

Bulletin de la Dialyse à Domicile

Peritoneal dialysis in indigenous australians: a critical review and personal opinion

(Dialyse péritonéale chez les indigènes australiens : une revue critique et opinions personnelles)

Johan Rosman ¹

¹Foundation Professor of Medicine, Curtin University Medical School
Nephrologist Royal Perth Hospital
Perth, Western Australia,
Australia

Note : ce texte est disponible en Français à la même adresse url : <https://doi.org/10.25796/bdd.v4i3.62753>

Résumé

Les populations aborigènes des pays riches ont des évolutions de maladies chroniques comparables à celles des patients des pays en développement à faible niveau socio-économique. Ce n'est pas différent pour la maladie rénale et les résultats des thérapeutiques de remplacement rénal. Ce chapitre aborde les dilemmes liés à l'utilisation de la dialyse péritonéale chez les patients aborigènes en Australie. L'accent est mis sur les aborigènes vivants dans des régions très éloignées. Nous exprimons nos opinions personnelles quant aux causes de l'écart entre les résultats obtenues chez les patients aborigènes et non aborigènes ; nous suggérons comment les nombreuses tentatives qui se sont avérées infructueuses pour combler l'écart pourraient être traitées.

Correspondence :

Johan Rosman, MD PhD FRACP
Foundation Professor of Medicine, Curtin University Medical School
Nephrologist Royal Perth Hospital
Perth, Western Australia,
Australia
Email: johan.rosman@curtin.edu.au

Mots clés : dialyse péritonéale, indigène, aborigène, privation, pauvreté, insuffisance rénale, The Kimberley, Australie

Summary

Indigenous people in wealthy countries have outcomes of chronic disease that are comparable to those of patients in low socio-economic developing countries. This is not different for renal disease and outcomes of renal replacement therapy. This chapter addresses the dilemmas of using Peritoneal Dialysis in aboriginal patients in Australia. The focus is on aboriginal people in very remote areas and some personal views are presented as to the causes of the gap between outcomes for aboriginal and non-aboriginal patients and how the many failed attempts to close the gap could be addressed.

Key words : peritoneal dialysis, indigenous, aboriginal, outcomes, deprivation, poverty, renal failure

INTRODUCTION

Australia is a country with the landmass of the USA, but has just 25 million inhabitants. Most people live close to the coast, where resources and access to water are available. Demographically the country is very multi-cultural, predominantly Caucasian, and only 3.3% identify as Aboriginal (indigenous). Many of them have integrated in the coastal communities (300'000), but a very significant number have maintained their rural/remote living style in communities spread over the country; 350'00 in outer regional areas and 150'000 in often very difficult to access remote places, hundreds of kilometres from the next village [1]. It is an indictment on post-colonisation Australian history that indigenous people have lived in this country for 50'000 years, yet were only recognized as Australian citizens and included in the census in 1967 [2]. Especially remote living indigenous people have the lowest possible socio-economic status and there is widespread poverty, childhood neglect and abuse, alcoholism, malnutrition and developmental disadvantage. Translated to renal disease, deprivation is correlated to glomerulomegaly, high incidence of diabetes and FSGS and other. Statistically, this leads to an 8-32 fold higher incidence of renal replacement-dependent renal disease with excessive mortality rates at a young age. The average live expectancy for remote aboriginals is 65.9 years for males and 69.6 years for females [1]. This is on average 15-22 years less than for non-aboriginal people. These figures are even obviously even worse for renal patients.

This overview will address the 'gap' between aboriginal and non-aboriginal health and the author will present some personal experiences and relate these to peritoneal dialysis as a modality for aboriginal patients. Many past governments have tried to solve the problem by ever extending funding, which does not seem to have made a difference. Critical thinking about the future, from aboriginal as well as from non aboriginal side is required.

Incidence and Prevalence of renal disease in indigenous people

The median age of aboriginal people at diagnosis of End Stage Renal Disease (ESRD) is 30 years younger than a comparable group of non-aboriginal Australians, and the incidence of renal replacement therapy shows an 8-32 fold rate (400 patients per million in the city, with an extreme 1600 ppm in remote areas) compared to non-aboriginal Australians [3]. The real rate of dialysis dependency would be even higher as for many reasons, indigenous patients do not reach dialysis treatment. These hurdles will be discussed below. Their transplant rates are also significantly lower than that of other Australians. Despite their extreme incidence and prevalence of dialysis, aboriginal patients contribute only 3% of total patients transplanted in 2016 (ANZDATA report 2018).

