

“All they said was my kidneys were dead”: Indigenous Australian patients’ understanding of their chronic kidney disease

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Indigenous Australians bear a disproportionate share of the burden from chronic kidney disease. Due to ongoing poor access to kidney transplantation,¹ the mainstay of treatment for their end-stage kidney disease (ESKD) is physically and socially demanding maintenance haemodialysis. Patients have the onerous responsibility of attending dialysis three times a week, taking multiple medications and following strict dietary restrictions.

Exploring accounts of patients’ “lived experience” of chronic disease can provide insights into their engagement with treatment.² How patients understand their disease and its causation moderates their coping with, and participation in, treatment.^{3–6} Understanding the causes of chronic kidney disease can be difficult, with current biomedical thinking pointing to environmental, lifestyle, developmental and genetic factors.⁷ This complexity challenges effective communication with patients, and such difficulties are intensified in cross-cultural settings, aggravated by differences in language and in views on health and illness.⁸

As part of a larger investigation of barriers faced by Indigenous Australians in obtaining a transplant, we aimed to explore the views of Indigenous Australians with ESKD compared with those of other patients through in-depth interviews. We investigated patients’ views on causation and explored how their views might affect their coping and engagement with treatment.

METHODS

Study design

A large interview study was conducted in 2005–2006 as part of the IMPAKT (Improving Access to Kidney Transplants) study.⁹ Five investigators conducted semistructured, in-depth interviews with patients with ESKD, their health professionals and other relevant people. Wherever possible, we used peer-to-peer interviews: a nephrologist interviewed the nephrologists, and an Indigenous Australian researcher interviewed many of the Indigenous Australian patients.

The interview structure aimed to elicit a life-story narrative that made sense to the

ABSTRACT

Objectives: To explore the understanding of both Indigenous and non-Indigenous Australians with end-stage kidney disease (ESKD) about the cause of their disease, and how this understanding could affect patients’ engagement with their treatment.

Design, setting and participants: Qualitative study conducted in 2005–2006 in nine hospital renal units and 17 associated dialysis centres in four states and the Northern Territory as part of the IMPAKT (Improving Access to Kidney Transplants) study. In-depth interviews were conducted with 146 Indigenous and 95 non-Indigenous Australians with ESKD, covering personal history of illness, social and psychosocial context, attitudes to treatments including transplantation, adequacy of information and communication, and satisfaction with services.

Results: Indigenous Australians were less certain about the cause of their illness and reported feeling uninformed but eager for information. They commonly reported lifestyle factors as potentially causal, with profound confusion about the role of alcohol. Indigenous Australians had considerable ambivalence towards biomedical explanations.

Conclusions: Indigenous Australians are confused, frustrated and feel poorly informed about their illness. This study confirms the need to develop shared understandings about chronic kidney disease and to put in place the high-quality and appropriate educational resources that patients need.

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patient.¹⁰ The conversational frame, recognisable and engaging for patients, covered personal history of illness, social and psychosocial context, attitudes to treatments including transplantation, adequacy of information and communication, and satisfaction with services. Analysis here focuses on the patients’ descriptions of the history of their illness, particularly of perceived causes.

Participants and setting

The nine hospital renal units and 17 associated dialysis centres that treat the majority of Indigenous Australian ESKD patients were included. A maximum diversity sampling strategy helped select patients on the basis of ethnicity, location, age, sex, treatment type, and illness duration.

Collection of data

Almost all interviews were conducted individually and face-to-face by three investigators (JD, CP, KA). They were digitally recorded and transcribed. Most of the Indigenous Australians spoke first languages other than English and had limited literacy. Although intended, it proved difficult to work through service-based interpreters. To

elicit more nuanced perceptions and attitudes from some patients, seven interviews were conducted entirely in Pitjantjatjara language by fluent non-Indigenous contract interviewers. These interviews were fully translated and transcribed.

Analysis

Thematic content analysis of the transcriptions was performed with QSR NVivo 7 (QSR International, Melbourne, Vic). Based on reading and coding a selection of 11 interviews, four investigators discussed and negotiated major thematic groups of the material. Two investigators (JD, KA) then coded all interviews, each separately coding a range of different topics. Participant demographics were self-reported. Descriptive statistics were generated using SPSS 15.0 for Windows (SPSS Inc, Chicago, Ill, USA).

