



“We Need a System that’s Not Designed to Fail Māori”: Experiences of Racism Related to Kidney Transplantation in Aotearoa New Zealand

Rachael C. Walker¹ · Sally Abel² · Suetonia C. Palmer^{3,4} · Curtis Walker⁵ · Nayda Heays⁶ · David Tipene-Leach¹

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Abstract

Background Reported experiences of racism in Aotearoa New Zealand are consistently associated with negative measures of health, self-rated health, life satisfaction, and reduced access to high-quality healthcare with subsequent poor health outcomes. In this paper, we report on perceptions and experiences of prejudice and racism by indigenous Māori with kidney disease and their family members and donors who took part in a wider study about experiences of kidney transplantation.

Methods We conducted semi-structured interviews with 40 Māori between September and December 2020. Participants included those with kidney disease who had considered, were being worked up for, or who had already received a kidney transplant as well as family members and potential or previous donors. We examined the data for experiences of racism using a theoretical framework for racism on three levels: institutionalised racism, personally mediated racism, and internalised racism.

Results We identified subthemes at each level of racism: institutional (excluded and devalued by health system; disease stigmatization; discriminatory body weight criteria, lack of power), personally mediated (experiencing racial profiling; explicit racism), and internalized racism (shame and unworthiness to receive a transplant).

Conclusions The wide-reaching experiences and perceptions of racism described by participants with kidney disease and their families in this research point to an unfair health system and suggest that racism may be contributing to kidney transplantation inequity in Aotearoa New Zealand. Addressing racism at all levels is imperative if we are to address inequitable outcomes for Māori requiring kidney transplantation.

Keywords Equity · Indigenous kidney · Transplant

Background

Chronic kidney disease disproportionately impacts the health and the social and economic well-being of indigenous peoples globally [1, 2]. In Aotearoa New Zealand, indigenous Māori constitute 16.5% of the total population. In 2019, 208 patients identified as Māori commenced treatment for kidney failure, representing 32% of all patients starting kidney replacement therapy. The rate of haemodialysis commencement in non-Māori, non-Pasifika patients was fivefold lower than for Māori [3]. Furthermore, preemptive kidney transplant as *first* treatment for kidney failure occurs fourteen times less frequently among Māori. In 2019, one Māori patient had a preemptive kidney transplant. In the last 5 years, 7 Māori patients have been provided with a preemptive kidney transplant compared with 125 non-Māori, non-Pasifika patients [4]. These outcomes breach the nation’s foundational document, the Treaty of Waitangi,

✉ Rachael C. Walker
rwalker@eit.ac.nz

¹ Eastern Institute of Technology, 501 Gloucester Street, Taradale, Napier 4112, Hawke’s Bay, New Zealand

² Kaupapa Consulting Ltd, Napier 4110, New Zealand

³ Department of Medicine, University of Otago Christchurch, Christchurch 8140, New Zealand

⁴ Department of Nephrology, Canterbury District Health Board, Christchurch, New Zealand

⁵ Department of Medicine, Midcentral District Health Board, Palmerston North 4442, New Zealand

⁶ Hawke’s Bay District Health Board, Hastings, New Zealand

that is acknowledged by New Zealand health authorities as the basis of Māori rights to equitable health outcomes [5].

Reported experiences of racism in Aotearoa New Zealand are consistently associated with negative measures of health, self-rated health and life satisfaction, and reduced access to high-quality healthcare with its subsequent poor health outcomes [6]. Our 2019 systematic review of the experiences and perspectives of indigenous peoples related to kidney transplantation documented prejudice and a lack of cultural competence by health workers, barriers to transplantation in systems that did not support effective and culturally appropriate delivery of information and care, and a subsequent mistrust of clinicians and the health system [7]. Similar studies among minoritized ethnic populations internationally were far more explicit in their reported experiences of racism related to transplantation care [8, 9].

We conducted a qualitative study of Māori patients', donors', and whānau (extended family) experiences and views related to kidney transplantation to better understand the barriers for Māori [10]. Despite not being asked specifically about racism, participants spoke eloquently of their perceptions and experiences of prejudice and racism. In this paper, we report specifically on those findings and discuss them within the context of the link between the experience of racism and inequitable transplant outcomes.

