

Indigenous Australians confused and frustrated by kidney disease

Indigenous Australians with kidney disease are confused, frustrated and feel poorly informed about their illness.

A new study by Indigenous health and kidney disease researchers at The George Institute at the University of Sydney and Menzies School of Health Research has found that Indigenous Australians feel inadequately informed and are considerably more uncertain about the cause of their illness compared to non-Indigenous patients with kidney disease.

Researchers conducted interviews with 146 Indigenous and 95 non-Indigenous patients with serious, or end-stage, kidney disease across Australia. Results of the large qualitative study were recently published in *The Medical Journal of Australia*.

"We found the way Indigenous patients understood their disease was markedly different from the non-Indigenous group," said Professor Alan Cass, Director of the Renal Division at The



George Institute and Professor of Indigenous Health and Co-Director of the Poche Centre for Indigenous Health at the University of Sydney.

"These real-life accounts provide insight into how patients engage with treatment. It is clear that Indigenous kidney patients are uncertain about what has caused their condition. Many Indigenous patients feel excluded from information and disempowered, suggesting potent reasons for apparent difficulties adhering to treatment."

Severe or end-stage chronic kidney disease, which requires ongoing dialysis or a kidney transplant to keep a person alive, is up to 30 times more common among Indigenous Australians compared to non-Indigenous Australians. This disproportionate share of kidney disease has placed considerable demands on Indigenous families and communities, including the need to attend dialysis usually three times per week, to take multiple medications and follow strict dietary restrictions. These demands are compounded by poor levels of access to kidney transplantation.

Many Indigenous patients expressed a desire for more information about their kidney disease. However, researchers also identified mistrust in health professionals, which they linked to a sense for many Indigenous Australians of being 'out-of-the-loop' and poorly educated about the cause of their illness.

"They just say 'end-stage', that's all I was told." (Indigenous patient, 3-5 years on haemodialysis)

"I don't know still to this day. I'm trying to find out. I wanna find out. I wanna know why it's stopped, what is the major cause of it, what made 'em stop. That's something I'm in the dark about. So I don't know much about it. They don't give me full explanation about certain things." (Indigenous patient, haemodialysis for 1-2 years)

The varying causes of kidney disease are complex, and present significant challenges when communicating with patients. This is intensified in cross-cultural settings, aggravated by language barriers and different views on health and illness.

The quality of the relationship between patient and health professional is vital. Ambivalence in the health care relationship and poor understanding of their condition can clearly weaken patients' confidence and ability to engage with recommended treatment. "Providing basic information is not enough. More effective communication and education is crucial," added Professor Cass.

For more information regarding the Indigenous health research program at The George Institute, visit www.thegeorgeinstitute.org.

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Limited access to cardiovascular treatments in the world's largest populations is causing increasing inequity between rich and poor

A cardiovascular disease based epidemic is gaining pace among many low- and middle-income countries (LMICs), exemplified at its worst in the world's largest populated countries – China and India. Preventive cardiovascular treatments that are extensively available in high-income countries are not yet widely accessed in LMICs, contributing to an escalating inequality in health status between rich and poor. Cardiovascular disease was the leading cause of death globally in 2005 with more than 80% of these deaths occurring in LMICs. In China, stroke, chronic obstructive airways diseases, cancer and heart disease are the four highest contributors to the country's total disease burden. Almost half of these are due to cardiovascular disease.

Cardiovascular disease risk factors such as obesity, high blood pressure, tobacco smoking and diabetes, are on the increase in LMICs. China's obesity rate, for example, has increased fourfold over the past two decades. In addition to the disease burden, there is a large economic burden from loss of family income and loss of long-term productive working years because people of working age in LMICs are most disease-prone. India, as an example, has twice the mortality rate from cardiovascular-related deaths among people of working age between 39 and 59 years, compared to the USA.

Author of a report on the issue, Dr Rohina Joshi, said, "Even with China's booming economy, the costs associated with the cardiovascular disease burden are unsustainable. China's poor now has less access to healthcare due to higher costs and lower levels of both insurance cover and public funding. Most patients in low- and middle-income countries have a choice between foregoing expensive treatment and facing financial ruin. There is no health system in place to deliver the affordable drugs that can treat and prevent the disease burden for those in need."



Little change has occurred since the 1978 Alma-Ata Declaration defining primary healthcare needs for LMICs and particularly deprived populations to ensure delivery of preventive interventions and early treatment of overt illnesses. Most LMICs have not invested in the declaration's recommended healthcare system and remain reliant on mostly hospital-based care and treatment. The primary healthcare facilities which were designed for infectious disease control and childbirth have not evolved with the changing pattern of disease burden in these countries, and they do not have the facilities to prevent and manage non-communicable disease such as cardiovascular disease.

