Breaking Down the Silence: Call for Action to Address Access Disparities to Transplantation in Indigenous Māori Peoples With Kidney Failure

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Māori are the Tangata Whenua, the Indigenous People, of New Zealand. They arrived more than 1,000 years ago, traveling from their Polynesian homeland of Hawaiki. In 2020, New Zealand's Māori ethnic population was estimated to number 850,500 (approximately 16.7% of the national population). Like many Indigenous peoples around the world, Māori face some of the worst health inequalities of any ethnic group.[1] The overall life expectancy at birth is 73.4 years for Māori men and 77.1 years for Māori women, compared with 80.3 and 83.5 years for non-Māori men and women, respectively.[2] Among all chronic illnesses, disparities in incidence, access to care, and health outcomes between Māori and non-Māori peoples are most marked for chronic kidney disease (CKD).[3] The excess risk of CKD and progression to kidney failure with replacement therapy in Māori is at least 3 times the rate observed in age- and sex-matched New Zealand European adults (in 2019, the incidence of kidney failure with replacement therapy in these groups was 256 and 72 per million population, respectively).[4] While the number of prevalent Māori patients with kidney failure continues to rise yearly, Māori receive kidney transplants at only one-fifth the rate of non-Māori populations (3% vs 15%).[4] Pre-emptive transplantation is almost nonexistent among Māori people with kidney failure. In 2016-2021, less than 1% received a pre-emptive kidney transplant.[4] Concerningly, the mortality rates of Māori patients receiving maintenance dialysis while waiting for kidney transplant are 4- to 6-fold higher than non-Māori patients.[4] Such disparities are stark and are driven by many factors that have not yet been fully characterized or understood.

In this issue of *AJKD*, Walker, alongside Māori and non-Māori colleagues,[5] reports a qualitative study of 40 Māori people comprising patients with CKD (n = 28, with 8 having received kidney transplants), caregivers/family members (n = 8), and living kidney donors (actual/potential, n = 4) to explore the values, perspectives, and experiences related to kidney donation and transplantation. Using a standard reporting framework for qualitative research[6] and guided by the Consolidated Criteria for Strengthening Reporting of Health Research Involving Indigenous Peoples (CONSIDER) statement,[7] 5 main themes were identified: actively seeking a kidney transplant, evolving attitudes toward traditional values and practices, confronted by interpersonal and systemic racism, poor information and communication, and challenged by social determinants of health. Several subthemes also evolved from these main themes. In contrast to the stereotypical views of aversion or disinclination to transplantation, Māori peoples with kidney failure considered transplantation as a desirable treatment option and recognized the survival and quality-of-life benefits of transplantation compared to dialysis.[5] Many believed transplantation practices are largely aligned with their traditional cultural beliefs and practices. While there may be unique and important considerations for those contemplating donating a kidney or receiving one, Māori peoples with kidney failure revealed the yearning to achieve optimal health as the motivation behind the acceptance of both deceased and living kidney transplantation.

However, Walker et al[5] report that multiple obstacles persist, and involve a wide spectrum of patient-, system-, and health care–related barriers at the various stages of the pretransplantation process. Māori people's experiences of discriminatory, biased, hurtful attitudes and actions by health care professionals reveal an urgency to deliver health care in Māori-preferred ways. Systemic racism and unconscious bias are some of the root causes for the observed health inequality and inequities. Apart from disease discrimination faced by the participants, key challenges encountered by the Māori peoples during the pretransplant journey include the lack of consideration for traditional and spiritual beliefs in decision-making; the fragmented, ambiguous, and exhausting processes for evaluating candidate suitability, coupled with the difficulties in accessing culturally appropriate, user-friendly educational information; the overwhelming financial stress associated with long-term chronic illnesses; and many other personal competing priorities.

This study is a valuable complement to the inaugural *Guideline for Management of Chronic Kidney Disease in Aboriginal and Torres Strait Islander Peoples and Maori*[8] because optimal health outcomes must be centered on health needs of the local population, and Māori preferences must be considered in standard care. The research from Walker et al is also an important addition to the literature on the disparities in access to quality care among Indigenous Peoples with kidney disease globally. Prior research has focused on other minoritized populations—including Aboriginal and Torres Strait Islander Peoples in Australia; First Nations, Inuit, and Métis people in Canada; and Native Americans in the United States—but for the first time, Māori values and perspectives on the topic of kidney transplantation are heard. Actions are desperately needed to overcome these inequalities. Previous studies have generated the evidence to support government policies to close the gap in Indigenous kidney health.[9] However, the progress in abolishing such disparities is slow and health inequalities continue to worsen among minoritized First Nations peoples. While there has been a growing awareness and recognition among settler-colonialist societies such as Australia, Canada, and the United States on the impact of colonization on health, particularly in terms of chronic diseases such as CKD, health actions that eliminate the inherent discrimination,[10] constant scrutiny, and prejudice experienced by Māori peoples with chronic diseases require bold and courageous patient–health system partnership and implementation.[11] A necessary first step is to address the unconscious bias within health care professionals and systems, particularly those directly involved in the clinical journey of patients with CKD. The preconceived notion that the poorer health states among Māori peoples are "self-inflicted" (a result of obesity or drug and alcohol use) may unjustifiably influence the judgment of clinicians when assessing the medical suitability for kidney transplantation.

