

Is Assisted Peritoneal Dialysis a Solution for Northern Manitoba?

La dialyse péritonéale assistée est-elle une solution pour le Nord du Manitoba?



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Abstract

Background: End-stage kidney disease (ESKD) continues to fundamentally impact the lives of First Nations (FN) patients. Home peritoneal dialysis (PD) offers patients more mobility and flexibility, but few Manitoba FNs have availed themselves of this option.

Objective: This paper discusses Manitoba FNs' experience of PD, to highlight enablers and barriers to expanding the use of PD in rural and remote Manitoba communities.

Methods: We analyzed interviews of individuals living with ESKD ($N = 14$), family caregivers ($N = 14$) and healthcare providers and administrators ($N = 27$).

Results: Barriers to PD uptake include medical suitability, patients' distrust of home modalities and fear in their ability to manage. Other factors include limited family support and lack of appropriate housing.

Conclusions: Assisted peritoneal dialysis (APD) is an emerging model where PD supplies are centrally located, and where a cohort of PD patients can provide mutual support with added assistance from an APD worker. This model could mitigate existing treatment barriers.

Résumé

Contexte : L'insuffisance rénale terminale (IRT) continue d'avoir un impact fondamental sur la vie des patients chez les Premières Nations. La dialyse péritonéale (DP) à domicile donne au patient plus de mobilité et de flexibilité, mais peu de membres des Premières Nations se prévalent de cette option.

Objectif : Cet article fait état de l'expérience des Premières Nations manitobaines quant à la DP et met en relief les facteurs favorables et les obstacles à l'expansion du recours à la DP dans les communautés manitobaines rurales et éloignées.

Méthode : Nous avons analysé des entrevues menées auprès de personnes atteintes d'IRT ($N=14$), d'aidants naturels ($N=14$) ainsi que d'administrateurs et de fournisseurs de services de santé ($N=27$).

Résultats : Les obstacles à l'adoption de la DP comprennent l'aptitude médicale, la méfiance des patients face aux modalités à domicile et la crainte envers leur habileté à gérer le traitement. Parmi les autres obstacles se trouvent le faible soutien familial et le manque d'hébergement adéquat.

Conclusion : La DP assistée constitue un modèle émergent dans lequel les installations pour la DP sont centralisées et où les patients peuvent s'entraider sous la supervision d'un professionnel de la DP. Ce modèle pourrait servir à atténuer les obstacles aux traitements.

Background

Indigenous populations experience a high burden of chronic kidney disease (CKD) and poorer outcomes internationally (Yeates et al. 2009). Important outcome inequities remain between Canadian Indigenous and non-Indigenous peoples (Canadian Institute for Health Information [CIHI] 2013). In 2004–2005, 30.9% and 22.4% of dialysis patients in Manitoba and Saskatchewan were Indigenous, respectively (Indigenous people constitute 15% and 11% of the population of Manitoba and Saskatchewan, respectively) (CIHI 2008).

A diagnosis of renal failure is devastating to anyone. For those living in rural and remote communities, this diagnosis may also involve relocating to an urban or a smaller regional centre, increased physical distance from family and community at a time where support is much needed and severe financial hardship because relocation and/or treatment demands often result in loss of employment. The development of satellite hemodialysis units in rural

communities, which has been the main innovation of the past three decades, had provided opportunities for some patients to dialyze closer to home. In Manitoba, dialysis modality uptake favours institution-based (in-centre) hemodialysis (ICHHD) available primarily in urban centres and some rural communities, which results in high numbers of First Nations (FN) patients requiring relocation to access treatment.

Home dialysis (which includes home hemodialysis or HHD, and peritoneal dialysis or PD) uptake remains limited. This is largely due to inconsistent access to a consistent clean water source and the influence of other social determinants of health, which make this option less viable in FN communities.

In this paper, we discuss evidence garnered from Manitoba FN patients who have undergone PD, as well as from healthcare providers who support them, to extract lessons and inform potential assisted peritoneal dialysis (APD) developments in FN communities. APD is performed at the patient's home or in a central community-based shared location, with the assistance of a healthcare professional or a family member (Dimkovic et al. 2009; Lobbedez et al. 2012). APD is an emerging modality that can mitigate community infrastructure limitations. Our paper begins with a discussion of current dialysis modalities and of the need for alternatives. We highlight key contextual issues that create barriers to the successful adoption of PD in FN communities. These findings then inform key factors that should be considered in the development of an FN-centric APD model.

