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## Māori patients' experiences and perspectives of chronic kidney disease: An interview study

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**Title: Māori patients’ experiences and perspectives of chronic kidney disease: An interview study**

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**Short title:** Māori patient perspectives of kidney disease

## Abstract

### **Objectives:**

To explore and describe Māori (Indigenous New Zealander's) patients' experiences and perspectives of chronic kidney disease, as these are largely unknown for Indigenous groups with CKD.

**Design:** Face-to-face, semi-structured interviews with purposive sampling and thematic analysis

**Setting:** Three dialysis centres in New Zealand, all of which offered all forms of dialysis modalities.

**Participants:** 13 Māori patients with CKD and who were either nearing the need for dialysis or had commenced dialysis within the previous 12 months.

**Results:** Transforming patient's whakamā (shame and embarrassment) into whakamana (sense of self-control and self-determination) was central to the four themes identified: disempowered by delayed CKD diagnosis (resentment of late diagnosis; missed opportunities for preventive care; regret and self-blame); confronting the stigma of kidney disease (multi-generational trepidation; shame and embarrassment; fear and denial); developing and sustaining relationships to support treatment decision-making (importance of family/whānau; valuing peer support; building clinician-patient trust); and maintaining cultural identity (spiritual connection to land; and upholding inner strength/mana).

**Conclusions:** Māori patients CKD experienced marginalisation within the NZ healthcare system due to delayed diagnosis, a focus on individuals rather than family, multigenerational fear of dialysis, and an awareness that clinicians are not aware of cultural considerations and values during decision-making. Prompt diagnosis to facilitate self-management and foster trust between patients and clinicians, involvement of family and peers in dialysis care, and acknowledging patient values could strengthen patient engagement, and align decision-making with patient priorities.

**Strengths and Limitations**

- In-depth face-to-face interviewing allowed for detailed understanding of patients’ experiences and values of experiencing kidney disease.
- The feedback from member checking confirmed our interpretation of raw data and grouping of themes and subthemes
- A limitation of this study is that we did not explore patients’ experiences and perspectives of transplantation
- We did not include or evaluate the considerations of wider determinants of health outcomes such as poverty

**Index words**

Indigenous, Māori health; primary care; health indicators; dialysis, chronic kidney disease, end-stage kidney disease, health equity

## Background

Indigenous people worldwide bear a greater burden of disease, disability and death than their non-Indigenous counterparts (1). Māori, the Indigenous people of New Zealand (NZ) experience inequities in most health conditions (2). Māori like many other Indigenous people are affected by end stage kidney disease (ESKD) disproportionately, contributing to persistent and marked inequity in health outcomes (3). Despite stabilized rates of dialysis in higher income countries, the incidence of ESKD continues to increase for Māori. Māori have been consistently 3.5 times more likely to commence dialysis than NZ Europeans, and have a very low likelihood of receiving best practice treatment including pre-emptive kidney transplantation and home-based dialysis (3-7).

Previous literature highlights marginalization for Māori within the NZ health system (8-10). Inequities in provision of preventative care, delayed specialist referral, and lower life expectancy among Indigenous peoples have been extensively quantified and explored using epidemiological methods, but remain incompletely explained by conventional individual and community risk factors for worse health outcomes, including socioeconomic opportunity and comorbidity (11). Previous international research has highlighted specific issues for Indigenous groups in chronic kidney disease (CKD) such as providing culturally competent care (12, 13), the need for flexible family-focused care, managing patient fear of mainstream services, (12) and miscommunication (14), however these issues have not been explored among Māori patients with CKD. This study aims to describe Māori patients' beliefs and experiences of CKD which may elucidate additional contextual, social and organizational factors that contribute to the persistent inequities in health outcomes among Māori with CKD.

**Methods**

This sub-study reports new data specific to Māori participants describing their experiences and beliefs of CKD collected as part of the larger Home First study (15).

*Participant recruitment and selection*

This analysis specifically focussed on interviews conducted with 13 participants from the Home First study who self-identified as New Zealand Māori and had received education about treatment modalities (dialysis and kidney transplantation) or who had commenced dialysis within the previous 12 months. Patients were recruited to the study by nephrologists and nurse specialists working within each dialysis unit. The study was approved by each hospitals ethics committee. The study is reported according to the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) (16).

*Data collection*

A semi-structured face-to-face interview was conducted with each participant between July 2014 and January 2015 by one author, who is a Nurse Practitioner in renal medicine (RCW). The interview guide included questions about cultural issues that influence decisions about dialysis choice or place of dialysis and how cultural and spiritual needs can be better met. This guide was developed after review of literature and discussion among the research team who consisted of renal clinicians and social scientists experienced in qualitative research and Māori cultural advisors (Supplementary File 1). All interviews were digitally recorded and transcribed with the participants' consent. Interviews were conducted till data saturation achieved.

### *Data Analysis*

All transcripts were entered into specialized software (HyperRESEARCH; version 3.7.2 ResearchWare Inc) to manage and analyse data. Field notes were also written during interviews. Using adapted grounded theory and thematic analysis, RCW, SW [who identifies as Māori and is an experienced Māori policy writer and cultural advisor], and SCP [nephrologist] independently coded the transcripts provided by the 13 participants line-by-line, and inductively identified concepts. Similar concepts were then grouped together into themes. The conceptual framework and data interpretation were independently reviewed by three authors (RCW, SW, and SCP) to ensure the themes reflected the full scope of the data and were consistent with the Māori world (Te Ao Māori) view. The coding schema was refined through a series of discussions among the investigator team. Once thematic analysis was complete, we convened a discussion group with four Māori patients including three who had participated in the qualitative interviews. We discussed the preliminary themes to ascertain whether they had been interpreted to reflect the range and depth of perspectives of Māori patients. We also offered an opportunity for patients to discuss and respond to the identified themes (i.e. member checking). This feedback was then integrated into the final analysis.

### **Results**

Of the 13 participants (Table 1), seven (54%) patients were not yet on dialysis (but had received education about dialysis), three (23%) were treated with home dialysis (either haemodialysis or peritoneal dialysis) and three (23%) were treated with in-centre haemodialysis. The participants were aged from 22 to 72 years (mean age 59 years). Ten participants (77%) had ESKD caused by diabetes. Participant characteristics are presented in Table 1.

We identified the over-arching concepts of transforming whakamā (disempowerment and embarrassment) into whakamana (enhanced self-esteem and self-determination) as central to the

four themes identified: disempowered by delayed CKD diagnosis, confronting the stigma of dialysis, developing and sustaining relationships to support treatment, and maintaining cultural identity. Illustrative participant quotes are provided in Table 2. Conceptual links between themes are presented in the Figure 1.

**Disempowered by delayed CKD diagnosis**

*Resentment of late diagnosis*

Some participants experienced delayed diagnosis of CKD despite the patients regularly attending their general practitioner for clinical assessment and diabetes checks. Patients felt frustrated and let-down that although they often voiced specific concerns these were often ignored. Reflecting on previous care participants were angry that their doctor had apparently failed to pay attention to their kidney function during their regular diabetes clinical checks, or neglected to communicate the risk or diagnosis of this to the patient.

*Missed opportunities for preventative care*

Many participants expressed disappointment that the system had let them down, as they were unaware of preventative measures they could have taken to protect their kidney function and delay dialysis. Participants described how health professionals implied there was an expectation that they already should have an awareness of their kidney problems and how to take care of themselves.

*Regret and self-blame*

Many participants, particularly those with diabetes expressed regret that they could have avoided or delayed dialysis. Despite many acknowledging they had not known enough to make significant changes earlier. Many blamed themselves for not proactively asking about treatment or lifestyle changes, or trying to understand more about their condition to help them self-manage their care, internalizing a sense of inadequacy. These experiences often led to loss of confidence in their own ability to care for themselves when considering home dialysis and disengagement with pre-dialysis education and dialysis decision-making.



## ***Confronting the stigma of dialysis***

### ***Multi-generational trepidation***

Stories of sickness and death on dialysis relayed to them by their family members instigated fears and anxiety of what life on dialysis would entail. Some patients had experienced first-hand close or extended family having dialysis, and associated dialysis closely with death. Although participants understood that many of these experiences were personal, and may not be the same for them, the bad memories or tales of dialysis often influenced their own dialysis choice, particularly increasing their fear of home dialysis modalities.

### ***Shame and embarrassment***

Participants felt embarrassed and ashamed of having kidney disease and the community stigma associated with kidney disease as it was perceived as self-induced. Many participants, often men associated sickness with weakness and inferiority from their peers. For men who had been always physically active and perceived as strong, the need to be dependent on others and a machine made them feel ashamed and often led to withdrawing from family and not participating in dialysis education and preparation.

### ***Fear and denial***

Fear of having to live with dialysis created uncertainty of the future for patients and often led to denial of their kidney disease. Many acknowledging that although they were conscious that they were in denial, they didn't have the strategies or support to reach acceptance. For this reason, participants chose to withdraw and not were reluctant to participate in dialysis education programs, support groups, or discussing their kidney disease with their families as they found this too confronting. Many described a lack of safe and relevant support networks to "*open-up and face their fears*" during the process of preparing for dialysis.

***Developing and sustaining relationships to support treatment decision-making***

*Importance of family/whānau*

Participants valued the importance of including family in their early care and decision-making. When not offered the opportunity to involve their family in the decision-making process about dialysis, this led to disconnection within the family and isolation of the patient. In contrast, for patients whose family had been actively involved and therefore had better understanding appreciated how important this had been.

*Valuing peer support*

Participants drew strength from the experience and support of other Māori patients during their preparations for dialysis treatment. For some participants who felt isolated and that no-one would understand the emotions they were dealing with, meeting someone similar who they could relate to allowed them a sense of belonging. Spending time with peers who had successfully established themselves on dialysis treatment reassured and emboldened patients and helped to allay their specific anxieties about dialysis.

*Building mutual clinician-patient trust*

Participants emphasised the importance of developing and sustaining a trusting and therapeutic relationship with their clinicians. Clinicians were considered more trustworthy when they knew and discussed what was valued and important to the patient. This aspect of care was seen as a crucial stage of maintaining engagement and active participation with clinical services. Participants who believed their clinician did not understand them, or their values, expressed doubt about their clinicians' recommendations, and were more hesitant to consider home dialysis.

Distrusting health professionals was often based on previous negative encounters with the health system. In contrast, other participants told of positive experiences with clinicians who actively tried to engage them and enabled participants to develop trust, allowing the participant to regain power and confidence in their decision-making.

## ***Maintaining cultural identity***

### *Spiritual connection to land*

For many participants, a marker of quality care was their clinician's acknowledgement and appreciation of the importance of the spiritual connections to their land and people. The importance of these connections was particularly spoken about by participants who lived in rural locations, who had contemplated having to relocate for dialysis. Some rural participants limited the range of dialysis options they considered to avoid extended relocation to the city to establish their dialysis care. This often meant these patients chose a home dialysis option, and predominantly chose peritoneal dialysis, as this had the shortest training time and enabled them to stay on their land.

### *Upholding inner strength/mana*

When considering choice of dialysis treatment, many spoke of making decisions to enable them to continue in their roles within the family and community, as this was seen as an important aspect of their personal and cultural identity. It was important to participants that clinicians recognised the significance of these roles. Many participants preferred a treatment that would enable continued employment as this was a highly-valued part of their identity, for some this meant they retained their "mana" inner strength and were still seen as a provider for their family.

## ***Discussion***

In this analysis of Māori patients' beliefs and experiences of CKD, Māori experienced delayed initial CKD diagnosis and missed opportunities for preventive care and loss of trust and disengagement with health services. Patients reported poor communication led to difficulty in patients translating clinical information to enable self-management, and feeling inadequate during clinical encounters. Multigenerational and community stigma and experiences of kidney disease invoked fear and shame, which isolated patients from peer and family support accentuated by an individual-based approach to decision-making and education. Having trusting and reciprocated relationships with

clinicians was integral to engaging fully with dialysis preparation, enabled self-care, and enhanced participatory decision-making. Feeling listened to and being confident to seek support within and outside of their families enabled patients to choose treatments that sustained cultural identity.

