>Aboriginal people are poorer than non-Aboriginal people- median family income was lowest in every state (1996 Census).</td>
</tr>
<tr>
<td>Aboriginal family size is larger overall. 15.2% Aboriginal families had 4 or more children under 15 years compared with 4.8% of non-Aboriginal families (1996 Census).</td>
</tr>
<tr>
<td>Fewer Aboriginal families than other families have more than one member employed.</td>
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<tr>
<td>Fewer Aboriginal people have skilled vocational qualifications.</td>
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</table>

Overcrowding
- In all States and Territories, Aboriginal people are more likely to live in overcrowded houses.
- 90% of all Australian 2-3 bedroom households which accommodate 12 people or more were Aboriginal households (from only 2% of the population) (1996 Census).
- Fewer Indigenous home ownership (31% c/f 71%).
- Significant basic unmet needs, such as reticulated water. In 1989, 54,000 Aboriginal people were served by reticulated water supply schemes that should have supplied less than 1,000 people.

This is certainly true of the classic diseases of poverty – such as rheumatic fever, trachoma, ear infections and skin infections. Mainstream health problems such as diabetes and cardiovascular disease are made worse through co-morbidity, poor access to health care, poor diet and a lifestyle that predisposes to alcohol and smoking, known to be the product of lower socioeconomic status [4].

Poverty confers a risk status through childhood malnutrition, because malnutrition has been linked with adult disease such as diabetes, cardiovascular and renal disease in adulthood. Given that Aboriginal children are born smaller and malnutrition is still prevalent, Australia faces a tremendous cost arising from political inaction. Key policy directions for the future are required to address health inequalities similar to those adopted in the UK through the Independent Inquiry into Inequalities in Health Report [4].


'Everyone has a right to a standard of living adequate for the health and wellbeing of themselves and family including food, clothing, housing and medical care and necessary social services'.

Best practice and clinical care guidelines
Since the ACCHSs were established nearly 30 years ago (beginning at AMS Redfern in 1971), best practice, standards and preventive medicine protocols have been defined within each service.

Best practice is about using the evidence to guide decision-making and developing organised approaches to primary health care. Clinical care guidelines are needed when there is uncertainty in clinical practice [6]. Clinical practice uncertainty is a critical driving force towards the development of best practice. The persistence of uncertainty in delivering care leads to significant practice variation (inappropriate care), gaps between what health professionals do and what the scientific evidence supports, and lost opportunities for health (inefficient care). Consequences for Aboriginal health can also be broad ranging and include disenchantment and poor recruitment and retention of general practitioners. A frequent staff turnover can cause a loss of 'collective memory' and be a costly process for the health service and the health system. Finally, the delivery of contrary and inconsistent care can confuse clients, promote confidence loss, delay the acquisition of best care, and lead to retaliatory responses from staff ('blaming the victim').
Despite this, many clinical practice guidelines developed in Australia are not applicable to the health problems faced by Aboriginal people (Box 2).

**Box 2. Why clinical practice guidelines may not be applicable to health problems of Aboriginal people.**

- Most guidelines to date have been consensus-based and this has created more clinical practice uncertainty.
- Many are not flexible enough to be applicable to the Aboriginal situation (e.g., staffing, geographical, climate barriers, etc.).
- Many do not address Aboriginal health priorities.
- Many do not provide answers to Aboriginal health priorities because the right questions were not asked.
- Many fail to consider population approaches to health problems.
- Integration of recommendations within a holistic framework can be problematic.

Guideline developers may misinterpret the applicability of research findings to Aboriginal people. Quite a bit has been written on this subject—much of it attempting to overcome the confusion and misconceptions that surround these issues. Often the question takes this form:

"Can the efficacy of the therapeutic agent be generalised to those outside the trial?"

It has been said that the question should be phrased:

"Is my patient (or their patho-biology) so different from those in the trial that its results cannot help me make my treatment decision?" [7].

In other words, there should be some evidence for a judgement against generalisability of the evidence. There are two types of differences that can emerge in the applying the intervention to people outside the trial—quantitative and qualitative. Quantitative differences are those one usually thinks of—matters of degree of risk and responsiveness. The less the absolute risk for disease, the less impact the intervention has. Qualitative differences are those which are helpful in the study group but harmful in the target group and vice-versa—which are generally quite rare [8].

The benefits of the therapeutic agent and risk of harm should be applied to the individual case. Health professionals should be piecing together the background or absolute risk for disease in clients, the effect of the intervention (through systematic reviews of the evidence) in reducing relative risk, and the risk of harm from the intervention.

Clearly, patients at greatest risk of disease will have the greatest net benefit as benefit tends to increase with risk. Those most at risk have most to gain. Furthermore, the risk of harm or adverse events tends to stay fixed regardless of the risk for disease in the patient.

At some point, those with low risk for disease will not achieve a marginal benefit high enough to overcome the risk of harm or adverse events [8]. So, rather than focussing on Aboriginal or non-Aboriginal, individual risk status should define the applicability of trial findings. Generally, because of their higher risk status, many Aboriginal people have the most to gain.

There is a need for evidence-based clinical care guidelines as many health professionals are unfamiliar with the primary care management of diseases such as rheumatic fever; chronic ear infections (chronic suppurative otitis media); trachoma; recurrent skin infections and scabies; chronic renal failure; and diabetes. This list may appear to be familiar, but does the primary health care practitioner really know how to diagnose these conditions? to treat the presenting problem? to manage and systematically prevent worsening of the chronic problem? to inform the Aboriginal Board on population interventions? or to organise health processes when clients have several of these health problems at once? And if they do, how sure are they that their information is correct? The following three examples illustrate the degree of clinical practice uncertainty in managing some of these health problems.

**Chronic suppurative otitis media**

The burden of chronic suppurative otitis media (according to World Health Organization criteria) is a massive public health problem in Aboriginal children [9]. While the disease is a manifestation of socioeconomic inequity, clinical practice uncertainty has obstructed a consistent primary health care approach to management. The international literature reports few clinical practice guidelines on the
management of this problem and most are consensus-based. Some refer to the commencement of oto-topical antibiotics at the time the diagnosis is made, some refer to delaying oto-topical treatment until several weeks of unsuccessful dry mopping of the ear discharge. Some also refer to systemic antibiotic therapy. There is also uncertainty on optimal ear toilets [10]. A recent systematic review of randomised controlled trials investigating the role of ear toilets and oto-topical/systemic antibiotic therapy [11] has for the first time provided an opportunity for the development of evidence-based consistent guidelines.

**Trachoma**

Australia is one of the few developed nations with an Indigenous population suffering from hyperendemic trachoma. This contrasts with the USA, Canada and New Zealand, whose Indigenous people are free from trachoma. This classic disease of poverty is a marker of environmental inaction within Australia desperately needed to address the health determinants of trachoma (which include access to water, elimination of overcrowding and environmental control). Furthermore, guidelines for the population control of this problem within Australia (who to screen? who to treat?) differ from those produced by the World Health Organization and differ between States and Territories.

**Pneumococcal pneumonia**

The rates of pneumococcal pneumonia in Aboriginal people exceed those for non-Aboriginal people by a factor of more than 20. The 24-valent polysaccharide pneumococcal vaccine, while known to be efficacious, particularly in those at high risk prior to the development of chronic disease, has been costly, and has not been widely promoted. Consequently, it has taken years before the medical profession has put this 'prevention into practice' with the announcement in 1999 of the free availability of this vaccine for Aboriginal people.

**Evidence-based decision-making**

These examples illustrate the need to apply evidence-based decision-making to direct choices for interventions in the management of Aboriginal health problems. Best practice is about making decisions that will lead to better health outcomes, do more good than harm, and be better investments that others. If decisions are not informed by the evidence, explicitly defining how historical, ideological, or political values and resources influence those decisions will be essential (Box 3).

**Box 3. Best practice and evidence-based health.**

<table>
<thead>
<tr>
<th>How do we know what is best practice?</th>
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<tr>
<td>• health service decisions that will lead to better health outcomes; and</td>
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<tr>
<td>• health service investments that are preferable to others (because the direction of effort to one alternative means that another is denied).</td>
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Evidence-based health is about:

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<th>Evidence-based health is about:</th>
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<tr>
<td>• making decisions explicit and informed by research, rather than on 'values' and resources or 'other forces and chance' — opinion-based medicine (values are influenced by historical models, cultural, and ideological influences).</td>
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</table>

Of course, the evidence-base is only one part of the process of best practice. Services have to be able to put recommendations into practice. They can’t do this if they don’t have the capacity for organising preventive health care delivery. The evidence also needs to be considered and influenced by the opinions and clinical experience of the people who will make local guidelines.

The development of local guidelines is essential for the ownership, relevance and subsequent implementation of guidelines [12]. The process can incorporate local or regional mechanisms to overcome barriers to implementation, encourage consensus particularly in the absence of research evidence, and support discretionary decisions in clinical care (such as follow-up times or preventive intervention frequencies). The Kimberley Aboriginal Medical Services Council (KAMSC) sought to define best practice approaches to primary care delivery within the ACCHSs using systematic review methodology beginning in 1995. The aim was to lessen a sense of isolation and empower practitioners, to speed up the acquisition of confidence in dealing with health problems about which practitioners had little formal training, to make interventions consistent and reduce unnecessary practice variation, and to form the basis of the periodic health examination prompted by computerised recall.
Such a resource could also serve as a framework from which health professionals could base their decision-making at the local level.

In conclusion, health professionals have a responsibility to Aboriginal people to be informed about the determinants of ill health. As they occupy a position of power, the broadcasting of ill-informed professional opinions may adversely influence health policy that may affect service viability. It may lead to desperate unsustainable health program responses, and a sense of hopelessness.

By every measure of health status, Aboriginal people are worse off than non-Aboriginal people. This situation is not helped when the health profession is not sure what to do. It must be remembered that finding answers to questions in health care depends on being able to ask the right questions, and these questions not surprisingly emerge from Aboriginal communities themselves through ACCHSs over the last 30 years.

The scene has been set for the refinement of clinical practice guideline development relevant to Aboriginal people. Making evidence accessible should encourage organised approaches to Aboriginal health care, promote interventions of proven benefit, discourage ineffective interventions and in many instances reassure practitioners of the appropriateness of their treatment policies. Guiding services towards the implementation of best practice will eventually lead towards improved health outcomes by reducing clinical practice uncertainty, the organised application of preventive interventions, and the integration of public health as part of primary care. Further work on curriculum development in undergraduate medical training and postgraduate training programs which address Aboriginal health problems may help to galvanise action on the determinants of health problems from health professionals and support the local development of relevant clinical practice guidelines.

Acknowledgment

The development of the KAMSC textbook on ‘Aboriginal Primary Health Care’ was a product of two decades of Aboriginal community-controlled health service delivery in the Kimberley; a decade of experience with computerised recall and the periodic health examination; Aboriginal and non-Aboriginal staff with cumulative expertise of long duration; and health leaders from Aboriginal communities devoted to organised approaches to improving the health of their communities.

References


Maternal and child health services for Indigenous people

Sandra Eades

Abstract

Aim: One of the major aims of the Bibbulung Gnarneep study was to ascertain whether there was adequate utilisation and access to antenatal health care for Aboriginal women.

Methods: The Bibbulung Gnarneep project is a birth cohort study of metropolitan Indigenous women. The major research tool is a series of five face to face interviews with the mother.

Results: Two hundred and seventy six women were enrolled in this study. Twenty percent of these women experienced difficulties accessing antenatal health care. The majority of these difficulties were related to transportation, distance from health care service and not having access to childcare. A smaller proportion of complaints was related to impersonal or rude attitudes by staff providing care loss of individual attention.

Conclusion: Antenatal care to urban Aboriginal women needs to be improved. Access to services is difficult despite the abundance of health care services in metropolitan areas.

Introduction

Bibbulung Gnarneep is a birth cohort study of urban Aboriginal women and their child during the first two years of life. Issues related to antenatal care and health status during pregnancy were addressed as part of this study.

Methods

Bibbulung Gnarneep is a birth cohort study of urban Aboriginal women in the first two postnatal years. The major research tool is a series of five face to face interviews carried out by Aboriginal health workers with each study mother in the family home. The midwives notification system was used to identify Aboriginal women with residential postcodes in the Perth metropolitan area. These mothers were approached during the first six to twelve weeks after the birth of their child and asked to participate in the Bibbulung Gnarneep study. Information about antenatal health status, pre-pregnancy health status and antenatal health care access was given in the initial interview during the period six to twelve weeks after the child's birth. The Western Australian Child Health data base was used to determine how representative the Bibbulung Gnarneep study's mothers were in comparison to other metropolitan Aboriginal mothers overall, and all Aboriginal mothers in Western Australia giving birth during the same time period.

Results

Two hundred and seventy women agreed to participate in the Bibbulung Gnarneep study. They completed their first interview with our Aboriginal health worker in the time period six to twelve weeks after the birth of their baby. Study mothers were identified from the WA Midwives notification system. All eligible mothers having babies during a fifteen-month period were invited to participate. Eighty seven percent of eligible mothers were contacted and sixty one percent of those contacted and eligible were enrolled.

Mothers in the Bibbulung Gnarneep study were compared to the total group of metropolitan Indigenous mothers who had given birth during the same time period and for total State Indigenous births during 1995. We ascertained the proportions of low birth weight and preterm births as well as maternal age, parity and postcode of residence. The Bibbulung Gnarneep study participants did better than comparison metropolitan and statewide mothers in all health indicators, but fared less well in comparison to the total population of mothers. When compared by postcode of residence, the Bibbulung study mothers were equally representative of all metropolitan Indigenous mothers.

The gestation at first visit to a doctor for care during pregnancy was determined for study mothers. Sixty five percent of study mothers saw a doctor for the first time during the first trimester of their pregnancy. A further 20% saw a doctor between thirteen and twenty weeks; hence 85% of mothers first attended a doctor for antenatal care during the first half of their pregnancy. The frequency of visits to a doctor for care during pregnancy was determined.
### Gestational age

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>&lt;37 weeks</td>
<td>9%</td>
<td>13%</td>
<td>13%</td>
</tr>
<tr>
<td>&gt;37 weeks</td>
<td>91%</td>
<td>87%</td>
<td>87%</td>
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</tbody>
</table>

Chi square = 2.98, p=0.08 (BG c/f Metropolitan); 7% of all WA babies are preterm

### Birth Weight

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<thead>
<tr>
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<tbody>
<tr>
<td>&lt; 2500</td>
<td>10%</td>
<td>14%</td>
<td>12%</td>
</tr>
<tr>
<td>&gt;2500</td>
<td>90%</td>
<td>86%</td>
<td>88%</td>
</tr>
</tbody>
</table>

Chi square = 2.7, p = 0.1 (BG c/f Metropolitan); 6% of all WA babies LBW

### Maternal age

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>&lt; 20</td>
<td>15%</td>
<td>21%</td>
<td>25%</td>
</tr>
<tr>
<td>20-24</td>
<td>39%</td>
<td>38%</td>
<td>35%</td>
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<tr>
<td>25-29</td>
<td>28%</td>
<td>25%</td>
<td>26%</td>
</tr>
<tr>
<td>30+</td>
<td>18%</td>
<td>15%</td>
<td>15%</td>
</tr>
</tbody>
</table>

Chi square = 4.5, p =0.2 (BG c/f Metropolitan; 6% of all 1995 WA births were to teenage mothers

### Parity

<table>
<thead>
<tr>
<th></th>
<th></th>
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</tr>
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<tbody>
<tr>
<td>0</td>
<td>20%</td>
<td>23%</td>
<td>27%</td>
</tr>
<tr>
<td>1-2</td>
<td>49%</td>
<td>42%</td>
<td>43%</td>
</tr>
<tr>
<td>3-4</td>
<td>22%</td>
<td>23%</td>
<td>21%</td>
</tr>
<tr>
<td>5+</td>
<td>9%</td>
<td>11%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Chi square = 3.7, p = 0.3 (BG c/f Metropolitan); 40% of all 1995 births in WA were to mothers with a parity of 0

Ninety-nine percent of study mothers had at least one visit to a doctor for care during their pregnancy. Sixty six percent had at least six doctor visits, but twenty five percent of mothers had five or less visits to a doctor for antenatal care. Nineteen percent of mothers stated they experienced difficulties...
accessing health care during their pregnancy. Thirty seven percent of complaints were related to transport and distance of the mother’s home from the point of health care delivery. Twenty percent of complaints were about receiving impersonal care, rudeness, and ignorance from health care providers. Twelve percent of complaints were about difficulty accessing the mother’s doctor of choice and nine percent were related to childcare difficulties for remaining children. A smaller proportion of complaints were about poor explanations and feeling ill (5% and 6% of complaints respectively).