Peritoneal Dialysis in indigenous people globally and in Australia

Indigenous patients in other countries have shown to have barriers regarding the use of peritoneal dialysis. Mathew et al conducted a prospective, observational cohort study in 3 remote areas in Canada [4]. They found that indigenous patients started PD around 11 years earlier than non indigenous patients. The 2 most significant barriers, as self reported by indigenous patients were lack of money and anxiety. The first barrier may seem unlikely in a country that has, like Australia, a universal health care program with no costs to any patient on any form of dialysis. However, inequality remains widespread in any Western society. In Mathews' study, one of 67 participating non indigenous patients died before initiation of dialysis compared to 5 of 32 indigenous patients.

This could be an indication of protracted decision processes, and resistance to start dialysis timely. Indeed, ANDATA statistics show that indigenous patients start RRT at a lower eGFR than non-indigenous (7 ml/min vs. 11 ml/min) matched patients, and many indigenous patients make a ‘crash start’, being flown in by medivac and started on Haemodialysis by Central Venous Catheters.

Prakash reported in 2011 [5], analysing peritoneal dialysis in indigenous patients that mortality, technique failure and peritonitis rates were significantly higher among indigenous patients and emphasized the importance of remoteness. These findings were later confirmed in an Australian study [6]

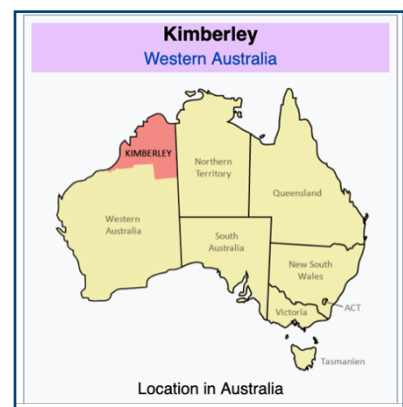
The situation specific to The Kimberley

Western Australia is the largest state of the country, slightly bigger than all of the 2021 size of the EU. The capital is the 2 million inhabitants- city of Perth with a well-developed infrastructure and 3 large tertiary hospitals. The author visits on a 6-8 weekly basis The Kimberley, a vast area in the North-west of Australia, partly coastal, partial desert, where aboriginal culture in small communities has been largely maintained with rituals, life style as well as a strong classical aboriginal culture. Visits are made to the 4 main towns that have haemodialysis centres and flights are taken in small planes to visit remote communities to see patients. Four months per year these communities are not accessible because of monsoon rain and disappearing sand-landing airstrips. Access by 4 wheel drive is also not possible.

Aboriginals in The Kimberley accept Western medicine, but only to a limited extent. Bush medicine and traditionally healing play an eminent role. Presentation to renal clinics are usually very late, non-attendance rate in clinics over 45%, and urgent air evacuation to the closest tertiary hospital (Perth) is over 2500 km away. On average, Royal Perth Hospital receives 3 patients per week that are evacuated by emergency flights. Haemodialysis units have been established in the towns of Broome, Derby, and Kununurra with each 10-14 dialysis chairs. Recently, Fitzroy Crossing (non coastal) was added with 4 dialysis spots. The demand is much higher, causing aboriginal patients having to start in Perth, in an environment that is strange and perceived as hostile to them, with waiting times up to 18 months before they can return to ‘country’, as they call their origin. There is a very strong connection in aboriginal culture to place of origin (land) and ancestors who lived there. This causes suffering, depression, non compliance, alcohol abuse and suicide when forced to live and dialyse 2500 km from home.

All forms of dialysis in Western Australia are outsourced to a globally renowned dialysis service provider (price per treatment principle), who is responsible for dialysing all patients in Perth (5 large satellites, hospitals only having small units for inpatients and unstable dialysis patients), but also for the provision of home-based services in The Kimberley.

Since around a decade there has been a strong push to use more home based treatments, to make an early return to country possible and also to allow for more autonomy. For countless reasons, the many projects that were launched have failed. (These will be discussed under ‘Barriers to Peritoneal Dialysis in The Kimberley’).



