

'You are just a puppet': Australian Aboriginal people's experience of disempowerment when undergoing treatment for end-stage renal disease

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Abstract

Aim: This research aimed to explore the experience of Aboriginal people undergoing treatment for end-stage renal disease.

Background: Literature relating to the experience of dialysis for people with end-stage renal disease reports challenges relating to self-care, compliance and dependence on dialysis. However, the literature exploring the experience of Aboriginal people on dialysis, particularly the cultural experience of dialysis treatment, is limited.

Methods: Using ethnographic methods, this research involved interviews with six Aboriginal people undergoing treatment for end-stage renal disease in April 2007. The interviews were guided by a list of topics to produce a narrative discourse.

Findings: The participants reported an overwhelming sense of disempowerment relating to their dependency on dialysis treatment and health care professionals. Their feelings of disempowerment were exacerbated by cultural differences between patients and caregivers. Disempowerment arose from interactions with, and dependence on, health professionals, dependence on dialysis treatment, a perceived lack of education, the challenge of self-care and hospitalisation.

Conclusion: This study has implications for the education and training of staff working in renal dialysis. Further research is needed to explore the nature of interactions between staff and patients, and the concept of disempowerment in Aboriginal people in various geographical settings.

Key Words

Ethnography, Narrative, Australian Aboriginal, End-Stage Renal Disease Dialysis, Disempowerment

Aboriginal people do not live long once their kidney disease reaches end stage. According to the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA), Aboriginal mortality rates between 1991 and 2000 were 70% across all forms of treatment for ESRD (McDonald, 2003) with cardiovascular disease implicated as the primary cause of death (Spencer, 1998). The death rate of Aboriginal people on dialysis in 2000-2002 was seven times that of the non-indigenous population (AIHW, 2004).

Aboriginal people with ESRD form by necessity a life-long relationship with the staff of their renal unit, who are predominantly non-Aboriginals. Hospitalisation is well documented as a more traumatic experience for Aboriginal people than non-aboriginal people, with Australian Aboriginal patients 12 times more likely to leave hospital before being formally discharged than non-Aboriginal patients (Franks, 2002). For many Aboriginal people the loneliness arising from removal from family and land is considered worse than the causative illness. Furthermore, breaching of the men's and women's business laws that often occurs in hospital can be difficult for Aboriginal people (Spencer, 1997).

Aboriginal tradition delineates between women's business, such as fertility and

Introduction

Australian Aboriginals are eight times more likely to develop end-stage renal disease (ESRD) than the general Australian population. The causes of renal failure in Aboriginal communities are both biological and socio-economic (Cass, 2002a). Diabetes, hypertension and glomerulonephritis are among the most common causes of renal disease in Aboriginal people (McDonald, 2003) and the incidence of renal failure in

Aboriginal people is doubling every four years (Spencer, 1998). In the Northern Territory (NT) Aboriginal people entering dialysis programs are generally younger and have a poorer survival rate than their non-Aboriginal counterparts (McDonald, 2003, Spencer, 1998). Haemodialysis was the most common form of treatment, occupying 44% of all hospital procedures performed on Aboriginal people in Australia between 1998 and 1999 (McDonald, 2003).

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'You are just a puppet': Australian Aboriginal people's experience of disempowerment when undergoing treatment for end-stage renal disease

child-birth and men's business, including hunting, conflicts, and the land. For an Aboriginal person, shame is associated with not respecting gender specific business (Spencer, 1997).

Aboriginal people living in rural and remote communities experience a range of difficulties in accessing the health system. Lack of transport and financial limitations in addition to overriding social obligations, such as traditional ceremonies and funerals, may result in appointments not being kept (Shannon, 1994). Language barriers, including not speaking English (Altman, 2003) and cultural language differences, such as 'yarning' (Spencer, 1997), pose significant challenges for Aboriginal people in dealing with health services. According to Cass (2002), miscommunication between Aboriginal patients and their caregivers is often undetected by the caregiver, and results from a lack of patient control over the language, timing and content of the interactions, the dominance of biomedical knowledge and a range of caregiver knowledge deficiencies (Cass, 2002b). Contrary to caregiver belief, Aboriginal people have the capacity for greater understanding of disease than is expected of them by health professionals, and they often have a detailed anatomical knowledge, and an understanding of complex medical information (Bryce, 2002).