The findings of our study suggest potential actions to improve kidney care for Māori which may also be relevant for other Indigenous peoples. The patient experiences in this study are concordant with the perspectives of Aboriginal and Torres Strait Islander patients treated with hemodialysis on ways to improve dialysis care including; the importance of family and relationships within healthcare models and service delivery; the need for service provision aligned with cultural preferences; and fear of healthcare processes generated by intergenerational dialysis experiences (12). These findings are also consistent with evidence that delayed initial CKD diagnosis is a potential cause of inequity in healthcare experiences and outcomes for Māori (17, 18) and may account for later presentations to renal services among Indigenous groups, preventing adequate preparation for home dialysis, permanent vascular access, and pre-emptive kidney transplantation (19-21).

The significance of developing and sustaining trusting relationships among clinicians, family, and the community has also been identified as central to improving health gains for Māori (2, 10, 22, 23) and other Indigenous groups (12). Previous literature has identified poor communication between Indigenous patients and clinicians (11-14) as a barrier to Māori accessing quality, effective healthcare and our study supports this and may explain the number of Māori developing ESKD from diabetes. In a previous study reporting Māori patient experiences of heart disease in New Zealand, patients considered that poor communication arose both from a lack of practitioner competency together with discrimination against Māori during clinical care (10). Based on our data, Māori recipients of CKD care in New Zealand do not consider that existing healthcare services are meeting their needs for adequate communication and engagement, with direct negative implications for their disease trajectory and dialysis preparation. Inclusion of Māori health frameworks within professional development to support health practitioners to translate principles of cultural

competency into standard clinical practice (24, 25) may help to address ineffective communication with Māori patients, although wider considerations of addressing clinician assumptions, understanding power imbalances between clinicians and patients, and exploring institutional structures that sustain ineffective practices are also likely to be required.

A central finding in this study is the failure of clinicians to disclose an initial diagnosis of CKD to the patient and act on this diagnosis despite regular patient attendance in the primary care setting and regular assessment of glycaemic control and kidney function. These findings are coherent with lower specialist referral rates of Māori than non-Māori by general practice (26) and are particularly important given the high rates of diabetes in Māori. Delayed referral is generally attributed to patient rather than practitioner behavior (11, 27), and requires a wider understanding of this issue and their impact on kidney disease and transplantation in Indigenous groups (28, 29).

The use of patient design thinking and journey mapping (30, 31) might aid in better alignment of health services and policies to patient priorities. Potential areas for development and evaluation include enhancing peer support and health literacy, developing Māori group education (10), strengthening cultural competencies for clinicians, strengthening family-focused care and education, and co-creating Māori specific care pathways with patients. Programs and care pathways designed and supported by Māori may also help to address distrust and increase engagement with health systems.

A strength of our study was the addition of member checking to validate the findings and interpretation of qualitative interviews. The feedback from member checking confirmed our interpretation of raw data and grouping of themes and subthemes. Our study does have limitations that should be considered when interpreting the findings. First, we did not include or evaluate in our study the consideration of the wider social determinants of health outcomes such as poverty, social, and educational opportunity (32-34). Second, we did not explicitly explore patient experiences of preparing for and accessing kidney transplantation. Finally, given kidney transplantation is less

common in Indigenous people (35, 36) and best practice care for ESKD this is a vital aspect worthy of exploration to improve health outcomes for Māori and is recommended for future research. Further research may explore and identify Māori patient’s priorities for care and future research and explore in more detail the experiences of institutional racism Māori experience in CKD.

In conclusion, Māori patients with chronic kidney disease experienced marginalization within the New Zealand healthcare system due to delayed diagnosis, a focus on individuals rather than family/whānau within health processes, multigenerational negative experiences of dialysis, and diminished awareness of patient values during decision-making. Prompt diagnosis to facilitate self-management and foster trust between patients and clinicians, involvement of family and peers in dialysis care, and acknowledging patient values could strengthen patient engagement, facilitate treatment planning and self-management, and align decision-making with patient priorities.

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**Contributors:** RW designed the study carried out the patient interviews, coded data, participated in thematic analysis and drafted the manuscript. SP and SW also independently coded data. RLM, KH and AT assisted in design of the study, participated in the thematic analysis and critical review of the first and subsequent manuscript drafts. SW participated in thematic analysis and critical review of first and subsequent drafts.

**Competing interests:** None.

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Table 1 – Patient Characteristics

Characteristics	Patients No. (%)
Age category	
20-40y	1 (8)
41-60y	3 (23)
61-80y	9 (69)
Marital Status	
Married/De facto	7 (54)
Divorced/Separated	0
Single	3 (23)
Widowed	3 (23)
Highest Level Education	
Some Primary School	4 (31)
Some Secondary	3 (23)
Completed Certificate or Diploma	3 (23)
Completed Degree/Higher	3 (23)
Employment status	
Full-time	4 (31)
Part-time/casual	2 (15)
Not employed	2 (15)
Social Welfare Beneficiary	3 (23)
Retired	2 (15)
Estimated gross annual household income	
NZ\$10-30,000	2 (15)
NZ\$31-50,000	7 (54)
NZ\$51-70,000	4 (31)
NZ\$71-100,000	0
>NZ\$101,000	0
Time to dialysis unit (travelled one way)	
0-20 mins	5 (65)
21-40 mins	4 (31)
41-120 mins	0
>120 mins	4 (31)

NB: NZ Annual Household Income\$85,000 (2013)

Table 2 – Participants Illustrative Quotes

Themes	Participant Quotes
<b>Disempowered by delayed CKD diagnosis</b>	
<i>Resentment of late diagnosis</i>	<p><i>"I kept going to him [General Practitioner], saying there's something else wrong, it's just not just my sugar diabetes that's wrong, there's something else" (Pre-dialysis 4).</i></p> <p><i>"why hasn't someone in the medical profession told me [about kidney disease], I'm not just coming in to have the wipers fixed or the door handle fixed, I'm coming in for you to give me a going over from top to bottom" (Pre-dialysis 2).</i></p>
<i>Missed opportunities for preventative care</i>	<p><i>"I just didn't understand it, and so I didn't make the changes to my diabetes it just didn't sound like something I needed to listen to, like it was a problem" (Peritoneal Dialysis 4).</i></p> <p><i>"It was really vague, your creatinine or something is really high, or you've got protein in your urine or something or rather, but no explanation of what that meant, but like I should automatically know what it meant and know what that meant for me and what to do about it" (Peritoneal Dialysis 3).</i></p>
<i>Regret and self-blame</i>	<p><i>"I hated going to the doctor, being told off, but now when I think back, I was dumb, I didn't go, didn't take my insulin, didn't take my pills, drunk too much, smoked, you know everything you shouldn't do" (Peritoneal Dialysis 4).</i></p> <p><i>"I'm embarrassed to say, it's actually a lot of education to learn it [home hemodialysis], I have to learn how to do the machine, and they said its hard, and it takes a long time, I guess I'm just not sure if I can learn it, and I'm not that good, and I felt a lot of pressure to learn at their level and I didn't really understand, but I don't want to tell them or they'll think I'm dumb" (In-centre Haemodialysis 2).</i></p>
<b>Confronting the stigma of kidney disease</b>	
<i>Multi-generational trepidation</i>	<p><i>"I knew some old people in town who had been on dialysis and they always looked terrible and died, I thought it was the dialysis that made them look terrible, and made them die, that's what lots of people think" (Peritoneal Dialysis 2).</i></p> <p><i>"My nan used to be on the bag [peritoneal dialysis], she told me not to go on the bag and do haemo [dialysis], she was sick when she was on the bags, and so was my nanas cousin. I haven't met anyone who did good on PD [peritoneal dialysis]" (Incentre haemodialysis 2)</i></p> <p><i>"The D word, dialysis and death" (Peritoneal Dialysis 1)</i></p>
<i>Shame and embarrassment</i>	<p><i>"I didn't tell anybody, I think that's the problem with half of us Māori, not wanting to tell, I think there's this thing, that if you're sick, you're like, embarrassed of it. You're not tough, you don't want people to feel sorry for you, so we don't tell. I couldn't even deal with what was hitting me in the face [dialysis]. There's a thing about kidneys, you know, dialysis, a stigma thing about it" (Peritoneal dialysis 2).</i></p> <p><i>"I didn't want to catch the bus, then everyone knows you're on the bus and everyone knows you're on dialysis, and this</i></p>

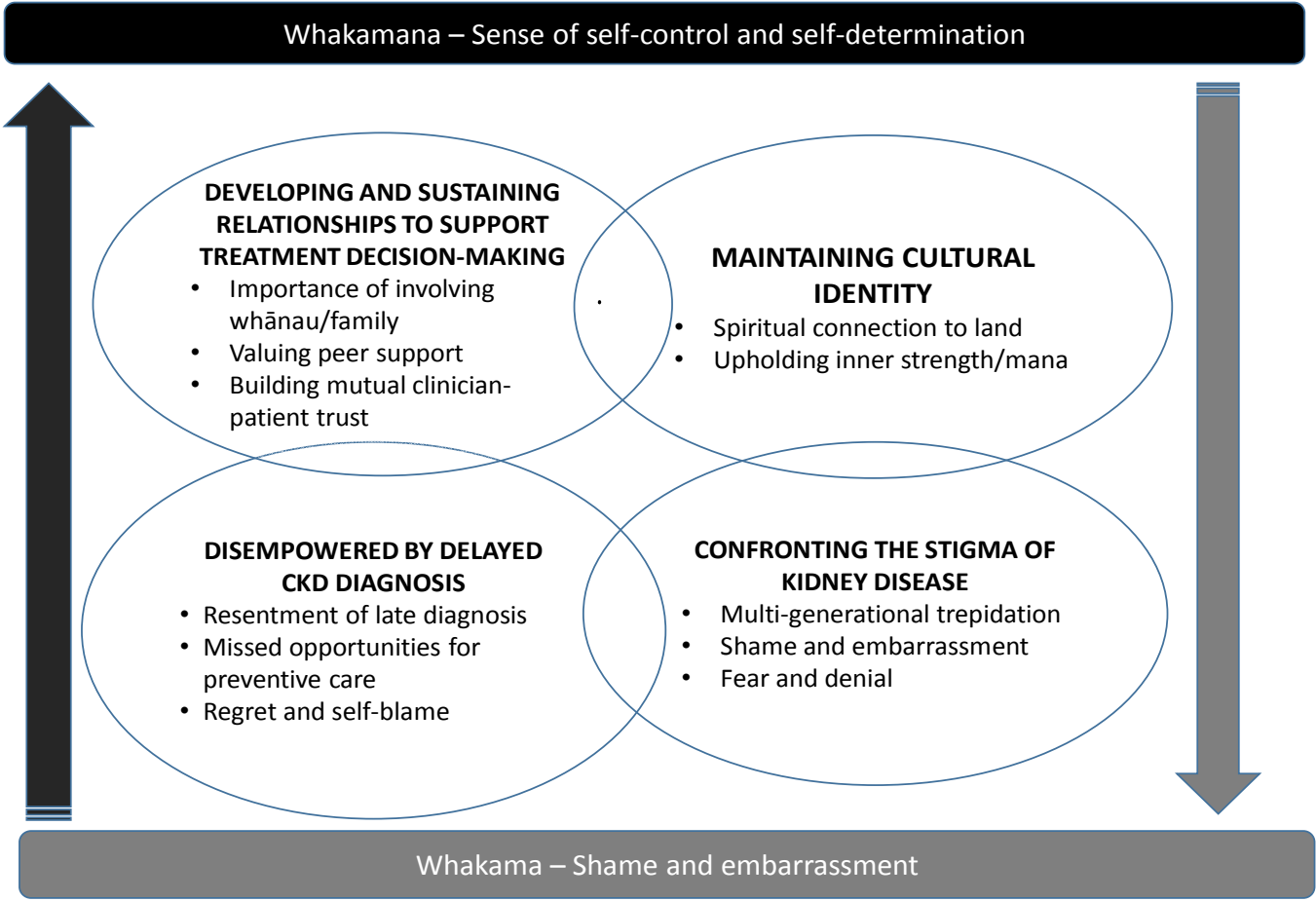
	<i>is a little town you know, I don't want everyone to know" (Peritoneal dialysis 2)</i>
<i>Fear and denial</i>	<i>"I had to put it to the back of my head, not think about it" (Peritoneal dialysis 1). "It was a big shock, and I did the normal Māori thing, I pretended it wasn't happening. Didn't listen. Tried to be tough" (Peritoneal dialysis 2). "For people like me, especially Māori men, we're not used to talking about our health and especially being sick or admitting we're sick, it's like you lose some mana [standing] if you are sick, so you just don't deal with it and you don't tell anyone, so you just put your head in the sand a little bit deeper" (Home haemodialysis 1).</i>
<b>Developing and sustaining relationships to support treatment decision-making</b>	
<i>Importance of family/whānau</i>	<i>"It's really hard to explain sometimes that family are first, that I am not an individual, that I am part of a unit, that then no decision is just mine, but it's also really hard to explain to my whanau what is happening with my kidneys when I don't really know it so well myself" (Facility Dialysis 2). "we had a meeting with my nana and my mum, one of the nurses came and talked and that was easier than me talking by myself and trying to answer questions when I didn't know what the right answer was" (Facility Dialysis 1). "If you've got the support of your family and your loved ones, everything is going to be ok" (Home Haemodialysis 1)</i>
<i>Valuing peer support</i>	<i>"They walk you through it. I learnt a lot in those sessions. Because it's from your own culture I guess. You just can see the reality there. I learnt a lot from those classes, more than talking to a doctor" (Facility Dialysis 3). "Knowing first hand" (Pre-dialysis 1)</i>
<i>Building mutual clinician-patient trust</i>	<i>"If they understood more about you they'd do things better and you'd do things better and then I'd trust them if they told me I could go home and do home, you know, but they don't know me and I'm not going to tell them if I don't think they don't care" (Facility dialysis 2). "I guess a lot of that was trusting, and then feeling comfortable about what [name] were telling me, I needed to hear it from someone I trusted" (Peritoneal dialysis 2).</i>
<b>Maintaining cultural identity</b>	
<i>Spiritual connection to land</i>	<i>"If I did have to move into town, then I wouldn't be with my family and they couldn't help me and I couldn't help them with the kids and then what would they do, that wouldn't work, so that's why this stomach one [Peritoneal Dialysis] will be better at home" (Pre-dialysis 1). "My involvement with the community at a lower level, I don't want to lose, so basically in terms of having a dialysis machine at my fingertips at home I still want to know I can do all of those things without any pressure on any of those things, cause I am nothing without those things" (Pre-dialysis 4)</i>
<i>Upholding inner strength/mana</i>	<i>"going to hui [meetings] and going to the marae [meeting house], I guess in a way, that was a lot of the thing why I wanted to do home [dialysis] too. I can work around it. I don't have to miss it" (HHD1). "Cultural too, is the male working thing, the identity of working and being a working man, and the stigma of being sick and on dialysis and not being the tough guy" (Pre-dialysis 3)</i>