↑ figure 1 : The Kimberley, location in Australia ([https://en.wikipedia.org/wiki/Kimberley_\(Western_Australia\)](https://en.wikipedia.org/wiki/Kimberley_(Western_Australia)))

Increasing the number of indigenous people on home based treatments, in particular peritoneal dialysis, is a well known challenge. Gray et al [5], performed an Australian study, linking remoteness to the uptake of peritoneal dialysis, and found that rural and remote patients had a significantly higher uptake of peritoneal dialysis and found, when failing PD, that they were more willing to relocate to places where haemodialysis is available. Their study, however, excluded aboriginal patients. Marley et al [8] analysed the peritoneal dialysis outcomes of aboriginal Australians in The Kimberley (71 between 2003 and 2009) with other Australian aboriginals in the same time period (384) and non-aboriginals (5285). The median age at the start of PD was 10 years younger in aboriginals in general, They found a significantly shorter median time to first peritonitis, higher technique failure and shorter median survival, despite the young age at which they started PD. They had double the number of peritonitis episodes, a real challenge in very remote areas. They concluded that the expansion of safer Kimberley haemodialysis options needed to continue. This conclusion may be the opposite of what internationally consensus is amongst nephrologists and policy makers.

Barriers to peritoneal Dialysis in The Kimberley

The author visits the main hubs and remote communities every 6-8 weeks for a full week to see dialysis patients and transplanted patients and review patients with earlier CKD stages. There are many barriers to expand a PD program, but there has not been a formal audit, apart from Marley et al [8], who concluded that in The Kimberley, PD was not a safe method and haemodialysis should be expanded.

The author has his personal views and will introduce these here:

1. Accomodation



↑ Figure 2a et b : Old pictures. One is that of a community with 65% diabetes and 7 dialysis patients in only 300 aboriginals !! They live outdoor and that is only for rain. In the summer aboriginal people sleep outdoors and I was completely perplexed to see a man doing his mid-day PD exchange on of the beds in the photo 2b. Interestingly, he had his first peritonitis after 18 months which is for here very good ! When we left the village at the end of the day (mainly seeing CKD 3 and CKD 4), there were 3 people sleeping on the beds you see in the photo. The PD patients had his last exchange bag ready on a drum next to his bed.....

Here old rituals and habits are maintained.

Aboriginal people in The Kimberley often have no form of income, apart from social support.

They often live in old, mouldy and poor maintained social housing. The culture demands that the door is always open to anyone of the extended family. This may mean that at a given moment 2 people live in a 2 bedroom house, and a few weeks later 15 in the same house. There is often no place for storage and PD bags can sometimes be found outside of the house in 40 degrees Celsius. Alcohol/drug use and domestic violence are regrettably frequent and understandably, this is not the environment that is conducive for the hygiene dependent peritoneal dialysis. Infectious diseases, like STD and leprosy are common. The complication rate and mortality, impacted by hesitations to see a doctor, and non-compliance with medication and clinic visits, are high. In general, an aboriginal liaison officer picks the patients up from home to be brought to the renal clinic.

2. Culture

Aboriginal culture is one of mobility, largely by foot. Although the primary residence may be in a small community, many aboriginals adhere to the customs of 'going bush', where they spend a significant time (weeks/months) away from home in the wilderness and exercise their important culture need for maintaining close contact to country. This is however not compatible with PD, and also not to haemodialysis, leading to remote death, increased all-cause mortality and urgent evacuations if help is available. There can also be a mistrust of western medicine, as patients in The Kimberley have seen relatives move to Perth to initiate dialysis and never saw them back. This is even stronger an argument against PD, as the high peritonitis rates with high mortality because of late presentation, creates resistance against this method. I noticed, as a doctor, that it can take years to be accepted in the aboriginal community as a person who offers help, and yet cannot achieve the compliance levels we need to provide adequate renal care. This is a challenge as few doctors are willing to live in The Kimberley, and hence the population is dependent on a constant flow of locums, often only staying for a few weeks.

3. Provider

In Western Australia, Hemodialysis and Peritoneal Dialysis are not provided by the hospitals, which have only very small haemodialysis units, meant for inpatients and unstable patients. The regular haemo-satellite and peritoneal dialysis program is outsourced to a major global player in renal replacement therapy. This means that costs play an even more prominent role than in the public service and there is, for example, no nephrologist or PD nurse available anywhere in The Kimberley. The closest nurse is also in Perth, which is over 2500 km away. There is also no competition amongst dialysis providers, as the State of Western Australia awarded the contract for haemo- as well as peritoneal dialysis for about one thousand patients to just the one provider. In The Kimberley, the over-arching governance for aboriginal care lies with an aboriginal organisation, the Kimberley Aboriginal Medical Services (KAMS) and all care provided is free, from primary to secondary care, medication and transport to and from clinics. Although KAMS as an extra bureaucratic layer, adds to the complexity, it helps preserve the unique aboriginal attitude in our care.

