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The Umoona Kidney Project

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Introduction

Kidney disease is one of the most serious problems facing Aboriginal Australians\(^1\). Nationally the number of Aboriginal people with advanced, or end-stage kidney disease is six times that of non-Aboriginal Australians\(^2\). It has recently been predicted that a further 500 Aboriginal people will develop end-stage kidney disease by the year 2004\(^4\). The only treatment options for Aboriginal people with advanced kidney disease are dialysis or transplantation, both of which cause significant social and cultural trauma for the individual and for their family\(^6\).

Early detection of renal disease is critical because, if identified early enough, progression to end-stage kidney disease can be slowed or even prevented. As a result, early detection has the potential to significantly reduce the number of Aboriginal people who may ultimately require dialysis or transplantation.

How the Umoona Kidney Project Came About

In mid-1997, a partnership was formed between the Umoona Tjutagku Health Service (UThS) and the Renal Unit at Flinders Medical Centre to conduct a renal disease screening and prevention program for adult members of the Umoona Aboriginal community at Coober Pedy in far north South Australia (some 850 kilometres from Adelaide). The request to conduct the project came from the then Director of the UThS, Waluwe Simpson-Lyttle. (Janice Braun has since replaced Waluwe as Director.) In mid 1998, the partnership was extended to include the Renal Unit at the Women’s and Children’s Hospital (WCH). This followed the community’s desire to include children in the screening and prevention program. As a result, the Umoona Kidney Project provides an integrated family or holistic approach to addressing the community’s renal health.

A Real Team Effort

The team working on the project is large and continues to grow. The Umoona Tjutagku Health Service team is Janice Braun (Director), a clinical nurse (Vicki McCormack, who has recently been replaced after 25 years sterling service to the community by Chris Durdin), and Aboriginal health workers (Michael Brown, Maryanne Hudson and Cissie Riessen). The Commonwealth Department of Health and Aged Care (through its Office for Aboriginal and Torres Strait Islander Health) has recently provided additional health worker salary support specifically for the renal project, and a fourth health worker (Gay McLeod) has now joined the team.

The Flinders’ renal team comprises Project Manager and Scientist, Mark Shephard, two renal doctors, Lindsay Barratt and Kathy Paizis, a nutritionist, Sally Zeunert, data manager Glen Allen, with computing and administrative support from David Heard and Karan Lavender respectively. The WCH team is made up of two renal doctors (Fred Jureidini and Margie van Renen), senior technical officer Sandra Harris, and a nutritionist Nadia Cerro.

Prior to commencing the project, six months of groundwork was spent with the Umoona Community, listening to the community’s thoughts and aspirations about renal disease, and working together to formulate the aims and objectives of the Umoona Kidney Project. This period of community consultation and liaison, facilitated mainly through a series of open community forums during field visits to Coober Pedy, was critical in forming the foundation on which the project has been built. The renal team also consulted with staff from the Coober Pedy Hospital, particularly the Senior Medical Officer, the Director of Nursing and CEO, as well as the local general practitioner at Coober Pedy in the lead up to commencement of the project. In addition, Catherine Morgan, Manager of Karpa Ngarrattendi Aboriginal Health Unit at Flinders Medical Centre, gave important cross-cultural training to the renal team.
Ownership and Direction of the Project

The foundation on which this work is based is that the Umoona community owns the renal project. It is a major long-term objective of the project that a strong sense of Aboriginal ownership continues to be fostered and advanced.

The FMC/WCH renal teams are responsible to the Board of the Umoona Tjutagku Health Service, and report directly to the Director of the Health Service. They work with the community, being respectful of Aboriginal time and space, and remaining sensitive to the cultural priorities of the community.

All data collected during the project (for example on screening, patient management and health promotion activities) remains the property of the Umoona community concerned.

Through community information sessions, community members receive feedback on how the program is progressing, what results have been generated and how the overall health of the community is improving over time. These forums are viewed as a critical priority to reinforce community ownership of the project and as a key strategy in ensuring long-term sustainability.

How Does the Umoona Kidney Project Work?

A major aim of the project is to identify those members of the Umoona community, both adults and children, who may be at risk of developing advanced renal disease. This has been achieved by implementing a screening program that began for adults in June 1998 and for children in November 1998. Participation in the screening program is on an entirely voluntary basis.