Methods

A preliminary interview guide was developed based on our recent systematic review of indigenous experiences of transplantation [7] and discussion among the research team (S1). We conducted semi-structured interviews with 40 Māori between September and December 2020. Participants included those with kidney disease who had considered, were being worked up for or who had already received a kidney transplant as well as family members and potential or previous donors.

Participants were recruited nationally through patient support and advocacy groups, and one renal service with a high percentage of Māori patients, and through a snowballing technique using word of mouth. Purposive sampling was used aiming to include a diverse range of participants' age, geographical location, and donor/recipient characteristics. Participants represented 18 different tribal boundaries across New Zealand.

Fifty-one people initially enquired about participation or were invited into the study. Eleven were not interviewed (2 due to their own time constraints, 1 declined to discuss the topic, and the remainder were unable to be further contacted). Patient recruitment and interviews occurred between September and December 2020. The study was identified as out of scope for national ethics approval and localities

approval was gained by the Northland District Health Board Ethics Committee (18/06/296) and institutional ethics.

Due to restrictions and safety concerns related to COVID-19, most interviews were conducted over Zoom or by voice call. The interview adhered strictly to Kaupapa Māori principles [11] which had been previously outlined to participants including the option of a Māori interviewer, *karakia* (prayer) to open and end the interview and *whakawhanaungatanga* (the mutual understanding and building of relationships, connections and trust). The interview contained questions which covered the participant's experience of transplantation, including spiritual and cultural considerations, and perceived barriers to transplantation for Indigenous peoples (Item S1). We did not ask specific questions regarding any form of racism. The study is reported according to the Consolidated Criteria for Reporting Qualitative Research (COREQ) [12] and guided by the Consolidated criteria for strengthening reporting of health research involving Indigenous Peoples (CONSIDER) [13].

The interviews were conducted by two of our authors. Most of them were conducted by NH (a Māori nurse). RCW (a non-indigenous researcher and renal nurse practitioner) also conducted some interviews. Some interviews were conducted by both to ensure consistency of interviewing.

Interview length varied from 25 to 120 min. Field notes were taken during each interview. All interviews were recorded and transcribed verbatim. This exploration of the data on racism is a sub-study within a larger study exploring Māori patients' and caregivers' and donors' experiences of transplantation services.

We examined the data for experiences of racism using a theoretical framework for racism on three levels: institutionalized racism, personally mediated racism, and internalised racism [14]. SA and RCW independently coded the transcripts line-by-line. Codes were entered into a table column under provisional headings and compared between the two researchers. Concepts were identified inductively and grouped into similar concepts specific to the three levels of racism. RCW and SA discussed coding differences and agreed on provisional subthemes. This preliminary thematic framework was reviewed by all authors, which included Māori physicians DTL and CW. In subsequent iterations, the coding schema was refined through a series of discussions among the investigator team, and the transcripts were re-coded as necessary following triangulation.

Results

The data were synthesized into subthemes for each level of racism: institutional (excluded and devalued by health system; disease stigmatization; discriminatory body weight criteria, lack of power), personally mediated (experiencing

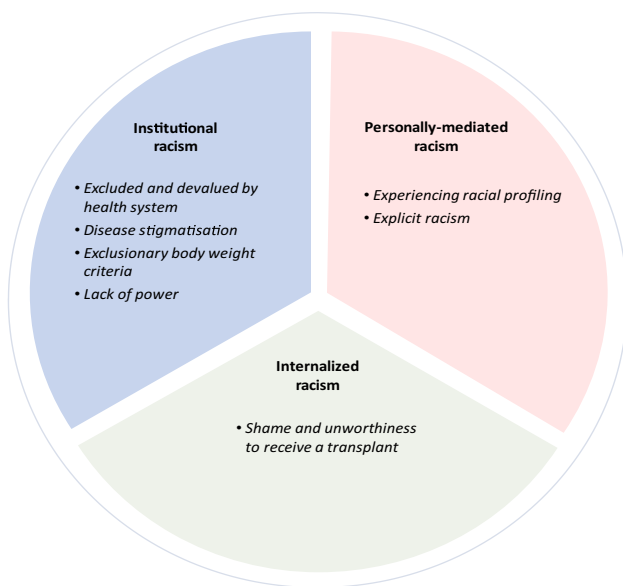


Fig. 1 Thematic schema of experiences of racism related to kidney transplantation in Aotearoa New Zealand

racial profiling; explicit racism), and internalized racism (shame and unworthiness to receive a transplant; loss of confidence in own abilities). All sub-themes pertain to all sub-groups of patients unless indicated otherwise. A summary of subthemes is provided in Fig. 1 and selected quotations to illustrate and support each subtheme are provided in Table 1. Participants also had suggestions for addressing inequitable outcomes in kidney transplant services (Table 2).