The Importance of Exploring Treatment Alternatives

Interventions to support patients with end-stage kidney disease (ESKD) are divided into three main options: transplantation, dialysis or palliative care. This paper focuses on dialysis only, a medical treatment required when a patient's kidney function has stopped. Dialysis replaces some of the regular functions of healthy kidneys by cleaning blood and removing waste and excess water from the body.

Dialysis care is most often provided in ICHHD, either in larger urban dialysis centres or rural satellite centres. ICHHD is usually scheduled three times a week. The process takes approximately four hours per treatment. This time commitment does not, however, include travel time, which for residents of remote communities can be considerable to the point of requiring relocation.

Independent or semi-independent (assisted) home dialysis options include HHD and PD. HHD is performed at home, using a hemodialysis machine and a water filtration system, which in Manitoba are provided by the Manitoba Renal Program at no cost to the patient. Dialysis can be done overnight or adapted to fit the patient's schedule and preferences. Once training is complete, patients only need to visit the home dialysis clinic once every one to two months for assessment by healthcare team members. The process for PD is slightly different, in that the blood is cleaned inside the body, using the peritoneum within the abdominal cavity as a natural filter, rather than being cleaned outside in a machine. PD requires access to the dialysis solution and equipment, also provided free of charge by the

Manitoba Renal Program. A patient choosing PD dialyzes seven days a week, usually overnight during sleep. Patients only need to visit the PD clinic every two to four months for assessment by healthcare team members.

Across Canada, most provinces have large urban dialysis units offering ICHD, staffed with large multidisciplinary teams that include nurses, nephrologists, pharmacists, social workers and dietitians. Satellite ICHD centres, staffed with smaller teams of nurses and sometimes nurse practitioners, exist in most provinces to serve a limited number of rural communities.

Capital investments are considerable for rural satellite ICHD centres (Ferguson et al. 2015), coverage of remote communities is variable to inexistent (Manns et al. 2007) and beds are limited. Few rural patients, including FN patients, currently have the opportunity to dialyze in their home community. In the fall of 2017, the Manitoba Renal Program reported that 116 people were on the Manitoba Renal Program's waiting list for a dialysis bed in rural Manitoba: of these, 99 (or 85%) were FN patients (Zacharias 2017, personal communication). A few FN communities have developed transportation systems to support patients' access to ICHD sites in rural communities (1–3 hours away). Most communities cannot afford such a service. Reliance on HHD and PD is low to nonexistent in Canadian remote communities (Manns et al. 2007).

Evidence suggests that it is not the distance travelled but relocation itself that is problematic for FN peoples (Tonelli et al. 2006), with reports of loneliness; role reversal between parents and children, with children becoming caregivers; alienation and, in some cases, stigmatization (Salvalaggio et al. 2003; Wilson et al. 1994). Colonization, historical trauma, culturally unsafe care, ill-informed assumptions by healthcare providers and racism remain huge barriers to accessing responsive care for FN peoples (Lavoie et al. 2015, 2016) and may explain the faster progression from CKD to ESKD.

Canadian data show that, nationally, ICHD remains the most prevalent modality used (44.2%), followed by transplants (41.5%), PD (11.5%) and then HHD (2.8%). Figures for Manitoba are sensibly the same, with a slightly higher use of ICHD and lower reliance on transplants (55.1% and 30.1%, respectively) (Tonelli et al. 2004). CIHI data show a 43.3% unadjusted five-year patient survival for patients on ICHD, compared with 51.0% for patients on PD (CIHI 2017, p. 3). Caution should, however, be exercised in interpreting these data, as unadjusted data do not account for the possibility of a selection bias: PD candidates are more likely to be younger and healthier than ICHD candidates, as a whole. CIHI does not provide an urban/rural breakdown when reporting data.

The literature we reviewed suggests that PD is less expensive to deliver than ICHD for patients living in remote locations (Newfoundland and Labrador Centre for Applied Health Research 2008; Tonelli et al. 2007). A recent health and technology report from the Canadian Agency for Drug and Technology Assessment (Canadian Agency for Drugs and Technologies in Health [CADTH] 2017) shows the estimated lifetime cost of PD at \$600,808 and APD at \$670,452, compared with HHD at \$561,962 and ICHD at \$637,101.

The cost of offering ICHD in rural and remote jurisdictions was, however, estimated to be 1.6–2.5 times higher than that in urban centres. When locality was factored in, the annual costs of PD and APD were estimated to be considerably lower than that of ICHD (with annual savings ranging from \$62,352 to \$271,592) (CADTH 2017, p. 69).