The healthcare workers are based in the hospitals where they both prescribe and dispense treatments – their main source of income. "Treatment choices become more about the price of the treatment and the amount of income to be paid to the health worker rather than the effectiveness of the treatment for the patient's illness. Over time, this has corroded people's confidence in the system. Although China's health reform is working on Urban Community Health Services and a new Rural Cooperative Medical System, an ideal system

that delivers safe, effective and a low-cost focus on prevention and treatments, in both urban and rural settings, remains far from being seen. There is so much to change before this can occur and there can be delivery of reliable, cost-effective primary cardiovascular healthcare in China", adds Professor Yangfeng Wu, Director of The George Institute, China and The Center for Evidence Based Medicine at Peking University Health Science Center, and a co-author of the paper.

Reductions in the world's cardiovascular disease burden and a more equitable health status between rich and poor will come only through the establishment of primary healthcare systems in LMICs that reliably deliver available, cost-effective therapy to those most in need. "China and many other LMICs require immediate national policy and institutional changes to have the long-term care provided for the control of cardiovascular disease. Researchers at The George Institute are well aware of the enormous difficulty in tackling the issue because they feel their previous efforts to call for this change have not been heard by the key players who determine priorities for international health investment." said Dr Joshi.

New research at The George

The George Institute has been awarded funding by Australia's National Health and Medical Research Council (NHMRC) for a major program to combat heart attack and stroke in Australia. The council also awarded funding to several key research projects - including funding for work on kidney disease, child road injury and back pain treatments.

Combating cardiovascular disease

Cardiovascular diseases such as stroke and heart attack are the leading causes of death and disease in Australia and the world. While there are many established treatment and prevention strategies, there remains great potential for further advances to avoid large numbers of death and disabling outcomes from these conditions. The Institute has been awarded a \$12 million NHMRC Program Grant which will generate evidence for new strategies to combat cardiovascular diseases.

The overall aim of this program is to inform and influence health care providers and policy-makers in their decisions about optimal strategies for the prevention and treatment of cardiovascular diseases. The program will address a broad range of key management issues from risk assessment through service delivery.

The program will see the group playing a major role in the cardiovascular component of the next cycle of the Global Burden of Disease (GBD) project with the World Health Organization, which provides a comprehensive description of the burden of diseases and the risk factors that cause them. The program will also include a number of clinical trials and meta-analyses to identify new treatment strategies. The team will also look to specifically assess the evidence-treatment gap. The research will help guide new treatment and prevention strategies for millions in Australia and hundreds of millions worldwide.

Treatment for kidney disease

The Institute will receive over \$1.2 million for a trial to test the outcomes of increasing the duration of dialysis treatments for people with kidney disease. The trial aims to assess whether increased duration of dialysis improves life expectancy and quality of life for affected patients.

Child road injury research

Despite overwhelming evidence that child restraints dramatically reduce the risk of death and injury, there are currently a large number of children globally who either do not use appropriate child restraints, or misuse them, contributing to the overwhelming burden of road traffic injury in children. The Institute received a NHMRC project grant to support a project that will assess the effectiveness of feasible, evidence-based interventions aimed at increased, correct use of appropriate restraints.

Improving long-term movement and preventing falls after hip fracture

Up to 20,000 older Australians suffer hip fractures each year. Many people do not fully recover. The Institute has been awarded funding to trial a self-management training program which incorporates individualised exercise prescription. The Institute will conduct a randomised controlled trial to test the effects of this program on disability, falls and hospital re-admissions.

The first placebo-controlled trial of paracetamol for back pain

Each year in Australia over \$1 billion is spent on treatments for low back pain. Yet, despite this expenditure, symptoms persist in about 10% of patients. An important approach to solving this problem is to evaluate back pain treatments that are readily available, safe, cheap and effective. Previous work by Institute researchers suggests that regular paracetamol may be such a treatment.

A promising new treatment for chronic whiplash

Following a whiplash injury, about one third of people develop persisting pain and disability. In a series of pilot trials, Institute researchers have developed a new physiotherapy treatment for chronic whiplash. Initial results are very promising and the Institute will now definitively establish the effectiveness of this new treatment in a large clinical trial.