Institutional Racism

Institutional racism is defined as differential access to the goods, services, and opportunities of society based on race. It is derived from structural racism that privileges white people across institutions and society and is codified in the policy, practices, and resourcing of health (and other) institutions [15]. Colonization further acts to maintain structural racism and privileges whiteness to normalize racist ideas in media, culture, social systems, and institutions [16].

Excluded and Devalued by Health System

Participants said they felt alienated in the health system that was not designed for indigenous people, leaving them feeling disempowered and disadvantaged. Participants experienced transplant services that did not acknowledge or incorporate Māori values, cultural protocols, and practices, known widely as *tikanga Māori*, causing disconnection and disengagement from staff and clinical processes. They said that the absence of *tikanga Māori* within healthcare aggravated

Table 1 Participant characteristics

Sex	
Female	20 (50%)
Male	20 (50%)
Transplant status	
Recipient	8 (20%)
Patient not listed	10 (25%)
Patient listed	10 (25%)
Family	8 (20%)
Donor	4 (10%)
Age, years	
20–29	1 (2.5%)
30–39	2 (5%)
40–49	11 (27.5%)
50–59	15 (37.5%)
60–70	10 (25%)
> 70	1 (2.5%)
Number living in household	
1–2	
3–4	25 (62.5%)
5–6	10 (25%)
Shared living	4 (10%)
	1 (2.5%)
Employment	
Beneficiary	17 (42.5%)
Full time	9 (22.5%)
Part time	6 (15%)
Retired	7 (17.5%)
Student	1 (2.5%)
Marital status	
Married/de facto	28 (70%)
Single/separated	11 (27.5%)
Widowed	1 (2.5%)
Not listed reason	(N=10)
Weight	5 = (50%)
Medical	3 = (30%)
Age	1 = (10%)
Refused	1 = (10%)
Self-reported cause of kidney disease	
Diabetes	14 (52%)
Hypertension	6 (22%)
Glomerulonephritis	1 (4%)
Other	3 (11%)
Unsure	3 (11%)
Interview	
Face to face	17 (42.5%)
Video	17 (42.5%)
Phone	6 (15%)
Highest qualification	
No formal qualification	9 (22.5%)
School certificate	8 (20%)
Trade certificate or equivalent	9 (22.5%)

Table 1 (continued)

Diploma	3 (7.5%)
Degree	5 (12.5%)
Postgraduate	2 (5%)
Masters	1 (2.5%)
Not answered	3 (7.5%)

previous negative experiences in the health system creating powerlessness and distrust.

Participants described how Māori health workers and non-Māori health workers with cultural competence had or had the potential to restore connection with health services through empathy, emphasizing the importance of the “understanding of Indigenous values and practices in care delivery”(P16) and of “[making] a connection straight away”(P14). Participants wanted a health system designed by Māori, with “more Māori, to get in the positions to change the systemic racism which comes from the top” (P38). They described ways that transplant services could incorporate *tikanga Māori* to improve power, connection, and engagement for Māori, such as the facility to formally acknowledge deceased donor whānau.

Disease Discrimination

Participants discussed the profound lack of awareness of kidney disease and transplantation within Māori communities despite the high prevalence of morbidity. This lack of knowledge was attributed to discriminatory inaction through low levels of government funding for public awareness campaigning compared with other diseases that were more common among non-Māori (mostly European) such as prostate and breast cancer. Participants felt frustrated at societal inaction in the face of overwhelming need as kidney disease grew within the Māori community and questioned whether this discrimination was because kidney disease affected mainly “brown people”(P12).