The journey to transplantation involves multiple complex steps. A series of intense investigations, education programs, and specialist referrals (often to quaternary transplant centers located in urban settings) are required before acceptance and placement on the transplant waiting list. These exhaustive steps may place significant inconvenience and burden on both patients and their families, delaying waitlisting.[12] Many patients are disheartened and become disengaged from the system during the prolonged and tiresome assessment process. Here, we call for an innovative whole-of-system approach to create a sustainable, culturally appropriate, and patient-centered health care system for the Māori peoples most affected by kidney disease. The key elements should include active and purposeful engagement with patients, families, and their communities. Their views and experiences should also be prioritized and embedded in all policy and practice recommendations, including where social and cultural determinants promote health.

As non-Māori kidney disease researchers dwelling in the settler-colonial society of Australia, we recognize our role as health professionals to support the self-determined advocacy of Māori to achieve equitable health outcomes. We recognize the essential role of policy makers to devote sufficient resources and support (financial, psychosocial, and infrastructural) to ensure that the health needs and uncertainties about living and deceased donor transplantation are appropriately addressed. Finally, a call for action is crucial to reduce the implicit and explicit consequences of social bias in transplantation care. This can only be achieved through a very strong Indigenous health leadership and a concerted effort by transplant health professionals, consumer groups, and governments to enhance the capacity and capability of Māori peoples with CKD to take charge of their lives and strengthen their communities.

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Support: None.

Financial Disclosure: The authors declare that they have no relevant financial interests.

Peer Review: Received February 13, 2022 in response to an invitation from the journal. Accepted February 24, 2022 after editorial review by an Associate Editor and a Deputy Editor.

Publication Information: © 2022 by the National Kidney Foundation, Inc. Published online April 22, 2022 with doi 10.1053/j.ajkd.2022.02.013

References

1. Hobbs M, Ahuriri-Driscoll A, Marek L, Campbell M, Tomintz M, Kingham S. Reducing health inequity for Māori people in New Zealand. *Lancet*. 2019;394(10209):1613-1614.
2. Ministry of Health – Manatū Hauora. NZ health statistics. Accessed February 14, 2022. https://www.health.govt.nz/nz-health-statistics
3. Huria T, Palmer S, Beckert L, Williman J, Pitama S. Inequity in dialysis related practices and outcomes in Aotearoa/New Zealand: a Kaupapa Māori analysis. *Int J Equity Health*. 2018;17(1):27.
4. ANZDATA Registry. *43rd Report, Chapter 9: Kidney Failure in Aotearoa New Zealand.* Australia and New Zealand Dialysis and Transplant Registry. Accessed February 13. 2022. https://www.anzdata.org.au/anzdata/publications/reports/
5. Walker RC, Abel S, Palmer SC, Walker C, Heays N, Tipene-Leach D. Values, perspectives, and experiences of Indigenous Māori regarding kidney transplantation: a qualitative interview study in Aotearoa/New Zealand. *Am J Kidney Dis*. 2022;80(1):20-29.
6. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-357.
7. Huria T, Palmer SC, Pitama S, et al. Consolidated criteria for strengthening reporting of health research involving indigenous peoples: the CONSIDER statement. *BMC Medical Research Methodology*. 2019;19(1):173.

8. CARI Guidelines: Current Guidelines in Development. Accessed February 13, 2022. https://www.cariguidelines.org/projects/current-guidelines/current-guidelines-in-development/
9. Huria T, Pitama SG, Beckert L, et al. Reported sources of health inequities in Indigenous Peoples with chronic kidney disease: a systematic review of quantitative studies. *BMC Public Health*. 2021;21(1):1447.
10. Bourke C, Truong M, Jones Y, Hunyor J, Lawton P. Addressing racism to improve healthcare outcomes for Aboriginal and Torres Strait Islander people: a case study in kidney care. Deeble Insitute for Health Policy Research. 2020. Accessed February 13, 2022. https://apo.org.au/node/303540
11. Hughes JT, Owen KJ, McDonald SP. Shifting power to improve First Nation Peoples' access and outcomes in kidney care. *Kidney Med*. 2021;3(6):881-882.
12. Majoni SW, Dole K, Hughes JT, Pain C. Review of current pathways to wait-listing for kidney transplantation for Aboriginal and Torres Strait Islander peoples with end-stage kidney disease in the Top End of Northern Australia. *Aust Health Rev*. 2021;45(2):185-193.