Investigating the causes of debilitating muscle contractures

Muscle contracture, or abnormal stiffening of muscles, can be very disabling. The mechanisms of muscle contracture are poorly understood. This project will gain an understanding of the mechanical causes of contractures of calf muscles in people with stroke, spinal cord injury and multiple sclerosis.

Iron is the key to reducing infant mortality in China

In China, the most populated developing country in the world, neonatal mortality accounts for more than 50% of the deaths of children under five. Children with low birth weight are at a higher risk of mortality, and one of the major causes of low birth weight in developing countries is the poor nutritional status of the mother before and during pregnancy.

A team of investigators involved in a new study in China have revealed the significant impact of iron supplements during pregnancy on preventing deaths in infants under four weeks of age.

“Our research demonstrates that nutrient supplements for pregnant women in developing countries need to have an adequate amount of iron to prevent premature births and reduce infant mortality,” said Principal Investigator, Professor Hong Yan, from Xi’an Jiaotong University College of Medicine.

The four-year study took place in two poor rural counties in northwest China and assessed the impact of taking iron/folic acid and multiple micronutrient supplements during pregnancy, compared with folic acid alone.

While the World Health Organization (WHO) and the United Nations Children’s Fund (UNICEF) have proposed the use of multiple micronutrient supplements during pregnancy, this study found that although multiple micronutrients did improve birth weight more than iron/folic acid, this greater increase in birth weight did not translate into reductions in neonatal mortality (infant deaths in the first month following birth).



“After comparing our results with other studies in Indonesia, India, the United States, and Bangladesh, it appeared the reduction in neonatal mortality was related to the increased duration of pregnancy from the iron in the supplements,” said Associate Professor Michael Dibley, School of Public Health and The George Institute for International Health at the University of Sydney.

“This research will provide vital evidence to the Ministry of Health to assist in formulating China’s public health policy on nutrient supplementation in pregnancy, which will hopefully result in a significant reduction in the number of infant deaths,” said Professor Lingzhi Kong, Deputy Director of Disease Control, Ministry of Health, China.

Kidney dysfunction markers a clue to coronary heart disease

The relationship between indicators of kidney dysfunction and coronary heart disease has been clearly established for the first time, suggesting that kidney disease markers should be incorporated into the assessment of an individual's cardiovascular risk.

Proteinuria and albuminuria are the presence of proteins in the urine that may be a signal of damage to, or disease of, the kidneys. One in 20 adults have such markers, and although they have previously been reported to be associated with coronary heart disease, the consistency and strength of the relationship between the two was not clearly defined.

In a new systematic review and meta-analysis of previously published cohort studies, George Institute researchers have shown a strong and continuous association between proteinuria and subsequent risk of coronary heart disease.



The findings of the new analysis suggest that proteinuria should be incorporated into individual cardiovascular risk assessments, say researchers.

Staff Profile



DR VLADO PERKOVIC

Co-Director, Renal Division and Scientific Director, George Clinical
MBBS, PhD

Vlado undertook training at the University of Melbourne and the Royal Melbourne Hospital, where he undertook PhD studies based in the Department of Nephrology.

Initially planning a clinical career, Vlado attended a meeting of the American Society of Nephrology in 2002, where "The meeting showed me what was

possible with well designed research. And so I set out on a career in researching kidney disease."

"My research focus is to successfully identify treatments that help improve lives for people with kidney disease, and then to see these treatments widely implemented. Cardiovascular disease is a big threat to people with kidney disease, and we are just beginning to understand how important it is, and how it can be prevented in these people. It is very exciting to be part of this process."

"I'm interested in research that can reduce the prevalence of kidney disease, and the impact that it has on patients. Kidney disease is common and treatable if identified early. Even very advanced disease can be effectively treated with dialysis or transplantation," says Vlado.

The ability to make a difference to people's lives was a major attraction for Vlado and continues to inspire him, "I regularly see people who are terribly sick with kidney failure, recover to a normal or near normal lifestyle with appropriate treatment – which is a real buzz."

As Co-Director of the Renal Division, Vlado is currently

working on ACTIVE Dialysis, which will be the largest trial of dialysis duration once completed. "This trial promises to have a major impact on dialysis practice around the world. We are at an exciting stage within the Division, with a large number of new projects underway and in development. Watch this space!"

Vlado is also the primary scientific contact for George Clinical, where he coordinates the scientific aspects of commercial studies and proposals.

"What's great about working at The George Institute is the ability to make a difference, and have a broader impact on medical practice. Many institutions do research, but I think The George Institute is unique in terms of its broader global impact in the areas that we work."