Exclusionary Body Weight Criteria

Frustration and anger were expressed by some recipients, potential recipients, and donors regarding the body mass index (BMI) criterion for kidney transplantation, which they described as exclusionary, discriminatory, and racist. Many potential recipients spoke about their experiences of being denied transplantation work-up because of their weight and that excessive weight was also a barrier for their potential kidney donors. Participants considered that BMI was used inappropriately, set at a level that excluded Māori from kidney transplantation. “If the [body mass] criteria was more relaxed or flexible depending on the case. I mean you can

imagine if we were all white faces, would that change the criteria?” (P14).

Despite the fact some had lost weight to achieve the criterion, they had experienced “the goal posts changing” (P2) with body mass index targets for transplantation changing during the process as they reached their specified weight. Participants could not understand how they were suitable for some operations and associated anaesthetic but not for kidney transplantation despite the substantial benefits transplantation would provide to them, their whānau, and the health system. They felt that the additional risks of surgery because of their weight should be a consideration, but this did not outweigh the disadvantages of dialysis, including the implications for their clinical and personal well-being. They also expressed frustration that there was a lack of funding for weight loss support including weight loss surgery, when the health, financial, and social costs of dialysis were so high. “So I WAS the perfect candidate. But NO, I didn’t even make it to the interview stage then because of weight” (P12).

Lack of Power

Participants described feeling unacknowledged within the health system, such that their individual and collective concerns were not “heard” (P19) and understood. Over time, many felt isolated and disconnected, “I don’t see anyone on my side” (P2) and became despondent in advocating for themselves, “how do you fight that, when you are down the bottom of the pile” (P12).

They felt that “knowledge is power, and we don’t have knowledge. We can’t advocate for ourselves because we don’t know the words to use, we don’t understand the process and how we can drive it” (P27). They wanted strong advocates to speak up for their rights and demand policy change to fight for equitable outcomes regarding transplantation. One person stated “we need a person in a position that’s got power that can hold them accountable, and a system that’s not designed to fail Māori” (P2).

Personally Mediated Racism

Personally-mediated racism includes prejudice and discrimination, where prejudice means holding differential assumptions about the abilities, motives, and intentions of others according to their race, and discrimination is expressed by differential actions, usually at a personal level, toward those others(14, 15).

Experiencing Racial Profiling

Many participants described feeling racially profiled within the healthcare system and how detrimental this was on their experience and interactions with clinicians. The profiling