Ethics approval

The study was approved by 14 relevant jurisdictional ethics committees, including six all-Indigenous committees. Site-based reference groups, including staff from some Aboriginal community-controlled health organisations, represented staff and institutional interests.

Number of patients interviewed, by ethnicity and state or territory

State or territory	Indigenous	Non-Indigenous	Total
New South Wales	10	28	38
Western Australia	45	20	65
Queensland	38	25	63
South Australia	10	16	26
Northern Territory	43	6	49
Total	146	95	241

RESULTS

Interviews were conducted with 146 Indigenous and 95 non-Indigenous ESKD patients in four states and the Northern Territory (Box).

There was great diversity in patients' views and understanding about causation of kidney disease. The Indigenous Australians' responses differed markedly from those of non-Indigenous respondents: uncertainty and disconnection from information were typical. This fostered ambivalence about biomedical explanations, which, in turn, affected their engagement with treatment.

Three interrelated factors are explored below: uncertainty about causation and perceived exclusion from information; frequent but tentative reporting of lifestyle factors; and ambivalence towards biomedical explanations.

Uncertainty about causation and perceived exclusion from information

They just say "end-stage" — that's all I was told. (Aboriginal man, 3–5 years on haemodialysis)

Uncertainty about what had caused their disease was common among Indigenous Australians. Many were unaware of or speculated about causes. They felt strongly that they were inadequately informed, were frustrated, and wanted more information.

An Aboriginal man aged in his mid 40s, M1, who had been on haemodialysis for 1–2 years, was living in a regional community before commencing dialysis. He then began renting city accommodation to obtain treatment at a major hospital, and attended an Aboriginal Medical Service for other health issues. His first language is English, and he was educated to early secondary school

level. His mother had been on dialysis before she died.

Interviewer: *Can you tell me what happened to your kidneys?*

M1: At that time I was living in [a regional town]. I was involved in alcohol and everything else. Ended up in the hospital three or four times last year. They were saying it was through my kidney was failing. They tell you it's there, hanging on, but it is not strong enough to continue the journey, I don't think. That was the impression I was getting from them. I'm not sure whether that's 100% correct, but that's what they were saying on their part. So I do understand that you can be deceived many times from other people as well.

Did they tell you what the cause was?

Oh, they were looking to find the cause themselves. And they didn't understand why, though.

So to this day, do they know what the cause was or you don't know to this day?

I don't know still to this day. I'm trying to find out. I wanna find out. I wanna know why it's stopped, what is the major cause of it, what made 'em stop. That's something I'm in the dark about. So I don't know much about it.

... do you get a full explanation of everything?

They don't give me full explanation about certain things. Only when it's called for to share something, I suppose ... My question is, how does, or why does, your kidney fail?

These comments are typical of Indigenous Australians' accounts. When asked about causation, almost a third said they did not know or could not speculate. Like M1, other people suggested that their health professionals were also unsure.

Nurses and doctors at the renal unit don't really tell us or pinpoint the problem of what we had, you know. I'd like to know ... I got the feeling that nobody really knows how people get a renal problem. (Aboriginal man, <6 months on peritoneal dialysis)

Several patients, both Indigenous and non-Indigenous, described receiving varying explanations from different health professionals. Many were waiting for more information, perceiving it to be the responsibility of the health professional to provide information, rather than theirs to seek it.

They should come around and keep you more informed, I think. I seem to be starved of information about what is happening inside. (Torres Strait Islander man, 6–12 months on haemodialysis)

Another articulated difficulty in asking for information:

I don't know how to talk to the nurse or doctor. He comes down here and just checks out how we're looking after our body. It's not enough time. (Aboriginal woman, 3–5 years on haemodialysis)

The translated response of a Pitjantjatjara-speaking patient, asked why he did not seek more information, echoes this difficulty:

You don't go knocking on their door, [that's the] "danger one". The door is locked. They sit behind closed doors. (Aboriginal man, 3–5 years on haemodialysis)

By contrast, non-Indigenous respondents displayed greater confidence in their knowledge. Their accounts did not exhibit a similar sense of disconnection from sources of information. When asked about the cause of her disease, one non-Indigenous respondent replied:

At 16, I got diagnosed as having reflux nephropathy, which means that your ureter, the valve in the ureter that stops your urine from backwashing up to your kidney ... it wasn't formed properly. So that destroyed one kidney. And then that started to destroy the other kidney ... as time goes by, it's chronic renal failure, so it's a gradual thing over time. (Non-Indigenous woman, 3–5 years on haemodialysis)

Some Indigenous Australians pointed to difficulty understanding the language and terminology of health professionals.

