# Navigating challenges: insights into chronic kidney disease care in South Auckland

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## ABSTRACT

The burden of chronic kidney disease is increasing throughout New Zealand, resulting in growing strain on patients, families and the healthcare system. The population of South Auckland is the most diverse in New Zealand and it is particularly vulnerable to the effects of chronic kidney disease due to its demography and its many communities that endure significant hardships. This article explores the prevailing challenges identified by renal physicians and nurse specialists over 35 years of caring for patients with chronic kidney disease in South Auckland.

resident population of South he Auckland was estimated to be 567,000 in 2018, representing 11% of New Zealand's population.<sup>1</sup> South Auckland is ethnically diverse, with 16% of the population identifying as Māori, 22% as Pacific, 28% as Asian and 34% as New Zealand European or Other.1 The Pacific and Māori populations residing in South Auckland are the largest and the second largest respectively in New Zealand.<sup>1</sup> The population of South Auckland is also young, with 66% of peoples aged between 15 and 64 years and 23% of peoples aged 14 years or younger, compared to 65.1% and 15.1% respectively for the total New Zealand population.<sup>1</sup>

The epidemiology of end-stage kidnev (ESKD) requiring renal replacement disease therapy (RRT) is well understood in New Zealand as a result of robust registry data; however, less is known about the regional variation in chronic kidney disease (CKD). The prevalence of CKD in Samoan peoples living in Auckland is estimated between 15.9% to 33.4%; however, data regarding the wider population of South Auckland are less robust.<sup>2</sup> The peoples of South Auckland also face a number of challenges in receiving care for CKD in both primary and secondary care. The purpose of this article is to outline common challenges identified by renal physicians and nurse specialists over 35 years of caring for patients with CKD in South Auckland.

Low socio-economic status has been associated with more rapid progression of CKD, unplanned RRT commencement, lower probability of pre-emptive renal transplantation and increased mortality.<sup>3,4</sup> The peoples of South Auckland endure significant socio-economic hardships, with 37% of its population residing in the most deprived New Zealand Index of Deprivation 2018 [NZDep2018] quintile and 49% of people aged 15 years or older have an annual income of NZ\$30,000 or less, compared to the national average of NZ\$105,000.<sup>1</sup> Residence within the most deprived NZDep2018 quintile of South Auckland disproportionately affects Pacific peoples (78%) and Māori (58%).<sup>1</sup>

South Auckland faces significant challenges related to housing. Compared to the national average, it has twice the prevalence of multifamily households-approximately 14% of households accommodate two families, while 2% house three or more families.<sup>1</sup> Additionally, an estimated 22% of residents in South Auckland live in crowded or severely crowded households.<sup>1</sup> These housing conditions may exacerbate income and food insecurity. Food insecurity is further perpetuated by the fact that the most socially deprived areas in South Auckland are essentially food deserts.<sup>5-7</sup> These areas lack access to nutritious, affordable food options and instead offer calorie-dense, low-nutrient and expensive foods, which have been linked to the progression of traditional risk factors for CKD progression, including obesity, diabetes mellitus and hypertension.5-7

Patients with CKD in South Auckland often highlight lack of transport as a significant barrier to accessing both primary and secondary care, which may adversely impact patient engagement and contribute to suboptimal outcomes.8 Notably, the most economically active family members often serve as the primary transportation providers for both younger and older family members in South Auckland. Furthermore, public transport coverage in the most socially deprived wards of South Auckland exhibits suboptimal frequency, high costs and uneven geographical distribution, disproportionately impacting Māori and Pacific communities.8 Functional decline often occurs in advanced CKD and this, coupled with visual impairment from diabetic or hypertensive retinopathy, complicates the safe transfer in and out of either private or public transport. CKD thus has a bidirectional effect on both income security and transportation, leading to secondary consequences for the broader family.4,8

Patients with CKD in South Auckland are also more likely to reside in temporary or transitional housing, which are associated with suboptimal living conditions, chronic illness and hospitalisation.9 Some patients reside in garages or makeshift annexes; their housing situation remains largely unquantified. Furthermore, suboptimal housing is often an insurmountable obstacle to performing home-based RRT; the provision of which would otherwise confer better quality of life, maintenance of employment and higher probability of renal transplantation.<sup>10</sup> In the aftermath of the pandemic, income insecurity has significantly affected the capacity and outreach of numerous community organisations in South Auckland. As a consequence, services available to patients living with advanced CKD-such as home assistance, social support and access to food banks—are experiencing significant strain.

