

# Indigenous Australian patients confused and frustrated by kidney disease

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New Australian research has shown that Indigenous Australians with kidney disease are confused, frustrated and feel poorly informed about their illness.

The study reveals Indigenous Australian's feel inadequately informed and are considerably more uncertain about the cause of their illness compared to non-Indigenous patients with kidney disease. The results of the large qualitative study are published in the *Medical Journal of Australia*.

Researchers from The George Institute for International Health and Menzies School of Health Research conducted interviews with 146 Indigenous and 95 non-Indigenous patients with serious, or end-stage, kidney disease across 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.

"These real-life experiences 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 necessitates ongoing

dialysis or a kidney transplant to keep a person alive, is up to thirty 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.

The study results showed that 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 hemodialysis]

"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, hemodialysis for 1-2years]

The authors noted 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 Dr Cass.

In a separate editorial published today in the *Canadian Medical Association Journal (CMAJ)*, Professor Cass and colleagues highlight barriers to access to necessary healthcare which can arise from the patient-provider interaction, from how health services are provided and health systems organised. These barriers contribute significantly to the health gaps between Indigenous and non-Indigenous people.

"We need to understand what is causing these inequities and to take a collaborative approach to healthcare reform so that Indigenous people can access the same level of care and achieve similar health outcomes to other Australians," Professor Cass added.

Source: Research Australia

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