The health beliefs of many Australian Aboriginal kin groups differ greatly from the dominant biomedical model of the Australian health care system. A combination of traditional and Western treatments are used by many modern Aborigines; Western medicine may relieve symptoms and provide explanation of the mechanism of the illness, and traditional treatments provide a reason for illness and address the ultimate cause (Maher, 1999).

The statistical evidence of renal disease in the Aboriginal population is plentiful. However, only a few qualitative research studies have examined the experience of dialysis for Aboriginal patients suffering

with renal disease. A recent study reported that Aboriginal people with chronic kidney disease felt poorly informed about their illness and noted a perceived exclusion from information by health professionals (Anderson, et al, 2008). There have been a number of qualitative studies conducted into the experiences of dialysis in the non-indigenous population. The recurring findings in many studies conducted in United States (US), Sweden, Canada, Spain and Australia include: the desire to maintain a normal life; hope for the future; the importance of the relationship with health professionals; the support from, and effects on, family; and the change process in adapting to renal replacement therapy. (Faber 2000; White 1999; Hagren et al. 2005; Velez 2006; Rittman 1993; Cohen 1995; Lindqvist 2000; Weil 2000). Studies conducted in the general dialysis population have noted experiences of disempowerment, self care challenges and dependence (Faber 2000; White 1999; Hagren et al. 2005; Velez 2006; Rittman 1993; Cohen 1995; Lindqvist 2000; Weil 2000). The concept of disempowerment for the Aboriginal patient may be representative of that experienced in other populations discussed in the literature, or, it may be culturally mediated. Previous research conducted into the concept of disempowerment describes the elements of disempowerment as impeding patient collaboration in care planning, domination and indifference to patient needs (Faulkner, 2001). This paper aims to discuss perceptions of disempowerment in a small sample of the Australian Aboriginal population with renal failure, alongside other issues specific to Australian Aboriginal peoples through their lived experiences.

The Study

Methodology

A narrated ethnographic approach was undertaken to explore the lived experience of Aboriginal people undergoing treatment for ESRD. Ethnographic methodology observes social phenomena, results in unstructured

data and produces a narrative description or 'story' (Higginbottom, 2004). Ethnography aims to find common meanings, and understanding, rather than trying to explain the findings (Henderson, 2005). Ethnography is suited to the Australian Aboriginal way of discourse, by allowing for 'yarning' (conversations) rather than structured questioning. A list of broad topics were developed based on the current literature and referred to only occasionally though-out the interview.

Participants

A purposive sample was selected from the Royal Perth Hospital satellite dialysis and home therapies units based on their ability to speak English on recommendation from nursing staff. The sample represents a group of patients willing to be interviewed, and familiar with the health system, and therefore the findings are limited to this particular group. Six participants consented to be involved and were interviewed in April 2007. Three of the six participants were of the Nyoongar tribal group; four were female. All participants were on a form of dialysis; four were undergoing satellite haemodialysis and the remaining two were receiving automated peritoneal dialysis. Two participants had been on dialysis for less than 12 months. One participant had previously received a transplant. All the participants in the study were aged between 36 and 65 years, and four of the six considered themselves to be an elder in their community.

