Gomeroi gaaynggal: empowerment of Aboriginal communities through ArtsHealth to understand health implications of research in pregnancy

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There is an increasing body of evidence indicating how critical good health in pregnancy is for both the short and long term health of an infant [1-4]. When the Aboriginal community suffers such a high burden of poor health and reduced life expectancy, it is appropriate to look at improving the health of Aboriginal women throughout their pregnancy as a mechanism for ‘Closing the Gap’. Sadly, Aboriginal women are more than twice as likely to deliver their babies prematurely than non-Aboriginal women (14.3% versus 7.9% respectively) and with abnormally low birthweights (13.2% versus 6.1%) [5]. In all other measurable outcomes, Aboriginal infants fare poorly in their first twelve months with increased rates of foetal, neonatal and perinatal death [5].

Recent research indicates that health in later life is programmed during intrauterine life [1-4, 6]. It is becoming increasingly important that the mother’s health is optimal in her pregnancy to reduce the impact of maternal health on the development of obesity, diabetes, kidney disease and cardiovascular disease in the next generation. Nutrition related disorders or lifestyle diseases are highly prevalent within the Aboriginal community. Coronary heart disease is one of the largest contributors to mortality rates in Aboriginal people, being responsible for 30% of all deaths [7]. For all cardiovascular diseases the attributable death rates are 12-17 times greater for Aboriginal than for non-Aboriginal people [7].

Hospitalisation rates in Aboriginal people related to circulatory diseases were 1.2 times that of non-Aboriginal people [7, 8]. Hospitalisation rates for Aboriginal people suffering heart failure and coronary heart disease were up to three times that of non-Aboriginal people [9]. The associated risk factors for cardiovascular disease are age, gender, BMI, blood pressure, total cholesterol, diabetes status, nutritional status, smoking and alcohol ingestion. A study by Shephard et al., (2003) found that 40% of Aboriginal participants had hypertension with 20% previously undiagnosed. Type 2 diabetes is more prevalent within the Aboriginal population, 11% compared to 3% in the non-Aboriginal population [10] with diagnosis occurring on average 14 years less than for non-Aboriginal diabetics [11]. Ongoing management of diabetes seems to be more difficult for Aboriginal patients with HbA1c levels typically higher [11, 12].

The most frequent and heartbreaking complication of diabetes in Aboriginal people is nephropathy leading to end stage renal disease. Sadly the incidence of end-stage renal disease is 20-30 times that of non-Aboriginal diabetic patients and requires permanent dialysis or kidney transplantation [13]. Internationally, end stage renal disease is an increasingly recognised problem for Indigenous and minority groups, particularly Torres Strait Islander and Aboriginal populations [7, 14].

The Gomeroi gaaynggal program began in the city of Tamworth, a rural community of New South Wales, with a population of approximately 50,000 people. In this location Aboriginal women seeking antenatal care have a number of different care options available. The Aboriginal and Maternal Infant Health Strategy operates clinics at the local community centre and also at the community controlled Aboriginal Medical Service. Public hospital clinics are held at the hospital servicing both Aboriginal and non-Aboriginal women. In addition, there are specialised clinics held for younger mothers, those wanting midwifery-led pregnancy care and those having a high risk pregnancy. Women also have the option of attending the general practitioner for shared care with the Obstetricians in private practice,
however, the expense of this type of arrangement makes it prohibitive for most Aboriginal women. Whilst there are certainly choices available for antenatal care, when the Gomeroi gaaynggal program began there was limited choice for antenatal education. In fact, for some time the antenatal education classes were held in the meeting room of the private hospital of the town. It was a widely held view within the Aboriginal community that this was not culturally appropriate for the Aboriginal women of the community.

The Gomeroi gaaynggal program is a two pronged approach committed to improving the health outcomes for Aboriginal people. Firstly, it comprises an empirical research program working at understanding the physiological, biochemical and immunological drivers behind the increased adverse health outcomes in pregnancy in an effort to reduce the burden of chronic stressors (physical, environmental, psychosocial) on mothers that impact on their health and on the long term health of their infants.

The study is a collaborative program between the Gomeroi gaaynggal staff and Obstetric staff of the local health service area. Participants are recruited by the Gomeroi gaaynggal Aboriginal staff at their place of pregnancy care. The Aboriginal staff members have all undergone extensive training in the Indigenous Research Capacity Building Certificate IV to develop their skills as beginning researchers. These staff are also responsible for collecting all samples for the study and have completed their Phlebotomy Certificate qualifications.