Gestation at first visit to doctor (Gestation weeks)

<table>
<thead>
<tr>
<th>Gestation (weeks)</th>
<th>All Bibbulung Gnameep mothers (n=270)</th>
<th>Mothers reporting pregnancy complications (n=201)</th>
<th>Mothers reporting pre-existing medical problems (n=132)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-12</td>
<td>65%</td>
<td>66%</td>
<td>64%</td>
</tr>
<tr>
<td>13-20</td>
<td>20%</td>
<td>20%</td>
<td>18%</td>
</tr>
<tr>
<td>21-30</td>
<td>9%</td>
<td>10%</td>
<td>11%</td>
</tr>
<tr>
<td>&gt;30</td>
<td>2%</td>
<td>1%</td>
<td>2%</td>
</tr>
<tr>
<td>Unknown</td>
<td>4%</td>
<td>2%</td>
<td>5%</td>
</tr>
</tbody>
</table>

*3 mothers with pregnancy complications did not see a doctor

Number of visits to a doctor

<table>
<thead>
<tr>
<th>Number of visits</th>
<th>All BG mothers percentage (n=267)</th>
<th>Mothers reporting pregnancy complications (n=204)</th>
<th>Mothers reporting pre-existing medical problems (n=132)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>0%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>1</td>
<td>6%</td>
<td>4%</td>
<td>5%</td>
</tr>
<tr>
<td>2-5</td>
<td>20%</td>
<td>19%</td>
<td>16%</td>
</tr>
<tr>
<td>6-10</td>
<td>37%</td>
<td>34%</td>
<td>37%</td>
</tr>
<tr>
<td>&gt;10</td>
<td>17%</td>
<td>22%</td>
<td>19%</td>
</tr>
<tr>
<td>Ongoing visits</td>
<td>5%</td>
<td>4%</td>
<td>3%</td>
</tr>
<tr>
<td>At least once per month</td>
<td>7%</td>
<td>8%</td>
<td>9%</td>
</tr>
<tr>
<td>Unknown</td>
<td>7%</td>
<td>8%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Difficulties accessing care

<table>
<thead>
<tr>
<th>Difficulties accessing care (n=49 mothers)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Types of difficulties accessing care</td>
<td></td>
</tr>
<tr>
<td>Transport and distance</td>
<td>37%</td>
</tr>
<tr>
<td>Impersonal care, rudeness, ignorance</td>
<td>20%</td>
</tr>
<tr>
<td>Difficulty accessing doctor of choice</td>
<td>12%</td>
</tr>
<tr>
<td>Waiting time</td>
<td>12%</td>
</tr>
<tr>
<td>Child Care</td>
<td>9%</td>
</tr>
<tr>
<td>Feeling ill or lots of care required</td>
<td>6%</td>
</tr>
<tr>
<td>Poor explanation</td>
<td>5%</td>
</tr>
</tbody>
</table>
We wished to determine the health status of women in the Bibbulung study and whether this had any relationship to patterns of health care access. Women were asked if they had pre-existing medical problems. Fifty percent of mothers in the Bibbulung study reported having one or more medical problems before this pregnancy. Of these mothers, thirty three percent had one problem, and a further thirteen percent had two problems. The remainder had three or more medical problems prior to this pregnancy. The most common pre-existing medical problems reported by mothers were anaemia (22%), asthma/wheezing/bronchitis (19%), kidney conditions (7%), heart conditions (3%) and type II diabetes (1%). Women were also asked if they had any pregnancy complications. The majority (76%) reported at least one pregnancy complication. Fifty three percent of mothers had experienced two or more pregnancy complications and thirty one percent of study mothers had three or more pregnancy complications. The most common reported pregnancy complication was anaemia, which was reported by 34% of mothers, and hypertension, which was reported by twenty one percent of mothers. Only four percent of mothers reporting hypertension required treatment. Fifteen percent of women reported having a urinary tract infection during this pregnancy. Bleeding problems during the first half of pregnancy was reported by 8% of women and bleeding problems during the second half of pregnancy were reported by 6% of women. Twelve percent of women reported having threatened premature labour and 22% reported prolonged rupture of membranes. Mothers were asked about their use of medications during pregnancy. Sixty nine percent of mothers took one or more medications during their pregnancy. The majority of these mothers took iron and or folate supplements.

Discussion

This population of metropolitan Aboriginal women generally attempted to access medical care during pregnancy. Nineteen percent of these women reported difficulties accessing medical care. This is a group with a high level of pre-existing medical conditions before pregnancy, therefore good care during pregnancy is important. Additionally they have a higher rate of poor pregnancy outcomes than the general population. Most of the problems accessing health care were due to difficulties with accessing transport and the distance which women live from their point of medical care. We believe an antenatal home visiting program is required which employs and trains Aboriginal health workers to visit mothers and act with an advocacy role as well as providing primary health care. Such a service should be run in conjunction with or by local Aboriginal health services. This model of care has been tested in rural centres such as Kalgoorlie and proved successful, but is also needed in metropolitan areas.
Diabetes mellitus

Dianne Howard

Preamble

It is easy when asked to speak on a subject such as 'Aboriginal diabetes' to make generalisations in a context that is inappropriate. We may be well-intentioned but often artlessly so.

Aboriginal people in Australia are a very heterogeneous group. This heterogeneity is both genetic and sociocultural. The genetic heterogeneity precedes the European invasion. The sociocultural heterogeneity encompasses variations in Aboriginal culture from group to group, varying degrees of destruction of that culture and varying experiences with the hitherto dominant Anglo-Australian culture.

This heterogeneity of the Aboriginal people is probably nowhere more evident that the in the 'Top End' of the Territory where I work.

There are central scientific facts relating to diabetes and core observations on the natural history of diabetes in Aboriginal Australians that we all share whether we work in metropolitan Australia, rural NSW, north Queensland, WA or Central Australia. There will be many areas where our experiences and our ideas and solutions differ according to our individual experiences. I will try to focus on the shared core issues, but it is inevitable that opinions based on my personal experience will intrude and that others will have differing opinions because of their own experiences.

Concepts of diabetes

We are frequently reminded of the differences between our own and Aboriginal concepts of disease mechanisms and aetiology. It is likely that these differences extend to treatment concepts as well. This is not a new concept. Anyone who has experienced the frustration of trying to explain complicated disease processes and solutions – diabetic or otherwise – to Aboriginal people with strong traditional backgrounds will be aware of the difficulties of finding common ground. The frustration I suspect is mutual.

There is no easy solution to this problem. It is not just a matter of 'finding out' what the Aboriginal concepts are, because the models of disease will be as diverse as the people themselves and, even within one group, will vary according to each individual's exposure to, and assimilation of, western concepts of disease. Nor is it a matter of forcing our concept of disease on Aboriginal groups.

I do not believe this aspect of the problem is substantially different to the difficulties in communicating the concepts of diabetes and its treatment to any other Australian. It is easier when there is shared cultural heritage, but it is always hard work. Any diabetes physician knows that diabetes management epitomises the need for explanation, exchange of ideas, negotiation and plain horse-trading at an individual level in order to achieve desirable outcomes. Any diabetes physician who fails to listen to his/her patient's ideas of what is the problem, the solution and the achievable, is doomed to fail that patient. The trick is to find the shared concepts and build on those, to compromise on priorities in terms of what is achievable and ironing out the differences of opinion as time goes by. Dealing with Aboriginal patients is no different in that regard. With many, whose educational and social experiences are more like our own, no modification will be needed. At the other extreme, there are likely to be major conceptual differences and the wise physician will proceed slowly increasing their own understanding as they goes. It is at this level where local knowledge from health workers and others in each community is so important.

Epidemiology of diabetes and natural history

Generally speaking, it is accepted that screening studies based on the 75gm OGTT are the most acceptable method of determining prevalence. Such studies demonstrate a discrepancy between previously diagnosed diabetes and abnormal screening tests.

It should be remembered, however, that the 'failed' GTT is only one marker of the syndrome and a relatively late one at that.

To obtain a better understanding of the extent of the situation, it is important to include other markers of the syndrome that will identify those at earlier stages of evolution of the disease. The only two markers for which prevalence studies are generally available are:
• impaired glucose tolerance; and
• gestational diabetes.

It is possible that recent changes in diagnostic criteria for all these conditions, espoused by the American Diabetes Association and more recently by the Australian Diabetes Society, will substantially alter prevalence estimates for the combined disorder. Truly definitive diagnostic criteria for the condition remain to be determined.

It is likely that prevalence rates are also changing as the epidemic evolves. It is therefore important to compare rates that have been determined contemporaneously where possible.

**Prevalence of diabetes [WHO 1985 75gm OGTT]**

Prevalence rates vary with geographic region and with age, with rates in the ‘over 35’ age groups generally being substantially higher than the overall rates. Rates of 10 to 25% are quoted for a wide range of communities in various states. In some communities, for example in central Australia, rates of 30% have been described in the age group >35years.

Despite this variability, the data consistently demonstrate a prevalence of between 2 to 4 times that for non-Aboriginal Australians.

Studies in the NT identified ‘urbanisation’ and increasing obesity as markers of increased risk. ‘Urbanisation’ is a general term used to describe loss of traditional life style and living in larger communities rather than town dwelling per se. This has implications for the next the next generation.

There are few data on the prevalence of diabetes in the age group 15-35 years. Two studies have shown rates of up to 13%. There are no data on prevalence under age 15 years. Given the evidence from other Indigenous populations, there is likely to be a significant level of both diabetes and IGT in childhood and adolescence. In the absence of effective prevention strategies, that may well become more obvious with time.

**Impaired Glucose Tolerance [WHO, 75 gm OGTT]**

Prevalence studies done in non-metropolitan areas of the NT and Western Australia have generally show high rates – in the range 25 to 45%. In some studies, the rates are lower in women which may be explained by the earlier progression to diabetes in women.

**Progression from IGT to diabetes**

There are differences between groups in the risk and rate of progression from IGT to diabetes. These specific issues have not been studied in Aboriginal populations.

However, based on data from other Indigenous peoples and ethnic groups (for example Native Americans, African-Americans and Latino people in the United States and Canada), the risk of progression and the rate of progression may be much higher than for non-Aboriginal Australians. For example the conversion rates from IGT to diabetes in the first 2 years of the Tiwi study was impressive and unexpected.

It should be remembered that impaired glucose tolerance itself or ‘prediabetes’ is associated with increased vascular risk, renal disease and also ophthalmic problems. For example, quoted rates of established vascular disease, micro-albuminuria, and retinopathy at diagnosis are in the range 10-15%. While in Aboriginal populations this may in part attributed to delayed identification of the frankly diabetic state, observations in more closely observed populations suggest that these complications do develop early in the course of evolution of the syndrome.

The significance of a higher and more rapid rate of progression to the diabetic state is that it is generally acknowledged that in the frankly diabetic state, by definition the risk and progression of complications is accelerated.

**Gestational diabetes**

The quoted expected rate of GDM for non-Aboriginal Australian women is approximately 6%.

The WHO study of diabetes in the child-bearing age group [20-39 years] for two groups of Aboriginal people in NSW demonstrated a combined prevalence of diabetes and IGT of approximately 10%.

Recent data from KGV Maternity Hospital, based on 100% screening, indicates a rate of about 10% for urban Aboriginal women. This is likely to be accurate.

Data from Royal Darwin Hospital for 1998 indicate a prevalence of GDM of 5% with a prevalence of pre-GDM of about 3%. These figures are likely to be underestimates.
Overall

Available data suggests a prevalence of diabetes in Aboriginal Australians that is 2 to 4 times the rate of non-Aboriginal Australians. Both IGT and diabetes are identified at significant rates in younger Aboriginals, consistent with the clinical impression that the syndrome evolves earlier and faster in Aboriginal Australians.

The data are also consistent with the clinical observation that young Aboriginal adults often present with complications such as ischaemic heart disease, proliferative retinopathy and renal disease. Some of these complications are uncommon in non-Aboriginal Australians, and all occur much later.

The Metabolic Syndrome

Physicians who work in the area of Indigenous health are more aware than most that type 2 diabetes is but one stage in the development of a complex syndrome that begins in utero. The ‘failed’ OGTT simply marks a point in the development of the syndrome where the complications of the disease process are well established and tend to accelerate in their progression.

The phenotype is established at birth. The genetic contribution is complex.

In addition, there are factors of the intra-uterine environment that are recognised as contributing to the prevalence of the phenotype. These include maternal diabetes in pregnancy both gestational and pre-gestational, and maternal malnutrition. Abnormal foetal growth is also a marker of increased risk of developing the syndrome of insulin resistance and its sequelae. Both LGFA and SFGA babies have an increased risk of manifesting the syndrome and its complications in later life. Offspring of mothers who had diabetes (gestational or pre-existing type 2) in pregnancy have a risk of diabetes in adult life twice that compared with the risk if only the father had diabetes. Studies with Pima Indian families have demonstrated significant insulin resistance and impaired glucose tolerance by adolescence in offspring of mothers who had gestational diabetes in that pregnancy. A longitudinal cohort study of infants examined at birth by Territory paediatrician Sue Sayers between 1986 and 1988 will include metabolic assessment as the children move into adolescence. It will be of some interest if the pattern seen in other Indigenous populations is confirmed. This ‘multiplier effect’ has serious implications for subsequent generations.

Adverse influences in early life believed to aggravate the metabolic defect include abdominal obesity, sedentary lifestyle, alcohol excess and multiparity. The role of repeated sepsis is speculative, but it is possible that repeated exposure to inflammatory cytokines (such as TNF alpha) not only aggravate insulin resistance but also are toxic to the beta cells, bringing forward the phase of ‘diabetes’.

The other important feature of this concept is the recognition of the fact that the morbidities are established even before the arbitrary point that we designate ‘clinical diabetes’. In the case of vascular disease, retinopathy and neuropathy this is well accepted. That there is also a metabolic renal lesion is less well known, but the renal biopsies done in the NT and the subsequent work led by Wendy Hoy in the Tiwi project is probably definitive in this regard.

Reducing the burden of disease

Current diabetes strategies are heavily biased towards treating late stage disease (that is, patients who are already identified as diabetic). By this stage of the disease complications are already established. The morbidity, mortality and expense are very significant.

If we are to reduce the burden of disease in any substantial way within 30 years, the strategy must include:
• reduction of the prevalence of the phenotype, by intervening in pregnancy and in early life;
• treatment of the ‘prediabetic’ state; and
• rigorous treatment of established diabetes and its complications.

Reducing the prevalence of the phenotype

The intra-uterine environment has been show to be a determinant of the risk of developing IGT, dyslipidemia and subsequent diabetes in adult life. Adverse influences include maternal malnutrition, gestational and pre-gestational diabetes, and abnormal foetal growth of whatever cause. Large and small for gestational age infants are at increased risk. Aboriginal maternal nutrition is still poor in many areas, small for gestational age infants are born with increased frequency, and diabetes in pregnancy is not well managed.

A recent study of diabetes in pregnancy in the NT revealed that pre-gestational diabetes is a major problem, occurring in at least 5% of Aboriginal women delivered at Royal Darwin Hospital. These
women presented late in pregnancy without pre-pregnancy control, control in pregnancy was poor, and 15% of the women had some other major medical problem. Lengthy separations from family were common, due to hospitalisation during pregnancy in attempt to improve metabolic control. Emergency obstetric interventions were frequent. Fifty per cent of the babies had abnormal foetal growth (defined as a ponderal index outside the 3rd and 97th centile for gestational age (25% SFGA, 25% LGFA)).

Interventions in pregnancy that will be necessary include:

- earlier and better obstetric care overall, including maternal health and nutrition;
- specific improvements in the management of gestational and pre-gestational diabetes. As well as pre-pregnancy counselling and control, the specific management of blood glucose control needs to be reviewed. It may well be that we will soon see the regular use of metformin in type 2 diabetes in pregnancy. This issue is currently being discussed by ADIPS; and
- post-partum issues such as contraception and the discussion of the impact of further pregnancies on maternal diabetes.

**Treating the pre-diabetic phenotype**

**Diet and exercise**

There are no data on interventions in childhood or before the onset of identifiable IGT. However, it is possible that targeting impaired infant growth, recurrent infection, alcoholism, obesity and the sedentary lifestyle will be of benefit.

By the stage of impaired glucose tolerance, there is evidence from several large population studies that specific diet and exercise programs can improve glucose tolerance to the point that the rate of progression from IGT to diabetes is significantly reduced and some people will normalise their glucose tolerance over a six-year period. This means that the time to reach that stage of the disease where the development of complications accelerates is prolonged. The two most well known studies of this sort are the Malmo and the DA Qing studies. While this concept is exciting, it must be remembered that in both studies there was intense contact and supervision for the duration of the study, Diet goals were very specific and there was close dietary supervision. Exercise was precisely defined and, in the Malmo study, closely supervised. In both studies there was continuing close supervision for the duration of the study.

It is misleading and unfair to encourage people to believe that non-specific ‘diet and exercise’ programs will achieve the same sort of results as these studies.

Diet guidelines must be specific, appropriate to circumstances, and sometimes the ‘cuisine’ will need to be taught as well (in the same way that Anglo-Australians had to be introduced to legumes lentils and ‘foreign’ vegetables). Returning to ‘bush tucker’ is not a realistic option for most Aboriginal Australians. Appropriate foods need to be accessible and affordable.

Exercise programs need to be specific, culturally appropriate and achievable in the local environment. This will involve local development of exercise facilities.

Diet and exercise programs can work, but not without design, financial expenditure and ongoing support and motivation. The long-term success of these programs is dependent on their becoming institutionalised in the life of the community.

**Drug treatments of the prediabetic state**

Current interest centres on alphaglucosidase inhibitors (such as acarbose, metformin), and the thiazolidinedione, troglitazone.

The NIH Prevention of Diabetes study will provide data on metformin. The ‘Stop NIDDM’ study will provide more information on acarbose.

Major issues will include:

- the identification of at-risk individuals; and
- the treatment of preclinical disease in young adults and possibly children.

We should be introducing these concepts to Aboriginal people now, so that they can be considering and discussing the issues involved.

**Treating diabetes [advanced disease]**

This requires access to appropriate food and exercise, and the availability of a large number of medications including:

- multiple oral hypoglycemic agents;
- an ACE inhibitor;
• lipid lowering medication;
• aspirin; and
• non-specific adjunctive agents such as vitamins and antioxidants.

Compliance involves the availability of medications, understanding of why they are necessary, and the will to take them. Even with PBS supplementation, the cost is significant and, in many instances, prohibitive. Supply under managed care programs is probably more appropriate.

Insulin therapy in late disease is problematical. It is not generally realised that the optimal insulin protocols in advanced type 2 diabetes are yet to be defined. Intensive insulin protocols (multiple dose regimes) are probably not justified. In the real world, less demanding regimes (twice daily mixed insulins, once daily long acting) have been shown to be just as effective in terms of reduction in HbA1c. Difficulties in insulin supply and delivery for Aboriginal people in rural areas can be largely overcome by technology and ingenuity. What is harder to overcome is the unpredictability and unreliability of food supply. In many instances problems with food may be so great as to preclude the use of insulin.

_Treating complications_

The major areas are:
• ischaemic heart disease;
• end-stage renal failure;
• retinopathy; and
• the threatened limb.

There are three major issues.

The first issue is defining ‘best practice’, specifically for Aboriginal Australians. This is compounded by the fact that in each of these areas, there are still differing opinions as to what constitutes best practice for type 2 diabetes and type 2 diabetics are, in general, a disadvantaged group when it comes to accessing these services.

Defining best practice for Aboriginal diabetics will also need a consideration of what is culturally acceptable for many. It is important that we, as providers, do not make assumptions in that regard.

The second issue is funding and access. The cost will be high and should probably come as specific funding from the Commonwealth, as it is likely to be beyond the resources of individual states and territories.