Outside of work? "The hardest and most enjoyable thing that I do outside of work is try to keep my three sons from being completely out of control! Adam (10), Gabriel (8) and Evan (5) are full of life but great fun!"

George Institute director awarded 2008 Young Tall Poppy of Science

Associate Professor Rebecca Ivers has been recognised as a 2008 NSW Young Tall Poppy, for excellence in research achievements and passion for communicating science.

Acknowledged for her work conducting much-needed research in road safety, Rebecca's extensive achievements in injury prevention were highlighted in an awards ceremony presented by the Governor of NSW and the NSW Minister for Science and Medical Research.

Director of the Injury Division at The George Institute, and Associate Professor at the University of Sydney, Rebecca's research contributes to prevention of road injury in both Australia and developing country settings in the Asia-Pacific region. "There is an important need for high-quality research focusing on prevention of road injury in Australia and worldwide. My research program aims to better understand how to save lives and prevent injury in Australia, as injury is the leading cause of death for young



Associate Professor Rebecca Ivers

Australians. I also investigate ways to translate effective road safety programs to developing country settings," said Dr Ivers.

Understanding that high-quality research should inform road safety policy, Rebecca has worked extensively with Government and key stakeholders.

Instead of winning prize money, the young scientists win the opportunity to take their research to school students around NSW, ACT and across Australia as part of the Tall Poppy Campaign to inspire a new generation to get passionate about science.

"The Young Tall Poppy Science Awards recognise scientific achievers who are in the early stage of their careers and already making discoveries," says Australian Institute of Policy and Science Executive Director, Elektra Spathopoulos. "These award winners represent the future of great science in Australia; they are not only the brightest young people addressing the crucial issues facing our society, they are also the best people for the job of inspiring the next generation in science."

"They will demystify science and demonstrate to the next generation that science careers in Australia are fun and rewarding, and can make a real contribution to the health, productivity, and sustainability of our society," adds Spathopoulos.

Research designed to help young drivers to be safer on our roads: DRIVE

- Largest study of young drivers ever undertaken
- Will provide insight into why young drivers are so highly represented in crash data
- Will investigate risky driving behaviour, mental health, sleep habits, education and training

Road safety researchers at The George Institute will release results of the largest study of young drivers in 2009.

Over 20,000 young drivers took part in the DRIVE study, all provisional drivers holding NSW red 'P1' plates and aged 17-24 years. The study will demonstrate the importance of potential determinants of motor vehicle-related crashes and injuries among young drivers, including road risk perceptions, risky driving behaviours, pre-licensing driving experience, training and education, mental health, and sleep habits.

Understanding young driver behaviour will help inform road safety policy and young driver education right across Australia.



World report on child injury prevention

Each day over 2,200 children and adolescents die from a preventable injury. The new World report on child injury prevention provides the first comprehensive global assessment of childhood unintentional injuries and prescribes measures to prevent them. It concludes that if proven prevention measures were adopted everywhere, at least 1,000 children's lives could be saved every day.

"Child injuries are an important public health and development issue. In addition to the 830,000 deaths every year, millions of children suffer non-fatal injuries that often require long-term hospitalisation and rehabilitation," said WHO Director-General, Dr Margaret Chan. "The costs of such treatment can throw an entire family into poverty. Children in poorer families and communities are at increased risk of injury because they are less likely to benefit from prevention programmes and high-quality health services."

"This report is the result of a collaboration of more than 180 experts from all regions of the world," said UNICEF Executive Director, Ann M. Veneman. "It shows that unintentional injuries are the leading cause of childhood death after the age of nine years and that 95% of these child injuries occur in developing countries. More must be done to prevent such harm to children."

The report finds that the top five causes of injury deaths are:

Road crashes: They kill 260,000 children a year and injure about 10 million. They are the leading cause of death among 10-19 year olds and a leading cause of child disability.

Drowning: It kills more than 175,000 children a year. Every year, up to 3 million children survive a drowning incident. Due to brain damage in some survivors, non-fatal drowning has the highest average lifetime health and economic impact of any injury type.

Burns: Fire-related burns kill nearly 96,000 children a year and the death rate is eleven times higher in low- and middle-income countries than in high-income countries.

Falls: Nearly 47,000 children fall to their deaths every year, but hundreds of thousands more sustain less serious injuries from a fall.

Poisoning: More than 45,000 children die each year from unintended poisoning.

The report outlines the impact that proven prevention measures can have. Professor Stevenson says "Policy makers must look to the best available evidence on these issues. This new report clearly outlines the best methods to address child injury."

The report can be found at www.who.int.