## Figure Legend

**Figure 1** - Thematic schema of Māori patients' experiences and perspectives of chronic kidney disease.

Delayed initial CKD diagnosis and missed opportunities for preventive care and loss of trust and disengagement with health services influenced all other aspects of CKD care for Māori patients and led to embarrassment and disengagement of kidney disease and dialysis (Whakamā). Poor communication led to difficulty in patients translating clinical information to enable self-management, and feeling inadequate during clinical encounters. Multigenerational and community experiences of kidney disease invoked fear, which isolated patients from peer and family support accentuated by an individual-based approach to decision-making and education. Having trusting and reciprocated relationships with clinicians was integral to engaging fully with dialysis preparation, enabled self-care, and enhanced inclusion and engagement in patient decision-making. Feeling listened to and being confident to seek support within and outside of their families enabled patients to choose treatments that sustained cultural identity, standing, and roles within the community.

Figure 1



## Patient interview guide

### Exploring patient and carer perceptions and experiences of home dialysis decision making.

#### 1. Introduction

- a. Explanation of study, obtain informed consent, demographic info
- b. Can you tell me about what happened when you first found out you had kidney disease?

#### 2. Information and decisions about dialysis

- a. When did you first hear about dialysis – what kinds of information or education did you get? (*decision-making process, preferences*)
- b. Who else was involved in your education and decision making – how did they influence your thoughts or decisions about dialysis (their manner, shared decision making?)
- c. What sorts of things influenced your beliefs/decisions about the different types of home dialysis (PD, APD, HHD)?
- d. Can you tell me about whether you felt you received enough information to make an informed decision about home haemodialysis or peritoneal dialysis?
- e. If you had to choose again, what sorts of things would help you make decisions about dialysis?

#### 3. Beliefs about home dialysis

- a. What were your first thoughts or reactions when you first heard about PD and home HD?
- b. What do you believe are the potential advantages of PD or HHD compared to dialysis in hospital - why?
- c. What do you believe are the potential risks of PD or HHD compared to dialysis in hospital - why?
- d. If someone asked you what dialysis they should choose, what would you tell them?

#### 4. Living with home dialysis

- a. Have you considered changing your place or type of dialysis– why?
- b. For you, what do you think are potential reasons that would stop you having home dialysis? For others?
- c. In NZ the number of people on home dialysis has reduced over the last 15 years, why do you think that might be?

#### 5. Socioeconomic and cultural issues impacting on home dialysis

- a. Will home dialysis have a financial impact on you or other members of your family - how? (paid work, unpaid work, benefits, expenses e.g. travel, costs, electricity, water)
- b. Do you think there are social or cultural issues that might influence decisions about home dialysis for you or your family?
- c. What are your beliefs/thoughts about financial assistance (i.e. whether adequate and/or accessible); and if it influences their thinking towards home dialysis?
- d. Are there cultural or spiritual factors which influence the place of dialysis for you? (non-medicalised environment, days of rest, whanaunatanga, wairua)
- e. How could the education and support you received about dialysis options better address your cultural or spiritual needs?

#### 6. Conclusion

- a. What kinds of support or services would you need if you did dialysis at home – why?
- b. Is there anything else that you think is important to add?



Supplementary File. COREQ Checklist

No.	Item	Comment
<b>Domain 1: Research team and reflexivity</b>		
1	Interview/facilitator	RW ( Domain 1 – refer Pg 5)
2	Credentials	RW (PhD candidate, NP, MN, RN, BN)
3	Occupation	RW (Nurse Practitioner); KH/RM (Health Economists); AT (Qualitative Researcher); SP (Nephrologists) SW (Indigenous Policy)
4	Gender	RW (Female)
5	Experience and training	RW has conducted and published qualitative research.
6	Relationship established	Some participants were known to RW.
7	Participant knowledge of the interviewer	RW is a Nephrology Nurse Practitioner currently undertaking her PhD.
8	Interviewer characteristics	RW is a Nephrology Nurse Practitioner with a special interest in pre-dialysis education, patient education and home dialysis.
<b>Study design</b>		
9	Theoretical framework	Adapted grounded theory and inductive approach (Study Design Refer Page 5 & 6)
10	Sampling	Purposive
11	Method of approach	Face to face
12	Sample size	Self-identified as New Zealand Māori and had received education about treatment modalities
13	Non-participation	N = 2
14	Setting of data collection	Patient home or renal clinic
15	Presence of non-participants	No interpreter required
16	Description of sample	Participants from pre-dialysis and all dialysis modalities
17	Interview guide	Attached (See Appendix 1)
18	Repeat interviews	Member checking with some participants
19	Audio/visual recording	Interviews were audio recorded
20	Field notes	RW recorded field notes
21	Duration	35 minutes to 120 minutes
22	Data saturation	Yes
23	Transcripts returned	No
<b>Analysis and findings</b>		
24	Number of data coders	RW/SP/SW – (Analysis and Findings – See Page 6 - 10
25	Description of the coding tree	No
26	Derivation of themes	Inductively derived from data
27	Software	HyperRESEARCH
28	Participant checking	Yes (Member Checking – Page 6)
29	Quotations presented	Yes (See Table 2)
30	Data and findings consistent	Quotations provided to illustrate each theme. (See Table 2)
31	Clarity of major themes	Yes
32	Clarity of minor themes	Yes



# BMJ Open

## Māori patients' experiences and perspectives of chronic kidney disease : A New Zealand qualitative interview study

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**Title: Māori patients’ experiences and perspectives of chronic kidney disease: A New Zealand qualitative interview study**

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Word count (body): 2917

**Short title:** Māori patient perspectives of kidney disease

## Abstract

### **Objectives:**

To explore and describe Māori (Indigenous New Zealander's) patients' experiences and perspectives of chronic kidney disease (CKD), as these are largely unknown for Indigenous groups with CKD.

**Design:** Face-to-face, semi-structured interviews with purposive sampling and thematic analysis

**Setting:** Three dialysis centres in New Zealand, all of which offered all forms of dialysis modalities.

**Participants:** 13 Māori patients with CKD and who were either nearing the need for dialysis or had commenced dialysis within the previous 12 months.

**Results:** Transforming patient's whakamā (disempowerment and embarrassment) into whakamana (sense of self-esteem and self-determination) was central to the four themes identified: disempowered by delayed CKD diagnosis (resentment of late diagnosis; missed opportunities for preventive care; regret and self-blame); confronting the stigma of kidney disease (multi-generational trepidation; shame and embarrassment; fear and denial); developing and sustaining relationships to support treatment decision-making (importance of family/whānau; valuing peer support; building clinician-patient trust); and maintaining cultural identity (spiritual connection to land; and upholding inner strength/mana).

**Conclusions:** Māori patients with CKD experienced marginalisation within the NZ healthcare system due to delayed diagnosis, a focus on individuals rather than family, multigenerational fear of dialysis, and an awareness that clinicians are not aware of cultural considerations and values during decision-making. Prompt diagnosis to facilitate self-management and foster trust between patients and clinicians, involvement of family and peers in dialysis care, and acknowledging patient values could strengthen patient engagement, and align decision-making with patient priorities.

### **Strengths and Limitations**

- In-depth face-to-face interviewing allowed for detailed understanding of patients’ experiences and values of experiencing kidney disease.
- The feedback from member checking confirmed our interpretation of raw data and grouping of themes and subthemes
- A limitation of this study is that we did not explore patients’ experiences and perspectives of transplantation
- We did not include or evaluate the considerations of wider determinants of health outcomes such as poverty

**Index words**

Indigenous, Māori health; primary care; health indicators; dialysis, chronic kidney disease, end-stage kidney disease, health equity

## Background

Indigenous people worldwide bear a greater burden of disease, disability and death than their non-Indigenous counterparts (1). Māori, the Indigenous people of New Zealand (NZ) experience inequities in most health conditions (2). Māori like many other Indigenous people are affected by end stage kidney disease (ESKD) disproportionately, contributing to persistent and marked inequity in health outcomes (3). Despite stabilized rates of dialysis in higher income countries, the incidence of ESKD continues to increase for Māori. Māori have been consistently 3.5 times more likely to commence dialysis than NZ Europeans, and have a very low likelihood of receiving best practice treatment including pre-emptive kidney transplantation and home-based dialysis (3-7).

Previous literature highlights marginalization for Māori within the NZ health system (8-10). Inequities in provision of preventative care, delayed specialist referral, and lower life expectancy among Indigenous peoples have been extensively quantified and explored using epidemiological methods, but remain incompletely explained by conventional individual and community risk factors for worse health outcomes, including socioeconomic opportunity and comorbidity (11). Previous international research has highlighted specific issues for Indigenous groups in chronic kidney disease (CKD) such as providing culturally competent care (12, 13), the need for flexible family-focused care, managing patient fear of mainstream services, (12) and miscommunication (14), however these issues have not been explored among Māori patients with CKD. This study aims to describe Māori patients' beliefs and experiences of CKD which may elucidate additional contextual, social and organizational factors that contribute to the persistent inequities in health outcomes among Māori with CKD.

**Methods**

This sub-study reports new data specific to Māori participants describing their experiences and beliefs of CKD collected as part of the larger “Home First study”: A semi-structured interview study with adult patients with CKD Stage 4-5D (on dialysis < 1 year) and their caregivers, recruited from 3 nephrology centers in New Zealand (15).

*Participant recruitment and selection*

This analysis specifically focussed on interviews conducted with 13 participants from the Home First study all who self-identified as New Zealand Māori and had received education about treatment modalities (dialysis and kidney transplantation) or who had commenced dialysis within the previous 12 months. Participants were recruited to the study by nephrologists and nurse specialists working across 3 nephrology units (2 large metropolitan urban units and 1 small regional unit). Each unit has an established pre-dialysis programs and offer all dialysis modalities. The 3 units were chosen as they offered a mixture of ethnicities representative of the NZ dialysis population. None of the Māori participants approached declined to participate in the study. The study was approved by each hospitals ethics committee. The study is reported according to the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) (16).