4. Being removed from country

To receive a PD catheter, and later the PD training, patients will have to come down to Perth, as no hospital in The Kimberley implants PD catheters. The large city is intimidating for them, and

has an average temperature about 10-15 degrees lower than The Kimberley which even in winter hardly drops below 30 degrees. They are deprived from their loved ones and away from country, as no family members are allowed to be in temporary housing in Perth with them. The situation is actually worse in haemodialysis, as the 4 units in The Kimberley (figure 3) cannot cope with demand and all patients need to start their dialysis in Perth. The waiting time to return to country can be 12-18 months.



↑ Figure 3 : Because patients are often dialysing in Perth, 3000 km from home, we have a bus, paid for by charity, with 2 dialysis chairs. Staff dialyse patients here for 2 weeks when patients can be briefly home, then return to Perth and the bus goes somewhere else.

This is a very sad scenario and alcohol problems, as well as depression and loneliness are very common in the city. Mothers do not see their young children for over a year. One would expect that this would be an incentive to choose PD, but interestingly, other factors prevail. Projects have failed to increase the number of patients on PD, mainly for reasons as outlined above. In 2011, the WA Government issued a 'Framework to improve home dialysis therapy in Western Australia'. After thorough analysis, it came to 6 key clinical recommendations. One of them was to have a resident nephrologist, who lives permanently in The Kimberley. Apart from lack of funding, it has not been possible to attract a permanent nephrologist and the prospect of ever changing locum nephrologists is likely to make the situation worse. The other recommendations were in place already, like 'adhere to evidence based guidelines' and could not contribute, as the decisive impediments to expansion, in particular overcrowded housing and cultural incompatibility with dialysis treatment remain largely unsolved because of a lack of compromise on aboriginal as well as on non-aboriginal sides to change attitude.

As of August 2020, The Kimberley has only 17 patients on peritoneal dialysis, 9 of them aboriginal, against 138 aboriginal patients on Haemodialysis. This despite 15 years of expensive quality improvement projects and the hard work of many who visit country in a professional capacity

and free healthcare, including cost-free medication and transport, also to and from renal clinics.

THE FUTURE

It is not easy to see the future rosy for peritoneal dialysis therapy in aboriginal communities. As in The Kimberley, aboriginal people adhere strictly to their historic culture and belief systems (to their credit), there is an ongoing 'clash of cultures', leading to non-compliance with clinic visits, medication, the will to start renal replacement therapy. Also, culture changes in favour of PD is then again failing because of extreme peritonitis rate with higher than usual mortality. The Australian government has through the years tried to solve the issue by investing more and more money, and by attracting more aboriginal people as liaison persons in the hospital workforce, but apart from first class dialysis satellites, built in Australia's poorest environments, outcome has not changed. I summarize some ideas Australia could pursue to move forward:

1. Adjustment of culture on both sides. An increasing number of especially younger aboriginal people, realise that to achieve success, a closer relation with western as well as aboriginal culture is required. We have an increasing number of aboriginals in the workforce in hospitals and aboriginal elders have stepped up to warn youth about unhealthy eating, exercise and support many forms of diabetes prevention. We finally see a levelling off of the incidence of renal disease in aboriginals, although it is too early to cheer. From a governmental view, it is time to realise that housing/accommodation is the main issue. This is true for becoming sick, having a larger number of infections, and we have recently showed that Acute Kidney Injury, related to childhood infections, related strongly to CKD later in life, the infections related the housing situation. Investing money in housing will do more good than handing out cash payments. In one of the communities where we visit, a renal hostel is built, where aboriginal people can live, do their PD or HD and share their stories.

2. Reduce Anxiety amongst Aboriginal People. It is often underestimated that a large part of non-compliance, failure to attend clinic, promises to comply with advice, are actually driven by fear. For many aboriginal patients in The Kimberley, the doctor and the nurse are highly regarded people in a place of authority, who intimidate. We have tried hard in our communities to break down this wall and think we were successful. Renal education, be it for CKD or dialysis is always given with the appropriate tribal liaison person present and special tools, that are mainly of a visual nature, like drawings and pictures are used instead of text and DVD's.

3. Start with the children. A thorough school teaching program should be developed where health is a very important part of the curriculum. This may reduce the number of infections at a young age, cardiac valve rheumatism and also diabetes. The children will bring these messages home, in the hope of achieving 'reverse teaching' of the parents.