The third issue is that these services should be provided as close to local level as possible, so that social disruption is minimised. For example, mobile eye services with laser facilities and renal dialysis units in communities are a reality in some areas and will need to become more generally available.

_The role of the physician_

Individual physicians will need to work at four levels:
• with individual patients;
• with primary health care providers;
• with local community health boards; and
• with regional health providers who control policies and purse-strings.

Treating individual patients will not be qualitatively different for the experienced diabetes physician. Education, explanation, prioritisation, negotiation and compromise are a part of life for the diabetes physician no matter who the patient is. The processes may be more complicated and attenuated in Aboriginal communities. It is sometimes necessary to modify one’s own ambitions, to focus on what can be achieved and work upwards from there. For example, if euglycemia cannot be achieved for complex reasons, it is possible to do some good by concentrating efforts on the use of an ACE inhibitor, blood pressure control, lipid lowering medication, and even aspirin.

It is important that the work of an individual physician does not disappear when he/she goes. Aboriginal health literature is full of good projects that died when the individual driving the project moved on.

Each physician needs to build a relationship with the health care team in the areas they service, to heed their advice, to work with them and to be an educational resource. When the physician goes home, it is they who will carry on. Each community needs a dedicated diabetes worker who has the skills, confidence and status of a diabetes educator to continue the close supervision and motivations of individuals on daily basis.

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In some regions, local management manuals will be appropriate. Current examples include the Kimberley protocols, the CARPA manuals, and the THS Chronic Disease Strategy manual. It is important, however, that we do not exhaust our energies by unnecessarily reinventing the wheel where it is not necessary. We would be wise to share these collections of wisdom and practicality and, where appropriate, use them rather than all writing our own.

Diabetes strategies need to be institutionalised in the life of each community. This means helping individual health boards to acquire the knowledge, motivation and the means, to drive diabetes management programs on a continuing basis. Not only must the physician be a knowledge resource for the community, but he/she must be a champion and negotiator for that community in its negotiation with government agencies who determine policies and dispense resources.

**Conclusion**

Diabetes related diseases will remain the major causes of morbidity and mortality for Aboriginal Australians for at least another generation. If we wish to change the outlook for subsequent generations, we will need a comprehensive strategy that directs more time and money to the prevention of diabetes, while not diminishing the resources provided for managing the current epidemic of disabling complications of late stage established disease. Solutions need to be institutionalised not only at a local level, but also in the health policies of the Australian community in general.

**Acknowledgments**

I am indebted to those many patients who continue to allow me to share in their life experiences, and have enhanced my knowledge and understanding of their heritage and health problems.

**References**

References on individual points will be provided on request.

For general reading, the following publications provide an excellent overview and literature review.

3. Territory Health Services remote area adult chronic disease management guidelines. Territory Health Services, November 1998
Renal disease in Australian Aborigines

Wendy Hoy, Paul van Buynder, John Mathews, Jiojong You, Philip Baker, and Zhiqiang Wang

Abstract

Background: Aborigines in the Australia's Northern Territory are experiencing an epidemic of cardiovascular disease (CVD) and renal failure; CV deaths are increased >5-fold, while end-stage renal disease (ESRD) incidence is increased >20-fold, and doubling every 3-4 years. Costs of ESRD treatment pose a crisis, but premature death is the greater human catastrophe.

Methods: We studied renal disease in one high-risk community (pop~1,800), using the urinary albumin/creatinine ratio (ACR, gm/mol) as the marker. More than 80% of the adult (20+ yr) population participated.

Results: Albuminuria was pervasive: 25% had microalbuminuria (ACR 3.4-33), and 30% had overt albuminuria (ACR 34+). GFR fell with increasing overt albuminuria. ACR levels correlated with age, BMI, blood pressure, glucose, insulin and lipid levels, with heavy drinking, skin sores and scabies, with a history of post-streptococcal GN, and with a composite CV risk score. ACR was also inversely correlated with birth weight, and ultrasound studies of renal volume suggest this is mediated through impaired nephrogenesis. Renal biopsies consistently show glomerular enlargement, suggesting nephron hypertrophy. BP and ACR increased and GFR fell over time, at rates strongly correlated with baseline ACR. All ESRD arose out of progressive heavy albuminuria. ACR levels also predicted natural deaths, with OR (95%CI) of 2.6 (0.7-9.2) and 5.3 (1.6-18) for those with baseline ACR 3.4-33 and 34+ respectively, relative to those with lower ACRs. There has been a dramatic fall in BP and ACR and GFR have stabilised on a group basis. Statistical estimates suggest a 62% reduction in natural deaths and ESRD, which is supported by a community-wide fall of >50% in ESRD and natural deaths. Estimated savings on dialysis costs alone are up to $3 million.

Conclusions: Renal disease is multi-determinant. It is intimately linked to CVD, and other chronic diseases. Socioeconomic and public health initiatives will reduce risk, and existing disease can be rapidly modified, with massive savings in ESRD, mortality and costs, even over the short term. The systematic application of these findings in all Aboriginal communities is of utmost urgency.

Introduction

Australian Aborigines are a disenfranchised and marginalised people struggling to survive in a crisis of epidemiologic transition. Most Aborigines in the Northern Territory of Australia live in remote areas, in serious poverty and disadvantage, with inadequate services of all sorts. Standardised adult mortality rates are more than five times those of non-Aboriginal Australians, with all major diseases, including cardiovascular disease, represented in excess [1],[2]. Premature death in young and middle age adults is contributing to family, community and cultural breakdown.

Renal disease and renal failure marks this 'force of mortality'. Renal deaths are increased 18 to 30-fold, and the incidence of treated ESRD is approaching 1,000 per million, and doubling every 3 to 4 years, as shown in Figure 1 [3],[4].

Increased ascertainment and referral probably contributed to this increase over the 1980s, but later increases have been real. Renal disease has attracted special concern because of the treatment costs of ESRD patients, with an annualised cost per patient on haemodialysis (the main form of treatment) estimated over 1996/1998 at $100,000 [5]. Currently, 96% of people on dialysis in the Northern Territory are Aboriginal, although they constitute only 28% of the population. The costs are enormous, quality of life is poor, and survival, reflecting the generally poor health of Aboriginal people, is short, with median integrated survival on ESRD therapy only 3.3 years [4].

One potential justification for the study of any catastrophic problem in Indigenous or transitional people is to illuminate risk factors for, and mechanisms of, disease that can be generalised to the broader population, where they might be obscured by lower disease rates and density of risk factors. An increase in rates of all the common categories of ESRD in Aborigines and most other high risk groups [4],[6] argue against single cause disease models; instead they favour an excess of risk factors, and
possibly a predisposition. The principal justification for such studies, however, is to arrive at, and model, solutions.

**Figure 1. Average annual ESRD incidence in Aboriginal people in the Top End of the NT**

![Graph showing ESRD incidence](image)

**Methods**

At the request and with the support of the Tiwi Island community (population about 1,800) we have been studying their rates and associations of renal disease since 1990. The annual incidence of treated ESRD incidence among Tiwis peaked at 2,706 per million between 1993 and 1996, and their recent cardiovascular death rates were 6-times those of an age-matched affluent non-Aboriginal population living in Canberra, Australia’s capital [7]. The albumin/creatinine ratio (ACR, gm/mol) on a random urine specimen was used as the renal disease marker. Eight hundred and one adults (20+ yr) participated in at least one examination, and 581 adults had a least two examinations (1 to 8 years apart, mean 3.9 years) before introduction of systematic treatment. In late 1995, we introduced a treatment program using the long acting angiotensin converting enzyme, perindopril (Coversyl, Servier, Australia), as the primary agent [8],[9],[10],[11]. Eligibility criteria were hypertension (SBP >140 or DBP >90 mmHg), diabetes with ACR 3.4+, (micro-albuminuria threshold) regardless of blood pressure, and progressive overt albuminuria (ACR 34+). Two hundred and forty people have been enrolled, with a mean time on treatment as of Dec 31, 1998, of 2.1 years.

**Results**

**Rates and associations of renal disease:**

On cross sectional examination of the community profile ([12], [13],[14],[15],[16], [17],[18], [19]), renal disease was pervasive. Only 29% of adults (20+ years) having a 'normal' ACR (<1.1), while 23% had microalbuminuria, (ACR 3.4-33) and 30% had overt albuminuria (ACR 34+), as shown in Figure 2. Factors that correlated significantly with ACR and with loss of renal function included increasing age, birth weight and infant weight at one year (inversely), adult weight gain with central fat deposition, and the accompanying features of Syndrome X (increasing blood pressure, insulin, blood glucose, and lipid levels), skin sores, scabies and a remote history of post-streptococcal glomerulonephritis (PSGN) heavy drinking, marked by a high GGT, multiparity in women (>3 children), and a family history of renal disease. All these 'risk factors' are related to ACR over a continuum. The estimated risk enhancement for overt albuminuria associated with 'diagnoses' in these categories is substantial, and has been reported previously [13],[14].

We thus propose a multi-determinant model of renal disease in which the simultaneous operation of several risk factors progressively enhance the increase in albuminuria that accompanies increasing age. Figure 3, predicted from a multivariate model [13],[14], illustrates this phenomenon in all adults, and shows that overt renal disease is almost inevitable by middle life in people with a full menu of risk factors, a fairly common situation. Rates of renal disease in persons with no risk factors are much lower at all ages, although still substantial. Similar models can be constructed for the probability of overt albuminuria by the simultaneous actions of age, blood pressure, BMI and (inversely) birth weight in young adults for whom birth weights were recorded the risk of microalbuminuria in young persons.
(<30 years) based on interactions of age, female sex, blood pressure, and a remote (>4 years prior) of PSGN.

**Figure 2 ACR category by age group**

![ACR category by age group](image)

**Figure 3. Predicted probability of overt albuminuria in adults**

![Predicted probability of overt albuminuria in adults](image)

In such a model, nephropathic factors potentiate renal disease expression and progression rather than act as 'single cause' agents. The diversity of findings and lack of specificity of many biopsies [20],[21],[22], making them a poor fit for any single morphologic or 'etiologic' category, support this view.

**Natural history of renal disease**

ACR increased and GFR fell in individuals with time, at rates that were strongly correlated with the severity of baseline disease. In people with ACR 34+ at baseline, there was an average annual increase in SBP of 3 mmHg, in DBP of 1 mmHg, in ACR of 9.4 gm/mol, in serum creatinine of 8.3 umol/L and fall in GFR of 4.1 ml/min. All renal failure rose out of a background of persistent heavy albuminuria, and developed only in people with ACR levels ≥100 gm/mol at baseline, as shown in Figure 4 [16]. There was also a strong correlation between baseline ACR and subsequent natural deaths (Figure 4), which included, but were not restricted to, cardiovascular deaths, (26 of 63 deaths, or 41.3%). After accounting for age and sex, the hazard ratio (95% CI) of persons with microalbuminuria for natural death compared with those of lower ACRs was 2.6 (0.7-9.2), and for persons with overt albuminuria was 5.6 (1.6-18). The estimated 5 year mortality (non-renal and renal) people with ACR 34+ at
baseline was 35%. Thus ACR in this population marks not only renal disease and risk of ESRD, but also the general force of mortality [16],[17].

**Figure 4** Natural deaths and ESRD by baseline ACR category

<table>
<thead>
<tr>
<th>Baseline ACR category</th>
<th>Natural Death</th>
<th>ESRD</th>
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<tbody>
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<td>100-199</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>200+</td>
<td>10</td>
<td>0</td>
</tr>
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Renal size and renal morphology

Our studies suggest that reduced nephron endowment or impaired nephron maturation might predispose to renal disease. These are reflected in the lower renal mass in autopsy studies and lower renal volume on ultrasound in some Aboriginal people [8]. This is probably related in part to intrauterine growth retardation and infant malnutrition [18],[19], as shown in Figure 5. In view of the 4-fold difference in nephron number described in the general population [23], lower renal volume might also have a genetic component. This is likely to be adaptive; a smaller number of nephrons might have been entirely adequate in the previous subsistence state, or even a survival advantage through limitation on filtering surface area in conditions of salt and water deprivation.

Findings in 'diseased' Aboriginal biopsies are compatible with these hypothesis. All the usual morphologic diagnoses are represented to some degree, but the single consistent finding is glomerulomegaly (Figure 6), often with little other change except glomerular sclerosis [20],[21],[22],[24]. Biopsies in non-Tiwi Aboriginal people show the same phenomenon. This glomerulomegaly probably represents excessive nephron hypertrophy. Nephron hypertrophy is the mechanism by which all kidneys enlarge until adulthood, and which is often exacerbated by the trophic effects of the Syndrome X state; the stimulus would be further magnified if original nephron endowment or maturation is compromised [25], or nephrons are destroyed by nephropathic factors during early life. Hyperperfusion associated with nephron hypertrophy provides a theoretical mechanism for increasing albuminuria and accelerated nephron loss in this state.

Health services and disease expression

Health and other services also influence renal disease expression. In addition to the obvious initiatives which will reduce risk factors and disease progression (environmental hygiene, vaccines, improved nutrition etc), improved services are also, ironically, enhancing disease expression. Reduced infant mortality has allowed low birth weight babies to survive to adult life at high risk for chronic disease [18], while prevention and better management of infections and postponement of cardiovascular deaths by patchy antihypertensive treatment, coronary angioplasties, bypass grafting and the like, allows the more leisurely development of nephropathy to run its full course.

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Pharmacologic renal and cardiovascular protection

By December 1998, 240 people, or 26% of the entire adult population had enrolled in the 'treatment program' [9], [10], [11], [26], [27]; 46% were diabetic, 64% hypertensive and 67% had overt albuminuria. Participation has been enthusiastic, and compliance good in 70%. Blood pressure responses have been dramatic with a mean fall of 14 mmHg in SBP and 9 mmHg in DBP, and an average reduction of 24 mmHg and 11 mmHg respectively in people who were hypertensive (SBP >140/90 at start). In people reaching one and two years of treatment, albuminuria and GFR have stabilised on a group basis. In contrast, in the pre-treatment natural history, SBP and DBP were
increasing in these people by 2.9 and 1.0 mmHg per year, ACR was progressing at 15% per year, and GFR falling by 3.5 ml/min/yr. The estimated hazard ratio of the 'intention to treat' group for the combined endpoint of natural death and ESRD, compared with historical controls matched for disease severity, was 0.38 (95% CI 0.18-0.66), suggesting that 62% of these events had been avoided by introduction of the program. There was benefit at all levels of disease severity in persons with overt albuminuria, in whom most of events were segregated, as shown in Figure 7.

**Figure 7. Natural deaths and ESRD: natural history vs ‘intention to treat’**

![Diagram showing the comparison between historical controls and 'intention to treat' groups for natural deaths and ESRD.](image)

Community rates of ESRD and natural deaths support these estimates [11]. We estimate savings on dialysis costs alone in this small community (est 1,800 people) from $700,000 Aust to $3.1 million, in the first three years, depending on whether ESRD and death rates would have continued to escalate or achieved a plateau in the absence of the program [5],[27]. The reduction in morbidity and mortality is, however, the greater human gain.

**Conclusions**

The excess of renal disease in this population is multi-determinant, educed by a number of potentially nephropathic factors operating in a high risk environment, and intimately related to the general health profile, and other chronic 'disease' states [28]. Risk factors derive from, or are exacerbated by, rapid epidemiologic transition, poverty and disadvantage, and the deficiencies and successes of health services. Environmental factors have undoubtedly also influenced genotypes over time.

Prevention depends on sustained improvements in socioeconomic circumstances, infrastructure and health services. Concerns over ESRD treatment costs might yet galvanise such changes. For people already afflicted, disease is easily diagnosed and progression is dramatically altered by interventions within our reach [29]. Control of blood pressure, adult weight and infections are especially important. Pharmacologic intervention reduce premature death in early and middle adult life; and might postpone renal failure beyond reasonable life expectancies in many people.

Meanwhile, academics and professionals must advocate for intersectoral initiatives and collaborations to improve the environmental and socioeconomic circumstances of high risk populations. We should also foster inter-specialty collaboration to permit a coherent unified approach to health issues. We must redirect significant intellectual and material resources from expensive high technology, diagnostic and interventional tracks for advanced disease, to community-based prevention and disease modification, and reposition basic medical and specialist training curricula to reflect those views. The need is less for more specialists than for systematic implementation at the community level of prevention, screening and treatment practices already known to be effective. Constant evaluation of outcomes is essential to modify strategies appropriately. Improved health, greater longevity and reduced health care costs can probably be achieved over a shorter term than ever imagined.
References:


The impact of injury among Indigenous people

Neil Thomson

Introduction

Injury is physical harm or damage to the body. It may be intentional or unintentional. If intentional, the injury may be self-inflicted (for example, suicide) or inflicted by another (for example, assault, homicide, etc.). The harm can be as a result of an external force (such as collision with a moving object or a moving person colliding with a stationary object) or energy (heat, electricity etc.); external or internal contact with a harmful substance (poisoning, etc.); or absence of essential elements (oxygen, heat). Generally, only harmful effects occurring over a short period of time are considered as injury [1]. (The term 'injury' is used generally in reference to those conditions classified within the ICD group 'external causes of injury and poisoning' (E888-E999).)

Assessment of the true impact of injury poses some difficulties, as the vast majority of injuries do not result in hospitalisation and/or death (see Figure 1). Thus, the vast majority of injuries is not recorded in routine data collections, and may not be brought to the attention of health policy makers and program managers.

Reflecting the availability of data from those sources, most of the information in this paper is summarised from death registrations (collected by the Australian Bureau of Statistics from the State and Territory registrars) and from hospital utilisation statistics. The paper draws also on some data from a pilot project of injury in Aboriginal communities in Cape York, Queensland.

Injury mortality is a major health problem in Australia for both the Indigenous and non-Indigenous communities, accounting for 6% of all deaths, 47% of deaths in the 0-44 years of age group and 70% of deaths in young males [3]. In line with the experience of other disadvantaged groups, internationally and within Australia, Indigenous people suffer a greater burden from injuries than the general population. Death from injury is 3-3 ½ times more common for Indigenous than non-Indigenous people, and injury is the most common cause of hospitalisation among Indigenous males and the third most frequent cause among Indigenous females (excluding renal dialysis for both males and females)[2].