*Data collection*

A semi-structured face-to-face interview was conducted with each participant in the patient’s choice of either their home or a clinic room at the hospital between July 2014 and January 2015 by one author, who is a female Nurse Practitioner in renal medicine, experienced in qualitative research(RCW), some participants were known to the interviewer. The interview guide included

questions about cultural issues that influence decisions about dialysis choice or place of dialysis and how cultural and spiritual needs can be better met. This guide was developed after review of literature and discussion among the research team who consisted of renal clinicians and social scientists experienced in qualitative research and Māori cultural advisors (Supplementary File 1). All interviews were digitally recorded and transcribed with the participants' consent, interview length ranged between 35 and 120 minutes each. Interviews were conducted till data saturation achieved.

### *Data Analysis*

All transcripts were entered into specialized software (HyperRESEARCH; version 3.7.2 ResearchWare Inc) to manage and analyse data. Field notes were also written during interviews. Using adapted grounded theory and thematic analysis, RCW, SW [who identifies as Māori and is an experienced Māori policy writer and cultural advisor], and SCP [nephrologist] independently coded the transcripts provided by the 13 participants line-by-line, and inductively identified concepts. Similar concepts were then grouped together into themes. The conceptual framework and data interpretation were independently reviewed by three authors (RCW, SW, and SCP) to ensure the themes reflected the full scope of the data and were consistent with the Māori world (Te Ao Māori) view. The coding schema was refined through a series of discussions among the investigator team.

Once thematic analysis was complete, we convened a discussion group with four Māori patients including three who had participated in the qualitative interviews. We discussed the preliminary themes to ascertain whether they had been interpreted to reflect the range and depth of perspectives of Māori patients. We also offered an opportunity for patients to discuss and respond to the identified themes (i.e. member checking). Participants from the discussion group validated our interpretation of the findings, sub-themes and themes.

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**Results**

Of the 13 participants (Table 1), seven (54%) patients were not yet on dialysis (but had received education about dialysis), three (23%) were treated with home dialysis (either haemodialysis or peritoneal dialysis) and three (23%) were treated with in-centre haemodialysis. The participants were aged from 22 to 72 years (mean age 59 years). Ten participants (77%) had ESKD caused by diabetes. Participant characteristics are presented in Table 1.

We identified the over-arching concepts of transforming whakamā (disempowerment and embarrassment) into whakamana (enhanced self-esteem and self-determination) as central to the four themes identified: disempowered by delayed CKD diagnosis, confronting the stigma of dialysis, developing and sustaining relationships to support treatment, and maintaining cultural identity. Illustrative participant quotes are provided in Table 2. Conceptual links between themes are presented in the Figure 1.

***Disempowered by delayed CKD diagnosis***

*Resentment of late diagnosis*

Some participants experienced delayed diagnosis of CKD despite the patients regularly attending their general practitioner for clinical assessment and diabetes checks. Patients felt frustrated and let-down that although they often voiced specific concerns these were often ignored. Reflecting on previous care participants were angry that their doctor had apparently failed to pay attention to their kidney function during their regular diabetes clinical checks, or neglected to communicate the risk or diagnosis of this to the patient.

*Missed opportunities for preventative care*

Many participants expressed disappointment that the system had let them down, as they were unaware of preventative measures they could have taken to protect their kidney function and delay



dialysis. Participants described how health professionals implied there was an expectation that they already should have an awareness of their kidney problems and how to take care of themselves.

### *Regret and self-blame*

Many participants, particularly those with diabetes expressed regret that they could have avoided or delayed dialysis. Despite many acknowledging they had not known enough to make significant changes earlier. Many blamed themselves for not proactively asking about treatment or lifestyle changes, or trying to understand more about their condition to help them self-manage their care, internalizing a sense of inadequacy. These experiences often led to loss of confidence in their own ability to care for themselves when considering home dialysis and disengagement with pre-dialysis education and dialysis decision-making.

## **Confronting the stigma of dialysis**

### *Multi-generational trepidation*

Stories of sickness and death on dialysis relayed to them by their family members instigated fears and anxiety of what life on dialysis would entail. Some patients had experienced first-hand close or extended family having dialysis, and associated dialysis closely with death. Although participants understood that many of these experiences were personal, and may not be the same for them, the bad memories or tales of dialysis often influenced their own dialysis choice, particularly increasing their fear of home dialysis modalities.

### *Shame and embarrassment*

Participants felt embarrassed and ashamed of having kidney disease and the community stigma associated with kidney disease as it was perceived as self-induced. Many participants, often men associated sickness with weakness and inferiority from their peers. For men who had been always physically active and perceived as strong, the need to be dependent on others and a machine made them feel ashamed and often led to withdrawing from family and not participating in dialysis education and preparation.

*Fear and denial*

Fear of having to live with dialysis created uncertainty of the future for patients and often led to denial of their kidney disease. Many acknowledging that although they were conscious that they were in denial, they didn't have the strategies or support to reach acceptance. For this reason, participants chose to withdraw and were reluctant to participate in dialysis education programs, support groups, or discussing their kidney disease with their families as they found this too confronting. Many described a lack of safe and relevant support networks to "open-up and face their fears" during the process of preparing for dialysis.

***Developing and sustaining relationships to support treatment decision-making***

*Importance of family/whānau*

Participants valued the importance of including family in their early care and decision-making. When not offered the opportunity to involve their family in the decision-making process about dialysis, this led to disconnection within the family and isolation of the patient. In contrast, for patients whose family had been actively involved and therefore had better understanding appreciated how important this had been.

*Valuing peer support*

Participants drew strength from the experience and support of other Māori patients during their preparations for dialysis treatment. For some participants who felt isolated and that no-one would understand the emotions they were dealing with, meeting someone similar who they could relate to allowed them a sense of belonging. Spending time with peers who had successfully established themselves on dialysis treatment reassured and emboldened patients and helped to allay their specific anxieties about dialysis.

### *Building mutual clinician-patient trust*

Participants emphasised the importance of developing and sustaining a trusting and therapeutic relationship with their clinicians. Clinicians were considered more trustworthy when they knew and discussed what was valued and important to the patient. This aspect of care was seen as a crucial stage of maintaining engagement and active participation with clinical services. Participants who believed their clinician did not understand them, or their values, expressed doubt about their clinicians' recommendations, and were more hesitant to consider home dialysis.

Distrusting health professionals was often based on previous negative encounters with the health system. In contrast, other participants told of positive experiences with clinicians who actively tried to engage them and enabled participants to develop trust, allowing the participant to regain power and confidence in their decision-making.

### ***Maintaining cultural identity***

#### *Spiritual connection to land*

For many participants, a marker of quality care was their clinician's acknowledgement and appreciation of the importance of the spiritual connections to their land and people. The importance of these connections was particularly spoken about by participants who lived in rural locations, who had contemplated having to relocate for dialysis. Some rural participants limited the range of dialysis options they considered to avoid extended relocation to the city to establish their dialysis care. This often meant these patients chose a home dialysis option, and predominantly chose peritoneal dialysis, as this had the shortest training time and enabled them to stay on their land.

#### *Upholding inner strength/mana*

When considering choice of dialysis treatment, many spoke of making decisions to enable them to continue in their roles within the family and community, as this was seen as an important aspect of their personal and cultural identity. It was important to participants that clinicians recognised the significance of these roles. Many participants preferred a treatment that would enable continued

employment as this was a highly-valued part of their identity, for some this meant they retained their “mana” inner strength and were still seen as a provider for their family.

Discussion

In this analysis of Māori patients’ beliefs and experiences of CKD, Māori experienced delayed initial CKD diagnosis and missed opportunities for preventive care and loss of trust and disengagement with health services. Patients reported poor communication led to difficulty in patients translating clinical information to enable self-management, and feeling inadequate during clinical encounters. Multigenerational and community stigma and experiences of kidney disease invoked fear and shame, which isolated patients from peer and family support accentuated by an individual-based approach to decision-making and education. Having trusting and reciprocated relationships with clinicians was integral to engaging fully with dialysis preparation, enabled self-care, and enhanced participatory decision-making. Feeling listened to and being confident to seek support within and outside of their families enabled patients to choose treatments that sustained cultural identity.

The findings of our study suggest potential actions to improve kidney care for Māori which may also be relevant for other Indigenous peoples. The patient experiences in this study are concordant with the perspectives of Aboriginal and Torres Strait Islander patients treated with hemodialysis on ways to improve dialysis care including; the importance of family and relationships within healthcare models and service delivery; the need for service provision aligned with cultural preferences; and fear of healthcare processes generated by intergenerational dialysis experiences (12). These findings are also consistent with evidence that delayed initial CKD diagnosis is a potential cause of inequity in healthcare experiences and outcomes for Māori (17, 18) and may account for later presentations to renal services among Indigenous groups, preventing adequate preparation for home dialysis, permanent vascular access, and pre-emptive kidney transplantation (19-21).

The significance of developing and sustaining trusting relationships among clinicians, family, and the community has also been identified as central to improving health gains for Māori (2, 10, 22, 23) and other Indigenous groups (12). Previous literature has identified poor communication between Indigenous patients and clinicians (11-14) as a barrier to Māori accessing quality, effective healthcare and our study supports this and may explain the number of Māori developing ESKD from diabetes. In a previous study reporting Māori patient experiences of heart disease in New Zealand, patients considered that poor communication arose both from a lack of practitioner competency together with discrimination against Māori during clinical care (10). Based on our data, Māori recipients of CKD care in New Zealand do not consider that existing healthcare services are meeting their needs for adequate communication and engagement, with direct negative implications for their disease trajectory and dialysis preparation. Inclusion of Māori health frameworks within professional development to support health practitioners to translate principles of cultural competency into standard clinical practice (24, 25) may help to address ineffective communication with Māori patients, although wider considerations of addressing clinician assumptions, understanding power imbalances between clinicians and patients, and exploring institutional structures that sustain ineffective practices are also likely to be required.

A central finding in this study is the failure of clinicians to disclose an initial diagnosis of CKD to the patient and act on this diagnosis despite regular patient attendance in the primary care setting and regular assessment of glycaemic control and kidney function. These findings are coherent with lower specialist referral rates of Māori than non-Māori by general practice (26) and are particularly important given the high rates of diabetes in Māori. Delayed referral is generally attributed to patient rather than practitioner behavior (11, 27), and requires a wider understanding of this issue and their impact on kidney disease and transplantation in Indigenous groups (28, 29).

The use of patient design thinking and journey mapping (30, 31) might aid in better alignment of health services and policies to patient priorities. Potential areas for development and evaluation

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3 include enhancing peer support and health literacy, developing Māori group education (10),  
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5 strengthening cultural competencies for clinicians, strengthening family-focused care and education,  
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7 and co-creating Māori specific care pathways with patients. Programs and care pathways designed  
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9 and supported by Māori may also help to address distrust and increase engagement with health  
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11 systems.  
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14 A strength of our study was the addition of member checking to validate the findings and  
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16 interpretation of qualitative interviews. The feedback from member checking confirmed our  
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18 interpretation of raw data and grouping of themes and subthemes. Our study does have limitations  
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20 that should be considered when interpreting the findings. First, we did not include or evaluate in our  
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22 study the consideration of the wider social determinants of health outcomes such as poverty, social,  
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24 and educational opportunity (32-34). Second, the interviewer (RCW) is non- Māori and therefore  
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26 may have overlooked cultural nuances, however we minimised this by ensuring involvement and  
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28 guidance by Māori health experts and advisors from development of the research questions through  
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30 to interpretation and coding of findings. Facilitating the group discussion to explore interpretation of  
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32 findings (member checking) also ensured we had interpreted the data correctly and our themes  
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34 were appropriate. Third, the interviewer was known to participants from one centre and this  
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36 relationship may have resulted in self-censoring answers; although when compared to participants  
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38 from other centres, similar themes were identified. Finally, we did not explicitly explore patient  
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40 experiences of preparing for and accessing kidney transplantation. Given kidney transplantation is  
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42 less common in Indigenous people (35, 36) and best practice care for ESKD this is a vital aspect  
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44 worthy of exploration to improve health outcomes for Māori and is recommended for future  
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46 research. Further research may explore and identify Māori patient's priorities for care and future  
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48 research and explore in more detail the experiences of institutional racism Māori experience in CKD.  
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51 In conclusion, Māori patients with chronic kidney disease experienced marginalization within the  
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New Zealand healthcare system due to delayed diagnosis, a focus on individuals rather than

family/whānau within health processes, multigenerational negative experiences of dialysis, and diminished awareness of patient values during decision-making. Prompt diagnosis to facilitate self-management and foster trust between patients and clinicians, involvement of family and peers in dialysis care, and acknowledging patient values could strengthen patient engagement, facilitate treatment planning and self-management, and align decision-making with patient priorities.

