Current Work in Australasian Epidemiology

Long conversations: Gomeroi gaaynggal tackles renal disease in the Indigenous community

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Abstract

The Gomeroi gaaynggal program in Tamworth and Walgett NSW, is working in partnership with Indigenous communities to understand the development of renal disease in women and their children. They are using innovative strategies of ArtsHealth to communicate the results of their NHMRC funded research programs and educate the community.

Introduction

Since the European colonisation of Australia, Indigenous Aboriginal and Torres Strait Islanders have suffered increasingly poor health, with profound effects on their life expectancy. The calorie-rich, nutrient-poor Western diet, smoking, drugs and alcohol contribute to the burden of chronic disease. In addition, Indigenous Australians suffer from dispossession of tribal lands and cultural disruption. They also suffer more severely from infections introduced by Europeans. In fact, Indigenous Australians have worse health outcomes when compared to other Indigenous peoples (Table 1).1, 2 In an effort to improve these outcomes, the Australian Federal government announced the ‘Close the Gap’ campaign in 2007 and increased funding for programs to improve the health of Indigenous Australians.

Pregnancy and the origins of chronic renal disease in Indigenous Australians

Aboriginal women have double the rates of preterm birth and birth of a low birthweight infants compared with non-Aboriginal women according to the latest Australian Perinatal Report (Table 2).1, 3, 4 Preterm birth and low birthweight are both likely to disrupt nephrogenesis (the formation of nephrons or the ‘filtering units’ which make up the kidney). Development of new nephrons is complete by about 34 weeks gestation. No new nephrons are formed after this time, so that an individual has the full complement of nephrons at birth. Nephrons are the functional units of the kidney, filtering the plasma and adjusting its composition through processes of excretion of waste products and reabsorption of essential substances. The fewer the number of nephrons a baby has at birth, the greater the relative loss of nephrons throughout life. Indigenous Australians have fewer nephrons.5, 6 Nephron loss causes chronic renal disease and end-stage renal disease. Kidney volume at birth or in late gestation (measured by ultrasound) is a surrogate measure of nephron number. Small babies have smaller kidney volumes.6, 7 In Indigenous communities among whom the proportion of low birthweight infants remains relatively constant at 13% (greater than double that of non-Indigenous communities at 6%), these small infants will be born with reduced kidney volumes.8

In addition, poor renal function predisposes to cardiovascular disease and hypertension. Among Indigenous Australians, the high prevalence of chronic diseases like hypertension, diabetes mellitus and cardiovascular disease, can establish a vicious cycle as they further damage the already-compromised kidneys. These factors contribute to high rates of early onset end-stage renal disease (ESRD) in Indigenous communities – 63% of Indigenous Australians listed on the kidney transplant list were under 55 years of age compared to 30% for non-Indigenous people; 44% of hospitalisations for Indigenous people were for chronic kidney disease and its complications. Of these hospitalisations, 98% were for dialysis.

Untreated diabetes mellitus is a leading cause of early onset renal disease. The age-standardised rate for onset of diabetes is 12% for Indigenous Australians compared to 4% for non-Indigenous Australians, leading to complications that need intervention by a general practitioner at twice the rate of non-Indigenous Australians.9 Again using age-standardised rates, the rate of death from diabetes is 7-times the rate for non-Indigenous Australians.9
For a long time it has been known that infections play a major role in the aetiology of end-stage renal disease in Indigenous Australians. Acute post-streptococcal glomerulonephritis (APSGN) poses a public health problem in tropical Australia, as pyodermia, skin infections and scabies are endemic; 50% of children are infested with scabies. The incidence of APSGN in the Northern Territory is the highest in the world with a 1991–2008 incidence in children under 15 years of 94/100,000. The same article reported that Indigenous children with skin infections during APSGN outbreaks were 5-times more likely to develop APSGN than their non-Indigenous counterparts.

There is a growing body of evidence that other infections play a role in the pathogenesis of chronic kidney disease. Two chronic infections, Helicobacter pylori and cytomegalovirus (CMV), are more prevalent among Indigenous communities than non-Indigenous communities. H. pylori is transmitted through an oral/oral route and prevalent in areas of poverty and overcrowded housing. Infants can become colonised with the bacteria during birth. CMV belongs to the Herpesviridae family and the infection is typically unnoticed in healthy people. The overall prevalence of H. pylori infection among Indigenous Australians is 76%; 60% of an urban community had evidence of H. pylori infection compared with 91% of a rural community.