[The doctors] started telling me what's going on and that. But they got a very funny way of communicating with people. When they talk to us, they need to bring it down and explain it to us. (Aboriginal woman, <6 months on peritoneal dialysis)

Others said that they might have been told the cause at the start of treatment, but were too ill to understand. One young woman, recently rushed onto dialysis after collapsing, said:

Well, I'm not sure [of the cause], because I had high blood pressure, so I'm not quite sure if that did it. I was too sick to even get any information,

most of the time I was vomiting and all that. (Aboriginal woman, <6 months on haemodialysis)

Some regarded the lack of information as deliberate withholding. M1 was sceptical and felt that he was not privy to all the information — “only when it’s called for”. In the translated words of a Pitjantjatjara-speaking patient:

There’s a whole lot of us who just don’t understand what’s going on. They know though, the doctors and the nurses know, but they don’t tell us. They don’t talk with us and we’re oblivious. (Aboriginal man, 3–5 years on haemodialysis)

For many, their sense of disconnection from information left them feeling ignorant and disempowered.

That’s what I’m mad about — the specialist has not told me exactly what the cause is. One of my kidneys is gone and the other one is diseased. That is all the information I’m told. (Aboriginal and Torres Strait Islander man, >6 years on haemodialysis)

A widespread desire for more information was clearly articulated. A Pitjantjatjara-speaking patient indicated how such uncertainty can torment people:

They didn’t tell me anything. What they said was, “Look, you’re sick”. They didn’t really talk to me about it ... I really didn’t understand. I was asking myself, “How did I become sick?” Yeah, I actually think about these things. I think, “Why did I become sick? How did I become sick?” I might be sitting down thinking that or lying down thinking that. (Aboriginal man, 3–5 years on haemodialysis)

Frequent but tentative reporting of lifestyle factors

Maybe I was having too much sugar ... but really, they haven’t really talked to me about that. (Aboriginal man, 3–5 years on haemodialysis)

Respondents identified many potentially causative factors, in six broad categories:

- pre-existing diseases/conditions;
- lifestyle;
- medication usage/side effects;
- environmental/work-related;
- birth defects; and
- accidents/other precipitating events.

Non-Indigenous Australians most commonly identified having a pre-existing disease or illness as a factor. Indigenous Australians spoke more about lifestyle-

related factors, which were rarely mentioned by non-Indigenous respondents. However, many Indigenous Australians seemed tentative about the extent to which these factors were responsible for their disease. The role of alcohol was a particular source of confusion: Indigenous Australians often reported receiving mixed messages from health professionals.

While poor diet, alcohol, smoking, stress and lack of exercise accounted for almost half of all factors cited by Indigenous Australians, the causative role of these factors confused and mystified many.

I don’t know what it was [that caused my kidney disease]. My family are all finished. We was all strong and I got [the disease]. Maybe it was from drinking before. I used to eat all sorts of stuff — sweet and fat things. I don’t know what started it. (Aboriginal woman, 1–2 years on peritoneal dialysis)

Some of the Indigenous Australians who identified lifestyle factors blamed themselves, while others pointed to external causes, such as the lack of disease prevention information.

Sometimes I get angry with myself because I know I done the wrong thing in my life ... this is all from alcohol. (Aboriginal man, <1 year on haemodialysis)

In terms of blame for our illnesses, we really had no awareness. We should have been told the story before, much earlier. (Aboriginal man, <2 years on haemodialysis)

Many Indigenous Australians commented on the role of alcohol. This common causal association was described by some as a source of distressing stigmatisation of dialysis patients.

Everyone seems to think it’s all caused solely by alcohol. So they are ignorant. That’s what they say: “All you Indigenous people who have got kidney disease, you’re all alcoholics”. That’s what they think. I just shake my head. I don’t want to get upset arguing with them ... it’s like saying all asthmatics are smokers. (Torres Strait Islander man, 6–12 months on haemodialysis)

M2, an Aboriginal man aged in his mid 40s, had been receiving haemodialysis in a remote unit for 1–2 years, lived in and owned his own home, and was employed full-time before starting dialysis. English is not his first language.