4. Acknowledgement of the 'culture clash'. As long as neither side is willing to accept that aboriginal- and non aboriginal cultures are inherently different no progress will be achieved. As non-aboriginal health care workers we should realise that not every aboriginal patients will want to be 'saved' by our methods of renal replacement therapy and stop pushing them for coming to clinics if something in them says they do not want to. The same is true for medication compliance. Aboriginal patients should understand that if for them there is value in living longer, that this can only be achieved by at least adopting the most basic principles of non-aboriginal care,

being adherence and compliance. Also, the cherished long trips during the year in the bush will regretfully no longer be possible. For many of the non-aboriginal health care workers it is hard to understand that in the aboriginal people there are many who do not want to live 'at all costs'. Persisting in our western ways of thinking we see the very dramatic consequences of patients dying 2500 km away in Perth, whereas the patients' heart and soul is in country.

CONCLUSION

Unless we are ready for a massive change in cultural acceptance on both sides nothing will change, as the gap has not closed since it first attempts in 2011 [10].

Additional materail for information



↑ Additional material 1 : an image from air of the village where we installed the 2 chair 'self dialysis' unit



↑ Additional material 2 : Because patients are often dialysing in Perth, 3000 km from home, we have a bus, paid for by charity, with 2 dialysis chairs. Staff dialyse patients here for 2 weeks when patients can be briefly home, then return to Perth and the bus goes somewhere else

CONFLICT OF INTEREST

the author declares not conflict of interest with this publication.

REFERENCE

1. Australian Bureau of Statistics website: www.abs.gov.au. Accessed 19 July 2021.
2. Australian Bureau of Statistics. Reflecting a Nation: Stories from the 2011 Census, July 2011, Cat No 2071.0
3. Australia-New Zealand Renal Database (ANZDATA). Website www.anzdata.org.au. Accessed 19 July 2021.
4. Mathew AT, Park J, Sachdeva M et al. Can J Kidney Health and Disease; 5: 1-9, 2018
5. Prakash S. An international perspective on peritoneal dialysis among indigenous patients. J Int Soc Perit Dial; 31: 390-398, 2011
6. Lim W, Boudville N, McDonald SP et al. Remote indigenous peritoneal dialysis patients have a higher risk of peritonitis, technique failure, all-cause and peritonitis-related mortality. Nephrol Dial Transplant; 26: 3366-333372, 2011
7. Gray N, Grace B, McDonald SP. Peritoneal Dialysis in rural Australia. BMC Nephrol; 14: 278-282, 2013
8. Marley JV, Moore S, Fitzclarence C et al. Peritoneal dialysis outcome of Indigenous Australian patients of remote Kimberley origin. Aust J Rural Health; 22: 101-108, 2013
9. Mohan J, Atkinson DN, Rosman JB et al. Acute kidney injury in Indigenous Australians in the Kimberley: age distribution and associated diagnoses. Med J Australia; 211(1): 19-23, 2019
10. Lim W, Johnson DW, McDonald SP et al. Impending challenges of the burden of end-stage kidney disease in Australia. Med J Aust; 211(8): 374-381, 2019

For further reading:

McDonald SP. End-stage kidney disease among indigenous peoples of Australia and New Zealand. Kidney Int; Suppl; 3: 170-173, 2013

Anderson K, Cunningham J, Devitt J et al. The IMPAKT study: using qualitative research to explore the impact of end-stage kidney disease and its treatments on aboriginal and Torres Strait Islander Australians. Kidney Int; Suppl; 3: 223-226, 2013.

Gorham G, Howard K, Zhao Y et al. Cost of dialysis therapies in rural and remote Australia – a micro costing analysis. BMC Nephrology; 20: 231-242, 2019
Grace BS, Clayton PA, Gray NA et al. Socioeconomic Differences in the Uptake of Home Dialysis. Clin J Am Soc Nephrol; 9: 929-935, 2014.

Hoy W. Kidney Disease in Aboriginal Australians: a perspective from the Northern Territory. Clin Kidney J; 7: 524-530, 2014.

Lim W, Johnson DW, McDonald SP et al. Impending challenges of the burden of end-stage kidney disease in Australia. Med J Aust; 211(8): 374-381, 2019

Hoy W, Mott SA, McDonald SP. An expanded view of chronic kidney disease in Aboriginal Australians. Nephrology; 21: 916-922, 2016

received **21/08/05**, accepted after review by the editorial board on **21/08/09**, published **21/09/21**



Open Access This article is licensed under a Creative Commons Attribution 4.0 International

License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons license, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this license, visit <http://creativecommons.org/licenses/by/4.0/>.