The Gomeroi gaaynggal program

Research Program

In an effort to reduce the burden of renal disease and improve birth outcomes in the Indigenous communities, the Gomeroi gaaynggal research team obtained research funds to examine the developmental origins of renal disease in Aboriginal women and their infants. Indigenous women are recruited in their pregnancy by Indigenous research staff and provide samples (blood, urine and saliva) each trimester of their pregnancy. Foetal ultrasounds monitor foetal growth and measure the growth of the foetal kidney on at least two occasions during the pregnancy. The participants undertake a number of surveys to assess exposure to cigarette smoke and maternal psychosocial stress. Samples are analysed to measure renal health (cystatin C, serum creatinine, albumin, protein) and immune function (C-reactive protein, IgG, IgM and IgA, white blood cell count, antibodies to H. pylori), stress hormones (cortisol), metabolic status (glucose, cholesterol, triglycerides), cardiovascular health (blood pressure, activity of the renin-angiotensin system) and standard markers of health and well-being (BMI, complete blood count, haemoglobin).

The team has subsequently obtained further funding and the project has expanded into a longitudinal cohort study that has been underway since 2009. The women and their infants continue to be monitored in a post-natal longitudinal follow-up. The follow-up study assesses maternal renal health and metabolic status. In addition, it monitors the nutritional intake of the mother/infant dyads taking anthropometric measures to determine growth and development of the infant and postnatal health of the mother.

Arts/Health

The Gomeroi gaaynggal cohort has become the largest cohort of Indigenous pregnant women in the world. The success of the research study, in particular in recruitment, has resulted from a long-term trust developed through the community ArtsHealth program that runs alongside it. The ArtsHealth program developed by community consultation with the Elders provides the foundations for the health-based research that is being undertaken. The Elders were supportive of this research occurring in their community, provided our research team found a way to improve health education for pregnant women within the Aboriginal community. When this program was initiated, the only antenatal education classes were held in a private hospital, an environment that was intimidating and culturally inappropriate for young Aboriginal women.

In 2010, with philanthropic funding, we moved into the Gomeroi gaaynggal Centre, within walking distance of one of the Aboriginal communities of Tamworth. It contains office space, an art gallery, an art studio, a crèche, and space for clinical assessments for the research study. It has a large outdoor gathering space, kid’s cubby house and sand pit and lots of seats for family members and a vegetable garden is in development.

The Gomeroi gaaynggal program aims to close the gap in Indigenous health by allowing Indigenous mothers to recreate a positive nurturing environment for their children, rich in culture with high levels of physical and mental well-being, so that they can live long, productive lives and contribute to the culture of their communities. The program utilises a creative strengths-based approach to developing health-related knowledge for Aboriginal women and their families. In addition, the Aboriginal artists leading the art program work collaboratively with health professionals from the health services, private health providers, University of Newcastle staff, researchers and health students. Health knowledge is imparted in an informal way. Artworks are being created by both the mothers and the health professionals and cultural knowledge is shared at the same time. This partnered project guides Aboriginal families into improved health behaviours and assists with the generation of a culturally appropriate health workforce. Disciplines covered in our education program include dietetics, physiotherapy, mental health, sexual health, population health, obstetrics and gynaecology, women’s health and child/family health. Other services that have worked within the Gomeroi gaaynggal program include financial services, TAFE, counselling services, Medicare Local, and Regional Arts NSW (Arts Northwest and Outback Arts).

Importantly, the ArtsHealth program is facilitated by an Elder and Aboriginal artist, Aunty Pearl Slater who works on artworks with the mothers each week. During their weekly art sessions, representatives from a variety of health areas can attend the centre. It is not unusual to have a midwife, a dietitian and oral health specialists all attending the centre at the same time. We have found that an informal but long-term approach has the most impact.
Findings from the Gomeroi gaaynggal study

We are in the unique position of having recruited, since 2009, detailed information on the health of 100 young Indigenous women throughout their pregnancy. Only a simple analysis of the data has been carried out to date. As Table 3 shows there is a high rate of elevated C-reactive protein levels in these women (75%). C-reactive protein is a marker of chronic inflammation and can indicate infection (chronic or acute) or inflammation and levels > 3mg/L are considered to be high risk for development of cardiovascular disease. The Gomeroi gaaynggal cohort shows a prevalence of 32% H. pylori infection compared with a prevalence of 15% in the general Australian population and over 10-times higher than non-Indigenous female blood donors in the childbearing age range examined as a comparison group (2/72, 3%).