The Flinders and WCH renal teams visit the community on a regular basis, around every six weeks during 1999, to carry out the screening (which is conducted at the Umoona health clinic). They work closely with the nurse and health worker team during these field visits. The health screen not only provides information about risk factors for developing renal disease but also the risk of cardiovascular disease, diabetes, and the state of nutrition. It includes a full medical assessment, a family history, and a blood pressure, blood sugar and weight check. In addition, each person also brings along a first-morning urine or “kumbu” sample, which is tested on-site for the urine albumin:creatinine ratio or ACR, using a machine called the DCA 2000. The ACR test is very much the cornerstone of the screening program. It detects low levels of protein in the urine (microalbuminuria), indicating early evidence of renal disease. The DCA 2000 instrument, marketed by Bayer Australia, is portable, simple to use, and provides a quantitative measurement of ACR in seven minutes'. Used for the first time in situ in an Aboriginal community, it has proven both robust and reliable in this setting. Following a consultation and after reviewing all the screening results, the renal doctor gives each community member immediate feedback on his/her risk factor profiles for renal and other lifestyle diseases.

The role of the health worker team in the screening process is pivotal. As Cissie explains: “We make appointment times for the people to see the renal doctors, we see the people and give them a reminder notice about their appointment, and we give each person a urine container (to collect their specimen for ACR testing) and a brown paper bag to keep the specimen in. On the day the person sees the doctor we provide transport to the clinic if needed, and we measure heights and weights and do finger-prick blood sugar tests.”

Between field visits by the renal team, there is also much to do, with the Umoona health team carrying on further screening tests requested by the renal doctors (such as repeat blood pressures, blood sugar levels and dipstick urinalyses). During field visits over the past six months, the health workers have been given regular training sessions about how to use the DCA 2000. Since September last year, the health worker team has been performing urine ACR testing on the DCA between visits of the renal team. This is seen as a critical step in the evolution of the project because it has always been a long-term aim of the project to facilitate Aboriginal control and empowerment of renal screening.

As Michael and Maryanne explain: “Doing the ACR testing ourselves really streamlines the project and spreads out the workload. It gives the community members more choice as to when they have their  

Umoona’s Aboriginal Health Worker team: Michael Brown, Maryanne Hudson and Cissie Riessen with former clinical nurse Sister Vicki McCormack
urine tested. They can come in at any time and not just when the renal team visits.”

By late 1999, 150 adults and 140 children in the community had been screened. Some of the important findings from the screening of adults include:

- Fourteen percent of people had early evidence of early kidney disease or “microalbuminuria”, as well as having other risk factors for renal disease. All are either diabetic, diabetic with high blood pressure, or hypertensive. This group is a special focus of the project because we hope to prevent or retard the progression of renal disease in these people through early intervention strategies (as outlined below).

- Eight percent of people had previously unknown established renal disease, indicating the critical need for screening and early detection of renal disease in Aboriginal communities.

- Forty two percent of people were not hypertensive or diabetic, but had other risk factors for renal disease, cardiovascular disease and diabetes such as obesity, smoking, and strong family history. Most people in this group were between 20 and 30 years of age, and they will need to be closely monitored in the next ten years for the future development of these so-called “lifestyle diseases”.

Screening has also identified three adults with previously undiagnosed diabetes, 38 adults with previously undiagnosed hypertension, one new case of hepatitis B and one new pregnancy.

Looking at the children,

- At present 14 children/young people are being followed for renal abnormalities detected by the screening project. These abnormalities include significant proteinuria, significant microhaematuria and recurrent urinary tract infections.

- Ten children, who were found to have a raised ACR, are undergoing appropriate renal investigations and two children with mildly elevated blood pressure readings on screening are under regular review.

- In addition, 28 children with minimally elevated ACR levels on initial screening are being followed regularly by analysis of an early morning urine specimen. This enables tracking of ACR levels over time to determine whether they have a potential ongoing renal problem. Eight children have also been identified with significant microhaematuria and are currently being investigated.

- Four children with previously diagnosed renal problems are now under regular review at the Health Service.

- A new non-insulin dependant diabetic (NIDDM) has been diagnosed as a result of screening and a further adolescent is currently being investigated for diabetes. These young people will be managed in the long-term by the regional pediatrician from Port Augusta, Nigel Stewart. Several more young people have been identified as having significant risk factors for Type II diabetes and are receiving appropriate management including dietetic advice.