Several studies in Australia and Canada have found increased rates of peritonitis, technique failure and mortality among Indigenous people undergoing PD (Bello et al. 2012; Buob-Corbett and Blundon 2007; Couchoud et al. 2012; Golper et al. 2011; McCarthy and Martin-McDonald 2007). These results were attributed to poor housing quality, overcrowding, periodic or no access to clean water and poorly designed sewage utilities (Hildebrand et al. 2010; Lim 2004; Lim et al. 2011; Sood et al. 2012). In addition, Manitoba Renal Program nephrologists observed that some FN patients express considerable discomfort and fear of PD, reporting that they believe it to be a substandard option. An Alberta study reported that Indigenous patients were 50% less likely to initiate PD compared with Caucasian patients (Tonelli et al. 2005).

PD's acceptability is influenced by systemic and personal factors. For example, patients living further away from points of care were found less likely to accept PD as their treatment modality (Wang et al. 2017) and less likely to have access to a nephrologist and good-quality renal care (Bello et al. 2012). A large US cohort study found that patients who opted for PD were more likely to have completed high school compared with those who opted for ICHD (Kutner et al. 2011). Maaroufi and colleagues also documented that limited awareness of PD was an important barrier (Maaroufi et al. 2013). The generalizability of these findings to FN patients is, however, unknown.

Further, the influence of previous experiences of trauma and neglect on patients' attitude towards PD remains undocumented. Previous poor experiences may have created a long-lasting fear and distrust of health systems (Lux 2016; McCallum and Perry 2014). In addition, the burden of self-managing a modality where errors may have life-threatening consequences is a likely deterrent.

Methods

This paper draws on a subset of interviews from a larger study focused on the challenges associated with FN peoples relocating for medical reasons, for which we partnered with *the First Nations Health and Social Secretariat of Manitoba* and four FN communities.¹ As shown in Table 1, a total of 129 people participated in the larger study. Findings from the broader data set have already been published (Lavoie et al. 2015, 2016). The main reason for relocation was the need for FN patients to access renal care. This paper is informed by an overall analysis of interviews conducted with FN patients, their family caregivers and healthcare providers with experience of renal care. This included in-depth, open-ended interviews with 29 patients or family members (19 women and 10 men) who spoke about their own healthcare experiences or those of family members with whom they were closely involved and 26

healthcare providers and program managers. We used the renal data set to contextualize findings from a smaller data set (20 interviews) focused on PD.

TABLE 1. Participants' characteristics

	All interviews		Renal-related interviews		Peritoneal dialysis-related interviews	
	Male	Female	Male	Female	Male	Female
Patients	11	23	5	9	1	4
Family member, parent, guardian	9	27	5	10	0	4
Healthcare provider, including social workers, physicians, nurses, navigators	4	21	4	18	3	8
Managers/decision-makers	1	4	4		0	
Focus group with program managers/decision-makers	29		0		0	
Total	129		55		20	

A partnership agreement was signed by the research team and the community leadership in each of the four FN communities, detailing the purpose and process of the study. Community-based healthcare providers with long-standing knowledge of the community invited patients and family members to participate in the research project. These workers identified potential participants, based on their knowledge, and contacted them to discuss the study and gauge interests. They then booked an appointment with the researchers. A consent form was provided and explained by a member of the research team to participants. Most interviews lasted 1–1.5 hours. In Winnipeg, potential patients and family members were identified and contacted through the AMC's Patient Navigation Unit and other key informants known to the health research team. Community-based and other healthcare providers were approached by the research team, and informed consent was secured if interested. Additional providers were identified using a respondent-driven sampling process. Ethical oversight was provided by the University of Manitoba Research Ethics Board.

Interviews were digitally recorded with permission, transcribed verbatim, cleaned of any personal identifiers and compared with the audio recordings for technical accuracy. Using interpretive thematic analysis for qualitatively derived data (Thorne 2008), the research team reviewed the transcripts to identify concepts, processes and linkages to theoretical perspectives as well as any recurring and contradictory patterns in the data. NVivo 10, a qualitative data analysis software, was used by two research assistants to independently code and organize the interview data, using the code book developed by the research team. The code books were periodically reviewed and discussed by the research team, and compared to independent coding of transcripts completed by research team members for validation. Over time, analysis shifted to a more abstract and conceptual representation of the processes and themes

reflected in the data. Credibility of the analysis was continually evaluated by members of our research team, which included experts in ethnographic research, healthcare services, FN health and health equity. Preliminary results were presented to FN Health Directors to seek advice on interpretation. In these meetings, on-reserve healthcare providers affirmed that the themes reflected in the data resonated with their experience of working with families and patients in the healthcare sector.