Interviewer: *How long did you say you’ve been here on the dialysis?*

M2: I’ve been, first of all, I got crook at my house, at my camp. I got short-winded. Too much drinking — because I been drinking through the rain, wet through, got soaked and everything. And then I went back home and that’s where I got sick. Couldn’t breathe properly and then I had to go down to the clinic at [town] and went to hospital there.

What did this kidney sickness come from, what do you reckon?

I don’t know. Some people say drinking. I don’t know, I don’t know. But once I’ve been drinking through the rain and the wind. I reckon I got sick from that, I don’t know. But what you reckon?

While some patients, like M2, reported being told that their disease was due to alcohol, others had been told that alcohol was not causative. Some Indigenous Australians wanted to warn their family and community that alcohol misuse caused kidney disease.

It’s a very hard lesson to learn. And I try to tell my family, “Don’t drink; you’ll stuff your kidneys up”. (Aboriginal woman, <1 year on haemodialysis)

Ambivalence towards biomedical explanations

I wouldn’t know ‘cause I was born and raised in the bush. (Aboriginal woman, 3–5 years on haemodialysis)

A certain ambivalence towards biomedical explanations was common in Indigenous Australians. Unlike their non-Indigenous counterparts, they described some scepticism and mistrust of the explanations given by health professionals. This was heightened by their perceived lack of information, as well as by incongruities between their understanding of biomedical explanations and their own experiences, observations and beliefs.

The following interview excerpt reveals some of these conflicts, which undermine trust in health professionals’ explanations and advice. M3, who is married and aged in his mid 40s, had been on haemodialysis in a satellite dialysis unit in a major metropolitan area for 1–2 years. He was living in a hostel in a major city to obtain treatment. Previously, M3 and his wife lived in a very remote community, where he was employed full-time. English is not his first language.

I knew that I was sick, because of my diabetes. I was on tablets, which I didn't take my tablet sometime ... I knew it, that's all. ... But I said, "I gotta do my own things. I'm a bushman. I go out fishing, do my cultural stuff". And you know, I think, to me, the way of being treated by the health people, I'm talking the medication stuff, I think the [diabetes] medication didn't work on me. It didn't work. It couldn't change my situation. Because when I started like going out, doing my cultural stuff — going out fishing, dugong, turtle, mangrove worms — that changed me a bit. And I started being like smart-arse, smart, you know, talking to the doctor, ignoring him and all this. And he said, "You getting sicker and sicker because you've got sugar, you got diabetes". I said, "I know I'm a diabetic bloke, I gotta stay in the bush, that's what I do. I look after myself. And you're telling me my kidney's gone?" I said, "I can't believe that because, in the first place, you should come over. Come over and talk to us people, you know. We won't chase you with a spear or something. Come and sit with us, you know, you're welcome to come and tell us. We want to know all these things". And [health providers] say, "Hey, you're taking too much sugar, take it easy". "Sugar's nothing!", some [Aboriginal] people say — I'm talking about old generation — "Why you telling me about my diabetes? In the first place, who brought the sugar here? You!" They point to the white people, you know. "You brought the sugar here. We can't stop now because you caught us, it's sweet! We like it! [laughter] You can't tell us to stop!"

Beyond his ambivalence, M3 describes a broader scepticism towards biomedical explanations, which is, he believes, common within his community. Other respondents pointed to the introduction of Western food and lifestyle as the major cause.

Before, we were living by eating really good food. Eating strong food. Now we are all sick. Whitefella food made us sick. (Aboriginal man, 3–5 years on haemodialysis)

Another pointed specifically to sugar:

You know, long time [ago], nothing been happen like that, sabby [you know]? No kidney trouble [for] anybody. We used to live in the bush, no sickness, no kidney [trouble], nothing. This new generation, I seen 'em kidney

[trouble], young people and all. Might be sugar got the poison eh? Sugarcane, you know ... and it makes you damage 'em kidney. (Aboriginal man, 3–5 years on haemodialysis)

The historical, cultural and social background of Indigenous Australians means that trust in the advice of health professionals is not assured. Doubts about the truth and motives behind biomedical diagnoses are apparent in varying degrees.