- Five children with previously unrecognised medical problems (namely, type 2 diabetes, heart murmur, asthma, endocrine and eye conditions) have been found during screening and have been referred to the pediatrician for ongoing management. Eight overweight/obese children are receiving advice and are being reviewed by the WCH nutritionist, both in family and school groups. Many non-renal problems identified during the screening physical examination have been referred to the local general practitioner and/or the regional pediatrician. Many of the children in the community have been found to have a strong family history of significant medical problems, for example hypertension (54%), diabetes (62%), renal disease (32%) and cerebrovascular disease (41%).

Screening will continue to be an ongoing priority of the project over the next year. The community has accepted the renal teams from FMC/WCH well. Maryanne says: “The community love the doctors and the whole renal team. They have good trust and respect for the team. Mothers are very keen to come because our children are very important to our community. Having seen the doctors working with their children, many of the parents have now come to see the adult renal team.” Michael adds: “The old people also like to see the doctors. Even if they don’t have an appointment, they still come in and like to be checked out.”

Helping those People At Risk for Kidney Disease

A medication called Coversyl (made by Servier Laboratories) is being offered, again on an entirely voluntary basis, to those adult community members who have been identified during screening and follow up assessment as having high blood pressure, diabetes with early renal disease, or established kidney disease. This medication helps protect both the heart and the kidney. There have been quite remarkable drops in blood pressure in the group of 36 people who have been taking the medication consistently (for example, average lying blood pressures of this group have fallen from 153/92 to normal values of 137/83). There has also been no increase in the degree of microalbuminuria in the group.

Again, the health worker team has a vital role in managing the medication. As Cissie explains: “We deliver tablets as part of a daily morning tablet run to particular clients, and we bring other people to the clinic to collect their weekly dose of tablets.”
A range of culturally appropriate health promotion strategies has been initiated concurrently with the provision of medication. These strategies are seen as vitally important for the long-term sustainability of the project and for the improvement of the general health and lifestyle of the community as a whole. They focus on nutrition, hygiene and exercise. The FMC and WCH nutritionists provide individual nutrition counselling following referral by the renal doctors and work with a range of community members and groups in response to particular requests for information and education (notably the Coober Pedy Area School and the Aboriginal Meals Program).

A recent initiative has been the introduction of a Nutrition Training Program for the health worker team. (This is in addition to kidney education sessions that are regularly run by the renal doctors for the health workers, with the topics for discussion and the agenda being set by the health worker team.) Cissie explains the background behind this Nutrition Training Program. “Our health workers have been keen to work with the community to improve nutrition, but we felt that we did not have an appropriate level of knowledge and skills to do this. So we identified for the renal nutritionists some areas where we felt we needed further education. These were general nutrition, nutrition for infants and children, nutrition during pregnancy, nutrition for obesity and heart disease, and nutrition for diabetes and renal disease. (Representatives from the Umoona Child Care Centre, the Child and Youth Health nurse and Aboriginal Education Workers from the Coober Pedy Area School were also invited for the Nutrition for Infants and Children session.) Maryanne continues: “The renal nutritionists have gone away and prepared education sessions on these five topics, and they come up to Umoona for separate visits to teach us about these areas. We can now pass this information on to the community in our own time, and we can focus on those people who need specific help such as young mothers.” Michael states: “As part of the first session, we are running a ‘healthy tucker’ poster competition at the school with a range of sporting prizes including a signed Port Power gurney.”

While discussing sport, the community as a whole is very keen to improve the level of fitness among their children in particular and to promote sport as a healthy activity. Michael has taken a leading role in this area. Recently the renal team has joined forces with the University of South Australia’s Physical Education, Exercise and Sport unit, headed by Jim Dollman and David Stuart, who have had a long standing interest in the fitness of South Australian schoolchildren. The University team has begun some preliminary work with the Coober Pedy Area School with a view to improving fitness and awareness of the benefits and opportunities that sport may provide.

Continually mindful of the community ownership of the project, the renal team has enlisted the health workers’ support in conducting a survey within the community to assess attitudes and perceptions of the project. The project must continually evolve and develop in directions that the Umoona community views as appropriate to its needs and priorities.

Summary
In summarising the project to date, Maryanne states: “The Umoona Kidney Project is culturally appropriate for our people. It’s been successful largely because of the education we have received from the renal team. We can now go and talk, in an informed way, to the community about kumbu, our kidneys, diet and tucker. We’ve now got the chance to educate our young children early about kidneys and nutrition. Everyone is happy working with the kidney team.”