Table 2 Selected participant quotations

Institutional racism <i>Excluded and devalued by health system</i>	<p>For mum's tangi (3–4 day funeral), for example, he (brother) missed his bloods... And you know [staff] not really understanding the kaupapa that is at play. That is really annoying for me... I know that a Māori person would understand that and that perspective and that's why it pisses me off (31)</p> <p>I like getting a Māori nurse, the Māori nurse will treat you different from the other nurse, the Māori nurse wouldn't do that to you. We are treated differently. (02)</p> <p>But basically what they're saying in the stats is that Māori are too fat to donate, or uncompliant with their treatment regimens so they can't be a recipient. And that's got to change because it's not that Māori can't do it. You've got to ask why. Maybe it's not a safe space for them to go to the hospital. Māori don't know how to advocate for themselves. They get a feeling that they're getting treated differently (38)</p> <p>I did think before I had a deceased donor I would like to know more about their background you know, so I understood where that person was from. Not that I am going to be picking and choosing of course, but it's about whakapapa (ancestry), and you know just understanding them and where they've come from. (14)</p>
Disease discrimination	<p>You know with prostate cancer, there's lots of awareness and everyone wears blue. Is that 'cause there are a lot of white people dying with that? Lots of white women get breast cancer so we have a pink day and everyone knows about it. Jonah Lomu (Pacifika rugby football star) dies with kidney disease and what do we celebrate, him, him scoring tries. We don't talk about his kidney disease, we don't make a day about kidney disease. That's systemic racism, that's how I view it. It's a brown disease (12)</p> <p>You know heart disease attracts a lot of funding and attention. Is that because it is predominantly a white disease? But you know kidney disease affects mostly Māori, and it gets no attention, so is there a bit of racism there I wonder? (14)</p>
Exclusionary body weight criteria	<p>You know what I honestly believe, they say weight is an obstacle, but I don't believe for one minute that weight is an obstacle. I think it's an excuse... And then they say, 'but you have to handle the anaesthetic', and I say 'I've just been under anaesthetic', and they say 'oh yeah' and they still have another excuse (02)</p> <p>So for Māori donors, I think weight is a big issue. They deny them getting through for that, with no support to lose the weight or deal with the rejection both for donors and people who aren't able to get listed because of their rules. (38)</p> <p>My beautiful cousin in Australia offered and the doctor said 'you're too obese, you're not going to do it.' And she got really down that she couldn't do it. I mean what a knock down! They didn't talk to her about losing weight; just said 'no'. (38)</p>
Lack of power	<p>Māori don't have much chance of doing things or getting things because we aren't pushy enough and we don't have anyone asking the questions for us. And we don't have anyone guiding us from here to here, you know, saying 'you're here now, now you need to go here' (02)]</p> <p>The lack of understanding, lack of education, being too shy to even ask (25)</p> <p>We don't understand what rules you in or out. We don't know the questions to ask when we are told you are off the list and how or whether you can even fight against that. We have to stick to the rules as they are, because we don't know about them. But also it's like, we actually are stuck in the rules, cause if we don't stick to them we might be kicked off (27)</p>
Personally mediated racism <i>Experiencing racial profiling</i>	<p>I found it quite challenging when one of the doctors said to me 'oh yeah you're from XX, so you'll have diabetes.' I don't have diabetes, I've never had diabetes in my life. (05)</p> <p>'Cause before they had asked have we got a house, a healthy house and a bathroom. They assumed 'cause we were Māori we were after money and we weren't. (01)</p> <p>I said can you call my taxi and she said "Sure, Camberley? [low socioeconomic suburb]" and I said, "No, Napier Westshore [higher socioeconomic suburb]." I've never lived there, that's just an assumption based on my skin, and that's the bias. And they are completely unaware of how that makes me feel. (12)</p>
Explicit racism	<p>I felt at times that I've been put in the brownie basket, if you like. And that's come from the staff (16)</p> <p>In the ward where he [partner] was being looked after one of the nurses came and said 'come and meet XX's wife XX. Aren't her grandchildren clean and tidy.' And I thought what the hell's that question! ... And I have never had to face anything like that until I came into contact with the health system. 'Oh xx they're so clean and tidy!' Of course they are! (01)</p> <p>And for my dad to ever pick up that somebody's racist is pretty bloody blatant because honestly he lives in his own little world. He lives in this world where he's just great and thinks everyone loves him. So for him to pick up on it, it's pretty blatant. (38)</p>

Table 2 (continued)

Internalised racism Shame and unworthiness to receive a kidney transplant	When it actually came to transplant, it's not a thing that's spoken of, within the realms of kidney patients. It's not something that we talk about together, if we know it's going to happen then we talk about it, if it's a sure thing, but otherwise we don't talk about it. (16) It's not about shame or blame, it's about improving things. 'Cause a lot of people today you're either diabetic or your kidneys [think] that it's your fault you go there, and because you aren't educated enough or understand what the outcomes could be we fall into that trap, or because they're scared like I was, you're left behind that closed door that people won't open, 'cause they're scared of the outcomes, like I was. (16)
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included clinician assumptions that all Māori had diabetes and the implication that therefore they were to “blame” for their kidney disease and that Māori all lived in areas of high deprivation or could not afford to dress or eat well. Some reported hearing conversations in clinical areas that labelled Māori as “non-compliant, they’re not following the rules, they’re being rude, they’re missing their appointments” (P38).

Many participants became visibly distressed talking about these experiences and “assumptions based on my skin” (P12) and talked about how this profiling impacted on their mental health and well-being. A donor felt a decision to initially refuse her being a donor because of her weight was based on a “racist stereotype of Māori” (P38) and she sought a second opinion which overrode the refusal.

Explicit Racism

Participants identified times when they experienced explicit and direct racism. At times, they felt this stemmed from a lack of cultural competence from staff, but other times, they described being treated as an inferior culture or placed in a “brownie basket” (P16). Some described being “offered less” (P9) resulting in a different level of care or being given inadequate information or “a feeling that they’re getting treated differently” (P38). This included potential kidney donors being told they were obese and declined donation as a future option without discussion about weight loss or targets. Future recipients and donors reported not being told about the transplant process or options, resulting in them having “to go find out myself” (P2).

