

Kidney Outcomes for First Nations Children



Rowena Lalji^{1,2,3}, Victoria Sinka^{4,5} and Jonathan C. Craig⁶

¹Centre for Kidney Disease Research, University of Queensland, Brisbane, Australia; ²Department of Nephrology, Queensland Children’s Hospital, Brisbane, Australia; ³Metro South and Integrated Nephrology and Transplant Services (MINTS), Princess Alexandra Hospital, Brisbane, Australia; ⁴Sydney School of Public Health, The University of Sydney, Sydney, NSW, Australia; ⁵Centre for Kidney Research, The Children’s Hospital at Westmead, Westmead, NSW, Australia; and ⁶College of Medicine and Public Health, Flinders University, Adelaide, Australia

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Health care is widely endorsed as a basic human right; however, the systems that provide it continue to be plagued with inequities related to sex, race, and socioeconomic status. 2021 is the 50-year anniversary of Julian Tudor Hart’s proposal that those most likely to require health care are the least likely to receive it—the “inverse care law.”¹ Sadly, this seems just as apt now as it was in 1971. Furthermore, there is a growing awareness that the social determinants of health (separate from biological factors) play a significant role in chronic disease outcomes for children and adults, particularly within socially disadvantaged families and minority communities.² More important, these determinants operate at multiple, dynamic, and interactive levels throughout the life course of the individuals and at different points of the disease process and may lead to

significant health decrements over time.²

In Australia, the First Nations peoples, the Aboriginal and/or Torres Strait Islander peoples (hereafter in this article referred to respectfully as Indigenous³) have unique traditions of community, connection with land, kinship, and ways of knowing and being for 60,000 years or more. Colonization, White privilege, racism, and European communicable diseases such as measles and smallpox, and noncommunicable diseases such as diabetes and chronic kidney disease (CKD) have wreaked havoc.⁴ The health of First Nations people in Australia (like those in New Zealand, Canada, and the United States) are unfortunate but powerful exemplars of the truth of the socioeconomic determinants of health and the inverse care law.

Within Australia, there is a known marked and persistent disparity in the incidence of kidney failure (and associated resultant complications) in Indigenous people—up to 15 times higher for adults aged 25 to 64 years and up to 20 times for Indigenous patients living in remote areas.⁵ Kidney failure is

one of the leading causes of the 10-year life expectancy disparity between Indigenous and non-Indigenous men and women.⁵ Once kidney failure is established, transplantation (compared with dialysis) confers the greatest survival and quality-of-life advantage, particularly for younger patients. Critically, for Indigenous people living in remote locations, transplantation allows them to remain with their community. Tragically, there currently remains stark disparities for Indigenous adults in all aspects of transplantation, including access to transplantation and poorer graft outcomes.^{5,6} In part, this was because of an eligibility criterion for transplantation that required a predicted 5-year graft survival probability of 80% or more.⁵ Although no longer an “absolute” requirement, candidates must still demonstrate a high likelihood of benefit from transplant. Given the challenges Indigenous patients face both pre- and posttransplant, these policies (past and present) could be interpreted as discriminatory against Indigenous patients, as a mechanism to promote efficient use of scarce organs, or both.

To date, there has been sparse information on the specific burden of kidney disease in Indigenous children and young adults and their access to kidney transplantation. In this issue of *Kidney International Reports*, Chaturvedi *et al.* have examined data from the Australian and New Zealand Dialysis and Transplantation registry (1963–2017) as well as population data from the Australian Bureau of Statistics (1997–2017) to review the incidence, prevalence, etiology, and kidney replacement therapy (KRT) modality access (i.e., dialysis or transplantation) for Indigenous children and young adult patients who

Correspondence: Dr. Rowena Lalji, Queensland Children’s Hospital, P.O. Box 3474, South Brisbane, Queensland 4101 Australia. E-mail: rowena.lalji@health.qld.gov.au

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commenced KRT at or before 24 years of age.⁷ One hundred seventy-eight patients (4.9%) identified as Indigenous. Reflecting the trend seen in adult kidney patients, children and young adults within the Indigenous group had significantly more comorbidities (type 2 diabetes, coronary artery disease, and chronic lung disease), were more likely to live outside of a major city (33.1% regional, 33.1% remote), and were more likely to be of female sex (55.6% vs. 40.2%).^{6,7}

The rates of treated kidney failure in Indigenous children and young adults have risen markedly over time.⁷ In contrast, KRT incidence and prevalence rates have remained relatively stable for the non-Indigenous population for the same period. What accounts for this discrepancy? Mirroring the trend seen in adult Indigenous patients, diabetic nephropathy in children and young adults increased at an exponential rate over the past 30 years (diabetic nephropathy 7.9% vs. 1.1% in non-Indigenous patients), especially in females.^{6,7} This has major implications not only for the health of these individual women but considerable inter-generational and epigenetic consequences for any potential children given what is already known about the risk of type 2 diabetes for the children of mothers' who are diabetic.⁸