Figure 1 Injury pyramid - likely proportions of injury responses/outcomes

Deaths from injury

Age-standardised death rates from all injuries were three-and-a-half times higher for Indigenous people living in Western Australia, South Australia and the Northern Territory than for non-Indigenous people (males: 213 deaths per 100,000 population compared with 61/100,000; females: 77 compared with 22) (Figure 2).12

12 These data come from a separate analysis undertaken by the author from ABS-provided mortality data for 1994-1996.
Motor vehicle traffic accidents were responsible for the largest number of deaths and were around four times more common among Indigenous than other Australians [2]. The numbers of deaths occurring among Indigenous people were greater than expected also for other accidents (SMRs: males - 3.5; females - 4.1), suicide and self-inflicted injury (SMRs: males - 1.7; females - 1.4) and homicide (SMRs: males - 7.6; females - 7.0).
In WA, SA and NT combined in 1994-1996, age-specific death rates from injury were substantially higher among Indigenous males than among non-Indigenous males in all age groups between 0 and 75 years (Figure 3). For females too, age-specific death rates were generally higher among the Indigenous population.

Generally, males aged 25 - 34 years experienced the highest death rates from injury. For Indigenous males in this age group, the rate (300 deaths per 100,000) was four times higher than the rate for the non-Indigenous males (75 deaths per 100,000). The greatest difference in death rates between Indigenous and non-Indigenous females occurred in the 34-44 years age group, where the rate was more than seven times higher for Indigenous women.
Greater detail about the types of motor vehicle accidents (land transport injuries) comes from an analysis undertaken on death data for Western Australia for the years 1985-1994 [1]. Interestingly, the age-standardised rates were substantially lower than those documented for WA, SA and NT combined in 1994-1996, but the Indigenous:non-Indigenous ratios were similar for the combined data. The largest contributor to the land transport injury death rates (and greatest differential) is for occupants in a motor vehicle (Indigenous people: 37 per 100,000; non-Indigenous people: 9 per 100,000) (Figure 4). Death rates were higher for Indigenous than non-Indigenous people for all categories except for motorcycle accidents.

Unfortunately, the understanding of risk factors is weak for most areas of injury, as the availability of information allowing for the determination of such factors is relatively scarce and varies across the specific topic areas considered. Land transportation injuries, though, are one of the few stronger areas of information collection. Some specific risk factors for land transportation injuries (such as riding in the open load spaces of vehicles) are receiving increasing attention in Western Australia and the Northern Territory, but it is not yet clear whether this information can be generalised to other jurisdictions.

**Hospitalisation as a result of injury**

Over the decade, 1985-1994, there were 344,032 hospital admissions in Western Australia for which the main diagnosis was injury-related [1]. Of these, 208,236 were males (60.5%) and 135,796 females (39.5%), giving a male:female ratio of 1.5:1.

Indigenous people accounted for 32,382 of these hospital admissions, and non-Indigenous people for 311,650. The age-standardised hospitalisation rate was 7,863 per 100,000, four times the rate of 1,968 per 100,000 for non-Indigenous people (Figure 5).

Transportation injuries were responsible for much smaller proportions of hospitalisations than they were for deaths. The general group, 'other unintentional injuries', was responsible for the highest hospitalisation rates for males and females. Of special note were the high rates of hospitalisation for the Indigenous people, particularly females, for injuries 'inflicted by another'.

The age-specific hospitalisation rates of injury in Indigenous people were markedly higher than those for non-Indigenous people with the trend being generally divergent (figure not shown). The rates for non-Indigenous people peak in the 15-24 years age group, decrease, and then increase with age from age 60 years onwards. On the other hand, those for Indigenous people peak in early middle age (to almost four times the non-Indigenous peak), gradually decline until the 55-64 years age group, then increase again [1].

![Figure 4: Age-standardised death rates for land transport injuries, by Indigenous status, Western Australia, 1985-1994](image)
The pattern of hospitalisation for land transport injuries was similar to that for deaths, with rates being highest for motor vehicle occupants and pedestrians (Figure 6). Indigenous rates were higher than those for non-Indigenous people, except for motor cyclists and for horse related injuries.

Age-specific rates were higher for Indigenous than non-Indigenous people until the 65-74 years age group. Beyond that age group, rates were higher for non-Indigenous than Indigenous people (the number of Indigenous people aged 75 years or more is very small).
Injury in a remote Indigenous community, Cape York, Queensland, November 1995 – October 1996

During 1996, a pilot project was undertaken to address the public health problem of injury in Aboriginal communities in Cape York, Queensland [4]. (Injury accounted for 51% of the excess deaths in the 15 to 44 year age group in the Cape communities between 1989 and 1994.)

The project involved narrative case studies, an epidemiological audit of injury in a community, focus group sessions and comparison of injury events in two communities. The researchers gathered data from two remote communities and studied the alcohol-attributed injury rate in a community with a canteen and in one without. Among the conclusions reached, alcohol appeared to be one of the many contributing factors of injury (see Figure 8).

Due to the poor quality of the daily clinic register in the Cape communities, a 12-month case note audit was undertaken in a remote community which had a canteen selling beer only. Injuries comprised 24% of all initial consultations and 34% of evacuations, and 49% of people experienced at least one injury during the twelve-month period, with the average number per person being 2.1.
As can be seen from Figure 7, an analysis of principal injury showed a similar number of head injuries among males and females. Upper and lower limb injuries were higher for males than females, with the number of upper limb injuries among males being twice the number among females.

**Alcohol as a contributing factor to injury**

Overall, the literature suggests that approximately one-quarter of Indigenous admissions to hospital are alcohol-related, and alcohol has been implicated as a direct cause of approximately 10 per cent of Indigenous deaths [4].

The Cape York community study examined alcohol consumption and the association of this consumption with injuries (Figure 8).

The findings included the following key points:
- 93% of people aged over 15 years were regular drinkers;
- 51% of all injuries were associated with alcohol use; and
- 91% of alcohol-related injuries occurred on Thursday, Friday, or Saturday.

The high percentage (93%) of regular drinkers in this community differs from other studies, which have documented lower proportions of regular drinkers [4]. In fact, the other studies have demonstrated that the proportion of drinkers in the Indigenous population is less than in the non-Indigenous population.
Conclusions

The available data leave a lot to be desired, but, as can be seen from this brief paper, they are adequate enough to show that the burden of injury is much higher for Indigenous people than it is for non-Indigenous people. The differentials observed are similar to those seen in other Indigenous populations, such as the Navajo people in the United States, but are more marked, possibly due to the interaction of Indigenous status and poverty in Australia.

Much remains unknown concerning injury in Australia's Indigenous populations, but enough is known to indicate that this issue intersects with other health and social issues. The proportion of Indigenous people living in rural and remote areas and the risks associated with these environments and differences in activities associated with cultural norms intersects closely with Indigenous injury. So does drug use, particularly the use of alcohol. These issues, in addition to land transport injuries, have been covered briefly within this paper and are among the various issues that have led to the following initiatives addressing the impact of injury among Indigenous people:

- Kimberley Road Safety Project;
- Northern Territory legislation re open rear tray travel;
- National Aboriginal and Torres Strait Islander Road Safety Strategy;
- Cape York – alcohol management strategy; injury prevention program by Queensland Transport; community initiatives in injury prevention; and
- NSW Aboriginal Family Health Strategy.

References


Issues in Indigenous mental health

Ernest Hunter

What is tormenting the youth of Palm?
A question that's been asked from Butler Bay to Farm.
Is it society or is it alcohol and dope, maybe no job?
That's when they think there's no hope.

Could it be so much pressure building up inside...
The young mind thinking perhaps there's nowhere to hide.
Maybe a drink will solve the pain, and a smoke to calm the brain.

One thing leads to another, arguing with family,
Your father and mother. Run and hide and let out the tears,
The pain is there but not the fears.

Is it some force that's taking them away,
Or pressure of society from living day to day?
No one knows what's in another's mind,
When a psychiatrist will try to seek and find.

Nothing works and nothing ever will,
It's over...it's gone over the hill.
It's slowly tearing the mind apart,
From head to toe then finally the heart.

Talking to someone but they just won't listen.
Life is full of hits and misses.
Finally it's back to the drink and smoke
Where it all ends at the end of a rope.

Winston Seaton, Palm Island

This poem, by a resident of Palm Island, an Aboriginal community a short flight or boat ride from Townsville, raises many issues. Alcohol and drug use, unemployment, hopelessness, emotional pressure and pain and fights within the family. Between the lines there is much more, allusions, perhaps, to childhood sexual abuse. There is also mention of a mental health professional. The psychiatrist in this presentation is seeking the solution inside that tormented individual's mind. But, as the author emphasises - 'No one knows what's in another's mind' - not even the psychiatrist. Perhaps because - 'they just won't listen'. Winston Seaton ends this poem on a fatalistic note, the rope appears, almost, as the inevitable end of the road.

Palm is a beautiful island, which has had a particularly odious history. In a nation founded on penal isolation, islands small and large - think of Norfolk and Tasmania - became favoured locations for containment and punishment as increasing distance was sought between settlers and convicts. The same logic was extended to Aboriginal Australians for whom isolation was necessary because of disease - Bernier and Bezout in Western Australia, the Channel islands in the Northern Territory and Fantome in Queensland - or because they were 'problems' for other reasons - miscegenation or resistance. Rottnest in Western Australia and Palm, near Fantome Island, in Queensland. Indeed, Palm Island continued in this role until very recently, reflecting Queensland's tenacious resistance to change. Palm was part of a system of total institutional control that was supported by statute from 1897 to the 1980s. Palm, in essence, was a penal colony, a kind of 'devil's island' spawned by a society founded on convictry.

Indeed, that is the very title used by Britain's Sunday Times Magazine in February 1998, for a sensationalised 'expose' of the culture of violence and an 'epidemic' of suicide on the island. This article reported, erroneously, that 40 individuals have taken their own lives on the island since 1994. Considerable attention was given by the Australian media and the article was rapidly copied and circulated through North Queensland, by both Indigenous and non-Indigenous people.
As with many other articles about various Indigenous social 'problems', the Indigenous victims are also clearly labelled as the perpetrators. Prevailing stereotypes are reinforced and extended – the drunken, violent Aborigine, now the suicidal Aborigine. Not that Palm Island is without experience in terms of community-level stereotyping, having been the focus of media attention regarding HIV in the early 1980s.

I am not trying to suggest that these reports are not based on some facts – the homicide rate for Indigenous Australians nationally is some ten times higher than for the wider Australian population. However, such 'info-byte', docu-drama constructions do not and cannot capture the complex interplay of underlying causes for violence, suicide or other health and social issues in Indigenous Australia. Unfortunately, as Winston Seaton seems to suggest, even if there is a greater sophistication of understanding within mainstream services – in this case psychiatry – that understanding does not translate into effective initiatives for change.

In this presentation, I will explore three loosely related areas. The first is to briefly examine the way in which psychiatry, as a proxy for institutional mental health, has developed in its response to the needs of Indigenous Australians over the last five decades. I will then use this historical frame to examine how nurturance and sustenance have changed over a longer timeframe. I do this because, while there is little reliable information regarding Indigenous mental health in general, we are particularly poorly informed about Indigenous child development. Indeed, we know very little about child mental health and almost nothing about the prevalence of emotional and social abuse and neglect, and sexual abuse – experiences which are related to the development of a range of mental health disorders, particularly those, such as personality disorders and self-harm, which reflect major disturbances in the construction of the self. In the last section I will look more closely at self-harm utilising information recently gathered in North Queensland.

To examine changing patterns of psychiatric engagement (figure 1), I will focus on the last five decades, for each of which I will try to identify some of the landmark political and health events and the dominant mode of interaction between Indigenous Australia and the institutions of the wider society.

**Figure 1**

<table>
<thead>
<tr>
<th>Decade</th>
<th>Defining events</th>
<th>Interactions</th>
<th>Health events</th>
<th>Psychiatric frame</th>
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<td>Psychopathology of the exotic</td>
<td>Fascination</td>
<td>Alien category</td>
<td></td>
</tr>
<tr>
<td>1960s</td>
<td>Referendum</td>
<td>Protest</td>
<td>Remote area ethno-psychiatry</td>
<td>Observation</td>
<td>Imposed category</td>
<td></td>
</tr>
<tr>
<td>1970s</td>
<td>Land rights/ Indigenous organisations</td>
<td>Protest</td>
<td>Community control NAIHO NAMHA</td>
<td>Social disadvantage</td>
<td>Rejected category</td>
<td></td>
</tr>
<tr>
<td>1980s</td>
<td>Land rights RCIADIC</td>
<td>Protest/ Professionalism</td>
<td>Research ethics NAIHO NAHO</td>
<td>Historical and political framework</td>
<td>Consultation</td>
<td>Appropriated category</td>
</tr>
<tr>
<td>1990s</td>
<td>ATSIC Mabo, Wik Commission on removal</td>
<td>Professionalism ?? resurgent protest</td>
<td>ATSIC NACCHO Burdekin NMHS Ways Forward OATSIHS</td>
<td>Collaboration</td>
<td>Culturally informed category</td>
<td></td>
</tr>
</tbody>
</table>

I shall try to identify a dominant 'psychiatric frame', that is, the way psychiatrists understood their project, the relationship between them and their Indigenous subjects and, finally, the way in which Indigenous people viewed this process. I acknowledge that this involves simplifications and generalisations.
Up until the 1950s Indigenous Australians were, I suggest, still in survival mode following the ravages of the previous century. Little was happening in the health field, which, for instance in Queensland, remained the domain of Aboriginal Affairs rather than the Health Department. Those psychiatrists who did engage with Indigenous peoples generally did so in remote settings, usually brief visits resulting in descriptions of the ‘psychopathology of the exotic’. As no real dialogue was involved, mental health was, in terms of Indigenous understandings, an alien category.

During the following decade the scene changed dramatically with the 1967 Referendum and an amplification of Indigenous voices in protest. Psychiatric engagement remained largely in remote settings with the beginning of systematic ‘ethnopsychiatric’ research by figures such as John Cawte who utilised short-stay field trips. This work remained largely observational and, in the context of increasing urban Aboriginal protest, was loudly, and I believe unfairly, criticised as being an imposed category, an exercise in disempowering labelling.

In the 1970s protest increased and coalesced around land rights and the beginnings of community-controlled organisations such as the Aboriginal Medical Services. A different group of researchers, such as Max Kamien who spent several years in general practice in Bourke, were influential in shifting the focus from description to association, speculating about the causal role of the obvious social disadvantage which was the lot of most Aboriginal Australians. In this decade of markedly more effective protest – think of the tent embassy – institutional mental health, already experienced as imposed, was rejected. Thus, the first national Aboriginal Mental Health Conference convened by the newly formed National Aboriginal Mental Health Association in Brisbane at the end of the decade, proceeded to heated division, the non-Indigenous conveners publishing the proceedings with the subheading – ‘hitting our heads against a brick wall’.

The defining events of the 1980s, I suggest, were land rights and the Royal Commission into Aboriginal Deaths in Custody, which brought particular attention to mental health services. In the health fields, the development of the NHMRC Research Ethics guidelines and the National Aboriginal Health Strategy at the end of the decade both signalled political shifts. Increasingly, Indigenous voices in this and related fields were those of Indigenous professionals who had, much belatedly, been able to access educational opportunities – most despite, I would hasten to add, rather than because of the system. Mental health researchers at this time were moving, in consultation with Indigenous communities and researchers, from the association of disadvantage and mental disorder, to questioning its historical and political origins and, in so doing, exploring its apparent resistance to change. Meanwhile, Indigenous organisations, communities and individuals were beginning to appropriate ideas from other areas, particularly primary health care, community development and holistic constructions of health, to their own ends.

Finally, in this decade, the political events have accelerated with the formation of ATSIC, the Mabo and Wik cases and, what I believe will be the most important and far reaching, the Human Rights and Equal Opportunity Commission’s Inquiry into the separation of Aboriginal children from their families. In the face of statutory reversals of gains won through the professionalism of Indigenous legal initiatives, for instance native title, there is a resurgence of protest. In the health field activity has been equally rapid, with respect to mental health the key development being the National Consultancy resulting in the Ways Forward report and Commonwealth strategies to support Indigenous emotional and social wellbeing. Those psychiatrists who are engaged at the moment are, I believe, far more cautious in their approach than previous decades. This is appropriate; they are no longer captains but must necessarily collaborate. One outcome of the wider process has been the development of a more culturally informed understanding of mental health. Unfortunately, while this is the vision of community-controlled organisations and, to a degree, the Commonwealth, at the State level, where most of the resources lie, it is largely given lip service, with the focus remaining on institutionally defined measures and outcomes. Community-controlled organisations are thus placed in an invidious situation, caught between these two, often conflicting constructions.

There is, at present, considerable interest and investment in population level mental health surveys and in how to adapt these approaches to Indigenous settings. Important as such initiatives are, I believe that to effectively use the information obtained those involved must have an appreciation of the historical and political context in which problems have emerged and in which they will be addressed. In this next section I will maintain this approach, albeit over a longer timeframe, but shift focus to explore the changes that have occurred in Indigenous family structure and function. To do this I will use five broad periods – precontact, frontier conflict, institutional control, ‘deregulation’, and contemporary settings, (figure 2). In each I will consider four aspects of life in that period – authority, economy, family structure and function, and sustenance and nurturance. It should go without saying that this approach
cannot take into account the diversity of Indigenous societies, past and present, and involves some gross simplifications and generalisations.

Figure 2 Social change implications for Indigenous families

<table>
<thead>
<tr>
<th>Authority</th>
<th>Economy</th>
<th>Family structures</th>
<th>Sustenance and nurturance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre contact</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frontier conflict</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Institutional control</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>De regulation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contemporary</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Broadly speaking, authority in precontact societies was mediated by older and socially mature men (figure 3). Authority stemmed from sacred knowledge and required social recognition, and allowed for control of resources, including women who were major providers in the economic domain. This arena of life was finely balanced, season and location determining resource utilisation, the family being the primary economic unit. Within the family there were clearly defined gender and generational roles, relationships informed by kinship systems, generally a significant age differential between parents (fathers being older). Maturity for women was primarily biologically determined, while for men being socially mediated. Age of first pregnancy would generally have been early and immediate family size relatively small, reflecting the lifestyle necessary to obtain sustenance resources. This would, in turn, have demanded sophisticated knowledge of a wide range of seasonal resources and skills – informed opportunism. The diet would have been diverse and nutrient rich, demanding effort for both securing and preparing food. Beyond these needs for survival, however, there would have been ample non-committed time allowing investment in sacred, cultural and family matters – time, culture and family rich.