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**Contributors:** RW designed the study carried out the patient interviews, coded data, participated in thematic analysis and drafted the manuscript. SP and SW also independently coded data. RLM, KH and AT assisted in design of the study, participated in the thematic analysis and critical review of the first and subsequent manuscript drafts. SW participated in thematic analysis and critical review of first and subsequent drafts.

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**Patient consent:** Obtained.

**Data sharing statement:** No additional data.



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Table 1 – Patient Characteristics

Characteristics	Patients No. (%)
Age category	
20-40y	1 (8)
41-60y	3 (23)
61-80y	9 (69)
Dialysis Modality	
Pre-dialysis	5 (38)
Peritoneal dialysis	4 (31)
Home haemodialysis	1 (8)
In-centre (facility) dialysis	3 (23)
Marital Status	
Married/De facto	7 (54)
Divorced/Separated	0
Single	3 (23)
Widowed	3 (23)
Highest Level Education	
Some Primary School	4 (31)
Some Secondary	3 (23)
Completed Certificate or Diploma	3 (23)
Completed Degree/Higher	3 (23)
Employment status	
Full-time	4 (31)
Part-time/casual	2 (15)
Not employed	2 (15)
Social Welfare Beneficiary	3 (23)
Retired	2 (15)
Estimated gross annual household income	
NZ\$10-30,000	2 (15)
NZ\$31-50,000	7 (54)
NZ\$51-70,000	4 (31)
NZ\$71-100,000	0
>NZ\$101,000	0
Time to dialysis unit (travelled one way)	
0-20 mins	5 (65)
21-40 mins	4 (31)
41-120 mins	0
>120 mins	4 (31)

NB: NZ Annual Household Income\$85,000 (2013)

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Table 2 – Participants Illustrative Quotes

Themes	Participant Quotes
Disempowered by delayed CKD diagnosis	
Resentment of late diagnosis	<p>“I kept going to him [General Practitioner], saying there’s something else wrong, it’s just not just my sugar diabetes that’s wrong, there’s something else” (Pre-dialysis 4).</p> <p>“why hasn’t someone in the medical profession told me [about kidney disease], I’m not just coming in to have the wipers fixed or the door handle fixed, I’m coming in for you to give me a going over from top to bottom” (Pre-dialysis 2).</p>
Missed opportunities for preventative care	<p>“I just didn’t understand it, and so I didn’t make the changes to my diabetes it just didn’t sound like something I needed to listen to, like it was a problem” (Peritoneal Dialysis 4).</p> <p>“It was really vague, your creatinine or something is really high, or you’ve got protein in your urine or something or rather, but no explanation of what that meant, but like I should automatically know what it meant and know what that meant for me and what to do about it” (Peritoneal Dialysis 3).</p>
Regret and self-blame	<p>“I hated going to the doctor, being told off, but now when I think back, I was dumb, I didn’t go, didn’t take my insulin, didn’t take my pills, drunk too much, smoked, you know everything you shouldn’t do” (Peritoneal Dialysis 4).</p> <p>“I’m embarrassed to say, it’s actually a lot of education to learn it [home hemodialysis], I have to learn how to do the machine, and they said its hard, and it takes a long time, I guess I’m just not sure if I can learn it, and I’m not that good, and I felt a lot of pressure to learn at their level and I didn’t really understand, but I don’t want to tell them or they’ll think I’m dumb” (In-centre Haemodialysis 2).</p>
Confronting the stigma of kidney disease	
Multi-generational trepidation	<p>“I knew some old people in town who had been on dialysis and they always looked terrible and died, I thought it was the dialysis that made them look terrible, and made them die, that’s what lots of people think” (Peritoneal Dialysis 2).</p> <p>“My nan used to be on the bag [peritoneal dialysis], she told me not to go on the bag and do haemo [dialysis], she was sick when she was on the bags, and so was my nanas cousin. I haven’t met anyone who did good on PD [peritoneal dialysis]” (Incentre haemodialysis 2)</p> <p>“The D word, dialysis and death” (Peritoneal Dialysis 1)</p>
Shame and embarrassment	<p>“I didn’t tell anybody, I think that’s the problem with half of us Māori, not wanting to tell, I think there’s this thing, that if you’re sick, you’re like, embarrassed of it. You’re not tough, you don’t want people to feel sorry for you, so we don’t tell. I couldn’t even deal with what was hitting me in the face [dialysis]. There’s a thing about kidneys, you know, dialysis, a stigma thing about it” (Peritoneal dialysis 2).</p> <p>“I didn’t want to catch the bus, then everyone knows you’re on the bus and everyone knows you’re on dialysis, and this</p>

	<i>is a little town you know, I don't want everyone to know" (Peritoneal dialysis 2)</i>
<i>Fear and denial</i>	<i>"I had to put it to the back of my head, not think about it" (Peritoneal dialysis 1). "It was a big shock, and I did the normal Māori thing, I pretended it wasn't happening. Didn't listen. Tried to be tough" (Peritoneal dialysis 2). "For people like me, especially Māori men, we're not used to talking about our health and especially being sick or admitting we're sick, it's like you lose some mana [standing] if you are sick, so you just don't deal with it and you don't tell anyone, so you just put your head in the sand a little bit deeper" (Home haemodialysis 1).</i>
<b>Developing and sustaining relationships to support treatment decision-making</b>	
<i>Importance of family/whānau</i>	<i>"It's really hard to explain sometimes that family are first, that I am not an individual, that I am part of a unit, that then no decision is just mine, but it's also really hard to explain to my whanau what is happening with my kidneys when I don't really know it so well myself" (Facility Dialysis 2). "we had a meeting with my nana and my mum, one of the nurses came and talked and that was easier than me talking by myself and trying to answer questions when I didn't know what the right answer was" (Facility Dialysis 1). "If you've got the support of your family and your loved ones, everything is going to be ok" (Home Haemodialysis 1)</i>
<i>Valuing peer support</i>	<i>"They walk you through it. I learnt a lot in those sessions. Because it's from your own culture I guess. You just can see the reality there. I learnt a lot from those classes, more than talking to a doctor" (Facility Dialysis 3). "Knowing first hand" (Pre-dialysis 1)</i>
<i>Building mutual clinician-patient trust</i>	<i>"If they understood more about you they'd do things better and you'd do things better and then I'd trust them if they told me I could go home and do home, you know, but they don't know me and I'm not going to tell them if I don't think they don't care" (Facility dialysis 2). "I guess a lot of that was trusting, and then feeling comfortable about what [name] were telling me, I needed to hear it from someone I trusted" (Peritoneal dialysis 2).</i>
<b>Maintaining cultural identity</b>	
<i>Spiritual connection to land</i>	<i>"If I did have to move into town, then I wouldn't be with my family and they couldn't help me and I couldn't help them with the kids and then what would they do, that wouldn't work, so that's why this stomach one [Peritoneal Dialysis] will be better at home" (Pre-dialysis 1). "My involvement with the community at a lower level, I don't want to lose, so basically in terms of having a dialysis machine at my fingertips at home I still want to know I can do all of those things without any pressure on any of those things, cause I am nothing without those things" (Pre-dialysis 4)</i>
<i>Upholding inner strength/mana</i>	<i>"going to hui [meetings] and going to the marae [meeting house], I guess in a way, that was a lot of the thing why I wanted to do home [dialysis] too. I can work around it. I don't have to miss it" (Home haemodialysis 1). "Cultural too, is the male working thing, the identity of working and being a working man, and the stigma of being sick and on dialysis and not being the tough guy" (Pre-dialysis 3)</i>

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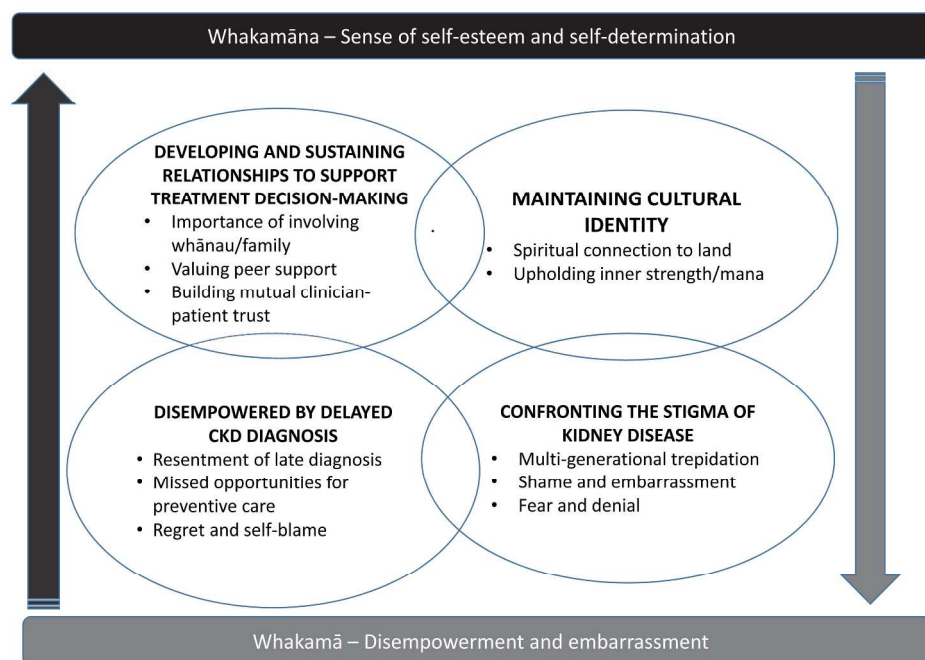


Figure 1: Thematic schema of Māori patients' experiences and perspectives of chronic kidney disease.† Delayed initial CKD diagnosis and missed opportunities for preventive care and loss of trust and disengagement with health services influenced all other aspects of CKD care for Māori patients and led to embarrassment and disengagement of kidney disease and dialysis (Whakamā). Poor communication led to difficulty in patients translating clinical information to enable self-management, and feeling inadequate during clinical encounters. Multigenerational and community experiences of kidney disease invoked fear, which isolated patients from peer and family support accentuated by an individual-based approach to decision-making and education. Having trusting and reciprocated relationships with clinicians was integral to engaging fully with dialysis preparation, enabled self-care, and enhanced inclusion and engagement in patient decision-making. Feeling listened to and being confident to seek support within and outside of their families enabled patients to choose treatments that sustained cultural identity, standing, and roles within the community.