Data collection

Individuals were approached by the researcher and the Aboriginal health worker. Each person was invited to an initial meeting, to explain the study and the list of 'topics' that would be covered. Participants were given the opportunity to have the health worker and/or a family member at the interview. While there was a potential for responses being affected by the presence of the Aboriginal health worker, it was understood

'You are just a puppet': Australian Aboriginal people's experience of disempowerment when undergoing treatment for end-stage renal disease

that some participants may not feel comfortable discussing sensitive issues without another Aboriginal person in the room. Two participants were interviewed by the researcher and the health worker, one of those also had his wife present. The remaining four participants indicated they felt comfortable to be interviewed by the researcher alone. A set of interview 'topics' was developed based on the limited literature and the researcher's own experience with caring for individuals with renal failure. These topics were designed to be a 'rough guide' and were referred to only occasionally throughout the interviews, and included the story of their renal failure, the perceived cause, and interactions with the renal services, including diagnosis and treatment. The interviews were conducted in a conversational style, with participation from the researcher in sharing stories. The interviews were taped and transcribed by the researcher, and transcriptions were then provided to the participants, to allow them to identify any inaccuracies.

Validity

The six participants were accustomed to an urban, 'Western' lifestyle, and to the health care system, as a result of their prolonged contact with the hospital renal unit and in some cases, their upbringing. This facilitated an authentic dialogue as the participants were comfortable with the questioning, willing to be honest and less concerned about giving the 'right' response. This study represents a small group of the indigenous Australian population who were acclimatised to the process and treatment of kidney disease, to the public health care system, and were able to communicate well to individuals of another culture.

Ethical considerations

Permission to conduct the study was granted by the Royal Perth Hospital Human Research Ethics Committee. All participants signed informed consent to

participate in the study and were advised of their right to refuse or withdraw from the study at any time. Tape recordings of the interviews were destroyed after transcription.

Data analysis

Data analysis commenced during the data collection process, guiding future interviews, as recommended in the literature (Glesne & Peshkin, 1992). The data was examined for themes inductively and categories established, including identification of relationships between the themes. The thematic coding of the interview transcripts were developed by the researcher with the assistance of the NVivo7 qualitative analysis program, through systematic categorising of each line and sentence into similar themes. Themes were then collapsed into key themes. Themes were then cross checked for relevance and cultural sensitivity by an experienced fellow researcher and the project supervisor, who is of Aboriginal descent.

Findings

Once diagnosed with renal failure, all study participants reported commencing a close and life-long relationship with the health system. Participants related that this relationship could be rewarding, and at the same time, expose them to a sense of vulnerability. Overwhelmingly, participants reported a sense of 'disempowerment'. Their experience of disempowerment had five themes: health professional interactions; dependence on dialysis; foreign nature of

hospitalisation; the challenges of self-care; and lack of education. Figure 1 displays the relationships between the themes of disempowerment. Each of the themes is presented in the following section.

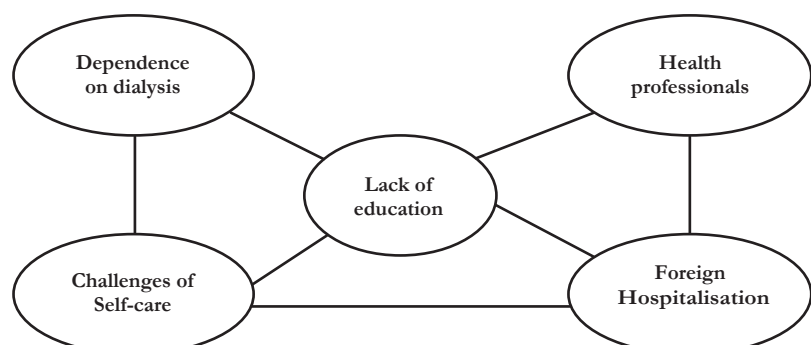
Dependence on health professionals

While camaraderie existed with the staff working in the renal services, frustration at being 'misunderstood' was reported by the study participants. Participants related challenges as a result of a sense of powerlessness regarding their own care and ownership of their own body. These included: tensions between treatment demands and cultural obligations; miscommunications with staff; and vulnerability in relationships with health care professionals.

Cultural obligations resulting in missed treatments.