There are disparities in educational achievement in South Auckland with 21.3% of school leavers not attaining a qualification in 2022 compared with the national average of 13.0%, and only 23.9% achieving university entrance compared to 39% for New Zealand as a whole.11 The relationship between level of education, self-management, CKD, multimorbidity and mortality is complex, particularly given the long lag time from development of risk factors to the occurrence of ill health.<sup>12,13</sup> Based on clinical experience in South Auckland, low health literacy is a central feature of suboptimal management of metabolic comorbidities, limited engagement with primary or secondary care and non-concordance with medications.

Low health literacy contributes to both delayed

diagnosis of CKD and its progression.<sup>12</sup> Low health literacy in advanced CKD is associated with an increased risk of complications, including renal anaemia, volume overload, acid-base disturbances, electrolyte abnormalities, CKD mineral and bone disorder, infection and hospitalisation. Nevertheless, robust evidence indicates that health literacy can be enhanced through targeted educational programmes. Additionally, selfmanagement interventions have the potential to improve knowledge, self-efficacy, quality of life and even mortality rates.<sup>12</sup> Based on local experience, community-based pre-dialysis education sessions have led to decreased complications in advanced CKD and increased planned initiation of RRT. Furthermore, these sessions have encouraged family members to attend primary care for metabolic screening.

Patient experience evaluations suggest that these group education sessions are both appropriate to, and well received by, predialysis patients in South Auckland. Pre-dialysis patients, however, account for a relatively small proportion of all patients with CKD in South Auckland; addressing the larger need requires engagement and resourcing of the education, public health and primary care systems. While there is some debate about the optimal form of CKD education, given the detrimental impact of metabolic risk factors on CKD and the long lag time to ill health, a multifaceted strategy is necessary.<sup>12</sup> This strategy should include school-based education, community group initiatives and selfmanagement strategies within primary care to address a broad range of topics, including CKD awareness, metabolic syndrome, diet and exercise.

Patients who are non-English speakers, or for whom English is a second language, encounter substantial challenges when navigating the health pathways between primary and secondary care. This issue seems to disproportionately impact Pacific patients.<sup>13–15</sup> Although access to interpretation services in secondary care is improving, there remain significant staffing constraints that result in some Pacific, Middle Eastern and Asian communities having access to a limited pool of clinical interpreters. Some patients have raised concerns about perceived risks to confidentiality, particularly if they hold prominent positions within their community, while others have reported selectively withholding sensitive information.

Interpreting via family members is an alternative that is avoided where practicable

due to issues including untrained medical language skills, lack of neutrality, emotional bias and difficulty sharing bad news.<sup>15</sup> Regardless of language proficiency, involvement of family is often essential for Māori, Pacific and Asian patients with CKD to understand, engage in and manage their condition.<sup>16</sup> Based on clinical experience, it is considered best practice to proactively involve the patient's family, facilitated by the designated family spokesperson(s), when navigating complex decisions for patients with CKD.<sup>13,16</sup> These decisions may include selecting the most suitable RRT modality, opting for best supportive care or contemplating treatment withdrawal.<sup>17</sup>

Another frequently encountered cultural issue in the management of CKD in South Auckland is whakamā (a noun referring to shame or embarrassment, or verb referring to being ashamed, bashful or embarrassed).18 While whakamā is predominantly described by Māori and Pacific individuals, patients of Asian heritage have also reported experiencing something similar. In clinical practice, whakamā may manifest as subtle psychological changes or confounding behaviours, including self-stigmatisation, fear of judgment, social isolation and avoidance.<sup>18</sup> It may be a confounding cause for variable patient engagement. The detection of whakamā necessitates that clinicians practise and maintain a high standard of cultural awareness, competency, sensitivity and humility in the face of clinical inertia and health system pressures.<sup>18,19</sup> Moreover, fostering a long-term patient-clinician relationship may alleviate the distress associated with whakamā.<sup>18</sup>

Both the demand for CKD care and the case complexity of CKD have increased significantly in South Auckland over the past three decades. This trend coincides with substantial population growth, the pervasive obesity-diabetes epidemic and an ageing population.<sup>1,2,20</sup> Patients with CKD in South Auckland frequently describe difficulty in accessing primary care appointments, which is due to a long-standing shortage of general practitioners and, latterly, increased demand following the pandemic period.<sup>21,22</sup> While existing health pathways offer guidance for managing patients with CKD in primary care, the practical adoption and implementation of this guidance remain uncertain.<sup>20,23–25</sup> Factors such as rising case complexity, clinical inertia, varying patient engagement and challenges in maintaining longitudinal follow-up within the primary care context may contribute to this uncertainty.<sup>1,20,23–27</sup>

There has been a parallel growth of wait lists

for secondary renal care, which has been exacerbated by increasing demand following the pandemic period.<sup>27</sup> The prioritisation of first specialist assessment appointments, a key performance indicator (KPI), typically takes precedence over follow-up appointments, which may contribute to more fragmented longitudinal management of patients with advanced or complicated CKD.<sup>27</sup> This is further compounded by the increased time and resources required to troubleshoot interacting multimorbidity, which now burdens the majority of patients with advanced CKD in South Auckland.<sup>24</sup> Accordingly, the issues of access may not only mitigate the clinical synergies of longitudinal management in, but may also precipitate variable engagement with, secondary care.