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**Supplementary File. COREQ Checklist**

No.	Item	Comment
<b>Domain 1: Research team and reflexivity</b>		
1	Interview/facilitator	RW ( Domain 1 – refer <i>Page 5</i> )
2	Credentials	RW (PhD candidate, NP, MN, RN, BN) <i>Page 5</i>
3	Occupation	RW (Nurse Practitioner); KH/RM (Health Economists); AT (Qualitative Researcher); SP (Nephrologists) SW (Indigenous Policy) <i>Page 5</i>
4	Gender	RW (Female) <i>Page 5</i>
5	Experience and training	RW has conducted and published qualitative research. <i>Page 5</i>
6	Relationship established	Some participants were known to RW. <i>Page 5</i>
7	Participant knowledge of the interviewer	RW is a Nephrology Nurse Practitioner currently undertaking her PhD. <i>Page 5</i>
8	Interviewer characteristics	RW is a Nephrology Nurse Practitioner with a special interest in pre-dialysis education, patient education and home dialysis. <i>Page 5</i>
<b>Study design</b>		
9	Theoretical framework	Adapted grounded theory and inductive approach (Study Design Refer <i>Page 5 &amp; 6</i> )
10	Sampling	Purposive <i>Page 8</i>
11	Method of approach	Face to face <i>Page 5</i>
12	Sample size	Self-identified as New Zealand Māori and had received education about treatment modalities <i>Page 5</i>
13	Non-participation	N = 0 <i>Page 5</i>
14	Setting of data collection	Patient home or renal clinic <i>Page 5</i>
15	Presence of non-participants	No interpreter required
16	Description of sample	Participants from pre-dialysis and all dialysis modalities <i>Page 5 &amp; Table 1</i>
17	Interview guide	Attached (See Appendix 1)
18	Repeat interviews	Member checking with some participants <i>Page 6</i>
19	Audio/visual recording	Interviews were audio recorded <i>Page 6</i>
20	Field notes	RW recorded field notes <i>Page 6</i>
21	Duration	35 minutes to 120 minutes <i>Page 6</i>
22	Data saturation	Yes <i>Page 6</i>
23	Transcripts returned	No
<b>Analysis and findings</b>		
24	Number of data coders	RW/SP/SW – (Analysis and Findings – See <i>Page 6 - 10</i> )
25	Description of the coding tree	No
26	Derivation of themes	Adapted grounded theory and thematic analysis <i>Page 6</i>
27	Software	HyperRESEARCH <i>Page 6</i>
28	Participant checking	Yes (Member Checking – <i>Page 6</i> )
29	Quotations presented	Yes (See <i>Table 2</i> )
30	Data and findings consistent	Quotations provided to illustrate each theme. (See <i>Table 2</i> )
31	Clarity of major themes	Yes <i>Page 7 &amp; Figure 1</i>
32	Clarity of minor themes	Yes <i>Page 7 &amp; Figure 1</i>



## Patient interview guide

### Exploring patient and carer perceptions and experiences of home dialysis decision making.

#### 1. Introduction

- a. Explanation of study, obtain informed consent, demographic info
- b. Can you tell me about what happened when you first found out you had kidney disease?

#### 2. Information and decisions about dialysis

- a. When did you first hear about dialysis – what kinds of information or education did you get? (*decision-making process, preferences*)
- b. Who else was involved in your education and decision making – how did they influence your thoughts or decisions about dialysis (their manner, shared decision making?)
- c. What sorts of things influenced your beliefs/decisions about the different types of home dialysis (PD, APD, HHD)?
- d. Can you tell me about whether you felt you received enough information to make an informed decision about home haemodialysis or peritoneal dialysis?
- e. If you had to choose again, what sorts of things would help you make decisions about dialysis?

#### 3. Beliefs about home dialysis

- a. What were your first thoughts or reactions when you first heard about PD and home HD?
- b. What do you believe are the potential advantages of PD or HHD compared to dialysis in hospital - why?
- c. What do you believe are the potential risks of PD or HHD compared to dialysis in hospital - why?
- d. If someone asked you what dialysis they should choose, what would you tell them?

#### 4. Living with home dialysis

- a. Have you considered changing your place or type of dialysis– why?
- b. For you, what do you think are potential reasons that would stop you having home dialysis? For others?
- c. In NZ the number of people on home dialysis has reduced over the last 15 years, why do you think that might be?

#### 5. Socioeconomic and cultural issues impacting on home dialysis

- a. Will home dialysis have a financial impact on you or other members of your family - how? (paid work, unpaid work, benefits, expenses e.g. travel, costs, electricity, water)
- b. Do you think there are social or cultural issues that might influence decisions about home dialysis for you or your family?
- c. What are your beliefs/thoughts about financial assistance (i.e. whether adequate and/or accessible); and if it influences their thinking towards home dialysis?
- d. Are there cultural or spiritual factors which influence the place of dialysis for you? (non-medicalised environment, days of rest, whanaunatanga, wairua)
- e. How could the education and support you received about dialysis options better address your cultural or spiritual needs?

#### 6. Conclusion

- a. What kinds of support or services would you need if you did dialysis at home – why?
- b. Is there anything else that you think is important to add?

# BMJ Open

## Māori patients' experiences and perspectives of chronic kidney disease : A New Zealand qualitative interview study

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Manuscript ID	bmjopen-2016-013829.R2
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<b>Primary Subject Heading</b>:	Qualitative research
Secondary Subject Heading:	Health services research, Renal medicine, Public health
Keywords:	NEPHROLOGY, Chronic renal failure < NEPHROLOGY, Dialysis < NEPHROLOGY, End stage renal failure < NEPHROLOGY, QUALITATIVE RESEARCH

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Manuscripts

**Title: Māori patients’ experiences and perspectives of chronic kidney disease: A New Zealand qualitative interview study**

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Word count (body): 2917

**Short title:** Māori patient perspectives of kidney disease

## Abstract

### **Objectives:**

To explore and describe Māori (Indigenous New Zealander's) patients' experiences and perspectives of chronic kidney disease (CKD), as these are largely unknown for Indigenous groups with CKD.

**Design:** Face-to-face, semi-structured interviews with purposive sampling and thematic analysis

**Setting:** Three dialysis centres in New Zealand, all of which offered all forms of dialysis modalities.

**Participants:** 13 Māori patients with CKD and who were either nearing the need for dialysis or had commenced dialysis within the previous 12 months.

**Results:** The Māori concepts of whakamā (disempowerment and embarrassment) and whakamana (sense of self-esteem and self-determination) provided an over-arching framework for interpreting the themes identified: disempowered by delayed CKD diagnosis (resentment of late diagnosis; missed opportunities for preventive care; regret and self-blame); confronting the stigma of kidney disease (multi-generational trepidation; shame and embarrassment; fear and denial); developing and sustaining relationships to support treatment decision-making (importance of family/whānau; valuing peer support; building clinician-patient trust); and maintaining cultural identity (spiritual connection to land; and upholding inner strength/mana).

**Conclusions:** Māori patients with CKD experienced marginalisation within the NZ healthcare system due to delayed diagnosis, a focus on individuals rather than family, multigenerational fear of dialysis, and an awareness that clinicians are not aware of cultural considerations and values during decision-making. Prompt diagnosis to facilitate self-management and foster trust between patients and clinicians, involvement of family and peers in dialysis care, and acknowledging patient values could strengthen patient engagement, and align decision-making with patient priorities.

### **Strengths and Limitations**

- In-depth face-to-face interviewing allowed for detailed understanding of patients’ experiences and values of experiencing kidney disease.
- The feedback from member checking confirmed our interpretation of raw data and grouping of themes and subthemes
- A limitation of this study is that we did not explore patients’ experiences and perspectives of transplantation
- We did not include or evaluate the considerations of wider determinants of health outcomes such as poverty

**Index words**

Indigenous, Māori health; primary care; health indicators; dialysis, chronic kidney disease, end-stage kidney disease, health equity

## Background

Indigenous people worldwide bear a greater burden of disease, disability and death than their non-Indigenous counterparts (1). Māori, the Indigenous people of New Zealand (NZ) experience inequities in most health conditions (2). Māori like many other Indigenous people are affected by end stage kidney disease (ESKD) disproportionately, contributing to persistent and marked inequity in health outcomes (3). Despite stabilized rates of dialysis in higher income countries, the incidence of ESKD continues to increase for Māori. Māori have been consistently 3.5 times more likely to commence dialysis than NZ Europeans, and have a very low likelihood of receiving best practice treatment including pre-emptive kidney transplantation and home-based dialysis (3-7).

Previous literature highlights marginalization for Māori within the NZ health system (8-10). Inequities in provision of preventative care, delayed specialist referral, and lower life expectancy among Indigenous peoples have been extensively quantified and explored using epidemiological methods, but remain incompletely explained by conventional individual and community risk factors for worse health outcomes, including socioeconomic opportunity and comorbidity (11). Previous international research has highlighted specific issues for Indigenous groups in chronic kidney disease (CKD) such as providing culturally competent care (12, 13), the need for flexible family-focused care, managing patient fear of mainstream services, (12) and miscommunication (14), however these issues have not been explored among Māori patients with CKD. This study aims to describe Māori patients' beliefs and experiences of CKD which may elucidate additional contextual, social and organizational factors that contribute to the persistent inequities in health outcomes among Māori with CKD.

**Methods**

This sub-study reports new data specific to Māori participants describing their experiences and beliefs of CKD collected as part of the larger “Home First study”: A semi-structured interview study with adult patients with CKD Stage 4-5D (on dialysis < 1 year) and their caregivers, recruited from 3 nephrology centers in New Zealand (15).

*Participant recruitment and selection*

This analysis specifically focussed on interviews conducted with 13 participants from the Home First study all who self-identified as New Zealand Māori and had received education about treatment modalities (dialysis and kidney transplantation) or who had commenced dialysis within the previous 12 months. Participants were recruited to the study by nephrologists and nurse specialists working across 3 nephrology units (2 large metropolitan urban units and 1 small regional unit). The study was explained to participants, they received written information and an opportunity to ask any questions before written consent was sought. Each unit has an established pre-dialysis program and offer all dialysis modalities. The 3 units were chosen as they offered a mixture of ethnicities representative of the NZ dialysis population. None of the Māori participants approached declined to participate in the study. The Counties Manukau (Ref: 1771), Hawke’s Bay (Ref: 14/06/160) and Capital Coast (Ref: CCDHB13/07/14) Research Ethics Committees approved the study. The study is reported according to the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) (16).

*Data collection*

A semi-structured face-to-face interview was conducted with each participant in the patient’s choice of either their home or a clinic room at the hospital between July 2014 and January 2015 by one

author, who is a female Nurse Practitioner in renal medicine, experienced in qualitative research(RCW), some participants were known to the interviewer. The interview guide included questions about cultural issues that influence decisions about dialysis choice or place of dialysis and how cultural and spiritual needs can be better met. This guide was developed after review of literature and discussion among the research team who consisted of renal clinicians and social scientists experienced in qualitative research and Māori cultural advisors (Supplementary File 1). All interviews were digitally recorded and transcribed with the participants' consent, interview length ranged between 35 and 120 minutes each. Interviews were conducted till data saturation achieved.

### *Data Analysis*

All transcripts were entered into specialized software (HyperRESEARCH; version 3.7.2 ResearchWare Inc) to manage and analyse data. Field notes were also written during interviews. Using adapted grounded theory and thematic analysis, RCW, SW [who identifies as Māori and is an experienced Māori policy writer and cultural advisor], and SCP [nephrologist]) independently coded the transcripts provided by the 13 participants line-by-line, and inductively identified concepts. Similar concepts were then grouped together into themes. The conceptual framework and data interpretation were independently reviewed by three authors (RCW, SW, and SCP) to ensure the themes reflected the full scope of the data and were consistent with the Māori world (Te Ao Māori) view. The coding schema was refined through a series of discussions among the investigator team. Once thematic analysis was complete, we convened a discussion group with four Māori patients including three who had participated in the qualitative interviews. We discussed the preliminary themes to ascertain whether they had been interpreted to reflect the range and depth of perspectives of Māori patients. We also offered an opportunity for patients to discuss and respond to the identified themes (i.e. member checking). Participants from the discussion group validated our interpretation of the findings, sub-themes and themes.



**Results**

Of the 13 participants (Table 1), seven (54%) patients were not yet on dialysis (but had received education about dialysis), three (23%) were treated with home dialysis (either haemodialysis or peritoneal dialysis) and three (23%) were treated with in-centre haemodialysis. The participants were aged from 22 to 72 years (mean age 59 years). Ten participants (77%) had ESKD caused by diabetes. Participant characteristics are presented in Table 1.

We identified the Māori concepts of whakamā (disempowerment and embarrassment) and whakamana (enhanced self-esteem and self-determination) provided an over-arching framework for interpreting the themes identified: disempowered by delayed CKD diagnosis, confronting the stigma of dialysis, developing and sustaining relationships to support treatment, and maintaining cultural identity. Illustrative participant quotes are provided in Table 2. Conceptual links between themes are presented in the Figure 1.

***Disempowered by delayed CKD diagnosis***

*Resentment of late diagnosis*

Some participants experienced delayed diagnosis of CKD despite the patients regularly attending their general practitioner for clinical assessment and diabetes checks. Patients felt frustrated and let-down that although they often voiced specific concerns these were often ignored. Reflecting on previous care participants were angry that their doctor had apparently failed to pay attention to their kidney function during their regular diabetes clinical checks, or neglected to communicate the risk or diagnosis of this to the patient.

*Missed opportunities for preventative care*

Many participants expressed disappointment that the system had let them down, as they were unaware of preventative measures they could have taken to protect their kidney function and delay

dialysis. Participants described how health professionals implied there was an expectation that they already should have an awareness of their kidney problems and how to take care of themselves.