Just to finish on a rather humorous note with a story that indicates the messages about healthy kidneys are being taken to heart by the community. The children’s renal team recently screened a young boy. The next day he turned up at the health clinic with his dog. He wanted the doctor to check his dog’s kidneys. The nurse wouldn’t let the dog into the clinic, but Dr Fred came outside and put his stethoscope onto the dog. The dog was so surprised, it ran across to the nearest post, cocked its leg and did a kumbu sample on the spot!

References

* This article has been published with permission of the Director of the Umoona Tjutagku Health Service, Janice Braun.
Umoona Kidney Project

case study of effective Aboriginal health care

WE KNEW we'd made an impact when a young lad from Umoona brought his dog along to the health clinic and requested that we check his dog's kidneys for early signs of renal disease. Every six weeks for the past two years, our renal team, comprising members from the Renal Units at both Flinders Medical Centre and the Women's and Children's Hospital, has religiously made the 1700 kilometre round trip along the black-topped Stuart Highway to Coober Pedy in South Australia's far north. There we have been working in close partnership with the Umoona Tjutagku Health Service (UTHS), a community-controlled Aboriginal health service responsible for looking after the health of the 500-strong Umoona Community.

At the request of the former Director of the Umoona Health Service (Walwe Simpson-Lyttle), we've been conducting a renal disease screening and prevention program for both the community's adults and children; that is, providing an holistic or family-oriented approach to Aboriginal renal health. I probably don't need to explain to readers the magnitude of the renal disease problem in contemporary Aboriginal society. Just a couple of the more damning facts are: the incidence of end-stage renal disease among Indigenous Australians is at least six-times the national average, with recent figures predicting that there will be a further 500 new cases of ESRD in Aboriginal people between 1997 and 2004.

Early detection of renal disease is critical because, if identified early enough, progression to end-stage kidney disease can be slowed or even prevented and, as a result, the number of Aboriginal people who may ultimately require dialysis or transplantation may be significantly reduced.

The Umoona Kidney Project, as the community calls it, is a real team effort. From the Umoona Tjutagku Health Service there is a Director (Janice Braun), a clinical nurse (Chris Durdin), and Aboriginal Health Workers (Michael Brown, Maryanne Hudson, Gissie Riesan and Gaye McLeod). The Flinders' renal team comprises Project Manager and Scientist (Mark Shephard), two renal doctors (Lindsay Barratt and Kathy Paizis), a nutritionist (Sally Zeunert), and data managers (Glen Allen and David Heard). The WCH team is made up of two renal doctors (Fred Jureidini and Margie van Renen), a senior technical officer (Sandra Harris), and a nutritionist (Marcelle Duff).

The Umoona Community "owns" the renal project and, in the long-term, this sense of Aboriginal ownership must be fostered and advanced. The FMC/WCH renal team is responsible to the Board of the Umoona Tjutagku Health Service, and reports directly to the Director of the Service. We work with the community, being respectful of Aboriginal time and space, and remaining sensitive to the cultural priorities of the community. All medical data collected during the project remains the property of the Umoona Community.

The screening program, which began for adults in June 1998 and for children in November 1998, aims to identify those members of the Umoona Community who may be at risk for developing advanced renal disease. Participation in the screening program is on an entirely voluntary basis. The health screen not only provides information about risk factors for renal disease but also the risk of cardiovascular disease, diabetes, and state of nutrition. It includes a full medical assessment, a family history, and a blood pressure, blood sugar and weight check. Each person also brings along a first-morning urine or "kumbu" sample, which is tested on-site for the urine albumin:creatinine ratio (ACR) using the Bayer DCA 2000. The ACR test, very much the cornerstone of the screening program, detects microalbuminuria (ACR between 3.5 and 35g/mol), indicating early evidence of renal disease. The DCA instrument is portable, simple to use, and provides a quantitative measurement of ACR in 7 minutes (1). Used for the first time in situ in an Aboriginal community, it has proven robust and reliable in this setting. Following a consultation and after reviewing all the screening results, the renal doctor gives each community member immediate feedback on his/her risk factor profiles for renal and other lifestyle diseases.

Between field visits by the renal team, the Umoona health team carry out further screening tests requested by the renal doctors (such as repeat blood pressures, blood sugar levels and urinalyses). During field visits over the past six months, the health workers have been given regular training sessions on how to use the DCA 2000. And since September this year, the health worker team has been performing urine ACR tests between visits of the renal team. This is a critical step in the evolution of the project because it provides the Community with greater self-sufficiency and empowerment to conduct its own health screening.