The requirements for participants are quite extensive so the Aboriginal staff spend plenty of time with each woman to ensure their complete understanding of the program. Participants are given the opportunity to ask questions of staff, and to go home and discuss the program with family members before they consent to become a part of the study. Often family members, particularly older members will attend to ask additional questions and we have found that older family members become our biggest advocates. The staff members collect contact details for each participant, and they work very hard to ensure that participants remember all appointments as part of the study. Participants are required to have blood, urine and saliva collected on three separate occasions throughout their pregnancy – preferably once in each trimester. At the same time, they complete a number of surveys designed to assess their: 1) exposure to cigarette smoke, 2) psychosocial health, 3) exposure to major life events and their impact, and 4) exposure to discrimination and racism. As a part of monitoring the foetus, participants have three ultrasounds where the regular parameters of obstetric care are used as well as additional measures of foetal kidney development. When the infant is born, a 24hour urine collection is taken from the infant using specially designed nappies and a cord blood sample is collected. All samples are tested for markers of kidney disease, inflammation, measures of stress, by-products of tobacco, indicators of diabetes and nutritional status.

The Gomeroi gaaynggal study was designed by reproductive scientists but was heavily influenced by the Aboriginal community of the local region. In 2003, the National Health and Medical Research Council released the “roadmap” for researchers and prioritised community consultation as a part of Aboriginal research [15]. The Gomeroi gaaynggal team spent two years in discussion and this consultation process now underpins all aspects of the program. The Gomeroi gaaynggal Science study with Aboriginal women in pregnancy initiated its community consultation in 2006 with Aboriginal controlled organisations, mainstream health services, Aboriginal Health workers, Elders and community members who were recommended to the team throughout the two year consultation phase. A number of aspects of the study would not have been included without the drive from Aboriginal community members, in particular, the development of the Gomeroi gaaynggal ArtsHealth program. Aboriginal community members in the Tamworth region were concerned that while pregnancy education happened on an individual level while attending a health practitioner, the only antenatal classes were held at a private hospital in the town – not a particularly culturally appropriate environment. Benefits of antenatal education classes are not only for the education that they give, but also for the social connections made by women that lead to ongoing social opportunities such as mothers’ groups. For young Aboriginal women, visiting the private hospital is a highly intimidating place to attend and their classes provide
limited opportunities for engaging with other women in similar situations to themselves. This led to the idea of creating a more culturally appropriate centre with an arts focus which would allow an exchange of cultural knowledge and the development of a mutually supportive network of young mothers.

Since 2009 in Tamworth, the Gomeroi gaaynggal program has had its own centre hosting an art studio and gallery, office space, a crèche room and clinical space for the Science study. ArtsHealth was defined more formally by the Centre for Arts and Humanities in Health and Medicine, ‘creative activities that aim to improve individual/community health and health care delivery using arts based approaches, and that seek to enhance the health care environment through provision of artworks or performances’ [16]. In an Australian context, the benefits of artistic and creative practices on health and wellbeing on individuals has been recognised for some time with organisations such as the National Rural Health Alliance lobbying Federal Government to develop the new draft National policy for support of ArtsHealth programs [17, 18]. For the Gomeroi gaaynggal program the ArtsHealth program is a constantly evolving program of art based cultural activities led by Aunty Pearl Slater, a talented and well known Indigenous artist from the region, combined with informal health education sessions. Gomeroi gaaynggal is an ArtsHealth program that aims to improve the understanding and knowledge of pregnancy related health issues of Aboriginal mothers and mothers-to-be so they can share it with their children. The mothers learn about health through the informal interactions with clinicians, health students and Aboriginal Elders.

Whilst the program of education was initially developed specifically for antenatal education, over time the focus has become broader at the request of the attendees. Health education can be cooking classes and painting about food choices for pregnancy with a dietitian, baby health checks and advice given over a ‘cuppas’, a Zumba class with the physiotherapist for return to fitness following birth, or belly casting and painting stories and yarning with the Elders about motherhood. Health professionals who attend address issues such as stress, depression, grief, quit smoking, sexual health, kidney disease and diabetes prevention.