Internalised Racism

Internalised racism is defined as acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth [14, 15].

Shame and Unworthiness to Receive a Kidney Transplant

For many participants, particularly those who had not yet received a kidney transplant and a few of the recipient patients, the prevailing views of society led them to

internalise the belief that kidney disease was a consequence of their own lifestyle and lack of self-care, often in respect to diabetes, smoking, or “unhealthy” habits. These participants did not identify familial links to such disease. Self-blame occurred despite many knowing they had not received adequate primary care to prevent complications of diabetes or high blood pressure, and therefore had not been provided the knowledge or information to make changes early in their disease trajectory. Shame and disconnection led to feeling undeserving of a kidney transplant. Sometimes, this resulted in being “whakamā” (a concept of shame) (P16) and ashamed to ask questions about the potential for transplantation as they felt “you’re left behind that closed door that people won’t open, ‘cause they’re scared of the outcomes” (P16).

Recommendations from Participants

Participants described a number of recommendations to address the racism and poor service outcomes they had identified within the healthcare system. These ranged from development of national policy to compulsory cultural safety training for staff, to the refinement of exclusion criteria like BMI. These recommendations are presented in Table 3 and are discussed in the context of the literature below.

Discussion

Māori patients, donors, and whānau reported all levels of racism during healthcare for kidney transplantation—institutional racism, personally mediated racism, and internalised racism [14]. Participants with experiences of kidney transplantation demonstrate the need to address the social determinants of health and the social determinants of equity, including racism, through adoption of policies, practices, and values that differentially distribute resources [17].

Many participants felt excluded and devalued by a healthcare system that did not incorporate or recognize their values and practices, resulting in increased alienation and disengagement. Incorporation of *tikanga Māori* and Māori leadership were suggested as structural responses that would improve connection and deliver change. Participants

Table 3 Participant recommendations

Institutional racism	
Government funding and policy change	<ul style="list-style-type: none"> • Appropriate resourcing for kidney disease awareness/media campaigns • Increased resourcing to ensure cost-neutrality or recipients and donors in work-up and post-surgery) • National Kidney Transplant Strategy to streamline services, enable more consistency, and be more conducive to Māori needs
Models of care	<ul style="list-style-type: none"> • Transparent pathways and communication of waiting times, criteria for being removed or reinstated on list • More sensitive and culturally appropriate psychological assessments • Increased counselling/support pre and post donation • Māori guidelines and acknowledgement rituals for whānau • Māori cultural, spiritual support and advocacy • Community and marae-based education programmes or whānau wānanga /experience sharing • Access to knowledgeable support person to translate jargon • Māori advocates at both personal and systemic levels;(Māori buddy to provide support and guidance and help them navigate their way through the transplant process)
Personally mediated racism	
Workforce development	<ul style="list-style-type: none"> • Cultural awareness training of staff • Increased Te reo and tikanga staff training • Increase in Māori staff • Increase in Māori renal service leaders and advisory group members, those in positions to influence decisions and challenge racist policies, practices and behaviours

described the inadequate resourcing and unfamiliarity of kidney disease and ascribed it to the stigma of being prevalent among “brown” families. Personally mediated racism was experienced as racial profiling and explicit forms of racism directed towards patients and their family and led to mistrust of the healthcare system and failures in shared decision-making. Racism was also internalized by participants; they felt unworthy, unconfident, and *whakamā* [shy or ashamed] with a loss of voice and power, and this caused disengagement with transplantation processes. The theme of internalized racism was identified to a lesser narrative than the other two forms of racism. This, however, is to be expected because internalization involves the unconscious normalization of received thoughts and beliefs and being able to articulate this involves deep self-reflection and introspection which is difficult when struggling with day to day health and other demands [14]. The theme, however, is expressed by implication in the participants’ comments on lack of confidence in the system, their sense of others deserving a kidney over them, and their fear of asking others. Although there may be overlap between shame and unworthiness related to kidney disease in general, this is also evident in participants when considering transplantation.