To date, 180 adults and 150 children have been screened. 18 per cent of the adult community...
have microalbuminuria; all of whom are either diabetic, diabetic with hypertension, or hypertensive. Seven per cent have previously undiagnosed established renal disease, 45 per cent have high blood pressure and 23 per cent have diabetes. Screening has also identified three adults with previously undiagnosed diabetes, 38 adults with previously undiagnosed hypertension, one new case of hepatitis B and one new pregnancy. 14 per cent of children screened are being followed for renal abnormalities, while 20 per cent of children have also been identified with a previously undiagnosed medical problem (including heart murmur, asthma, endocrine and eye conditions, and two new children with non-insulin dependent diabetes). Screening will continue to be an on-going priority of the project over the next year.

On a positive note, we have seen significant improvement in the health profile of a number of community members. The ACE Inhibitor Coversyl (Servier Laboratories) is being offered, again on an entirely voluntary basis, to those adults who have been identified as having hypertension, diabetes with microalbuminuria or established kidney disease. There have been quite remarkable drops in blood pressure in the initial group of 36 people who have been taking the medication consistently (for example, the average lying blood pressure for this group has fallen from 153/92 to 137/83). There has also been no increase in the degree of microalbuminuria in this group.

A range of culturally appropriate health promotion strategies has been initiated concurrently with the provision of medication. In response to the Umoona health workers’ request for greater knowledge about nutrition, our two dietitians set up and delivered a Nutrition Training Course for the health workers. The health workers themselves set the topics for presentation at the training course, namely general nutrition, nutrition for infants and children, nutrition during pregnancy, nutrition for obesity and heart disease, and nutrition for diabetes and renal disease. The health workers now feel comfortable in talking to their Community about nutrition issues and developing community initiatives in nutrition in their own time and space. Our nutritionists also provide individual nutrition consultations for people, and are working closely with the local school and a range of community groups and representatives.

The Community is very keen to improve the level of fitness among their children in particular and to promote sport as a healthy activity. Recently the renal team has joined forces with the University of South Australia’s Physical Education, Exercise and Sport unit, headed by David Stuart and Jim Dollman, who have a long standing interest in the fitness of South Australian schoolchildren. The University team has begun some preliminary work with the Coober Pedy Area School with a view to improving fitness and overall awareness of the benefits and opportunities that sport may provide.

Continually mindful of the Community ownership of the project, the renal team has enlisted the health workers’ support in conducting a survey to assess Community attitudes towards the project. The survey indicated that the community is very happy with the kidney project and trusts the renal team to help them. The project must continually evolve and develop in directions that the Umoona Community views are appropriate to its needs and priorities.

In summarising the project to date, I’d just like to finish the story about the young boy and his dog because this shows just how deeply the Umoona Community is taking the messages about healthy kidneys to heart. The children’s renal team had recently screened the young boy. The next day he

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the cycle in poor health in Aboriginal communities throughout the country.

"We need to see more Aboriginal people in health care. We not only need more Aboriginal doctors, but also more Aboriginal nurses, dentists, physiotherapists; in fact, we need more Aboriginal people in health care roles across the board. Just 1 per cent of Aboriginal people are employed in health care roles — half the rate of the rest of the community.

"The scale of the problem should not be forgotten.

- At birth, Aboriginal Australians have a life expectancy 15 to 20 years less than other Australians. Their life expectancy is lower than for most countries of the world with few exceptions;
- For all causes of death combined, there are 3.5 to four times more deaths than expected among non-Aboriginal Australians;
- Aboriginal people are two to three times more likely to be hospitalised; and
- In the past 10 years, there has been little improvement in the mortality of Aboriginal Australians.

Dr Brand said that the AMA recognised that progress was being made and singled out the Federal Health Minister, Dr Wooldridge, as having a sound understanding and a personal commitment to the health of Aboriginal Australians. "But having committed individuals is one thing; having committed parties and governments commit adequate funding is another," Dr Brand said.

umboona Kidney Project, Flinders Medical Centre

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turned up at the health clinic with his dog. He wanted the doctor to check his dog's kidneys. The nurse wouldn't let the dog into the clinic, but Dr Fred came outside and put his stethoscope onto the dog. The dog was so surprised, it ran across to the nearest post, cocked its leg and did a kumbu sample on the spot!

by Mark Shephard, Medical Scientist Renal Unit and Project Manager Umoona Kidney Project, Flinders Medical Centre


Footnote: This article has been published with the permission of the Director of the Umoona Tjutagku Health Service, Janice Braun.

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