### *Regret and self-blame*

Many participants, particularly those with diabetes expressed regret that they could have avoided or delayed dialysis. Despite many acknowledging they had not known enough to make significant changes earlier. Many blamed themselves for not proactively asking about treatment or lifestyle changes, or trying to understand more about their condition to help them self-manage their care, internalizing a sense of inadequacy. These experiences often led to loss of confidence in their own ability to care for themselves when considering home dialysis and disengagement with pre-dialysis education and dialysis decision-making.

## **Confronting the stigma of dialysis**

### *Multi-generational trepidation*

Stories of sickness and death on dialysis relayed to them by their family members instigated fears and anxiety of what life on dialysis would entail. Some patients had experienced first-hand close or extended family having dialysis, and associated dialysis closely with death. Although participants understood that many of these experiences were personal, and may not be the same for them, the bad memories or tales of dialysis often influenced their own dialysis choice, particularly increasing their fear of home dialysis modalities.

### *Shame and embarrassment*

Participants felt embarrassed and ashamed of having kidney disease and the community stigma associated with kidney disease as it was perceived as self-induced. Many participants, often men associated sickness with weakness and inferiority from their peers. For men who had been always physically active and perceived as strong, the need to be dependent on others and a machine made them feel ashamed and often led to withdrawing from family and not participating in dialysis education and preparation.

*Fear and denial*

Fear of having to live with dialysis created uncertainty of the future for patients and often led to denial of their kidney disease. Many acknowledging that although they were conscious that they were in denial, they didn't have the strategies or support to reach acceptance. For this reason, participants chose to withdraw and were reluctant to participate in dialysis education programs, support groups, or discussing their kidney disease with their families as they found this too confronting. Many described a lack of safe and relevant support networks to "open-up and face their fears" during the process of preparing for dialysis.

***Developing and sustaining relationships to support treatment decision-making***

*Importance of family/whānau*

Participants valued the importance of including family in their early care and decision-making. When not offered the opportunity to involve their family in the decision-making process about dialysis, this led to disconnection within the family and isolation of the patient. In contrast, for patients whose family had been actively involved and therefore had better understanding appreciated how important this had been.

*Valuing peer support*

Participants drew strength from the experience and support of other Māori patients during their preparations for dialysis treatment. For some participants who felt isolated and that no-one would understand the emotions they were dealing with, meeting someone similar who they could relate to allowed them a sense of belonging. Spending time with peers who had successfully established themselves on dialysis treatment reassured and emboldened patients and helped to allay their specific anxieties about dialysis.

### *Building mutual clinician-patient trust*

Participants emphasised the importance of developing and sustaining a trusting and therapeutic relationship with their clinicians. Clinicians were considered more trustworthy when they knew and discussed what was valued and important to the patient. This aspect of care was seen as a crucial stage of maintaining engagement and active participation with clinical services. Participants who believed their clinician did not understand them, or their values, expressed doubt about their clinicians' recommendations, and were more hesitant to consider home dialysis.

Distrusting health professionals was often based on previous negative encounters with the health system. In contrast, other participants told of positive experiences with clinicians who actively tried to engage them and enabled participants to develop trust, allowing the participant to regain power and confidence in their decision-making.

### ***Maintaining cultural identity***

#### *Spiritual connection to land*

For many participants, a marker of quality care was their clinician's acknowledgement and appreciation of the importance of the spiritual connections to their land and people. The importance of these connections was particularly spoken about by participants who lived in rural locations, who had contemplated having to relocate for dialysis. Some rural participants limited the range of dialysis options they considered to avoid extended relocation to the city to establish their dialysis care. This often meant these patients chose a home dialysis option, and predominantly chose peritoneal dialysis, as this had the shortest training time and enabled them to stay on their land.

#### *Upholding inner strength/mana*

When considering choice of dialysis treatment, many spoke of making decisions to enable them to continue in their roles within the family and community, as this was seen as an important aspect of their personal and cultural identity. It was important to participants that clinicians recognised the significance of these roles. Many participants preferred a treatment that would enable continued

employment as this was a highly-valued part of their identity, for some this meant they retained their “mana” inner strength and were still seen as a provider for their family.

Discussion

In this analysis of Māori patients’ beliefs and experiences of CKD, Māori experienced delayed initial CKD diagnosis and missed opportunities for preventive care and loss of trust and disengagement with health services. Patients reported poor communication led to difficulty in patients translating clinical information to enable self-management, and feeling inadequate during clinical encounters. Multigenerational and community stigma and experiences of kidney disease invoked fear and shame, which isolated patients from peer and family support accentuated by an individual-based approach to decision-making and education. Having trusting and reciprocated relationships with clinicians was integral to engaging fully with dialysis preparation, enabled self-care, and enhanced participatory decision-making. Feeling listened to and being confident to seek support within and outside of their families enabled patients to choose treatments that sustained cultural identity.

The findings of our study suggest potential actions to improve kidney care for Māori which may also be relevant for other Indigenous peoples. The patient experiences in this study are concordant with the perspectives of Aboriginal and Torres Strait Islander patients treated with hemodialysis on ways to improve dialysis care including; the importance of family and relationships within healthcare models and service delivery; the need for service provision aligned with cultural preferences; and fear of healthcare processes generated by intergenerational dialysis experiences (12). These findings are also consistent with evidence that delayed initial CKD diagnosis is a potential cause of inequity in healthcare experiences and outcomes for Māori (17, 18) and may account for later presentations to renal services among Indigenous groups, preventing adequate preparation for home dialysis, permanent vascular access, and pre-emptive kidney transplantation (19-21).

The significance of developing and sustaining trusting relationships among clinicians, family, and the community has also been identified as central to improving health gains for Māori (2, 10, 22, 23) and other Indigenous groups (12). Previous literature has identified poor communication between Indigenous patients and clinicians (11-14) as a barrier to Māori accessing quality, effective healthcare and our study supports this and may explain the number of Māori developing ESKD from diabetes. In a previous study reporting Māori patient experiences of heart disease in New Zealand, patients considered that poor communication arose both from a lack of practitioner competency together with discrimination against Māori during clinical care (10). Based on our data, Māori recipients of CKD care in New Zealand do not consider that existing healthcare services are meeting their needs for adequate communication and engagement, with direct negative implications for their disease trajectory and dialysis preparation. Inclusion of Māori health frameworks within professional development to support health practitioners to translate principles of cultural competency into standard clinical practice (24, 25) may help to address ineffective communication with Māori patients, although wider considerations of addressing clinician assumptions, understanding power imbalances between clinicians and patients, and exploring institutional structures that sustain ineffective practices are also likely to be required.

A central finding in this study is the failure of clinicians to disclose an initial diagnosis of CKD to the patient and act on this diagnosis despite regular patient attendance in the primary care setting and regular assessment of glycaemic control and kidney function. These findings are coherent with lower specialist referral rates of Māori than non-Māori by general practice (26) and are particularly important given the high rates of diabetes in Māori. Delayed referral is generally attributed to patient rather than practitioner behavior (11, 27), and requires a wider understanding of this issue and their impact on kidney disease and transplantation in Indigenous groups (28, 29).

The use of patient design thinking and journey mapping (30, 31) might aid in better alignment of health services and policies to patient priorities. Potential areas for development and evaluation

include enhancing peer support and health literacy, developing Māori group education (10), strengthening cultural competencies for clinicians, strengthening family-focused care and education, and co-creating Māori specific care pathways with patients. Programs and care pathways designed and supported by Māori may also help to address distrust and increase engagement with health systems.

A strength of our study was the addition of member checking to validate the findings and interpretation of qualitative interviews. The feedback from member checking confirmed our interpretation of raw data and grouping of themes and subthemes. Our study does have limitations that should be considered when interpreting the findings. First, we did not include or evaluate in our study the consideration of the wider social determinants of health outcomes such as poverty, social, and educational opportunity (32-34). Second, the interviewer (RCW) is non- Māori and therefore may have overlooked cultural nuances, however we minimised this by ensuring involvement and guidance by Māori health experts and advisors from development of the research questions through to interpretation and coding of findings. Facilitating the group discussion to explore interpretation of findings (member checking) also ensured we had interpreted the data correctly and our themes were appropriate. Third, the interviewer was known to participants from one centre and this relationship may have resulted in self-censoring answers; although when compared to participants from other centres, similar themes were identified. Finally, we did not explicitly explore patient experiences of preparing for and accessing kidney transplantation. Given kidney transplantation is less common in Indigenous people (35, 36) and best practice care for ESKD this is a vital aspect worthy of exploration to improve health outcomes for Māori and is recommended for future research. Further research may explore and identify Māori patient's priorities for care and future research and explore in more detail the experiences of institutional racism Māori experience in CKD.

In conclusion, Māori patients with chronic kidney disease experienced marginalization within the New Zealand healthcare system due to delayed diagnosis, a focus on individuals rather than

family/whānau within health processes, multigenerational negative experiences of dialysis, and diminished awareness of patient values during decision-making. Prompt diagnosis to facilitate self-management and foster trust between patients and clinicians, involvement of family and peers in dialysis care, and acknowledging patient values could strengthen patient engagement, facilitate treatment planning and self-management, and align decision-making with patient priorities.

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**Contributors:** RW designed the study carried out the patient interviews, coded data, participated in thematic analysis and drafted the manuscript. SP and SW also independently coded data. RLM, KH and AT assisted in design of the study, participated in the thematic analysis and critical review of the first and subsequent manuscript drafts. SW participated in thematic analysis and critical review of first and subsequent drafts.

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Table 1 – Patient Characteristics

Characteristics	Patients No. (%)
Age category	
20-40y	1 (8)
41-60y	3 (23)
61-80y	9 (69)
Dialysis Modality	
Pre-dialysis	5 (38)
Peritoneal dialysis	4 (31)
Home haemodialysis	1 (8)
In-centre (facility) dialysis	3 (23)
Marital Status	
Married/De facto	7 (54)
Divorced/Separated	0
Single	3 (23)
Widowed	3 (23)
Highest Level Education	
Some Primary School	4 (31)
Some Secondary	3 (23)
Completed Certificate or Diploma	3 (23)
Completed Degree/Higher	3 (23)
Employment status	
Full-time	4 (31)
Part-time/casual	2 (15)
Not employed	2 (15)
Social Welfare Beneficiary	3 (23)
Retired	2 (15)
Estimated gross annual household income	
NZ\$10-30,000	2 (15)
NZ\$31-50,000	7 (54)
NZ\$51-70,000	4 (31)
NZ\$71-100,000	0
>NZ\$101,000	0
Time to dialysis unit (travelled one way)	
0-20 mins	5 (65)
21-40 mins	4 (31)
41-120 mins	0
>120 mins	4 (31)

NB: NZ Annual Household Income\$85,000 (2013)

For peer review only

Table 2 – Participants Illustrative Quotes

Themes	Participant Quotes
Disempowered by delayed CKD diagnosis	
Resentment of late diagnosis	<p>“I kept going to him [General Practitioner], saying there’s something else wrong, it’s just not just my sugar diabetes that’s wrong, there’s something else” (Pre-dialysis 4).</p> <p>“why hasn’t someone in the medical profession told me [about kidney disease], I’m not just coming in to have the wipers fixed or the door handle fixed, I’m coming in for you to give me a going over from top to bottom” (Pre-dialysis 2).</p>
Missed opportunities for preventative care	<p>“I just didn’t understand it, and so I didn’t make the changes to my diabetes it just didn’t sound like something I needed to listen to, like it was a problem” (Peritoneal Dialysis 4).</p> <p>“It was really vague, your creatinine or something is really high, or you’ve got protein in your urine or something or rather, but no explanation of what that meant, but like I should automatically know what it meant and know what that meant for me and what to do about it” (Peritoneal Dialysis 3).</p>
Regret and self-blame	<p>“I hated going to the doctor, being told off, but now when I think back, I was dumb, I didn’t go, didn’t take my insulin, didn’t take my pills, drunk too much, smoked, you know everything you shouldn’t do” (Peritoneal Dialysis 4).</p> <p>“I’m embarrassed to say, it’s actually a lot of education to learn it [home hemodialysis], I have to learn how to do the machine, and they said its hard, and it takes a long time, I guess I’m just not sure if I can learn it, and I’m not that good, and I felt a lot of pressure to learn at their level and I didn’t really understand, but I don’t want to tell them or they’ll think I’m dumb” (In-centre Haemodialysis 2).</p>
Confronting the stigma of kidney disease	
Multi-generational trepidation	<p>“I knew some old people in town who had been on dialysis and they always looked terrible and died, I thought it was the dialysis that made them look terrible, and made them die, that’s what lots of people think” (Peritoneal Dialysis 2).</p> <p>“My nan used to be on the bag [peritoneal dialysis], she told me not to go on the bag and do haemo [dialysis], she was sick when she was on the bags, and so was my nanas cousin. I haven’t met anyone who did good on PD [peritoneal dialysis]” (Incentre haemodialysis 2)</p> <p>“The D word, dialysis and death” (Peritoneal Dialysis 1)</p>
Shame and embarrassment	<p>“I didn’t tell anybody, I think that’s the problem with half of us Māori, not wanting to tell, I think there’s this thing, that if you’re sick, you’re like, embarrassed of it. You’re not tough, you don’t want people to feel sorry for you, so we don’t tell. I couldn’t even deal with what was hitting me in the face [dialysis]. There’s a thing about kidneys, you know, dialysis, a stigma thing about it” (Peritoneal dialysis 2).</p> <p>“I didn’t want to catch the bus, then everyone knows you’re on the bus and everyone knows you’re on dialysis, and this</p>