The need to attend dialysis sessions at times competed with cultural obligations, including Sorry Time (funerals) and the Law (initiation ceremony for Aboriginal teenage males). This often resulted in participants giving priority to cultural obligations and therefore not complying with treatment expectations, resulting in a sense of 'disobedience'. Participants were aware of the consequences of missing dialysis sessions, but felt their cultural obligations overruled these consequences. Participants reported that staff lacked cultural understanding, and they felt nursing staff became anxious about missed dialysis sessions without fully understanding the cultural reasons. One participant explained:

Figure 1: Disempowerment of Aboriginal people on dialysis



'You are just a puppet': Australian Aboriginal people's experience of disempowerment when undergoing treatment for end-stage renal disease

For an elder, his greatest achievement is seeing his first grandson going through the Law. I came half way through the middle. It showed little respect, a little one, not very much for me. Didn't give me enough, didn't make me proud to be an elder

Miscommunication with staff

Miscommunication between staff and participants aggravated the feeling of disempowerment and led to poor outcomes. Some participants reported negative experiences in communicating with health professionals; others felt the staff simply failed to communicate. European health professionals were seen to be 'different', as one participant described:

No, they think differently, than us. Different lifestyles to us.

Another participant contrasted European nurses with nurses from other cultural backgrounds, saying:

The Asian nurses, are very good. And Indian nurses. They talk to you. They say, 'We're indigenous too.' But these European nurses, they [are] the type that, something gotta be done, we do it. If it hurts, it hurts.

In this way participants, at times, could not relate to staff, and moreover, felt staff could not relate to them. Many examples were provided by participants, such as:

Some nurses are good, some are bad; bad in the way, they won't listen to you, they won't talk to you. They'll put you on [the dialysis machine] and [won't] talk. I had that many blues in hospital; I just think some of the staff in hospital don't understand where we come from. They misinterpret what we're saying, and all this sort of stuff, you can end up with a bit of a blue on your hands and I been there before.

Vulnerable relationships

Participants reported a dependency on the health professionals providing their care.

You are just a puppet.....I don't know whether the nurses are in charge of me, or the doctor. It's not me. When I walk into a clinic [dialysis unit], one-on-one, and I tell the nurse, 'I'm going out to [the remote community] tomorrow.' They say, 'You are?

You tell the doctor that?' I say, 'Should I tell the doctor or what? I'm telling you'

Although the participants experienced difficulties with the health system, a sense of camaraderie was present with the staff. This resulted in a vulnerable relationship for the patient, simultaneously respectful and admiring of the staff while being dependent upon them. When positive experiences were mentioned, it was with a sense of gratitude, rather than entitlement.

Dependence on dialysis: a love-hate relationship

Choice of dialysis modality often related to practicalities of location and support, rather than personal preference. Peritoneal dialysis allowed the person to return home, and participants reported satisfaction with this more independent means of dialysing, allowing them to return to their community.

The main findings relating to dependence on dialysis included: recognition of the necessity of dialysis; the effectiveness of dialysis treatment; time restrictions; lifestyle restrictions; and satisfaction being modality dependent. The therapy became part of their life by necessity.

When I first started on dialysis, after the first couple of weeks, I noticed the difference, a new person, breathe better, walk better, eat, like a new person. They'd say 'you were sick the other day' and I say 'not now.

Dialysis was accepted as an effective treatment for end-stage renal failure and was perceived to improve the well-being of people with renal failure. Some participants reported a lack of control over when dialysis was commenced.

They should treat Aboriginals with respect, attend to the illness straight away, don't just let it deteriorate.

Time restrictions placed on the individual by dialysis included the restriction of having to be 'on-time' for dialysis, which was culturally counterintuitive.

When I come to dialysis, they're "hurry, hurry, hurry".... Sometimes I feel stressed when they're telling me to hurry

up, at dialysis... Doesn't matter if I'm late, neither here nor there for me, so long as I get dialysed. I know there's other people besides me, but that's how I am. Slow.... Noongar time.