The lack of clinical, administrative and information technology integration between primary care, secondary care, community pharmacies and social services exacerbates the challenges faced by patients with CKD in South Auckland.<sup>25,28</sup> The timely communication of treatment plans, referrals and medication changes is essential for the management of CKD; however, the experience of patients in South Auckland is often more fragmented, which leads to medication complexity, suboptimal engagement and missed opportunities for holistic care.<sup>29</sup>

Patients with CKD also face the burden of multiple primary care, secondary care and allied health appointments for interrelated conditions. There is also the potential for duplication of work and blurring of the lines of care coordination between primary and secondary care.<sup>29</sup> It is also not currently possible to address clinically significant KPIs in real time. These issues result in suboptimal outcomes, such as fewer than two thirds of patients with diabetes in the Auckland Metro area meeting guideline targets for HbA<sub>1c</sub> (61%), systolic blood pressure (59%) and primary prevention of cardiovascular disease (54%).<sup>20</sup>

In summary, the peoples of South Auckland encounter multiple challenges—both within and outside the health system—when seeking care for CKD. There are several possible adjustments within the health system that may enhance both patient experience and outcomes. First, provision of out-of-hours renal clinics may help address issues of engagement relating to either employment or transport. Second, multidisciplinary renal clinics, where patients receive sequential reviews from a nephrologist, a nurse specialist, a dietitian and possibly a psychologist, have the potential to streamline care and improve engagement for those with advanced CKD.

Third, localities-based integration of the secondary renal service into primary care may result in synergies, including early detection and management of CKD, fostering of collaborative care and potentially reducing referrals to secondary care. Community pharmacies are uniquely placed to provide medication education and guidance, which are often reinforced by their long-term relationships with patients and families. Thus, fourth, fostering collaboration between primary care, secondary care and community pharmacies—with a particular emphasis on monitoring medication dispensation frequency—could be used to facilitate hypertension and diabetes management and promote patient engagement.

Fifth, there is a clear need for enhanced health promotion and prevention relating to obesity, diabetes and hypertension in South Auckland. Considering the significant impact of CKD, it may be prudent to integrate health promotion and prevention initiatives into the education system. Furthermore, these efforts should also be delegated to community groups, including churches and maraes, which are important in the dayto-day lives of most families in South Auckland. There is also a role for self-management interventions in primary and secondary care, which have been shown to increase self-efficacy and quality of life.<sup>12</sup>

Sixth, addressing the long-standing systemic issue of the primary care workforce in South Auckland will not only enhance outcomes for patients with CKD, but may also yield cost efficiencies by preventing morbidity and optimising the utilisation of secondary care services. There are additional opportunities for improvement beyond the health system that would benefit the people of South Auckland living with CKD. Expansion of the public transport system will likely address some aspects of access and patient engagement. This includes expanding the availability and frequency of health shuttle services in Māngere, Manurewa and Ōtara.

In addition, there is a pressing need to expand the availability of affordable housing in South Auckland. This expansion will help alleviate the social and health challenges linked to temporary housing, transitional housing and homelessness. This is supported by evidence that stable housing may improve healthcare engagement, reduce hospitalisations and improve survival.<sup>30</sup> Regulatory initiatives are required to encourage supermarkets to establish a presence, expand and actively compete in low socio-economic communities like Mangere, Manurewa and Ōtara. This approach is essential for addressing health challenges related to food deserts and may play an important role in safeguarding future generations of children from the impact of metabolic syndrome.

In summary, the need and case complexity of patients with CKD in South Auckland has increased significantly over the past 35 years. These have been perpetuated by factors including changes in demographics (increasing population, obesitydiabetes epidemic and ageing), socio-economic instability (income inequality, housing, transportation and nutrition) and healthcare provision (resourcing, staffing and service integration). Despite these challenges, there is scope to improve the quality of care for patients with CKD in South Auckland. Adequate resourcing and adjustment of standard care are required to improve access to, and flexibility of, primary and secondary care in the near term. Long-term structural changes are required within and outside of the health system to both address the increasing demand for CKD care in South Auckland and safeguard future generations from developing CKD.

#### **COMPETING INTERESTS**

Nil.

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