This article highlights inequities across all domains of kidney care and access for Indigenous children and young adults. Indigenous patients were most likely to commence haemodialysis (vs. peritoneal dialysis or a preemptive transplant), spend twice as long on dialysis (22.3 vs. 10.6 months), and, if transplanted, were most likely to receive a deceased donor

kidney.⁷ Alarming, almost two-thirds of Indigenous patients transitioned from pediatric to adult care on dialysis (compared with approximately one-quarter for their non-Indigenous counterparts).⁷ With such clear structural and systemic inequities in kidney care and access from childhood, is it any wonder that their eventual adult graft and overall health outcomes are conspicuously worse than their age matched kidney failure peers?⁵

As the authors point out, there is likely to have been under-reporting for kidney failure in Indigenous children, particularly in the earlier decades of ANZ-DATA (likely reflective of historical Australian governmental policies and societal biases). Furthermore, there are no data for children where KRT was either declined by patients (and/or their families) or not offered as treatment by clinicians because ANZ-DATA does not capture CKD data before commencement of KRT. How many Indigenous children and young adults who were eligible for KRT could (and should) have been treated over the decades but have since been forever lost?

It is unsurprising to see such low rates of live donor transplantation for Indigenous children and young adults given the significantly increased background increased lifetime risk in type 2 diabetes and kidney failure for their potential live donor pool (e.g., parents, aunts, uncles).⁵ With no live donor option, Indigenous children must wait for a deceased donor organ. This is fraught with racial inequity and systemic bias given that the donor pool in Australia is predominantly European, therefore unlikely to be a close human leukocyte antigen match. Longer deceased donor waiting times increase the risk of

transitioning to adult care on dialysis. The current Australian deceased donor organ allocation model directly translates to a loss of pediatric priority status, thereby further increasing time to transplantation and patient morbidity and mortality. Clearly, at each step of the kidney care journey from diagnosis to transplantation, Indigenous children and young adults face multiple barriers and prejudices that both perpetuate and exponentiate their poorer kidney outcomes.

A First Nations' data issue within Australia and globally remains the use of inadequate and potentially damaging "data of surveillance."⁴ These data provide a deficit-based narrative of Indigenous health (rather than their strengths and priorities) with an emphasis on blaming, aggregate, decontextualized, and restricted access data.⁴ Pleasingly, both ANZDATA and the Australian Bureau of Statistics have been proactive in culturally sensitive engagement with Indigenous communities to address these structural inequalities in health care data collection and reporting within Australia.

How Kidney Outcomes for Australia's First Nations Children Compare on the Global Stage

Sadly, the disparities in kidney disease burden and inequities in access to kidney care for Indigenous children and young adults in Australia are not dissimilar to that of other First Nations children. Higher rates of kidney disease in First Nations children and young adults have been reported in countries such as New Zealand, Canada, and the United States and have been attributed to several factors, including (but not limited to) an increased rate of glomerulonephritis, the rising prevalence of type

2 diabetes worldwide, and the potential for a familial or genetic predisposition for chronic kidney disease in certain populations.^{9,S1-S3} Furthermore, despite the increased burden of kidney disease in these minority populations, access to every transplantation avenue (preemptive, live donor, deceased donor waiting list) is reduced.^{S3,S4} The disparities in access to transplantation by race is a significant contributor to the increase in both morbidity and mortality risks for First Nations children and young adults.^{S3}

Each First Nations population has a distinct set of cultures, beliefs, and needs—there can be no “one size fits all” approach to this issue. The implementation of national strategies and policies to improve kidney health outcomes by overcoming health barriers and systemic inequities for First Nations peoples requires the direct involvement and consultation with these communities’ key stakeholders and representatives.^{5,S5,S6} This strategy for health improvement is already being implemented through groups such as the CAN-solve CKD network and BRIDGE to transplantation initiative in Canada, as well as the Aboriginal and Torres Strait Islander Renal Health Roadmap and the National Indigenous Kidney Transplantation Taskforce in Australia.^{5,S6,S7} Additionally, the concept of Indigenous Data Sovereignty, governance, and stewardship over Indigenous data could be expanded to other First Nations populations to avoid perpetuation of the presents gaps and failures in current data collection and policy formation for these vulnerable and marginalized groups.⁴

Another suggested strategy is the use of Patient Navigators (PNs)

to improve engagement and foster trust with health services.⁵ PNs have been successfully utilized in adults with chronic diseases and to overcome the social determinants of health many patients (and their families) face when trying to access health care.^{S8} The NAVKIDS study (a national randomized controlled crossover study) is currently underway within 5 pediatric nephrology units within Australia, looking specifically at the use of PN for socioeconomically disadvantaged and rural or remote children with CKD, the results of which are expected to be published by 2023. If successful, this intervention has the potential to be implemented worldwide.

It is tempting to believe we have vanquished systemic racism to history; however, it persists in a more insidious form, as unconscious bias. As a kidney community, we must have the courage both to recognize and overcome these biases. Until our health systems and future health policies are redesigned to counter inequity in health care and remove barriers to access, Indigenous children and young adults in Australia and worldwide will continue to suffer poor kidney outcomes.¹

DISCLOSURES

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SUPPLEMENTARY MATERIAL

[Supplementary File \(PDF\)](#)
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