Overcoming the “bad story about tummy dialysis” – the perspectives and experiences of health professionals in Central Australia of peritoneal dialysis

Dr Nicki Scholes-Robertson, PhD

Patient Partner, Physiotherapist and Researcher

Sydney School of Public Health, The University of Sydney

ANZSN ASM Sept 2025

THE UNIVERSITY OF SYDNEY

Celebrating 175 years

Acknowledgement of Country

The work involved in this project was conducted on the lands of the Arrernte people of Central Australia.

THE UNIVERSITY OF SYDNEY

Celebrating 175 years

Aim

To describe health professionals' perspectives and experiences of patients from remote and very remote communities on access to peritoneal dialysis in Central Australia

THE UNIVERSITY OF SYDNEY

Celebrating 175 years

Background- Central Australia

- Diabetes prevalence in Central Australia in 2018/19 in adult Indigenous population – 39.5% (Highest in the world) (O'Hare 2020)
- 600000 square kilometers with 41 000 people
- 43% of population is Aboriginal or Aboriginal and Torres Strait Islander
- 64% of housing need extra bedrooms (due to overcrowding)
- Mean age at death of Aboriginal people is 54.5 years

ANZDATA Annual Report 2024 Chapter 5 – Peritoneal Dialysis

*Percentage of all Dialysis Patients on Peritoneal Dialysis^*

State	2019	2020	2021	2022	2023
Queensland	17%	16%	15%	15%	16%
New South Wales	22%	23%	23%	22%	21%
Australian Capital Territory	12%	15%	12%	12%	12%
Victoria	17%	17%	18%	18%	17%
Tasmania	14%	17%	19%	20%	20%
South Australia	14%	14%	15%	15%	16%
Northern Territory	6%	7%	7%	5%	5%
Western Australia	14%	15%	14%	15%	15%
Australia	**17%**	**17%**	**18%**	**17%**	**17%**
New Zealand	**29%**	**29%**	**26%**	**25%**	**23%**

Incident PD patients at Alice Springs Hospital (19-81 yrs)

Year	N
2014	2
2015	5
2016	1
2017	0
2018	0
2019	2
2020	0
2021	0
2022	1
2023	2

Table 1 Participant Demographics

Characteristics	N=17(%)
Age (years)	
31-40	2 (12)
41-50	6 (35)
51-60	6 (35)
61-70	3 (18)
Occupation	
Nurse	7 (41)
Nephrologist	6 (35)
General practitioner	2 (12)
Physician	1 (6)
Aboriginal Health Practitioner	1 (6)
Gender	
Female	11 (65)
Aboriginal	1 (6)
Years of Experience (kidney disease)	
1-10	7 (41)
11-20	7 (41)
21-30	2 (12)
30+	1 (6)

Themes

- Excessive accommodation obstacles
- Pervasive risk of peritonitis
- Preference for incentre “machine” dialysis
- Centralisation of specialist workforce
- Missed opportunities for meeting health literacy needs
- Compounding complexities of comorbidities reducing treatment options

THE UNIVERSITY OF SYDNEY
Celebrating 175 years

Excessive accommodation obstacles

Overwhelmed by overcrowding

“Life in community is hard. And a lot of people are in very overcrowded housing.” (Nurse)

Without sustainable supply of electricity

“Continuous supply of electricity is not guaranteed due to the token system, when it runs out, it can be off for days till some one can get a new token” (Nurse)

Lack of secure storage space

“With the overcrowding- there are very limited options for safe storage of a month worth of supplies at people's houses” (Nurse)

Pervasive risk of peritonitis

Perpetuated storytelling of bad tummy dialysis

“We haven't had a good story about PD for a long time.” (Neph)

Limited caregiver availability

“People are already looking after quite a few family members with chronic diseases in their immediate family” (AHP)

Narrowing the selection of patients

“We can't push people into PD and set them up for failure.”(Neph)

Living with environmental hygiene risks

“Infection rates in general are quite high here for all people.” (Nurse)

Preference for incentre “machine” dialysis

Seeking the benefits and convenience of incentre treatment

“There is air-conditioning, and you get fed” (Nurse)

Generational trust in the safety of HD

“They know about dialysis. They know about this machine (HD).” (Neph)

Financial sustainability of very remote hemodialysis

“We have the Medicare number for very remote Hemodialysis. There's no funding stream for remote PD or assisted PD.” (Nurse)

Centralisation of specialist workforce

High staff turnover and shortages

"The clients that engage more in follow up are those that are known by stable remote community health staff who they know and have built trust with over time." (Nurse)

Limited primary health knowledge of PD

"We don't know about PD; we don't see any patients with it. It would be hard for us to manage in a remote community without a lot of training for us too" (GP)

Missed opportunities for health literacy needs

Dearth of linguistically and culturally appropriate education

“They need visual aids (about PD) in their languages” (Nurse)

Reduced access to technology and data

”There are a lot of resources from Baxter, but they are online. I don't think they have computers at home. They don't always have data on their phones” (Nurse)

Compounding complexities of co-morbidities reducing patients' options

“Our problem now is the youth onset diabetes. In as young as five years old. And it's a terrible phenotype. Plus, you can imagine a five or 8-year-old who does not take medications. So, by the time they reach us, they're as young as 20, 21, 22. And multiple organ and body involvement, kidneys, eyes, limbs, heart and they cannot be considered for peritoneal dialysis” (Nephrologist)

Conclusion

Health professionals believe that the low uptake of PD in Central Australia is influenced by structural barriers such as:

- overcrowded and insecure housing,
- persistent negative perceptions of PD related to infection risk,
- the relative safety and familiarity of haemodialysis.

Addressing housing inadequacies and improving culturally appropriate education may support greater acceptance and utilisation of PD in this setting.

Thankyou

- Dr Sachin Kodgire
- Dr Cherian Sajiv
- Prof Allison Tong
- Dr Eric Au

The health professionals from Central Australia who provided their valuable insights for this project.