The ArtsHealth program is integral to the success of the Gomeroi gaaynggal Science study and likewise the Science study is providing immediate feedback of research results to the community through the ArtsHealth program (See Figure 1).

Figure 1
To date, the Science study has recruited over 100 Aboriginal women making it the largest international study of Indigenous women in pregnancy. It is much more difficult to quantify the number of participants in the ArtsHealth program - because attending the centre in Tamworth qualifies a person as a participant, but so does attending an exhibition of artworks exploring health issues generated by those fledgling artists. In 2011, the Gomeroi gaaynggal ArtsHealth program received the National Excellence award for an Indigenous ArtsHealth program and in 2012 six exhibitions were held in locations around the state of New South Wales. Since its inception in 2009, the Gomeroi gaaynggal program has expanded and now is recruiting participants and developing ArtsHealth programs in Tamworth and Walgett. There have been additional requests from Aboriginal people to begin work in other communities within the state and interstate.

In a pilot study, the research team have identified the current renal status of the Aboriginal women in pregnancy. The average age of our participants is 24 years of age. Our study has shown that 37% of our participants had high plasma glucose levels suggestive of previously undiagnosed gestational diabetes. In addition, 34% showed early signs of renal stress with microalbuminuria evident. Sadly, the data is showing reduced glomerular filtration rate in 12.5% of participants indicates overt kidney damage. We have identified rates of infection with *H. pylori* of between 24 (Tamworth) and 29% (Walgett) of the participants with the more remote participants having increased infection rates. Our ongoing studies include ultrasound evaluation and determination of birth outcomes to analyse of the effect of maternal stressors on foetal renal development.

As we have begun accumulating data from our Science study, the benefits of the ArtsHealth program has become immediately apparent for the research team and the community. We have been able to immediately increase the health discussions/information related to impacts of diabetes, reducing risk of kidney disease through diet changes, importance of being tested for gestational diabetes in pregnancy and post-pregnancy testing for diabetes.

The ArtsHealth program runs a number of programs with different focuses. Initially we have focused our attention on programs specifically aimed at working with women in pregnancy. Through ongoing discussion with attendees, the program has continued to evolve so that we have opened the Centre to the Elders groups to use for Elders specifically, and also in combined programs between mothers and Elders. Elders of Aboriginal communities are the keepers of traditional practices, knowledge and old ways that they like to share and pass onto the next generation. In the Elders’ eyes, sharing stories is a way of teaching younger generations. The beauty of having our own Centre has meant that we have been able to host whole-of-community events. For example, we have an annual Christmas party and Melbourne Cup day event for the Elders that the Gomeroi gaaynggal mums prepare and serve. We have had the pleasure of hosting a visit and singalong from the late Indigenous musician Jimmy Little where he spoke most sincerely to our mothers, their families and local Elders about the terrible burden that long term kidney damage can cause. Having suffered through years of dialysis and a kidney transplant himself, Jimmy set up the Jimmy Little Foundation to further educate Aboriginal people about kidney disease and diabetes.

By having a program that engages with the whole of the Aboriginal community about health issues that we have local scientific evidence for, and that the community themselves have deemed relevant, we have the opportunity to develop health education strategies for whole of community. In addition, it is hoped that the opportunity to engage with the wider community through art exhibitions will encourage those viewing artworks to consider their own health challenges and consider options for improving health.

Whilst the Science study is an international first it has taken many years to develop the relationships between the Aboriginal community and the research team. These long delays meant that recruitment was very slow and consequently costly. Thankfully, recruitment has improved with implementation of the program. Unfortunately, it must be noted that funding for ArtsHealth programs like this one is scarce. To date, we have had enormous financial support from a philanthropic group, however this is not ongoing.
It is already apparent to the Gomeroi gaaynggal research team that Closing the Gap has to be a long term investment by researchers and by the Indigenous community in partnership. Empowering Aboriginal research participants to understand the data as it unfolds will assist with driving changes to improve health through education. Researchers and governments need to commit to enduring community based programs that directly feed their results into promoting health literacy. The Gomeroi gaaynggal program has the enormous potential to improve the health of Aboriginal people. Our ongoing promotion of health education through the Gomeroi gaaynggal ArtsHealth program has the potential to reduce the risks of chronic kidney disease in Aboriginal mothers and their children.

References
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