Health Economics Collaboration Workshop

Economics of prevention: Developing a framework for policy analysis

Investing more in health promotion, prevention and early intervention is on the policy agenda of State and Federal Governments in Australia. There is a wide range of options for investment ranging from increasing expenditure on new pharmaceutical therapies to health promotion strategies aimed at reducing childhood obesity. This workshop is to discuss an economic framework to decide on the best way of allocating more resources to prevention and promotion.

INTERNATIONAL SPEAKERS:

David Meltzer, University of Chicago

Louise Russell, Rutgers University

AUSTRALIAN SPEAKERS:

Philip Clarke, University of Sydney

Bob Gregory, Australian National University

Deborah Schofield, University of Sydney

Leonie Segal, University of South Australia

LOCATION: Sydney University Village, University of Sydney

DATE: 13 March 2009

TIME: 9:00 am – 5:00 pm

ENQUIRIES: heconomics@med.usyd.edu.au

Course fees and further details at: <http://www.health.usyd.edu.au/heconomics/activities/shortcourses/>

Contributing author, Professor Mark Stevenson, Senior Director at The George Institute says, "The George Institute is working to reduce the impact of road injury, both in Australia and across the world. Road traffic crashes are a leading cause of death and serious injury in Australia and other high-income countries. Child restraints are just one pertinent issue to Australia. What's concerning is that there is a high proportion of children who are inappropriately restrained. Misuse of restraints can downgrade the level of protection in a crash, and legislation should encompass increased use of restraints".

A new study at The George Institute will uncover the best methods to increase the use of appropriate restraints and decrease misuse of child restraints in pre-school aged children in cars.

While the new World Report highlights that many high-income countries have been able to reduce their child injury deaths by up to 50% over the past 30 years, the issue remains a problem for them, with unintentional injuries accounting for 40% of all child deaths in such countries.

Back pain still an issue for over five million: are we treating it right?



Low back pain is the most prevalent and costly musculoskeletal condition in Australia, estimated to cost up to \$1 billion per annum with indirect costs exceeding \$8 billion. It is also the most common health condition causing older Australians to be absent from the labour force.

According to author of a new study published in *Spine*, Professor Chris Maher, Director of Musculoskeletal Division at The George Institute, "After an episode of back pain resolves, one in four people will experience a recurrence within one year. This explains why around 25% of the Australian population suffers from back pain at any one time."

Professor Maher believes patients and clinicians need to shift their focus to prevention. "We tend to treat the pain when it's there, but when you recover, patients rarely take steps to prevent the problem from returning. People understand the message about lifting correctly but heavy lifting is only one of the risk factors for developing back pain. What many people do not understand is that some of the risk factors for back pain are also the risk factors for other chronic diseases like heart disease. My advice is that people should take a similar approach to

back health, as they do for heart health – eating right, exercise and a healthy lifestyle is definitely good for your heart, and also your spine," he added.

"Good, previous research has shown participation in an exercise program after the original episode of low back pain is highly effective in preventing recurrence. Those in the exercise group had half the rate of recurrence of the control group. Other studies have indicated that strengthening muscles and developing fitness show some benefit in avoiding recurring back pain. Mental stress also increases the risk of back pain so including stress management in a health promotion approach would be a sensible way to reduce your chances of back pain. Just paying attention to lifting correctly is probably not enough, a holistic approach is really best."

Researchers reviewed patients who had recovered from their initial back pain within six weeks. Patients saw a range of treatments from general practitioners, physiotherapists and chiropractors in Australia. 353 patients were followed over one year and contacted at 6 weeks, three months and 12 months.



THE GEORGE INSTITUTE
for International Health

Postal Address

PO Box M201, Missenden Road, NSW 2050 AUSTRALIA

Hospital

Level 10, King George V Building
Royal Prince Alfred Hospital
Missenden Road, Camperdown Sydney NSW
AUSTRALIA

Telephone +61 2 9993 4500 Facsimile +61 2 9993 4501
info@george.org.au www.thegeorgeinstitute.org

City

Level 7, 341 George Street
Sydney NSW 2000
AUSTRALIA

Telephone +61 2 9657 0300 Facsimile +61 2 9657 0301

China

Room 1302, Tower B, Horizon Tower
No. 6 Zhichun Road, Haidian District
Beijing 100088
PR CHINA

India

Plot No. 839C
Road No. 44 Jubilee Hills, Hyderabad
INDIA

United Kingdom

London International Development Centre (LIDC)
36 Gordon Square, London WC1H 0PD
UNITED KINGDOM

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