Figure 3 Precontact

<table>
<thead>
<tr>
<th>Authority</th>
<th>Economy</th>
<th>Family structure</th>
<th>Sustenance and nurturance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Socially mature (older) males mediate authority through power over sacred and economic domains and over women as providers. Authority clearly defined.</td>
<td>Sustenance economy balanced with ecology – women the major providers of food resources which determine tribal range. Family is primary economic unit. Limited exchange between groups.</td>
<td>Clearly defined generational and gender roles. Unions defined by kinship. Age differential between parents (fathers older). Resources inform family size and larger seasonal gatherings.</td>
<td>Informed opportunism - Diverse, nutrient rich, seasonally variable diet requiring effort, knowledge of environment and range of skills. Energy balance. Family, culturally and socially ‘time rich’.</td>
</tr>
</tbody>
</table>
As the frontier expanded across Australia (figure 4), Indigenous communities were exposed to unprecedented levels of violence and disease which undermined traditional social structures and authority. Absolute authority was claimed by Europeans and exercised through the often arbitrary use of overwhelming force. Certain Indigenous figures, think of the Aboriginal ‘kings’ or, in Queensland, the Native Mounted Police, were selected to mediate European authority. Disrupting the primary economic unit – the family – and dislocation from the traditional resource base clearly sundered traditional economic balance. Those who sought safety further from the frontier necessarily impacted the economic balance of those already there, the destabilising effects thus clearly preceding actual contact. The consequences for family structure and function will be obvious, dislocated from the landscape and social relations that made such structure and function meaningful and promoting competition and conflict between Indigenous groups. Sustenance was where it could be found – scavenging for survival – utilising whatever resources. Thus, a diverse diet but probably with episodic hunger and starvation. Survival would leave little time for social, family and sacred needs, the family as a unit, and children in particular, being far more vulnerable.

Figure 4 Frontier conflict

<table>
<thead>
<tr>
<th>Authority</th>
<th>Economy</th>
<th>Family structure</th>
<th>Sustenance and nurturance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Undermining of traditional (male) authority through violence and disease. Authority imposed, arbitrary and unpredictable, supported by superior weapons and via ‘selected’ representatives.</td>
<td>Dislocation from economic base (land) and disruption of primary economic unit (family). Increased competition for resources beyond European control. Restriction of activities within European areas.</td>
<td>Social/family unit fragmented by loss and dislocation. Increased inter-group conflict for resources (with white settlers and other tribes). Safety in remote areas or on fringe.</td>
<td>Scavenging for survival. Diverse range but limited quantities due to competition. Hunger common. Increasing effort required for survival; less ‘time’ for social, sacred and family. Infants and children more vulnerable.</td>
</tr>
</tbody>
</table>

Across most of Australia, relative safety came with institutionalisation on government, mission or station settlements (figure 5). How and where this occurred largely reflected European economic investment and the needs for Aboriginal labour. Thus, where pastoralism was the primary activity, for instance the Kimberley, local Aboriginal families were ‘settled’ on stations in or close to traditional lands, in small homogeneous groups with a primary interest in them being their work value. In Far North Queensland, however, where no such use of Aboriginal labour existed, Aborigines were centralised and isolated in large diverse groups often far from traditional country on missions where interest in them reflected their symbolic value. Regardless, wherever they were, Aborigines were contained and controlled and, particularly on missions, the traditional authority of older males was undermined. Institutionalisation assured dependence and the emergence of a ration economy based on the family as institutionally defined. Particularly on missions that reflected European ideals with prohibition of traditional bestowal practices, unions thus between individuals of relatively similar ages, later first pregnancies and, ultimately, larger families. This is also the period of the most devastating state-sanctioned family terrorism, from dormitorisation to abduction and permanent separation. Even where families remained intact, economic demands, for instance on stations, often removed fathers for protracted periods. Institutionalisation brought predictable nutrition which was generally marginally sufficient in quantity but substantially less variable, with separation of nutrition from the energy expenditure necessary to obtain it. This left time – but time that was often, particularly on missions, to be used in prescribed ways. Family roles were often similarly prescribed with authority and ‘discipline’ often devolving to European functionaries – thus a developmental separation of nurturance (the Aboriginal domain) from structure and discipline (the European domain).
The following period I have chosen to call ‘deregulation’ (figure 6) because there was, in remote Australia at least, a sudden, unplanned and uncoordinated withdrawal of European controls and the creation, often overnight, of so-called ‘communities’ based on European ideals of governance. Often, under the surface, nothing had changed, with functionaries becoming brokers. There was little transfer of administrative skills and the replacement of selected by elected Indigenous authority often resulted in factionalism and family-based conflict. While the visible institution was gone, the dependence remained, but now welfare dependence. Parenting women became major providers in a welfare economy. Alcohol emerged as a significant factor in this economy, a vehicle for recycling Commonwealth dollars back to the European economy or, as in Queensland, for rescouring local governance. A parallel economy of ‘sly’ grog responded to Indigenous credit demands not available through the wider economy. Alcohol also destabilised family function and structure with increasing unions outside of traditional sanctions and serial partnership, the concertina family, constituting and reconstituting around a central female. Males were less constant figures and age of first pregnancy fell to pre-institutional levels with family size remaining large. Children were again increasingly vulnerable in environments of normative instability. Sustenance incomes were compromised by expenditure on alcohol — welfare ‘feast and famine’ with nutrition during periods of relative abundance being high energy and low nutritional value — an imbalance of energy consumption and effort expenditure. Time rich but activity restricted in areas of heavy alcohol use, responsibility for nurturance and childcare often devolved to siblings and older abstinent women.

And now? (figure 7) Well, of course the situation is very variable across the nation but there is clearly the emergence of an Indigenous middle class, generally through government services and bureaucracies

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**Figure 5 Institutionalisation**

<table>
<thead>
<tr>
<th>Authority</th>
<th>Economy</th>
<th>Family structure</th>
<th>Sustenance and nurturance</th>
</tr>
</thead>
</table>

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**Figure 6 Deregulation**

<table>
<thead>
<tr>
<th>Authority</th>
<th>Economy</th>
<th>Family structure</th>
<th>Sustenance and nurturance</th>
</tr>
</thead>
</table>
with the slow development of an educated elite. Authority frequently devolves to those with influence in these institutions and organisations. Despite the growth of a middle class, welfare dependence remains, now often masked by the veneer of the Community Development Employment Program (CDEP). As liminal as the Indigenous economy is, it is open to the unrestricted depredations of white entrepreneurs, often through the alcohol sub-economy. Particularly in areas where alcohol has been a significant factor, contemporary children and young adults are the first generation to have been raised in the environments of normative instability characteristic of the period of deregulation. This has implications in terms, particularly, of paternal roles and, thus, for the construction of male identity. Many young men continue to be removed by the state, now as a result of widespread criminalisation and incarceration which, in some settings, has become a normative developmental experience. The poor, intermittent and vulnerable diet of the previous period continues, now compounded by substance abuse. In such settings, creative and nurturant family time remains compromised and children unsupervised, increasing their vulnerability to immediate harm and to the developmental consequences of family instability.

Figure 7 And Now?

<table>
<thead>
<tr>
<th>Authority</th>
<th>Economy</th>
<th>Family structure</th>
<th>Sustenance and nurturance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Authority of elders and intergenerational ties weakened.</td>
<td>CDEP welfare dependency. Slow growth of middle class (government jobs) – slower of private enterprise. Restricted credit and inherited wealth. Welfare as entrepreneurial (white) resource (e.g. taxis, alcohol).</td>
<td>First generation raised in normative instability. Fathers’ roles further compromised – absence and alcohol. ‘Criminalisation’ of Indigenous male youth for minor offences – family separations continue.</td>
<td>Entrenched poor nutrition – energy rich, nutrient poor, minimal effort to obtain and prepare, toxic loaded (alcohol, tobacco, drugs). Time rich and unstructured. — less family focused.</td>
</tr>
</tbody>
</table>

In presenting this picture I am, of course, guilty of problematising. However, the contemporary picture that I have constructed is common in many of the remote communities in which I have worked clinically. I would also add that in all of those communities, there are individuals and families who have emerged, against the odds, to be resourceful, supportive and caring parents and members of the community. Unfortunately, and predictably, there are others who have not. To avoid simply criminalising or pathologising them requires understanding how those circumstances arose. That demands looking at the inter-cultural context and developing an explanatory frame which may, perhaps, be other than the one I have offered.
I would now like to turn to a specific issue which has been cause for national concern – Indigenous suicide. Suicide, as is commonly understood in the wider society was, at most, very uncommon up to two decades ago, but the situation has changed dramatically since then. Nationally, Indigenous suicide is largely a young adult male phenomenon (figure 8).

Figure 8: Age-specific death rates from suicide (per 100,000), by Indigenous status, Australia (except Qld), 1990-92.

More recent data from Queensland reveals that for the period 1990-1996 the suicide rate for Indigenous males was twice that for the non-Indigenous population, and the rate for those aged 15-29 years was nearly four times higher. By contrast, the aggregate rates for females are not dissimilar to those for non-Indigenous women. Since 1990 there has been a nearly four-fold increase (figure 9) in the number of suicides occurring in Queensland, most of this increase being since 1993.

Figure 9: Age-standardised death rates from suicide, Queensland, 1990-1996
Indigenous suicide is thus increasing and remains concentrated among young adult males. Alcohol is commonly associated (figure 10) — in three quarters of deaths by firearms and nearly 85% of deaths by hanging, alcohol is detected post-mortem, with levels being greater than 0.15 in one third and nearly 60% respectively.

**Figure 10  Recorded blood alcohol concentrations for Queensland**

Indigenous suicides by hangings and firearms

<table>
<thead>
<tr>
<th>Alcohol level</th>
<th>Firearms (21 deaths) - %</th>
<th>Hanging (112 deaths) - %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-alcohol detected</td>
<td>26.8</td>
<td>14.3</td>
</tr>
<tr>
<td>&lt; 0.15</td>
<td>40.2</td>
<td>38.6</td>
</tr>
<tr>
<td>0.15 - 0.25</td>
<td>20.5</td>
<td>42.9</td>
</tr>
<tr>
<td>&gt; 0.25</td>
<td>12.5</td>
<td>14.3</td>
</tr>
<tr>
<td>Total</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Source: Australian Institute of Suicide Research and Prevention (AISRP)

Examining trends in suicide by gender and means (figure 11) reveals that the increase in Aboriginal suicide for Queensland is entirely due to increasing male deaths and, furthermore, that the increase is made up entirely of deaths by hanging.

These aggregate figures hide further important differences. Within Queensland, the north of the State is responsible for a disproportionate percentage of Indigenous deaths. Within the northern region itself, deaths by suicide are not evenly distributed, with a greater than expected contribution from a small number of communities. Indeed, three communities account for a far higher than expected proportion of these losses (figure 12). Utilising community data to check and supplement those obtained from coroners' reports, and constructing a three-year moving average, it also emerges that for these three communities there appear to be three overlapping ‘waves’ of suicide occurring at different times in different places. The first of these waves relates to the community of Yarrabah, which has been much in the news because of the number of suicides occurring there in the past and, more recently, because there have been no suicide deaths since 1996. This has been attributed, somewhat simplistically, to better mainstream and local crisis services.

Work conducted by myself, Joseph Reser, Mercy Baird and Paul Reser challenges this assumption. The wave affecting Yarrabah dates back to the late 1980s and a series of Yarrabah deaths in custody. Subsequently, there were a variety of mainstream and other external expert initiatives, none of which seem to have had any impact. In 1995, however, there was a significant shift in the community response to this tragedy, which can best be described as ‘owning the problem and its potential solution’. The responses which followed came from within the community, including setting up a local crisis team, focusing on life promotion, curtailing alcohol sales in the community and dedicating community funds to this issue. While there were many presentations with threatened or actual self-harm through 1996, from that point in time on there has been a substantial and sustained reduction (figure 13). We believe that this reflects a positive shift from initiatives which had focused effort on the individual at risk at the moment of crisis, to addressing community level risk through community action. It raises, of course, the possibility of the experiences and lessons learned at Yarrabah being utilised in other Indigenous settings, potentially to attenuate and abbreviate such ‘waves’ of suicide.

That, of course, does not provide an explanation for why such ‘waves’ are initiated in the first place. At least for north Queensland, and probably elsewhere, we believe that the deaths in custody that became the focus of the Royal Commission in the late 1980s were critical. At that time, not only was there intense media scrutiny, but constructions by the media and within Indigenous communities, of suicide.
as an act which had particular connotations, often politically framed. The accompanying examples are provided by my colleague Joseph Reser who has considered this issue in considerable depth. Media coverage fell dramatically after the release of the initial findings of the Commission which shifted focus from suicides in custody to the underlying causes of Indigenous over-representation in custody. Subsequently, suicides in police custody fell quite dramatically but have continued, we believe, in the wider community where suicide has now been internalised and come to be understood in particular ways.

Figure 11: Queensland Indigenous suicide by method and sex, 1990-1996

These factors may provide some explanation of the initiation of this increase over the last decade which is, of course, also present to a significant but far less marked degree in the young adult male population nationally. Common understandings and meanings may also explain why suicides continue. However, this construction does not explain why particular communities appear to be vulnerable at particular points in time. Our analysis suggests the importance of shifting from preoccupation with individual risk factors per se, to considering the risk condition, that which informs a ‘community at risk’. It also suggests shifting focus from the individual in crisis to considering the ‘lifestyle of risk’. These two are related, a community is at risk when lifestyles of risk are common in a community and when such
lifestyles are accepted, tolerated or accommodated. However, there is also another connection. Where lifestyles of risk are common, as was suggested by my earlier discussion of the period I chose to call ‘deregulation’, they have very real consequences for the developmental environment of children who are exposed to and internalise that which surrounds them. The current group at greatest risk, young adult males, is the first generation to have grown to maturity in that environment and who, we contend, demonstrate the consequences of normative instability, including widespread alcohol misuse and violence, on child development.

This construction has implications for the interpretation of contemporary suicide patterns. While the concentration of deaths among young adult Aboriginal males may be attributed to characteristics of age (heavy drinking, reckless and endangering behaviour), it may also be a consequence of all that has preceded. In other words, as I have already suggested, the vulnerability of contemporary young adult males may have been informed by the nature of their childhood development and socialisation which, in turn, is a function of the social circumstances of Indigenous communities in the 1970s and 1980s.

If this interpretation is correct, that is, that young adults are at greater risk of death by suicide because of developmental factors rather than, simply, because of their age, then it has significant implications both for this group as a cohort, and for those younger Indigenous people exposed to similar developmental influences. It suggests, first, that those currently at risk may carry that risk with them as they age and, second, that this age-group will retain particular vulnerability if the context of development and socialisation remains unchanged.

Figure 12: Three year moving averages of suicide in three communities (community data)

Figure 13: Presentations of threatened or actual self-harm to the Yarrabah Life From other Offense Program, October 1995 to March 1998
In this discussion I have wandered over three loosely linked issues. To understand how institutional mental health relates to and is responded to by Indigenous people, communities and organisations, practitioners and planners should be aware of the history of their profession’s engagement in Indigenous affairs. To understand contemporary Indigenous social practices, such as the critical arena of family life, health practitioners should be aware of the historical, cultural and political forces that have been involved. Finally, a better understanding of contemporary social and mental health problems, such as suicide, requires knowledge of the circumstances of social adversity affecting Indigenous communities, an appreciation of how those circumstances have developed and persist, and an awareness of their developmental implications. To develop effective responses to the social and mental health issues of Indigenous Australia (figure 14) will demand utilising these insights broadly, from supporting reconciliation at the level of society, to adapting, appropriating or developing new therapeutic approaches at the level of the individual. At all these levels I believe that practitioners will be more effective to the extent that they reflect on their professional roles, are informed about Indigenous circumstances and motivated to understand ‘why it is so’.

Figure 14: Levels of intervention in Indigenous social/mental health

<table>
<thead>
<tr>
<th>Society</th>
<th>Reconciliation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community</td>
<td>Community development</td>
</tr>
<tr>
<td>Family</td>
<td>Life promotion programs</td>
</tr>
<tr>
<td>Individual</td>
<td>Adapted therapies</td>
</tr>
<tr>
<td></td>
<td>- culturally sensitive</td>
</tr>
<tr>
<td></td>
<td>Appropriated therapies</td>
</tr>
<tr>
<td></td>
<td>- e.g. narrative therapy</td>
</tr>
<tr>
<td></td>
<td>Indigenous therapies</td>
</tr>
</tbody>
</table>

The final words are from a famous Western Australian, Jack Davis.

*Big brown eyes, little dark Australian boy*

*Playing with a broken toy.*

*This environment his alone,*

*This is where a seed is sown.*

*Can this child at the age of three*

*Rise above this poverty?*

Jack Davis, Slum Dwelling (1988)

The following recommendations regarding Indigenous suicide were based on a mental health spectrum of interventions approach and derived from the research quoted above.