The limitations of having to base their plans around dialysis sessions, included the inability to attend cultural obligations.

Sometimes I like going out bush, you know, cook a feed out bush on the camp fire, can't do that anymore.

Satisfaction with dialysis was modality dependent. The two patients on peritoneal dialysis reported greater satisfaction.

When I came here he [son who is also on dialysis] asked me which way [I] go when I go for dialysis, the machine. 'Go on the bags, it's easier doing that'.... This one here [is better] [motions peritoneal dialysis machine.] You can go shopping.

The challenge of self-care

Self care behaviours were a common thread of conversation with many of the participants. Caring for themselves was discussed on a community and individual level. The necessity of self-care was recognised by the participants. Self-care activities discussed included:

- the necessity to adhere to the specific renal diet
- fluid restrictions
- avoiding infection through good hygiene
- attending dialysis treatments, and
- setting up one's own dialysis machine.

However, self care required significant effort for the participants. Participants expressed frustration at health professionals' failure to understand the importance of cultural obligations which may impede self care, and discussed their attempts to restrict fluids and diet.

Sometimes you don't know when to stop. You have to be very careful, you either have a mouthful or you don't... sometimes I might not drink for 3-4 hours. Then you kind of make up for it and you have too much. So you try to balance it, but you don't balance it, you miscalculate.

'You are just a puppet': Australian Aboriginal people's experience of disempowerment when undergoing treatment for end-stage renal disease

Lack of education

The education pertaining to their renal disease and treatment was felt to be lacking by participants, and contributed to the feeling of powerlessness. Participants felt they were not informed they had kidney disease, and the sense of secrecy to the diagnosis was viewed as a poor reflection on the intelligence of Aboriginal people.

They think black people, they don't understand. We need them to tell us, you know, about the bags and all that.

Patients did learn more about their illness as the treatment progressed, but the knowledge was gained in passing, rather than in a focused manner. Most participants reported that they felt the health system simply assumed they were 'stupid' and failed to initiate any conversation regarding their renal failure and treatment.

I have not yet seen any staff talk to Aboriginals about their renal failure. I'm pretty certain, what goes on around me, I just haven't seen it. Nobody told me about my illness.... I think that they think Aboriginals don't understand, but we're not stupid.

The foreign nature of hospitalisation

Hospitalisation was a foreign and frightening experience for the Aboriginal people interviewed during the study. The hospital experience resulted in isolation for a group of patients not familiar with limited contact with their own kin group. This was alleviated somewhat if relatives or even other Aboriginal people were also inpatients. It was frightening to be placed in a room with no other patients, or in a ward with no other Aboriginal people.

I felt very strange, I get very homesick when I go to hospital, for my family. I miss my house, but mostly my family, or even another Aboriginal person not being in the ward."

Hospitalisation also resulted in culturally inappropriate mixed-gender room sharing and a change of dialysis routine.

There was men in there. Just lay there and cover ourselves, cover our body. I was telling all the nurses. They say 'We got no room.' I said, 'I want to go to another room.'

Discussion

This study involved six indigenous Australians, who were acclimatised to the processes and treatment of kidney disease and to the public health care system. They were able to communicate well to individuals of another culture. While the findings are limited to this group of people they do provide some insight into the range of challenges and issues faced by indigenous people when needing treatment for ESRD.

The Aboriginal people interviewed felt that the dialysis was effective, enjoyed camaraderie with health professionals and some even expressed satisfaction with their current dialysis modality. However, in addition to dealing with the 'normal' change process of adjusting to and coping with dialysis, these Aboriginal patients experienced disempowerment, not only related to dependence on the machine as noted in other non-Aboriginal studies (Velez, 2006, Hagren et al., 2005, White, 1999, Al-Arabi, 2006), but associated with the cultural incongruity with the health system providing their care. Throughout many of the discussions describing interactions with the health system, a prevailing aspect was the nature of that interaction. Negative experiences (miscommunication and misunderstandings) which contributed to a poor view of the health system contrasted with the positive experiences (camaraderie, feeling better). This left patients with a confused sense of vulnerability, simultaneously 'appreciating' the staff, but resenting the lack of cultural identification or autonomy over their own care and future. This 'struggle' between dependence and independence on dialysis was also noted by Hagren and colleagues (2001) and may be further compounded for Aboriginal patients as a result of cultural discrepancies between Aboriginal and Western culture.