Table 1. Life expectancy data for Indigenous people of Australia, New Zealand and other nations. The two most recent life expectancy reports for Australian Aboriginal people have been shown. Whilst it seems that there have been dramatic improvements in life expectancy in Australia the differences in the reported life expectancy for Australian Aboriginal people in recent years are most probably due to the differences in calculation by the reporting bodies. Taken and modified from 1, 2

<table>
<thead>
<tr>
<th>Females (years difference)</th>
<th>Males (years difference)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Aboriginal Australian vs. Aboriginal Australian</td>
<td>9.7 years</td>
</tr>
<tr>
<td>Non-Maori New Zealanders vs. Maori people</td>
<td>17 years</td>
</tr>
<tr>
<td>Canadians vs. First Nations</td>
<td>7.1 years</td>
</tr>
<tr>
<td>Canadians vs. Canadian Inuit</td>
<td>5.4 years</td>
</tr>
<tr>
<td>Canadian vs. Canadian Metis</td>
<td>12.2 years</td>
</tr>
<tr>
<td>Canadian vs. Canadian Inuit</td>
<td>4.3 years</td>
</tr>
</tbody>
</table>

Table 2. Comparison of Aboriginal to non-Aboriginal measurable foetal outcomes. Modified from Australian Perinatal Report 4

<table>
<thead>
<tr>
<th>Measurable Outcomes</th>
<th>Aboriginal n (%)</th>
<th>Non-Aboriginal n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of deliveries</td>
<td>11,895</td>
<td>287,149</td>
</tr>
<tr>
<td>Preterm deliveries</td>
<td>13.8%</td>
<td>8.1%</td>
</tr>
<tr>
<td>Low birthweight</td>
<td>13.5%</td>
<td>6.5%</td>
</tr>
</tbody>
</table>

Table 3. Preliminary data from the Gomeroi gaaynggal cohort

<table>
<thead>
<tr>
<th>Prevalence (%)</th>
<th>(n/total)</th>
<th>Mean (+SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>H. pylori IgG (g/L)</td>
<td>32.2%</td>
<td>28/87</td>
</tr>
<tr>
<td>C Reactive Protein &gt;3 mg/l</td>
<td>75.3%</td>
<td>70/93</td>
</tr>
<tr>
<td>Microalbuminuria &gt;3.4mg/mmol</td>
<td>13%</td>
<td></td>
</tr>
<tr>
<td>Diabetes (any type)</td>
<td>11.1%</td>
<td>10/91</td>
</tr>
<tr>
<td>Serum creatinine umol/L</td>
<td>46.6%</td>
<td>34/73</td>
</tr>
<tr>
<td>Cotinine ng/ml (indicating exposure to smoking)</td>
<td>59/80</td>
<td>74.81 (10714)</td>
</tr>
</tbody>
</table>

In 15 women (16 obs) who had urinary albumin/creatinine >3.4mg/mmol, the H. pylori titre was higher (23.5 ± 5.5 g/L) compared with 15 ± 2.4g/L measured in the rest of the cohort; cotinine levels tended to be higher (97.5 ± 28.2) compared with 58 ± 10.7 ng/mL, but C-reactive protein levels were lower (5.2 ± 4 mg/L) compared with 8.4 ± 0.9 mg/L. There were striking correlations between urinary albumin and urinary protein (p<0.001) and between these two variables and urinary AGT (p<0.001). In 19 women who had plasma CysC > 1.15 mg/L (indicative of a lower GFR), they also had higher serum creatinine.

Renal focus of the ArtsHealth program and community education

Whilst we had always talked to mums at the Centre about kidney disease, and mothers would often ‘yarn’ about family with kidney issues, the data coming out of our study on young women continues to be concerning. These women (average age 24 years) are already showing signs of kidney dysfunction and it has meant that our health education/promotion needed to be innovative in developing new strategies to improve maternal and child health.

Indigenous people see that good health is more than having a healthy body – they take a holistic view of health and see it as mind, body, spirit and community. If any one of these has problems then it will affect a person’s health. The ongoing burden of ill health within Indigenous communities has...
an impact on all community members through family connections, financial stress, worry for others, and the burden of grief when there is another funeral to attend. Any health education program for Indigenous people needs to address each of these components (mind, body, spirit, community). We have long felt that our ArtsHealth program utilises cultural artistic practices and assists young mothers attending the centre with some of these 'life' problems.

To raise awareness of the prevalence of kidney disease for Indigenous people we decided to find an Indigenous role model and organise a number community events in an effort to spread the message about kidney health to the broader community. For our first event, we contacted the Country Music icon, Mr Jimmy Little. Jimmy was a well-respected Aboriginal man from Yorta Yorta country who suffered from kidney disease himself and had been a kidney transplant recipient. Jimmy attended the Gomeroi gaaynggal Centre with his guitar and spent a long day at the Centre singing songs and telling tales. His beautiful singing voice had everyone singing along and relaxing very quickly. His ongoing message throughout the day was to look after your kidneys – he spoke about symptoms of diabetes, cutting down smoking and improving diet. He spoke about the mistakes he had made in not making healthy choices when he was younger and this encouraged Elders to share their own stories of poor health choices. The Elders and Jimmy then spent much of the day talking with the younger attendees about how important having good health was for your family and community.