**Health promotion and universal prevention**

- Support for community development initiatives, particularly those fostering family wellbeing and an optimal childhood developmental environment
- Support for community to community dialogue and the exchange of experiences, knowledge and skills relating to community-level responses to Indigenous self-harm
- Support for health promotion and prevention initiatives aimed at reducing population level alcohol consumption
- Fostering intersectoral cooperation and collaboration such that communities have access to best practice, evidence-based, multidisciplinary programs and expertise
• Avoidance of negative stereotypes of Indigenous peoples and of Indigenous suicide in the mainstream media
• Culturally appropriate school-based and community organisation-based programs to foster the development of emotional coping skills
• Empowering communities through the collection and provision of information including:
  • Collection of accurate, reliable and relevant material at a community level which is available in a timely fashion for service and community planning
  • Aggregate collection of accurate information relating to Indigenous suicide at National, State and regional levels, and mechanisms for making this available in a timely manner to health and social workers and researchers engaged in and with Indigenous communities
• Development of Indigenous expertise at all levels to collect, analyse and utilise the above information with adequate resources and support to sustain these activities
• Development of social indicator systems relevant to the area of community risk

Selective prevention
• Dissemination of information regarding the potential negative impact of particular constructions of Indigenous suicide through Indigenous organisations and to Aboriginal and Torres Strait Islander communities
• Development of strategies informed by an understanding of the potency of representations of violence and self-harm to influence media portrayals
• Development of a strategy to address and counter current beliefs and understandings which view suicide as a reasonable and normative response to experienced pressures and emotional pain, and understandings which promote the notion that an individual is being encouraged or compelled to take their own life by others who have died in this way
• Support for health promotion and prevention initiatives aimed at Indigenous drinkers to prevent or reduce binge drinking
• Statutory and resource support for communities to develop local strategies to address alcohol misuse
• Family support programs for those families impacted by lifestyles of risk, particularly those with a cross-generational history of coping problems and high-risk behaviour patterns

Indicated prevention and early intervention
• Appropriate and adequately resourced community-based crisis response strategies capable of responding to instances of threatened or actual self-harm
• Community-based capacity to respond to the immediate needs of individuals affected by a recent suicide (postvention)
• Support for the development of appropriate approaches to counselling in communities
• Appropriate mainstream support for the above activities
• Ensuring that primary care practitioners working with Indigenous patients are trained in the primary care management of alcohol-related problems and have the knowledge and skills necessary to manage self-harmful behaviours

Standard treatments
• Direct access for Indigenous Australians to the same range and quality of emergency and mental health services as is available to the wider Australian population
• Ensuring that these services are functionally accessible, that is, appropriately adapted to the cultural needs of Aboriginal and Torres Strait Islander people
• Developing appropriate programs for the effective management of Aboriginal and Torres Strait Islander people with dual diagnoses
• Support the development of alternative treatment approaches, including appropriated therapies (such as narrative therapy) and Indigenous therapies

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Infectious diseases and Aboriginal health: should we be optimistic?

Aileen Plant, Katie Coles and Robyn McDermott

Introduction

Many of the areas where data are readily available are covered by others during these conference sessions concerning Indigenous health, especially in the infectious diseases area. Rheumatic fever, respiratory diseases, skin diseases, ear diseases, even nutritional aspects (presumably including gastrointestinal diseases) are some of the headings. So we have decided to take a more general look at communicable diseases using some data as illustration, and to concentrate more on how we usually consider communicable disease control, and whether the situation with communicable diseases is reason for optimism. When we first went to prepare this talk I thought that the communicable disease story was relatively successful, and thus a ‘good’ story in Aboriginal health. However, the more we thought about it the less clear it was as to whether it was a ‘good’ story, and whether or not we had reason for optimism.

Four areas will be discussed throughout this paper:

i. The state of Aboriginal health as far as communicable diseases are concerned,

ii. The reasons for optimism

iii. The reasons for despair

iv. The relationship with chronic diseases

Mortality from communicable diseases

Before Europeans arrived in Australia, we can be fairly confident that a range of diseases did not exist, diseases such as measles, flu, tuberculosis and syphilis. With European arrival, many of these diseases arrived with a vengeance causing a great deal of morbidity and mortality.

Consider the rates of infectious disease mortality as judged by diseases found in the first chapter of the International Classification of Diseases (called ‘Infectious and parasitic diseases’). [1] This chapter includes diseases such as diarrhoeal disease, and tuberculosis. They have decreased a little between 1979 and 1991, but the rates still remain 20 to 50 times higher in Aborigines than in non-Aborigines, [2] as shown in figure 1.

Figure 1. Mortality from infectious and parasitic diseases, 1979-91
More encouraging however, is the work done by Greg Dore when he looked at the whole range of infectious diseases and considered their mortality (see figure 2). [3]

Figure 2. Trends in infectious disease mortality, by State 1979-94

This means that he used the data throughout the disease classification chapters in the ICD that reflect infectious disease, so, for instance, the data include rheumatic fever from the circulatory disease chapter, pneumonia and influenza from the respiratory disease chapter, and infections out of the chapter on skin diseases and so on.

This attempt to use all the categories that relate to infectious diseases shows a clear decrease in the Northern Territory and while this includes both Aborigines and non-Aborigines, the greatest contribution to infectious disease data is made by Aborigines, as can be seen in figure 1.

Another piece of evidence about the decrease in infectious disease mortality is that the mortality rate changed so much from some limited early data from Moodie, published in 1973 using data from 1964-65. The rates of mortality from pneumonia and influenza have fallen to about one third of what they were 20 years earlier. Gastroenteritis and dysentery rates of mortality have decreased from about 200 per hundred thousand, down to about 5 per hundred thousand. Tuberculosis mortality has decreased from nearly 100 per hundred thousand to less than 5 per hundred thousand.

Contrast this with one of the chronic diseases, heart disease where the mortality rates have doubled in the same time period.

So that is message number one, that mortality from infectious diseases has fallen substantially in recent years.

Excess deaths and excess hospitalisation from communicable diseases

Turning now to a different way of looking at some of the data from the Northern Territory, and this is by using the concept of excess deaths or excess hospitalisations.

Excess deaths means the deaths that occurred over and above those that would have been expected if Aborigines had the same death rates as the total population, and similarly with hospitalisations. Of course, all deaths, and all hospitalisations are ‘excess’, but this is a way of making comparisons. It is reasonable to assume that Aboriginal mortality and morbidity, while they will change from area to area, will be of the same order of magnitude throughout Australia.
In looking at those excess deaths or hospitalisations, what proportion were due to the various categories of disease? By looking at the solid black bar on figure 3, which represents excess deaths, almost one quarter of the excess deaths were due to circulatory disease whereas only about 6 or 7% of the excess hospitalisations (hatched area) were due to circulatory disease.

Figure 3. Causes of excess deaths & hospitalisations: male Aborigines

Respiratory disease, even though we know that mortality has decreased so much from 20 or 30 years ago, still causes in excess of 20% of the excess deaths and about 20% of the hospitalisations.

For some disease categories, such as infectious and parasitic diseases, we know that the mortality has fallen substantially and remains just over 6% of the total excess mortality. The proportion of the excess for in-hospital morbidity is much closer to 20%, however. Deaths from skin-related diseases have entirely disappeared, but skin diseases still remain a significant cause of excess hospitalisation. Similar results are seen for females (see figure 4).

Figure 4. Causes of excess deaths & hospitalisations: female Aborigines

This leads to message number two, which is that, while the mortality has improved, there is still a very large amount of excess hospitalisation due to infectious diseases.
What we know in regard to communicable diseases

What these data reflect is that we know a great deal about deaths, we know somewhat less, but still a substantial amount, about hospital morbidity, we actually know very little about community morbidity and we know even less about some of the predisposing factors.

The following diagram shows the money that has been spent on data collection, research, attention, judged by headlines and so on, goes in the opposite direction. We know the most about deaths and the least about the predisposing factors.

That is message number three, we still know relatively little about the factors that predispose people to infectious diseases.

Success with communicable disease and areas for improvement

Turning now to the past problems, the current problems and the future problems, the following examples are illustrative rather than meaning to be a comprehensive list. For instance, in the past there were large outbreaks of diseases like measles, whooping cough, and Haemophilus influenzae B. All of those have declined; measles, whooping cough and HiB through immunisation, but also the use of antibiotics especially in the last two instances.

While some conditions are declining, there is still an increased risk of disease in Aboriginal populations. We have many current problems, four of which are rheumatic fever, invasive pneumococcal disease/ARI, sexually transmissible diseases and gastrointestinal disease. Rheumatic fever for which (usually) we can at least prevent recurrence by appropriate use of antibiotics, invasive pneumococcal disease which we can sometimes prevent with vaccine, and sometimes moderate the outcome with antibiotics, sexually transmissible diseases which we can actually treat, and gastrointestinal disease – where we can use curative mechanisms to stop (at least) the mortality. So all of these can be moderated with antibiotics, vaccines or curative measures.

Turning now to future problems such as HIV and hepatitis C.

We know that both of these problems are of great concern in the Aboriginal community, though we have very little idea about the dimension of the problem, and we have limited expertise in actually preventing the spread, and of course there is neither a vaccine nor a curative treatment available.

That is message number 4 – we have had some successes where we have been able to invoke a ‘magic bullet’ such as vaccine or antibiotic, but not so much where there is no readily applicable and deliverable control measure.

Infectious diseases and underlying factors

I would like to turn now to looking at a model of how we normally think about infectious disease. We know that there is an interaction between environmental issues such as housing or sanitation or nutrition and some of the social constructs such as education and the effects of peer pressure and the
control over one's own life, autonomy, culture, and access to health care. If the socio-environmental situation is bad or getting worse, there is an increased risk of infection and then once infected there is an increased risk of disease. As the following diagram shows, this actually gives us multiple potential intervention points.

From the following diagram, based on the previous one, you can see, for instance, that for gonorrhoea and chlamydia (and tuberculosis) we would be able to treat the person with antibiotics and generally speaking they would get better.

For a few diseases we can treat a person between infection and disease so preventing an infected person getting the actual disease. A good example of this is tuberculosis.

For some diseases, we can prevent people becoming infected (eg measles, pertussis, and HIB can be prevented by immunisation) but, for hepatitis C and HIV, the diseases that we have already identified as some of the future problems that we will see in communicable diseases, we are dependent on intervening at a higher point in the cycle, in other words around environment and social factors.
It would be better for all of these diseases if we actually prevented them all before they occurred or at least did as much modification as we could so that we weren't so dependent on vaccines and antibiotics.

A similar way of looking at it is thinking about some of the factors, not all of the factors but some of the factors predisposing to disease risk. This includes those of poverty, overcrowding, and malnutrition which we know work together. If you are poor, you are more likely to be malnourished. If you are poor, you are more likely to be living in circumstances that are overcrowded. If you live in overcrowded circumstances, the effects of poverty are made worse. If there is no control over your life and if people don't have access to health services, we know these have an enormous effect on people's lives and health. Each of these factors leads to an increased risk of infection and disease (see diagram below).

Some work that is coming out of Britain at the moment and reported by Michael Marmot and colleagues shows that people who are on the second rung are always worse off than people who are on the top rung, whether they be doctors or other groups, so it is very interesting and relevant, and seems to indicate that lack of control over your own life has an enormous impact on your health outcomes.

As well, we are well aware of the importance of access to health services and at least part of the improvements in communicable disease control we have seen in recent years are undoubtedly due to better access to health services and thus an increased capacity to intervene when need be.

But all of these factors interact together and increase the risks of infection. Imagine a malnourished child living in overcrowded circumstances in poverty, with poor access to health services and as a family little control over their own life. You can imagine there is an increased risk of infection and of...
course an increased risk of disease such as measles, TB, Hib and many others. But if we think now about the underlying factors, we could just as easily put those underlying factors into a model for the chronic disease.

With these same factors we know that poorer people are more likely to smoke and we know that if you smoke and you are malnourished, it changes your risk of disease. A good example of that is tuberculosis. Smoking of course increases the risk of ischaemic heart disease and chronic obstructive pulmonary disease. We know that you can intervene through health services but we also know that these complex social factors have a huge impact on the risk of disease throughout people’s lives.

The same goes with high blood pressure - we know that if you are poor, in a difficult situation, if you can’t find your pills because the house is so overcrowded, and if you can’t actually get access to health services; then there is a risk of poor hypertensive control and an increased risk of disease such as ischaemic heart disease.

Indeed (as the diagram below shows) there is no difference with alcoholism where the social factors increase the risk of overt alcoholism.

So this is the next message – the same underlying factors that affect communicable diseases, also affect the non-communicable diseases and that by relying on antibiotics and vaccines, we have not sufficiently benefited our colleagues in the chronic diseases or our patients. Now this is not to say that we shouldn’t treat people with antibiotics, it is essential of course that we do. We should give people vaccines, it is again essential that we do but we should also be thinking about the underlying factors and how we can prevent disease.
The same model can be applied for diabetes. Diabetes is a good model for disease interactions as opposed to risk factors. Once someone has a chronic disease like diabetes, they have an increased risk of infection so the factors that lead to them having an increased risk of infectious disease also leads to the increased risk of non-infectious disease. The non-infectious disease may in turn increase the risk of infection. For instance, we know that most people with melioidosis, and many of the people with pneumococcus, with skin infections and so on are actually diabetics or alcoholics (see diagram below).

So the next message is that if we don't fix up the predisposing factors for the infectious diseases, they are still there for the chronic diseases.

**The effect of chronic disease on susceptibility to communicable disease**

And the next message is that chronic diseases in themselves, sometimes predispose the person to infectious diseases.

The next diagram demonstrates underlying risks, chronic disease and infection, but could also include another column called infectious diseases.

The diseases and their associated risks can actually go on to have inter-generational effects. We know that poverty and overcrowding and malnutrition etc can actually lead to problems with the next generation either by effects before they are born or the environment after they are born. We know that people have chronic diseases and that in turn will have an effect on the next generation, again sometimes through depriving people of their role models, but very often just through the effects of alcoholism and inadequate food supply perpetuating the cycle of malnutrition and so on. We also know that those chronic diseases can lead to infection associations and that many of those infections can also
Conclusions

Firstly I think there have been some improvements, but it is fair to say I think that we have done the easy bits, that some areas are going to get worse, particularly in the area of HIV and hepatitis C.

I think it is fair to say that the underlying issues haven’t been tackled and that they remain an important issue as far as both infectious and chronic diseases are concerned.

Any interaction with chronic diseases and communicable diseases is likely to be inter-generational so while I think we should be pleased that we have achieved some things we have to recognise the fact that we should be only guardedly optimistic.

Of course this begs the question about what we can actually do, as doctors, about some of these problems. I acknowledge that it is easy for researchers to say that we need to get back to the underlying issues that underpin so many of these problems but I do believe there are things we can also do as clinicians and as public health doctors.

For instance we can interact better with both patients and public health services, recognising their particular problems that they present with. We can interact with the non-health sector because we have to recognise that the non-health factors are some of the major factors that predict healthy outcomes in the future.

We can certainly facilitate access to the health sector, we can be very mindful in our approach and our management whether it is a patient or whether we are actually dealing with the whole health service or a whole population, about where people are coming from and recognise that what we might be doing is substituting one problem with another if we think that just antibiotics and vaccines are sufficient.

A good example of what happens when we concentrate on mortality, is perhaps seen in maternal and child health where we saw great improvements in mortality and we all felt very comfortable with that, however, we haven’t seen any great changes in recent years and we haven’t found better ways of actually intervening with the mother/child relationship or indeed the parent/child relationship, recognising the importance of male role models in children’s lives as well as the mother’s role in the child’s life.

So while we have seen some improvement in infectious disease mortality, this improvement has been achieved mainly by medical rescue with antibiotics and immunisation programs, and hospitalisation rates still reflect high incidence. A mortality gap still exists and its persistence is due to a failure to address underlying causes: poverty, poor housing, overcrowding, substance abuse and poor nutrition. These underlying causes are contributing to a steadily increasing burden of chronic disease which in turn increases susceptibility to infections in young adults. The intergenerational perpetuation of chronic disease risk (after the Barker hypothesis) could contribute to a changing pattern in communicable disease risk in adults. In summary, while some infectious diseases have declined, further gains will probably only be had from effectively dealing with underlying causes.

References

Indigenous health in Australia – skin infections and infestations

Bart Currie and Jonathan Carapetis

Abstract

The most important skin infections in Aboriginal communities in central and northern Australia are scabies and streptococcal pyoderma. Scabies is endemic in many remote Aboriginal communities, with prevalences in children up to 50%. The cycles of scabies transmission underlie much of the pyoderma. Up to 70% of children have skin sores, with Group A Streptococcus (GAS) the major pathogen. GAS is responsible for the continuing outbreaks of poststrep-tococcal glomerulonephritis and acute rheumatic fever (ARF). Rates of ARF and rheumatic heart disease (RHD – cumulative valve damage from recurrent ARF) in remote communities are amongst the highest reported in the world. Recent studies implicate GAS as one factor associated with the high rates of chronic renal failure in Aboriginal communities. Molecular epidemiological studies of scabies and GAS have provided important new information for public health initiatives. The cycles of scabies transmission in dogs and humans do not appear to significantly overlap. The large genetic diversity of GAS isolates in communities, together with the very high rates of skin carriage but paradoxically low GAS throat carriage, support both the need for substantial improvements in living conditions and the importance of coordinated RHD programs which emphasise secondary penicillin prophylaxis. Guidelines for community control of scabies and skin sores have been developed and successful community initiated coordinated programs have occurred. In one study, a scabies control program had a significant effect on pyoderma prevalence and severity. The anthropophilic dermatophyte, *Trichophyton rubrum*, is ubiquitous in many communities, again reflecting living conditions. Other skin infections which relate to the tropical environment include melioidosis, nocardiosis, *Chromobacterium violaceum* and chromoblastomycosis.

Sustainable and long term improvements in scabies, skin sores and GAS related disease and tinea require fundamental changes which address social and economic inequities, and in particular living conditions and overcrowding.

Introduction

The most important skin infestations/infections in Aboriginal communities in central and northern Australia are scabies and streptococcal pyoderma. While there is evidence that fungal skin infections may have been introduced by Macassan trepangers to coastal communities before British colonization [1], streptococcal pyoderma was possibly absent and unsustainable in traditional hunter-gatherer populations [2] [3]. Furthermore, it is only over the last several decades that scabies has become endemic in many remote Aboriginal communities [4] [5] [6].

There are many studies in the international literature on the epidemiology of pyoderma and scabies which focus on the importance of poverty and socioeconomic disadvantage. An analysis of specific factors as independent risks for these skin conditions has been problematic because of their interdependence [7] [8]. However, it is likely that household crowding [9] [10], access to adequate quantities of water [7] [11], hot weather and humidity [12] [13], education and implementation of personal hygiene [12] [14] [15] are all important (Figure 1).

