

# 'Institutionalised racism' reason for fewer Indigenous kidney transplants

Kidney specialist Paul Lawton says Indigenous 'compliance' challenges misunderstood so patients thought high-risk and less likely to go on waiting list



Theatre staff prepare surgical equipment for a kidney transplant operation. Photograph: Frances Roberts/Alamy

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Institutionalised discrimination against [Aboriginal and Torres Strait Islander Australians](#) may be behind a widening gap between Indigenous and non-Indigenous patients receiving kidney transplants, a kidney specialist and researcher has claimed.

Indigenous patients are much less likely to be put on the waiting list for a kidney than a non-Indigenous patient, Dr Paul Lawton, a kidney specialist and researcher with the Menzies school of health research told Guardian Australia.

This was likely because doctors misunderstood the challenges faced by an Indigenous patient and made an assessment of “non-compliance” with current or future treatment.

Compliance was a concern rated in a survey of nephrologists as second only to age when considering offering a transplant, and Indigenous patients are more frequently identified as high-risk patients.

“One of the problems is systematic bias, which you can also call racism at an institutionalised level,” Lawton said after appearing on a panel at the annual [Garma festival](#).

“There’s no standardised way that kidney specialists decide for any Australian who is suitable and who is not,” he said.

“What that means is people who are similar to kidney specialists – older, middle-aged, white men – are more likely to get a kidney transplant than middle-aged white women, and white people are much more likely to get a kidney transplant than an Indigenous Australian.”

[Indigenous Australians](#) suffer kidney disease at rates up to 50 times that of non-Indigenous people.

Despite common misconceptions that the high rate is due to alcohol abuse, it is largely caused by factors associated with socioeconomic disadvantage, such as low birthweight and poor childhood nutrition which put people “behind the eight ball” early in life, said Lawton.

The number of people reaching end-stage kidney disease and requiring dialysis treatment is growing, and is particularly prevalent in remote Indigenous communities.

Chronic kidney disease contributes to 50% of all Northern Territory hospitalisations, according to an Arnhem Land clinic, Miwatj [Health](#). Large numbers of Aboriginal patients are forced to relocate to town centres from remote communities for dialysis.

A kidney transplant is the alternative to the thrice-weekly four-hour treatments, but the chances of an Indigenous person compared with a non-Indigenous person in similar circumstances getting a transplant have worsened in recent decades.

In the past 15 years, with other factors accounted for, the gap between Indigenous and non-Indigenous dialysis patients’ survival had narrowed and closed, but the gap in chances for kidney transplant has widened.

Living in remote or regional areas increased the chance of a transplant for non-Indigenous people, but decreased it for Indigenous. This suggested the “tyranny of distance” was surmountable, but other barriers existed for Indigenous patients, one paper said.

Multiple studies have pointed to the disparity, with no clear explanation beyond serious concerns raised around preconceived notions of non-compliance based on a patient being Indigenous.

“The way in which non-compliance and social and cultural circumstances were conflated in the nephrologists’ accounts revealed a common pattern of thinking whereby individuals would be pre-judged as high risk, with accordingly reduced chances of referral,” read one research paper for the International Journal for Equity in Health, co-written by Prof Alan Cass, a leading kidney specialist.

Cass, who is also president of the Australian and New Zealand Society of Nephrology, said compliance and adherence assessment “is not always a science”.

“There is a need to go deeper to understand the factors that might lead to a person not attending dialysis regularly from a remote community,” Cass said.

“It might be because they have to go back to the community for critically important cultural needs, or it might be women – the majority of patients are women – providing care for families, extended families and having a multitude of roles which might need to be placed before management of their health.

“Unless we understand that, it is possible we label people as non-compliant or non-adherent and decide they’re not good transplant candidates, and that is a concern.”

A cross-cultural resources project, of which Cass is a team member, seeks to create tools to train and educate health workers and patients about the issues and requirements associated with treatment of kidney disease among Indigenous Australians.

Recordings of doctor-patient interaction found “pervasive miscommunication”, Cass said.

“It was around critical issues of health illness and treatment patients were receiving that would impact directly on patient outcomes, and it was often unrecognised by both patients, their families and practitioners.”

An impact study of 150 Indigenous patients reinforced frustrations around poor communication which then affected their engagement with care and making informed decisions on treatment.

At the end of the project Cass hoped to have definitive resources for doctors to better understand the issues faced by Indigenous patients, improve communication so as not to wrongly attribute non-compliance, and educate Indigenous communities on preventive health and how to work with the health system and better present as suitable transplant candidates.

The federal and Northern Territory governments recently [increased funding to dialysis services](#) and supportive accommodation, in a move welcomed by Lawton. However, “the time has passed” for a dialysis-only focus.

To stem the rising number of current and future dialysis patients, a well documented strain on the Australian health system, he called for a multi-pronged, albeit expensive, approach, including a major focus on preventive health.