Well, I had some problem with my kidney. It's sudden because I didn't know and the doctor found it ... Every time they talk about the kidney and how that works, they scare you, you know, by saying this. It may be true or not, you know. (Aboriginal man, 3–5 years on haemodialysis)

Few of the causes to which Indigenous Australians attributed their illness were "spiritual" or "religious"; most that were directly reported accord with biomedically recognised risk factors. While describing their own condition in these terms, some suggested that other community members thought differently.

A lot of the young Indigenous ones from out there [a remote community], they still regard it as being "caught". Like if someone has a kidney problem, that's when he was "caught" or what do you call it? Like black magic. (Aboriginal woman, >6 years on haemodialysis)

A lot of the time people think it's witchcraft, you know. "Oh, that person made me sick, you know. That person sung me, sung me, and made me get sick." That's our belief anyway, you know, Aboriginal way. (Aboriginal man, <6 months on peritoneal dialysis)

This kind of indirect reporting of attributed causes might also be a way to express ideas about which people are undecided, tentative or wary of a negative reaction from non-Indigenous people.

Impact of uncertainty and ambivalence on patients' engagement with treatment

Uncertainty and ambivalence about disease causation were associated with poor engagement by some patients in their treatment regimen. A certain mistrust in, or wariness of, health professionals is exacerbated for many Indigenous Australians by their sense of being inadequately informed or excluded from information about the cause of their illness.

While declaring that she did not pay attention to the advice of her doctors, one patient blamed them for not informing her early on that she had diabetes and kidney disease:

I blamed the doctor because they the one made me think nothing, diabetic and kidney ... I still blame them ... I don't care what these mobs say, I like my salt on everything I eat. (Aboriginal woman, 3–5 years on haemodialysis)

Such comments highlight the importance of the quality of the relationship and communication between the patient and the health professional. While improving Indigenous Australians' understanding of their disease will not of itself ensure compliance with treatment, it would appear to be the only basis for informed engagement.

DISCUSSION

In 2002, after analysing videotaped interactions between patients and health care professionals in a Darwin dialysis unit, the "Sharing the true stories" team reported pervasive miscommunication and a lack of shared understanding of fundamental concepts concerning kidney disease.⁸ Our current project, amalgamating insights from 146 Indigenous Australians receiving treatment in urban, rural and remote sites across Australia, shows that little has changed. More alarmingly, it notes Indigenous Australians' frustration and ambivalence and suggests potent reasons for their apparent "non-compliance" with treatment.

Many Indigenous patients articulated a strong desire to be better informed and outlined the difficulties and tensions experienced in obtaining and understanding such information. Non-Indigenous respondents, by contrast, were substantially more confident. Indigenous Australians feel excluded from information, alienated from the health care system, and have difficulties engaging in treatment. Confusion and stigma surrounding lifestyle factors, particularly alcohol misuse, further perplex them.

Consistent with Lawton and colleagues' theories,⁴ our findings support the notion that patients' everyday experiences and their broader social, historical and cultural circumstances together influence their views and understanding about health and illness. The ambivalence of some Indigenous Australians towards biomedical explanations clearly weakened their confidence in the prescribed treatment regimen and their ability or resolve to engage with it. Their com-

mon reports of waiting for more information might be interpreted by health professionals as a lack of interest — of patients failing to ask for information. When patients seem to lack interest or motivation, providers are unlikely to persist in attempting to better inform them, creating a vicious cycle of inadequate education and patient disengagement.

Merely providing information is not effective education; the quality of the communication and the appropriateness of the information are crucial to their efficacy. The mode, timing and clarity of education all emerged as key barriers (and possibly key future facilitators) to improving patients' understanding of both their illness and their need for treatment. Furthermore, the dearth of Indigenous Australian health care staff emerged as a key barrier to adequate communication.

More effective and appropriate communication and education are clearly required. The commonly held view that Indigenous Australians do not engage with their treatment regimen should be reconsidered in the light of their low levels of awareness of, and confidence in, biomedical explanations. Until we reach a shared understanding and address pervasive miscommunication, there is little chance that health outcomes for Indigenous Australians with kidney disease will substantially improve.

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COMPETING INTERESTS

None identified.

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