	<i>is a little town you know, I don't want everyone to know" (Peritoneal dialysis 2)</i>
<i>Fear and denial</i>	<i>"I had to put it to the back of my head, not think about it" (Peritoneal dialysis 1). "It was a big shock, and I did the normal Māori thing, I pretended it wasn't happening. Didn't listen. Tried to be tough" (Peritoneal dialysis 2). "For people like me, especially Māori men, we're not used to talking about our health and especially being sick or admitting we're sick, it's like you lose some mana [standing] if you are sick, so you just don't deal with it and you don't tell anyone, so you just put your head in the sand a little bit deeper" (Home haemodialysis 1).</i>
<b>Developing and sustaining relationships to support treatment decision-making</b>	
<i>Importance of family/whānau</i>	<i>"It's really hard to explain sometimes that family are first, that I am not an individual, that I am part of a unit, that then no decision is just mine, but it's also really hard to explain to my whanau what is happening with my kidneys when I don't really know it so well myself" (Facility Dialysis 2). "we had a meeting with my nana and my mum, one of the nurses came and talked and that was easier than me talking by myself and trying to answer questions when I didn't know what the right answer was" (Facility Dialysis 1). "If you've got the support of your family and your loved ones, everything is going to be ok" (Home Haemodialysis 1)</i>
<i>Valuing peer support</i>	<i>"They walk you through it. I learnt a lot in those sessions. Because it's from your own culture I guess. You just can see the reality there. I learnt a lot from those classes, more than talking to a doctor" (Facility Dialysis 3). "Knowing first hand" (Pre-dialysis 1)</i>
<i>Building mutual clinician-patient trust</i>	<i>"If they understood more about you they'd do things better and you'd do things better and then I'd trust them if they told me I could go home and do home, you know, but they don't know me and I'm not going to tell them if I don't think they don't care" (Facility dialysis 2). "I guess a lot of that was trusting, and then feeling comfortable about what [name] were telling me, I needed to hear it from someone I trusted" (Peritoneal dialysis 2).</i>
<b>Maintaining cultural identity</b>	
<i>Spiritual connection to land</i>	<i>"If I did have to move into town, then I wouldn't be with my family and they couldn't help me and I couldn't help them with the kids and then what would they do, that wouldn't work, so that's why this stomach one [Peritoneal Dialysis] will be better at home" (Pre-dialysis 1). "My involvement with the community at a lower level, I don't want to lose, so basically in terms of having a dialysis machine at my fingertips at home I still want to know I can do all of those things without any pressure on any of those things, cause I am nothing without those things" (Pre-dialysis 4)</i>
<i>Upholding inner strength/mana</i>	<i>"going to hui [meetings] and going to the marae [meeting house], I guess in a way, that was a lot of the thing why I wanted to do home [dialysis] too. I can work around it. I don't have to miss it" (Home haemodialysis 1). "Cultural too, is the male working thing, the identity of working and being a working man, and the stigma of being sick and on dialysis and not being the tough guy" (Pre-dialysis 3)</i>

Figure Legends

**Figure 1:** Thematic schema of Māori patients’ experiences and perspectives of chronic kidney disease.

Delayed initial CKD diagnosis and missed opportunities for preventive care and loss of trust and disengagement with health services influenced all other aspects of CKD care for Māori patients and led to embarrassment and disengagement of kidney disease and dialysis (Whakamā). Poor communication led to difficulty in patients translating clinical information to enable self-management, and feeling inadequate during clinical encounters. Multigenerational and community experiences of kidney disease invoked fear, which isolated patients from peer and family support accentuated by an individual-based approach to decision-making and education. Having trusting and reciprocated relationships with clinicians was integral to engaging fully with dialysis preparation, enabled self-care, and enhanced inclusion and engagement in patient decision-making. Feeling listened to and being confident to seek support within and outside of their families enabled patients to choose treatments that sustained cultural identity, standing, and roles within the community.



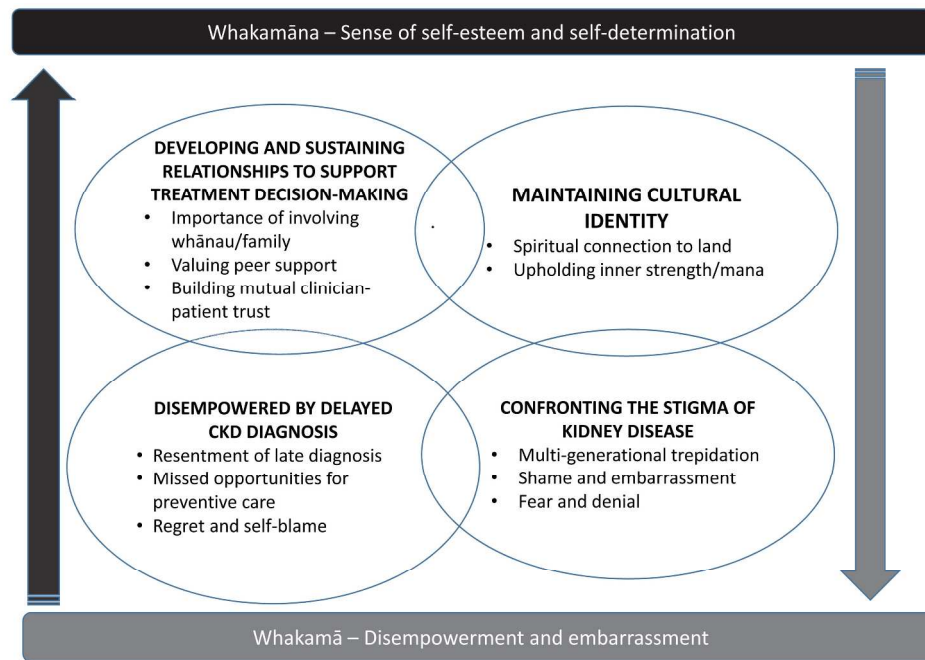


Figure 1: Thematic schema of Māori patients' experiences and perspectives of chronic kidney disease.

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**Supplementary File. COREQ Checklist**

No.	Item	Comment
<b>Domain 1: Research team and reflexivity</b>		
1	Interview/facilitator	RW ( Domain 1 – refer <i>Page 5</i> )
2	Credentials	RW (PhD candidate, NP, MN, RN, BN) <i>Page 5</i>
3	Occupation	RW (Nurse Practitioner); KH/RM (Health Economists); AT (Qualitative Researcher); SP (Nephrologists) SW (Indigenous Policy) <i>Page 5</i>
4	Gender	RW (Female) <i>Page 5</i>
5	Experience and training	RW has conducted and published qualitative research. <i>Page 5</i>
6	Relationship established	Some participants were known to RW. <i>Page 5</i>
7	Participant knowledge of the interviewer	RW is a Nephrology Nurse Practitioner currently undertaking her PhD. <i>Page 5</i>
8	Interviewer characteristics	RW is a Nephrology Nurse Practitioner with a special interest in pre-dialysis education, patient education and home dialysis. <i>Page 5</i>
<b>Study design</b>		
9	Theoretical framework	Adapted grounded theory and inductive approach (Study Design Refer <i>Page 5 &amp; 6</i> )
10	Sampling	Purposive <i>Page 8</i>
11	Method of approach	Face to face <i>Page 5</i>
12	Sample size	Self-identified as New Zealand Māori and had received education about treatment modalities <i>Page 5</i>
13	Non-participation	N = 0 <i>Page 5</i>
14	Setting of data collection	Patient home or renal clinic <i>Page 5</i>
15	Presence of non-participants	No interpreter required
16	Description of sample	Participants from pre-dialysis and all dialysis modalities <i>Page 5 &amp; Table 1</i>
17	Interview guide	Attached (See Appendix 1)
18	Repeat interviews	Member checking with some participants <i>Page 6</i>
19	Audio/visual recording	Interviews were audio recorded <i>Page 6</i>
20	Field notes	RW recorded field notes <i>Page 6</i>
21	Duration	35 minutes to 120 minutes <i>Page 6</i>
22	Data saturation	Yes <i>Page 6</i>
23	Transcripts returned	No
<b>Analysis and findings</b>		
24	Number of data coders	RW/SP/SW – (Analysis and Findings – See <i>Page 6 - 10</i> )
25	Description of the coding tree	No
26	Derivation of themes	Adapted grounded theory and thematic analysis <i>Page 6</i>
27	Software	HyperRESEARCH <i>Page 6</i>
28	Participant checking	Yes (Member Checking – <i>Page 6</i> )
29	Quotations presented	Yes (See <i>Table 2</i> )
30	Data and findings consistent	Quotations provided to illustrate each theme. (See <i>Table 2</i> )
31	Clarity of major themes	Yes <i>Page 7 &amp; Figure 1</i>
32	Clarity of minor themes	Yes <i>Page 7 &amp; Figure 1</i>

## Patient interview guide

### Exploring patient and carer perceptions and experiences of home dialysis decision making.

#### 1. Introduction

- a. Explanation of study, obtain informed consent, demographic info
- b. Can you tell me about what happened when you first found out you had kidney disease?

#### 2. Information and decisions about dialysis

- a. When did you first hear about dialysis – what kinds of information or education did you get? (*decision-making process, preferences*)
- b. Who else was involved in your education and decision making – how did they influence your thoughts or decisions about dialysis (their manner, shared decision making?)
- c. What sorts of things influenced your beliefs/decisions about the different types of home dialysis (PD, APD, HHD)?
- d. Can you tell me about whether you felt you received enough information to make an informed decision about home haemodialysis or peritoneal dialysis?
- e. If you had to choose again, what sorts of things would help you make decisions about dialysis?

#### 3. Beliefs about home dialysis

- a. What were your first thoughts or reactions when you first heard about PD and home HD?
- b. What do you believe are the potential advantages of PD or HHD compared to dialysis in hospital - why?
- c. What do you believe are the potential risks of PD or HHD compared to dialysis in hospital - why?
- d. If someone asked you what dialysis they should choose, what would you tell them?

#### 4. Living with home dialysis

- a. Have you considered changing your place or type of dialysis– why?
- b. For you, what do you think are potential reasons that would stop you having home dialysis? For others?
- c. In NZ the number of people on home dialysis has reduced over the last 15 years, why do you think that might be?

#### 5. Socioeconomic and cultural issues impacting on home dialysis

- a. Will home dialysis have a financial impact on you or other members of your family - how? (paid work, unpaid work, benefits, expenses e.g. travel, costs, electricity, water)
- b. Do you think there are social or cultural issues that might influence decisions about home dialysis for you or your family?
- c. What are your beliefs/thoughts about financial assistance (i.e. whether adequate and/or accessible); and if it influences their thinking towards home dialysis?
- d. Are there cultural or spiritual factors which influence the place of dialysis for you? (non-medicalised environment, days of rest, whanaunatanga, wairua)
- e. How could the education and support you received about dialysis options better address your cultural or spiritual needs?

#### 6. Conclusion

- a. What kinds of support or services would you need if you did dialysis at home – why?
- b. Is there anything else that you think is important to add?