Fundamental to addressing the issues of pyoderma and scabies are initiatives addressing social and economic inequities in Aboriginal communities and in particular living conditions and overcrowding [8] [16]. In addition, specific preventive programs for pyoderma and scabies which are initiated at community level can make a difference [17] [18]. Finally there are standards of care and best practice guidelines for individuals with specific skin conditions which need to be accessible and for which adequate resources and numbers of health staff need to be in place in remote communities [19] [20] [21] [22] (Figure 2).
Scabies

Scabies is currently endemic in many remote Aboriginal communities with prevalence’s in children up to 50% and in adults up to 25% [17] [23]. Molecular typing of scabies mites has showed multiple overlapping epidemic cycles [24]. In some communities individuals with hyper-infestation (crusted or Norwegian scabies) are 'core-transmitters' [23] [25]. Apart from the individual discomfort caused by scabies, it underlies 50% to 70% of streptococcal pyoderma [17].

Control of scabies is therefore critical in controlling streptococcal pyoderma and its sequelae. A successful model for control of scabies in communities using 5% permethrin cream was documented from Panama [26]. This program involved treatment of all community members and led to a reduction
of scabies from 33% to low levels sustained at 3 years at 1.5%. Furthermore, without specific interventions involving antibiotics the pyoderma rate in children decreased from 32% to 2%. This program using whole community treatment with 5% permethrin cream has been adapted successfully and separately by two remote Northern Territory (NT) communities. In one, the scabies rate decreased from 29% to under 10% at 2 years [17]. In addition, without specific antibiotic interventions the prevalence of pyoderma in children was decreased from 69% to around half that rate and the residual pyoderma was documented as significantly less severe using a 'sore score' quantitative assessment. The most recent program was in 1998 where whole community treatment resulted in a decrease in scabies from 33% to 5% [18].

Because of the movement of people between communities, treatment of single communities in isolation will result in improvements which are likely to be sustainable only in the short term, with scabies and streptococcal infections reintroduced by people moving into the community from elsewhere. Coordination of programs on a regional level is therefore more likely to result in benefits sustainable over a longer period.

A recently developed molecular typing method for scabies mites has shown that the cycles of scabies transmission in dogs and humans do not appear to significantly overlap in Aboriginal communities [27]. Therefore while Sarcoptes scabiei var hominis and Sarcoptes scabiei var canis are morphologically indistinguishable, control of the scabies epidemics in Aboriginal communities requires emphasis on treating children and adults rather than resources directed towards dog programs. This is supported by the success of the two NT community based programs [17] [18].

The availability of 5% permethrin cream means that community based interventions to control scabies are now possible provided that there is adequate support for the resources and coordination required. Oral ivermectin is being increasingly used for treatment of scabies and is currently the drug of choice for those with crusted scabies [28] [29], although multiple doses are often required for severe disease [25]. There may well be a wider role for ivermectin in community based programs in Australia if the Therapeutic Goods Administration is satisfied with its safety in younger children and females who may become pregnant, based on the increasing international experience which includes community scabies programs which are currently being evaluated overseas [30].

**Pyoderma**

Pyoderma (impetigo or skin sores) currently has point prevalence's in children in remote communities in central and northern Australia of 10% to 70% [17] [31] [32] [33] [34]. As in other tropical areas Streptococcus pyogenes (Group A streptococcus – GAS) is usually the primary pathogen [35] [36] [37]. Staphylococcus aureus is commonly found in pyoderma lesions but is usually a secondary wound coloniser [36]. While there is some evidence that impetigo in affluent temperate Australian cities may be increasingly due to S. aureus as a primary pathogen [38], this assumption requires further study and does not appear to be applicable to Aboriginal communities where over 80% of pyoderma lesions may still be GAS culture positive [17] [34]. The primary importance of GAS is reflected in the excellent clinical response to benzathine penicillin [20] [35] [36] [39].

GAS is responsible for the continuing outbreaks of acute poststreptococcal glomerulonephritis (APSGN) and acute rheumatic fever (ARF) in remote communities [31] [33] [40] [41]. Rates of ARF and most importantly prevalence’s of rheumatic heart disease (RHD), which is the result of cumulative valve damage from recurrent ARF, are amongst the highest reported in the world [42]. In the Top End of the NT the annual incidence of ARF (1989-1993) is between 2 and 7 cases for every 1,000 children aged 5 to 14 years, while up to 3% of all people in some of the remote Aboriginal communities have established rheumatic heart disease [43]. In contrast the prevalence of rheumatic heart disease in the non-Aboriginal population is 0.014% and no non-Aboriginal children had acute rheumatic fever over the same 5 year period. Similar incidences have been reported from the Kimberley in Western Australia [44].

Pyoderma is also the predominant source of GAS invasive disease in Aboriginal communities. GAS invasive disease with bacteraemia is five times more common in Aboriginals than in non-Aboriginals in the Top End of the NT [45]. Skin has been the focus of nearly all severe GAS infections [45], unlike in southern Australia and Europe and North America where there may be prior throat carriage and pharyngitis from GAS [46] [47] [48] [49]. Scabies was found to commonly underlie the initial GAS infection in those with invasive disease in the NT [45]. Molecular typing of GAS isolates has shown that there is no dominant strain or clone of GAS responsible for the invasive disease in tropical Australia [45]. This is in contrast to the USA, Europe and southern Australia, where resurgence of invasive GAS disease has been associated particularly with M serotype 1 or 3 [48] [49] [50]. The
enormous diversity of GAS isolates in remote communities is demonstrated by the presence of up to 14 genetically distinct strains circulating at one time in a single community [34]. Furthermore, in the Top End study of invasive isolates there were 32 distinct molecular types from 50 isolates and the commonest type was present in only 4 of the isolates [45].

Recent studies have implicated GAS as one factor associated with the high rates of chronic renal failure in Aboriginal communities [51] [52]. This is in contrast to some previous studies which suggested that chronic renal disease was unusual following APSGN [53]. It is possible that repeated exposure to a large diversity of GAS isolates is the reason for this postulated association with renal disease.

An important paradox is that despite the high rates of GAS skin carriage and pyoderma in remote communities, there is a much lower rate of GAS throat carriage. Point prevalence’s of GAS throat carriage in remote communities are between 0% to 14% [17] [31] [32]. While the association of APSGN with GAS in skin sores is well recognised, speculation that ARF may also result directly from GAS in skin as well as throat requires further study. However, the overwhelming proportion of GAS being present in the skin provides strong support for ARF and RHD control programs to include measures to reduce the reservoir of circulating GAS in skin sores [54] [55].

The magnitude of streptococcal pyoderma in remote communities is also reflected in anti-streptokinase IgG levels being 10-20 times those in non-Aboriginals, with a functional assay showing streptokinase resistance levels in people from remote communities to be 10-15 times those in non-Aboriginals [56]. These high streptokinase antibody levels were enough to neutralise a standard streptokinase thrombolytic dose in at least 23% of adult Aboriginals. Concern about the lack of efficacy of streptokinase has led to the recommendation that primary thrombolytic therapy for myocardial infarction in Aboriginals in central and northern Australia should not be with streptokinase, but with the far more expensive tissue plasminogen activator [56].

**Fungal skin infections**

The anthropophilic (human to human transmission) dermatophytes, *Trichophyton* spp. are ubiquitous in many Aboriginal communities [57]. The granular variant of *T. rubrum* predominates in particularly the warmer humid northern communities, where it causes extensive skin (tinea corporis) and nail (tinea unguium) disease [1] [58] [59]. In central Australia and South Australia other ringworms are also common such as *T. tonsurans* which frequently causes scalp lesions and *T. violaceum* which causes tinea corporis [6] [57]. Zoophilic (from animals) ringworm appears far less common in remote communities in comparison to southern Australia [57]. Pityriasis versicolor (tinea versicolor), which is caused by *Malassezia furfur* and is often called 'white spot' or 'hanky' is also common in remote communities [6] [59].

While tinea versicolor usually responds to topical therapy with selenium sulfide or imidazoles ( clotrimazole, miconazole, econazole), skin and nail disease from *T. rubrum* is usually so extensive that topical therapy is useless and prolonged oral therapy is required [20] [60]. Traditionally griseofulvin has been used for treatment of tinea corporis and unguium. It is cheap but only fungistatic and daily therapy for 3-6 months is required for skin disease and for as long as 12 months for nails. Newer therapy options include daily therapy with oral terbinafine which is fungicidal but expensive [60]. Up to 3 months of therapy will still be required for nail disease and the requirement of confirmation of fungal infection for access to terbinafine on the Pharmaceutical Benefits Scheme disadvantages many communities where health resources are limited. Therapy with supervised fluconazole given orally once every week [61] is currently being assessed in the NT.

**Other skin infections**

There are a number of other skin infections which are occasionally seen in Aboriginal communities and are important because appropriate microbiological diagnosis is necessary to enable specific therapy. Melioidosis is caused by the soil and water bacterium *Burkholderia pseudomallei* and cutaneous disease may lead to potentially fatal septicaemia, with fulminant pneumonia and multi-organ abscesses. Nocardiosis, caused by a number of bacterial species, is sometimes difficult to culture and requires prolonged therapy, usually with cotrimoxazole in high dose. *Chromobacterium violaceum* is another environmental pathogen which can occasionally lead to fatal septicaemia and which is not responsive to commonly used penicillins and cephalosporins. Chronic fungal infections which can involve subcutaneous tissue and which can initially be mistaken for tinea include various organisms grouped as chromoblastomycosis. Surgery or prolonged antifungal therapy with expensive agents such as itraconazole may be required. Sporotrichosis is also occasionally seen and requires prolonged therapy with potassium iodide or newer agents such as itraconazole or terbinafine. New cases of leprosy are now rare in central and northern Australia but an awareness of the possibility of leprosy remains
important as skin lesions can be difficult to differentiate from tinea. Occasional cases of erosive ulcers from *Mycobacterium ulcerans* are seen. Yaws has been eradicated from Australia for many years.

**Preventive programs and standards of care and best practice**

Guidelines for community control of scabies and skin sores [21] [22] have been developed and successful community initiated coordinated programs have occurred, as noted above. Guidelines for control of APSGN have also been developed [62]. These involve interventions where an outbreak of APSGN has been identified and include community education and scabies treatment as well as the option of community wide treatment, with an injection of benzathine penicillin for selected contacts and community members in order to break the transmission of the nephritogenic GAS. A RHD education and control program has commenced in the NT [43]. This program is based on World Health Organisation guidelines [63, 64]. The emphasis is on identification of individuals at risk for worsening RHD and prevention of cumulative valve damage using monthly injections of benzathine penicillin to prevent recurrent ARF. In addition, the program attempts some primary prevention of ARF, including aiming to decrease the burden of streptococcal carriage and infection via scabies and skin sore programs.

Standards of care and best practice for individuals with specific infestations/infections have been developed [19] [21].

Unfortunately, despite appeals for improved health resources since early in the century [4], the reality remains for many remote Aboriginal communities that levels of staffing and resources for Aboriginal health workers, nurses and doctors, are often inadequate for implementing the standards of care for individuals with their specific illnesses, let alone for implementation of preventive programs [65] [66].

**Conclusion**

Scabies, pyoderma and tinea are responsible for significant morbidity in Aboriginal communities and there is some mortality from their sequelae. Guidelines for individual patient management and for public health interventions in the form of preventive programs have been developed and should make a difference. However, inadequate numbers of health staff in remote communities often mean individual treatment becomes the priority for busy clinics and even achieving this is difficult. Successful implementation of preventive programs requires support for improving clinic staff levels and resources, as well as provision of extra staff and infrastructure for both short term interventions and sustainable programs.

Improvements in staff levels and infrastructure should lead to improvements in skin disease. However, as with most areas of Aboriginal health, sustaining long term improvements requires fundamental changes which address social and economic inequities and in particular living conditions, overcrowding, education and employment.

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Nutritional aspects of Indigenous child health

Michael Gracey and A.M. Lilburne

Better standards of nutrition are essential if Aboriginal and Torres Strait Islanders (ATSI) infants and children are to have better health and improved growth patterns in future. Improved infant and childhood nutrition depends not only on supplying regular and more nutritious foods and encouraging better infant feeding practices, it depends also on better standards of living and hygiene for ATSI people.

Influence of maternal health during pregnancy

Low birthweight (LBW) is prevalent among ATSI babies [1]. There is still some discussion about how much of this may be due to prematurity or intrauterine growth retardation or IUGR [2]. The effects of undernutrition before and after birth are quite different. A developing fetus that is exposed to undernutrition is born small and tends to stay small throughout adult life; that is, it stops growing at the normal chronological age and so does not 'catch up' during adulthood. Babies who are exposed to undernutrition after they are born tend to have delayed growth, development and sexual maturation; they may continue to grow after the normal chronological age and so may have 'catch up' growth incorporated into their eventual, attained adult body size. This can be affected adversely by repeated or chronic episodes of infections or parasitic infestations; this can restrict growth for years, particularly if children live in overcrowded and unhygienic environments.

A study of risk factors for LBW in Aboriginal babies in Darwin showed that infants born to mothers with a body mass index (BMI) of < 18.5kg/m² had five times the risk of having LBW and more than double the risk of IUGR [3]. Low birthweight and IUGR were much less likely in infants of women with a BMI of > 25.5. The combination of these risks with the prevalence of maternal malnutrition suggests that 28 per cent of low birthweight and 15 per cent of intrauterine growth retardation could be attributed to continuing poor nutrition of Aboriginal women in the Darwin Health Region. Infants born to mothers who smoked more than half a packet of cigarettes a day had almost 3 times the risk of having LBW and more than one half the risk of IUGR.

Cigarette smoking has a negative impact on intrauterine growth and birthweight [4]. Young maternal age is also important. Aboriginal mothers often have multiple risk factors that may contribute to LBW and impaired growth of their babies in the first two years of life [5]; these include anaemia, genitourinary tract infections, hypertension, proteinuria, poor maternal weight gain during pregnancy, smoking and alcohol consumption.

Obstetric outcomes of Aboriginal women living in urban centres, having access to conventional medical services and living in an environment were similar to that of the lower class non-Aboriginal population [6]. So, even in cities it seems that outreach obstetric services are needed to locate and provide a wider range of services to Aboriginal women.

Prospectively collected measurements showed that Aboriginal infants of LBW were lighter and shorter throughout the first 5 years of life than other Western Australian infants and showed little evidence of 'catch-up' growth although linear growth at 3 to 4 years of age in Aboriginal children exceeded the reference values and the length deficits at 5 years were somewhat less than at earlier ages [7]. This is similar to experience with Aboriginal children in Cape York, far north Queensland [8].

Maternal malnutrition occurs in Aboriginal women and this may be an important contributor to LBW in their infants [9]. A prospective study of 49 Aboriginal mothers and their babies in the Kimberley region of WA showed that satisfactory birthweight and growth in the first 2 years of life were associated with maternal health during pregnancy, regular antenatal supervision and lack of drinking alcohol or smoking, as well as personal and family hygiene [5].

LBW infants have a much higher risk of death than infants of normal birthweight. In the neonatal period, when most infant deaths occur. On a population basis, the proportion of LBW infants, especially those with a very low birthweight (VLBW), is the major cause of their high mortality rates. As well, differences in LBW rates account for the higher neonatal death rates that happen in some groups, particularly those with socioeconomic disadvantages [10].
Infants who were small in terms of birthweight for their gestational age have a high risk of Sudden Infant Death Syndrome (SIDS). The SIDS rate in the Aboriginal population was 3.7 times that in the non-Aboriginal population. There is also a high risk of Sudden Infant Death Syndrome (SIDS) in Aboriginal infants who are small in terms of birthweight for their gestational age [11].

Babies with IUGR are more prone to particular conditions including non-insulin-dependent diabetes mellitus (NIDDM) and cardiovascular disease (CVD). They have abnormal glucose-insulin metabolism, elevated serum triglycerides and high levels of plasma hormones and cortisol [12].

Barker and his colleagues [13] showed that babies who are small at birth or during infancy have higher rates of CVD and NIDDM when they reach adult life. Some of these babies were of LBW, some were small in relation to the size of their placentas, some were thin at birth, and some were short at birth and had inadequate growth during infancy.

Poor utilisation of antenatal services by Aboriginal women in urban and rural areas has been found by others to be a very important cause of poor pregnancy outcomes. [14]; [15]. The high cultural significance of 'Women's Business' must be taken into account when trying to provide appropriate and acceptable obstetric services to Indigenous women [16]. The following could help provide better services for these women:

- Expanded and upgraded outreach services from tertiary, regional and district hospitals,
- More specialist obstetricians and gynaecologist working and living in regional and remote area [16].

**Growth patterns**

In many remote and rural areas, a substantial proportion of Indigenous pre-school children have unacceptable levels of malnutrition.[17]. The minimum prevalence of malnutrition (defined as either weight-for-height [WFH] or height-for-age [HFA] below the 3rd centile) was 20 percent in children below two years in the Darwin region [18]. Muller, [19], reported lower prevalence but also noted that the prevalence varied by season in the Top End of the NT. Among almost 2000 Aboriginal children aged 4 to 17 years studied in the Kimberley (WA), heights and weights were about the 25th and 10th centiles, respectively. Children living in towns were taller and heavier than those in remote localities; overall, the Kimberley Aboriginal children were lighter than non-Aboriginal children living in Perth [20].

Aboriginal children in remote communities and in gazetted towns in the Kimberley region in the tropical north of WA had different growth patterns [21]. From 1979-1983 town children were significantly taller and heavier than those in remote communities. However, from 1984-1988 and afterwards there were no significant differences in the growth patterns of children in towns and remote communities. Overall, weight-for-age (WFA) and height-for-age (HFA) of children in remote communities has improved since the 1970s relative to their town-dwelling counterparts in that region. In a comparison of five communities in Queensland, WFA was lower in the more northern and/or remote communities and failed to show the observed improvement in growth over time which occurred in those communities which were closer to population centres [22].

There does not appear to be any substantial recently published information concerning growth of Aboriginal or Torres Strait Islander children living in the major cities although earlier studies indicate that malnutrition was common [23]. Further investigation is warranted to determine whether urban Aboriginal children also are not reaching their full growth potential.

At a population level, growth failure in young children is due to inadequate energy and nutrient intake. However, this does not mean that faulty diet is the only cause, or always the major cause. Infection increases dietary energy needs, and repeated infections during childhood are a common cause of growth failure in Aboriginal infants and young children. Inadequate dietary intake causes weight loss and/or growth failure, and results in low nutritional reserves and eventually malnutrition (Figure).