Having Jimmy come to the centre meant that we had a large crowd and the day was attended by Aboriginal people from school age, our mothers, partners, aunties, and lots of Elders. Sadly Jimmy passed away in 2012 but the Gomeroi gaaynggal program is still working with the Jimmy Little Foundation to improve kidney health knowledge. Since that day, we have held an annual community event that coincides with National Kidney Health day and ensure that we have health promotional activities on that day that stress smoking reduction, healthy diet and early recognition of symptoms of diabetes. Regular attendees to the centre work on artworks prior to these events and then invite family members and friends to attend. These community days allow health workers to connect with the broader Indigenous community to build ongoing relationships and to assist with changing health behaviours.

Nutrition: novel strategies for improving nutrition

Jimmy began what has become a 'long conversation' about kidney disease in our centre. We have followed it up by spending time getting to understand the health behaviours of our participants and trying to educate them as to ‘best practice’ for them and their families. Over our weekly ‘yarning’ with attendees at the centre we felt that the self-reported levels of sugary drinks and Coke being consumed on a daily basis was of most concern. Discussions with our participants indicated that there was a limited understanding of what the ‘appropriate level of consumption’ of these and other food additives such as salt. In addition, very few women or their infants were drinking enough water, as they consumed cordial, juice, tea or coffee as well as the soft drinks.

This led to the development of a poster placed on the front of the fridge used by our participants. The posters asks ‘Is your fridge kidney healthy?’ and states that a kidney healthy fridge contains lots of water, no coke, no soft drink and lots of fresh fruit and veggies. Whilst this is a simple thing, it has started conversations about kidney health and nutrition in the homes of participants. I know that someone could ask one of the attendees ‘why should I give up salt?’ and they would be able to tell them that it increases blood pressure and that an increased blood pressure makes kidneys work too hard. Most recently, we have had a number of artworks developed by participants related to kidney health. Figure 1 uses the analogy of two healthy platypus to represent two healthy kidneys (by artist Megan Porter) whilst Figure 2 uses a simplified diagram of the kidney in traditional style to show a healthy mother and infants kidney.

Figure 1. Waterhole. (Megan Porter) The two platypus represent two healthy kidneys

As we developed increasingly strong relationships with the women attending our centre, we have been rewarded by our participants suggesting health programs.

Their first choice was a cookbook for healthy diet in pregnancy as we knew that nutritional knowledge is limited in young women, particularly in younger mothers. With this in mind we felt it was extremely important for the women to be...
Health education delivery

It is quite difficult to articulate exactly how we deliver health education at the centre. What we have found is that a PowerPoint presentation is close to useless; but sitting down sharing life stories establishes trust and builds relationships. For example, discussions that occur over a ‘cuppa’ about transmission of Hepatitis C through backyard tattooing don’t quite fit as an ‘intervention’. The vast majority of our education program now occurs with this approach. The women attending the centre have been doing so, for such a long time that they have very strong relationships with all of us. They don’t hesitate to share their stories of life challenges (domestic violence, pregnancy, ill-health, death, financial issues, and depression). This provides us with the opportunity to ask the group if they would like to have someone come and talk further about these issues. Health professionals attend the centre for extended periods of time which further encourages the development of trust between our women and health professionals. As that trust is developing, the health staff are more willing to share their stories of life’s challenges (domestic violence, pregnancy, ill-health, death, financial issues, and depression). This provides us with the opportunity to ask the group if they would like to have someone come and talk further about these issues. Health professionals attend the centre for extended periods of time which further encourages the development of trust between our women and health professionals.

The more sensitive the issue, the more difficult it is to share the story and the longer the commitment of time that is required. Establishing trust is an important priority for us and we have encouraged health professionals to make it a serious priority in their own practice. We have focused on shifting dialogues from a ‘you can’t do this, stop doing that…’ to a conversation about ‘would you like to change things? And what is your priority?’ For example, these approaches are used to introduce difficult conversations about reducing smoking. Population health staff that work on the Quit for Life programs attend the centre each fortnight and we are beginning to see groups of women trying to quit smoking together and support one another through the challenges.

Summary

The success of building our research cohort has come from the partnered approach of our community ArtsHealth program, and the data coming from our research cohort is continuing to influence the educational focus delivered by health professionals and future research grants. We are continuing to recruit pregnant women into the cohort. These women and their infants are then being recruited into our follow up study. We should have significant data coming from both of these studies in the future. This will help scientists and clinicians to develop strategies for detection, treatment and prevention of renal and other chronic diseases in our Australian Indigenous communities.

References