Negative experiences with health professionals impact upon perceptions of empowerment. Disempowerment transmutes through the Aboriginal community, combining with dislocation

from family and country (cultural homeland) to discourage Aboriginal people from seeking treatment. The concept of 'country' for Aboriginal people is an essential component of their sense of health (Burgess, 2007). The fear of accessing treatment for Aboriginal people is real, and encompasses removal from one's home; dealing with the health system; and losing control over one's own body and own cultural identity.

Fulfilling cultural obligations was mentioned by all participants as creating stress in their lives on dialysis. It also appeared to the participants that nursing staff became anxious about time missed from dialysis, contributing to miscommunication and feelings of disempowerment. While cultural education allows staff to better understand the cultural priorities for Aboriginal people, the provision of support for patients to return home for funerals, including transport and dialysis, would allow patients to meet their cultural obligations and remain well while doing so.

Interestingly, despite the patient education programs in place, and exposure to a wide range of health professionals providing opportunities for educational discourse, Aboriginal participants felt poorly informed about their renal failure. These findings were congruent with those of Anderson et al (2008). More research is required to closely examine the reasons for this perception. It is beyond the scope of this study to explore whether the participants had participated in the education program, and it may be possible that they had not recalled the encounters when information had been provided. The question need to be asked about whether the lack of education arises from lack of cultural awareness in staff or staff time restrictions, or whether it is a manifestation of the late referrals taking place which prevent education taking place in a timely manner before the patient becomes too unwell to absorb the information.

The renal services struggle to provide basic resources for renal patient education,

'You are just a puppet': Australian Aboriginal people's experience of disempowerment when undergoing treatment for end-stage renal disease

resulting in precious few programs and facilities to cater for specific groups, such as Aboriginal people. At present, cultural awareness training provided to health staff is not enforced at the renal unit where this study was conducted. Such training would assist with understanding Aboriginal culture and meanings of illness. Non-Aboriginal staff, as well as patients, would benefit from the employment of Aboriginal health workers trained in the care of renal patients, who could then be involved in the development and delivery of staff training programmes. Aboriginal health workers also provide support to staff when dealing with Aboriginal patients and bridge the cultural divide when misunderstandings arise.

Implications for practice and/or policy

This research study highlights the need for further qualitative research into the experience of end stage renal disease for Aboriginal people. Other recommendations include: the employment of Aboriginal people within the renal services; provision of mandatory cultural awareness training to all staff dealing with Aboriginal people; and the provision of culturally appropriate care for Aboriginal renal patients in their own community.

Conclusion

The challenges relating to renal replacement therapy for Aboriginal people is an accumulation of the predicament faced by any renal dialysis patient, augmented by the specific cultural obligations and responsibilities and dealing with a health system ignorant of their cultural background and needs. It is hoped this research forms the basis of further enquiry into exploring the nature of the experience of kidney disease for Aboriginal people, from an individual and community perspective. By understanding this information, in the face of increasing incidence of ESRD in the Aboriginal community, we can be better armed to make improvements to the care and prevention of renal disease in Aboriginal people. Specifically, future research directions should include further exploration of the

cultural disempowerment experienced by Aboriginal people. Recommendations from this research include: the implementation and evaluation of Aboriginal cultural education programmes for dialysis staff; the use of Aboriginal health workers in bridging the cultural gap; and a system to allow patients to attend to cultural obligations such as attending funerals.

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