There is increasing recognition of the importance of cultural competency and safety for both clinicians and organizations to achieve equitable healthcare. Previous research has discussed the paradox of well-intentioned healthcare practitioners providing inequitable care through unconscious bias [18]. The data indicate that poor communication and a lack of partnership in shared decision-making between Māori families and clinicians, together with a lack of clinician safety with respect to cultural values, also potentially

contribute to inequities [19]. While we do not doubt that clinicians value optimal transplant and kidney health outcomes, the fundamentals of cultural safety require clinicians to acknowledge potential barriers to clinical effectiveness. These include considering power imbalances, self-reflecting, and enabling patients and families to determine whether a clinical encounter is safe [20, 21]. Our findings therefore challenge the NZ health system to explore cultural safety in this area and clinicians to question our own biases, attitudes, assumptions, and prejudices that may be contributing to inequities in kidney transplantation.

The experiences of lack of power and transparency identified by our participants are not specific to kidney transplantation. Māori are less likely than non-Māori to receive understandable answers to healthcare questions, to have conditions explained satisfactorily, feel listened to [22], or to feel that staff treated them with respect and dignity [23]. Acknowledging *tikanga Māori* is vital to ensure patient engagement and to building culturally important connections in the pursuance of optimal treatment outcomes [24, 25]. Participants discussed the importance of growing the Māori workforce, but also how non-Māori have effectively engaged and enhanced care delivery when acknowledging *tikanga*. Acknowledgment and inclusion of *tikanga* in the transplantation process may help ensure a culturally safe and more acceptable pathway to Māori and facilitate transplantation. In respect to this point, our participants recommended Māori guidelines and acknowledgement rituals for whānau; Māori cultural, spiritual support, and advocacy; access to a knowledgeable support person to support communication; and Māori advocates at individual and system levels (Table 3).

Previous research has found that culturally tailored social media campaigns to promote living kidney donation and transplantation through success stories for Native American communities increased engagement and conversations about live kidney transplantation [26, 27]. Campaigns were considered more memorable if they shared stories of hope and cultural significance [26]. These findings suggest that resourcing a media campaign developed by indigenous peoples that discusses positive stories and how people have overcome cultural transgressions could help encourage Māori to talk about transplantation and challenge the consequences of internalised racism.

The BMI criterion for transplantation or donor status may be limiting the number of Māori who are both receiving and donating a kidney. International evidence indicates that based on survival rates, higher body mass alone should not be a barrier for kidney transplantation [28] and that BMI thresholds should be significantly modified by patients' characteristics and careful risk stratification [29]. Previous research in Aotearoa New Zealand has shown that ethnicity-specific criteria would provide more accurate measures of surgical and transplantation risk [30], as universal BMI categories fail to account for ethnic differences in fat distribution, muscularity, bone mineral mass, and leg length [31]. Without the benefit of such knowledge, patients and donors in our study posited that if this surgical risk criterion based on BMI must remain, then effective interventions for weight loss are required. Weight loss surgery in people with kidney failure is associated with increased kidney transplantation and improved post-transplant outcomes [32–34]. Recent research in NZ, however, has demonstrated evidence of unequal access to publicly funded bariatric surgery after adjustments for comorbidity, with lower access for Māori and Pasifika Peoples compared to non-Māori and non-Pasifika and a lower likelihood of access with increasing socioeconomic deprivation and rurality [35]. Prioritizing Māori for weight loss surgery if this is the main barrier to transplantation may therefore address this issue.

Our participants identified a number of suggestions for increasing transplantation rates. These included a national Māori kidney transplant strategy, and resourcing of awareness campaigns. They suggested changing models of care to include more transparency, culturally specific assessments and counselling, inclusion of whānau and cultural practices into clinical practice, additional Māori-led navigation, and community- and *marae* (traditional Māori meeting places)-based education. Participants recommended workforce development to increase cultural safety, *Te Reo* (language) and *tikanga* training, Māori workforce expansion, and Māori leadership to address racist policies and practices. There is much potential to explore these, in future research.

Conclusion

The wide-reaching experiences and perceptions of racism described by participants with kidney disease and their whānau in this research point to an unfair health system and suggest that racism per se contributes to kidney transplantation inequity in Aotearoa New Zealand. Addressing racism at all levels is imperative if we are to address inequitable outcomes for Māori requiring kidney transplantation.

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Declarations

Ethical Approval All procedures performed in this study were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Consent to Participate Informed consent was obtained from all individual participants included in the study.

Competing Interests The authors declare no competing interests.

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