Infants and children who are malnourished become trapped in a 'vicious circle' of malnutrition-infection-malnutrition because of the damaging effects of undernutrition on immune defences; This is made worse by living in highly contaminated environments and being repeatedly and constantly exposed to respiratory and gastrointestinal pathogens, intestinal parasites and other potentially disease-causing microorganisms.
With malnutrition and vitamin A deficiency there can be progressive damage to mucosal surfaces, such as the gut, with lowered resistance to microbial colonisation and invasion by pathogens. If the two major defence mechanisms were compromised, diseases would have potentially increased incidence, severity, and duration. This cycle begins in utero and can have detrimental effects on adult health status with poor maternal and infant diet contributing to immune deficiency and making the infant more susceptible to the deferred effects of infection.

Psychomotor development is delayed in populations with a high prevalence of childhood malnutrition. Such groups also suffer from many other social disadvantages so it is difficult to separate the effects of malnutrition itself from the effects of general social deprivation. The consistent evidence from various countries indicates that 'when severe malnutrition occurs in the first two years of life in the presence of sociocultural deprivation it appears to have a detrimental effect on mental development which lasts at least though childhood and that the role of stimulation may be critical' [24]. Sociocultural stimulation should be a part of the treatment of malnourished children.

In most children, so-called 'energy malnutrition' usually reflects a total shortage of food causing a deficiency in both energy and all other nutrients. Energy malnutrition in early childhood is associated with growth retardation, impaired neurological development, anaemia and increased susceptibility to infection. The interactions of infections and nutritional status are complex. Three key factors are: anorexia, malabsorption, and catabolic losses [25].

Monotony of the diet can contribute to nutrient deficiency thus causing anorexia which in turn leads to further weight loss making the child susceptible to infection and further anorexia.

The achievement of normal nutrition and growth during infancy and childhood is very complex and, in impoverished, unhygienic circumstances, is often very difficult. This is despite it being accepted as the norm in communities where standards of living and hygiene are high, where food shortages are non-existent and where maternal knowledge and practices about infant and child nutrition and hygiene are well founded.

A prerequisite for satisfactory intrauterine nutrition and fetal growth is good maternal health during pregnancy. This means the absence of disease and high standards of antenatal care and supervision as well as antenatal education for mothers. Avoidance by pregnant females of risk factors for the foetus, such as cigarette smoking and alcohol consumption, are also important.

Breast-feeding for at least 4 to 6 months is one of the most important factors in supporting the nutrition and growth of infants and young children in early life. Bottle-feeding has serious risks which include that of contamination of the infant’s feeds with harmful enteric microorganisms and other pathogens; bottles can be contaminated during preparation and while they are lying about in houses and camps.
which are quite often fouled by dogs and other animals or generally unhygienic living conditions. Infant feeding formulas can also easily be made up at the wrong concentration or with unbalanced non-human milks, such as unfortified cow’s milk, these are unsatisfactory alternatives for mother’s milk. These will not support normal growth of infants and young children and may be nutrient-deficient, including iron-deficient.

Even after infancy and early childhood, a balanced and adequate diet and a microbiologically clean housing environment and safe personal and family hygiene are required to sustain normal growth.

Approaches to eradicating malnutrition and its consequences need to be multi-faceted and include improved physical infrastructure, better food supplies, health and nutrition education and access to clinical care.

**Iron deficiency**

Iron deficiency and anaemia associated with it are important in young Aboriginals. Based on rural and remote surveys done more than two decades ago, the prevalence of iron deficiency in Aboriginal groups was much higher than in the general population [26].

In a community in north-east Arnhem Land in the Northern Territory the prevalence of anaemia (haemoglobin level <110g/L) was 11 per cent. Most subjects were iron deficient and this deficiency was attributed at least in part to hookworm infestations [53].

In a 1997 study, the iron status of Aboriginals from four remote communities in WA (326 persons) was determined by measuring haemoglobin, serum ferritin, transferrin saturation, serum iron and by measuring serum transferrin receptor levels. Serum transferrin receptor testing was useful in identifying iron deficient individuals. Standard tests of iron deficiency did not show a high rate of iron deficiency perhaps due to effective use of iron supplementation [27].

Low iron status in infants and young children is associated with several factors including low birthweight [28], low socioeconomic status [29], early introduction of cow’s milk (before 12 months) [30], excessive intake of cow’s milk after 12 months [31], late introduction of solids [32], [33], and low total iron intake [34]. Pre-term birth has also been linked to anaemia in the mother [35].

Tea drinking reduces the absorption of non-haem iron [36]. A number of studies report that young Aboriginal children often receive tea and this may be one reason why the anaemia rates are so high [26, 37]. Breast milk contributes greatly to the iron intake of infants in the first six months of life and early cessation of breast-feeding and introduction of unfortified cow’s milk and cereal products may also contribute to poor iron status [38]. Also, over reliance on breastfeeding as a source of nutrition in older infants, who should also be having weaning foods, may contribute to low dietary iron intakes.

Hookworm infections are present in some coastal and inland communities in the northern Kimberley region of Western Australia [39]. Hookworm disease manifests as iron deficiency anaemia resulting from gastrointestinal blood loss caused by worms attaching to the small-intestinal mucosa. Inadequate dietary iron intake contributed to the high levels of iron deficiency (50 percent) as 31 percent of Aboriginal women aged over 14 years who were hookworm-negative had iron-deficiency anaemia [39].

Iron deficiency anaemia in infants and children is associated with lower scores on tests of development, learning and school achievement [40],[41] [42]; [40]; [41] and prospective studies in Costa Rica and Chile have demonstrated that the effects of iron deficiency anaemia on IQ may be irreversible [43],[41].

**Impact of environmental health**

Standards of personal, domestic and community hygiene have important influences on Aboriginal health [44], particularly for infants and young children and especially in relation to diarrhoeal disease, intestinal parasites, respiratory tract infections, urinary tract infections and infections of the skin, the eyes and the ears, nose and throat [45]. These infections and infestations are often accompanied by growth faltering and sometimes by clinical malnutrition and stunting which may be permanent. They are also sometimes complicated by nutritional anaemias and nutrient deficiencies as well as impaired intakes of dietary energy. Retarded psychomotor development may also occur as a result of these combined problems in infancy and early childhood.

Diarrhoeal disease is a good example of the impact of unsatisfactory hygiene, exposure to high levels of microbiological contamination of the environment and undernutrition which combine into a ‘vicious cycle’ in which repeated and sometimes chronic episodes of diarrhoea co-exist to harm the human host and undermine nutritional status [46]. Undernutrition makes children more susceptible to infections
because of its negative effects on immune protection. On the other hand, episodes of infectious diarrhoea have negative impacts on nutritional status because of stool losses, vomiting, poor appetite, the common practice of withholding of food, and the catabolic effects of infection on the body. Reduced absorption by the gastrointestinal tract as well as excessive losses of important dietary components such as carbohydrates, fat and vitamins from the gut worsen these negative effects.

Many of the bacterial and parasitic agents that infect Aboriginal children are spread by the faecal-oral route such as by person-to-person contact or from contaminated utensils such as plates, spoons, cups, dirty feeding bottles, contaminated bedding or clothes, contaminated food or drinks, or by unsafe personal hygiene practices. Maternal hygiene practices are extremely important, particularly for infants and for children.

Food-borne diarrhoea is a major potential cause of diarrhoea in Aboriginal families and communities. These illnesses are due to the presence of pathogenic microorganisms or their toxins in food. Contaminated water supplies are another potential source of infectious diarrhoea, particularly in remote areas because of difficulties with regular water treatment and testing for microbiological cleanliness.

Gastrointestinal infections in infants and young children, particularly those caused by viruses, often cause extensive damage to the mucosal lining of the upper small intestine. This is important, because the small intestinal mucosa is rich in the enzyme which is needed for the digestion of lactose, the main sugar in human milk and in cow’s milk. Disaccharides cannot be transferred intact across the gut wall into the body’s circulation but must first be digested into monosaccharides which are transported actively into the circulation. This process of intestinal digestion occurs within the small intestinal mucosa through the activity of the enzyme-rich components of the so-called mucosal ‘brush border’ [47].

Extensive damage to the small intestinal mucosa can, therefore, interfere with the normally quick absorption of lactose in the upper small intestine. When this process fails, the undigested sugar in the intestinal lumen provides an osmotic load which draws fluid into the gut, distends the gut wall and causes frequent loose or watery stools (that is, diarrhoea. This is known, clinically, as lactose intolerance. If this is severe it can cause dehydration which can be clinically serious if it is unrecognised and untreated.

If lactose intolerance is prolonged and severe, it can cause significant wastage of nutrients. Combined with the common symptom of anorexia and the widespread practice of withholding feeding from the infants and young children with diarrhoea, these patients are prone to develop malnutrition. This is particularly so if they are in environments where recurrent gastrointestinal infections or parasitic infestations are likely.

Lactose intolerance is more likely to occur after episodes of infectious diarrhoea in infants and children who are undernourished. This form of lactose intolerance is known as 'secondary' because it is due to an underlying disorder, in this case, gastrointestinal infections which damage the small intestinal mucosa [48]. This is an important cause of diarrhoea or prolonged diarrhoea in Aboriginal children [49] particularly when lactose-containing milks are given to infants and children after an episode of infectious diarrhoea.

Apart from 'secondary' lactose intolerance, Australian Aboriginals are, predominantly non-digesters of lactose after early childhood. This is a characteristic which Aboriginals share with many other races or ethnic groups such as Chinese, many other Asian populations, most Africans, Papua New Guineans, Indonesians and American Negroes [50]. Feeding lactose-hydrolysed milk to slightly undernourished Australian Aboriginal infants and children resulted in better weight gains than if full-cream powdered milk was given [51]. It has been recommended that lactose-hydrolysed milk replace normal milk in the supplementary feeding of Aboriginal infants and children [51]. However, other approached to dietary management have become more widely used in recent years. These include the use of locally appropriate solids or weaning foods in a form that is 'chewable' and can be easily swallowed by young children, and the use of traditional, local foods in the period after gastroenteritis.

All infections can impair growth and nutritional status in infants and children [52] because of their high requirements for energy and nutrients to sustain normal growth. Respiratory tract infections are the other main types of infections (apart from diarrhoea) that significantly impair growth of Aboriginal infants and children.
References:


Review of Sudden Infant Death Syndrome among Indigenous infants in Western Australia

Anne Read, Louisa Alessandri and Sandra Eades

Abstract

Sudden Infant Death Syndrome (SIDS) is the major cause of death for Indigenous infants in Western Australia where, unlike most other States, there is good identification of Indigenous status. The SIDS rate for non-Indigenous infants has significantly decreased in recent years but this decrease has not occurred for Indigenous infants. These disparities in SIDS rates have been investigated using several methods.

Results showed that the SIDS rate for Indigenous infants born in 1996 was 5.6 per 1000 live births compared with 0.6 for non-Indigenous infants. A pathology review gave no evidence of differential misclassification or diagnostic transfer with regard to the cause of death but case-control studies showed that much of the disparity in the rates was due to the higher prevalence of SIDS risk factors in the Indigenous population.

Many of these risk factors, such as low birth weight, are very difficult to change. Other factors, such as exposure to cigarette smoke, may respond to an increase in community awareness. Thus, in collaboration with Indigenous communities, educational campaigns to increase awareness and decrease the prevalence of risk factors for SIDS, must be funded and implemented, and their impact must be monitored.

Introduction

The SIDS rate for Indigenous infants born in Western Australia (WA) in 1996 was 5.6 per 1000 live births compared with 0.6 per 1000 for non-Indigenous infants (unpublished data). SIDS is the major cause of death in Indigenous infants in WA and this is likely to be the case in other States. However, the problems of appropriate identification of Indigenous people in other Australian States make it very difficult to arrive at accurate figures [1] In WA, we have the Maternal and Child Health Research Data Base (MCHRDB) [2] which has enabled us to conduct good epidemiological studies of infant mortality according to Indigenous status for infants born from 1980. In this paper, we review the program of research conducted to monitor and investigate these different patterns of SIDS in the WA population.

Methods

Using the MCHRDB, SIDS rates for Indigenous and non-Indigenous infants were calculated for the years before and following the ‘Reducing the Risks of SIDS’ education campaign. Case-control studies, using routinely collected data, a pathology review and other methods were used to investigate the disparities in these rates.

Results

During the 1980s the SIDS rate for Indigenous infants was 6.1 per 1000 live births compared with 1.7 for non-Indigenous infants, that is about four times higher for the Indigenous infants [3] After the ‘Reducing the Risks campaign, the rates were 5.3 for Indigenous infants and 0.7 for non-Indigenous infants, so that the Indigenous rate became 7.6 times higher [4] For the non-Indigenous infants the SIDS rate was stable during the 1980s followed by a sharp decline after the ‘Reducing the Risks’ campaign whereas, for the Indigenous children, the rates increased dramatically during the 1980s, and there was a small (non-significant) decrease in the early 1990s [4].

There is a paucity of data in Australia with which to compare these rates but a report from the Northern Territory found that the SIDS rate for Indigenous infants for 1991 to 1993 was 7.6 per 1000 live births compared with 0.4 for non-Indigenous infants [5]. Indigenous populations in other countries also have high SIDS rates in comparison with their non-Indigenous populations [6], [7].

When we investigated the causes of infant death in WA during the 1980s, we found that the increases in the SIDS rates for Indigenous infants appeared to be accompanied by decreases in the rates for birth defects and the complications of low birth weight and preterm birth. There were few changes in these rates over time for non-Indigenous infants except that the rate due to low birth weight declined slightly [8]. Thus, for the Indigenous infants, we were worried about the possibility of diagnostic transfer or differential misclassification.

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A decrease in deaths due to low birth weight was not unexpected due to improvements in neonatal care and the in utero transfer of women in preterm labour to deliver in a tertiary centre. With regard to birth defects, we carried out extensive investigations of the WA Birth Defects Registry to validate our classification system [9]. These investigations did not change our initial results and we were confident that there was no diagnostic transfer over time.

In order to address the possibility of differential misclassification, we conducted a pathology review of sudden and unexpected death in infancy, the aim being to determine if there had been differences in the diagnosis and/or classification of SIDS according to whether the infants were Indigenous or non-Indigenous [10]. This review was conducted in two stages with Indigenous status of the child and the original cause of death diagnosis unknown to the pathologists reviewing the histology slides and other information.

The first stage involved the pathologists reviewing all available histology slides for the 105 Indigenous and 105 non-Indigenous infants in the study. The second stage comprised a review of all associated paper records such as death scene investigations, laboratory tests and medical reports. The Kappa statistic was used to assess agreement between the original and the final review diagnosis, with excellent agreement found for both Indigenous and non-Indigenous infants. In addition, there were no significant differences between Indigenous and non-Indigenous infants for normality of any individual organ, except for those infants who had originally been diagnosed as deaths from causes other than SIDS. In these infants, the Indigenous infants had significantly more lung abnormalities. This reflected the greater number of Indigenous infants with deaths attributed to respiratory causes. We concluded from this work that there was no evidence of significant diagnostic transfer in the classification of sudden and unexpected death in Indigenous infants. Thus, the review supported the observed increase in the Indigenous SIDS rate.

The next part of the research program was to conduct case-control studies using the routinely collected data held on the MCHRDB [11], [12]. Here I will briefly refer to a study where we aimed to identify factors that might be important in explaining the disparity in the incidence of SIDS between Indigenous and non-Indigenous infants [12]. Cases were all singleton infants born in WA from 1980 to 1990 inclusive and classified as dying from SIDS in WA (n=497). Controls comprised a 2% random sample of all singleton Indigenous and a 2% random sample of all singleton non-Indigenous infants born in WA from 1980 to 1990 inclusive and not classified as dying from SIDS (n=5127).

Results showed that the risk of dying from SIDS in Indigenous infants was 3.86 times (95% confidence interval 2.98 to 5.02) that in non-Indigenous infants. Multiple logistic regression analysis which included marital status, age and parity of mother, and gestational age, sex and small-for-gestational age status of baby indicated that Indigenous infants were 1.43 times (95% confidence interval 1.04 to 1.95) more likely to die from SIDS than non-Indigenous infants. Interactions in the model were used to investigate differences in the risk factor profile between Indigenous and non-Indigenous infants. The only important differences found were that the risk of SIDS in Indigenous infants, unlike that in non-Indigenous infants, appeared not to be strongly related to male sex or to single marital status.

Conclusions
The conclusions from this thorough series of investigations were:-

1) that the disparities in the Indigenous and non-Indigenous SIDS rates were real and not due to diagnostic transfer or differential misclassification;
2) that the high incidence of SIDS in Indigenous infants was largely due to a higher prevalence of known SIDS risk factors, such as being born small-for-gestational age or preterm;
3) that the residual excess risk may be due to the recognised postnatal risk factors (such as sleeping position and smoking) about which we had no information in this study, or to unknown factors; and
4) that it is vital to collect information about these risk factors in collaboration with Indigenous communities.

Discussion
Many of the risk factors for SIDS amongst Indigenous infants, such as being born small-for-gestational age or preterm, are very difficult to change. Other factors, such as exposure to cigarette smoke, whilst still difficult to affect, may respond to an increase in community awareness. Thus, in collaboration with Indigenous communities, educational campaigns to increase awareness and decrease the prevalence of risk factors for SIDS, must be funded and implemented, and their impact must be monitored.
The Bibbulung Gnameep team have produced a ‘Reducing the Risks of SIDS’ brochure for the Aboriginal communities of Perth and the south-west of WA, but more intensive educational campaigns throughout Australia are required if the prevalence of risk factors for SIDS in Indigenous populations is to decrease. SIDS Australia together with Indigenous communities, SIDS Western Australia and the Bibbulung Gnameep Team are working to attract funding to achieve this aim.

Acknowledgments

We would like to acknowledge all colleagues who have worked on this series of studies, their names are included in the relevant references. We would also like to thank the funding bodies, including the SIDS Foundation of WA, the National SIDS Council of Australia, and the PHRDC of the National Health and Medical Research Council of Australia. The cooperation of the Health Department of WA (in particular Mrs Vivien Gee), the Registrar-General of WA and the WA Coroner is gratefully acknowledged. A special acknowledgment is made to Dr Louisa Alessandri, who died unexpectedly in 1997. Louisa’s major research focus was the epidemiology of SIDS and infant mortality, and much of this body of work is due to her commitment, her scientific rigour, and her determination to achieve useful results.

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