Findings

Participants clarified that all dialysis is initiated in Winnipeg, no matter where the patient is from, whether a satellite centre exists in their community or whether they qualify for home modalities. Dialysis initiation generally requires a six-to-eight-week stay in Winnipeg. The modality chosen at the time of initiation is most often ICHD, but a minority of patients may initiate home dialysis, either HHD or PD.

[A] patient will come in, in renal failure and they'll be at a really critical state. So we get them stabilized and, then, we'll put them on hemodialysis (Healthcare provider 25).

Once training is completed, a patient's ability to dialyze in their home community may be contemplated, but there are important barriers impeding this option:

- ICHD beds in satellite sites are limited, and often in use. It may take one to two years for a bed to become available (Patient 407; Healthcare providers 001 and 40).
- Limitations to the local infrastructure (crowding, lack of safe running water, limited storage for the dialysis solution, over/underheated house, insufficient water pressure to the house, etc.) may simply exclude the option to dialyze in the patient's home (Patient 407, for example).

Limited opportunities to go home might lead individuals to decide to go home, and endanger their life, to be able to attend to their family, community and ceremonial obligations:

You know, someone in the community who's prominent dies, everyone wants to go to the funeral and it's a big deal. So these patients put themselves at risk. And I've seen patients die from this – where they go for a funeral ... and there's no way to always provide them with dialysis (Healthcare provider 40).

Understanding the decision-making process

From the Manitoba Renal Program's perspective, decision-making surrounding the choice of a dialysis modality is based on a number of key factors related to patient characteristics that

go beyond *clinical suitability*. PD requires considerably more commitment and patient investment in the treatment process than ICHD. *Ability to self-manage* is, of course, key.

[F]or the patient to go home ... [t]hey've got to be able to grasp the needles and the tubes to be able to connect, disconnect – those kinds of things (Healthcare provider 36).

Another key factor is *social and family support*.

Depending on what kind of supports they have in community, they may be able to just go home, right? ... [I]t doesn't matter what the state of the family is; they still need them ... (Healthcare provider 25).

A number of patients and caregivers recounted their/their loved one's journey on PD. In this first story, family caregivers' reticence was overcome through the continued support of healthcare providers. This patient was on dialysis for a decade, and then passed away in his teen years. He lived in Winnipeg.

[T]he nurses and doctors were very supportive there. And they did everything they can to help us ... [B]efore he got discharged from the hospital, both my husband and I went on training ... because he was on [PD]. [W]e both went for the training to look after him at home ... And we brought him home with – after we got trained and we were *brave* enough to bring him home ... I guess that's the best – what I can do because *it was scary*. I took him and I said, "Well, what if I do something wrong?" You know? There was *a lot of fear* ... But the nurses came and ... [t]hey helped us through the process – like, letting us do the dialysis, them being there, supervising it. And they done that for about 2 months and then finally we went on our own (Patient 44, emphasis added).

In this second story, related by a patient's mother, the patient also lived in Winnipeg. He chose PD but eventually switched to ICHD in Winnipeg. At the time of the interview, he was waiting for a dialysis bed to open in one of the satellite units closer to his home community.

He was on home [PD]. He didn't want to go to the hospital for dialysis. *He wanted to do it on his own* because he was okay ... He was feeling good; he – he wanted to work, besides that, doing his dialysis at night time, and then maybe do something – find work or maybe part-time, maybe – but they were in the evening – day-time, because he was on dialysis at night. And then, he got sick ... *I don't trust that home dialysis* (Patient 218, emphasis added).

The next two stories are of patients who were using PD in their own community. Patient 30 initiated PD while living in her community, which is remote. The family's involvement in ensuring that she remained on PD in her community is remarkable. She, unfortunately, had to relocate to Winnipeg because of recurrent health issues that forced her to travel frequently to Winnipeg to receive care.

She did [PD in her home community] by herself in the beginning. I went for training along with her. And then I helped on the side here and there. And eventually, like, she couldn't – like, her pain. So eventually I did the dialysis for her. And then, eventually, I would teach, like, my children. They were about, like, maybe 10 at the time. And then they would learn it also ... the nephews and the nieces. And they all learned it; they were all under 15. So we just took turns and the sisters. I taught them how to do it, and my brothers, as well. So we all shared the responsibility ... And then, when she got really sick ... That's when she did the relocation to Winnipeg. We had to move (Patient 30).

In the following story, as in the one above, moving to Winnipeg was eventually required for other health reasons.

I looked after my mom and dad when they were sick ... My dad [f]irst he started off with ... [PD] ... And then, after a while, it didn't work. He got really sick and we had to relocate. He had no choice (Patient 203).

According to one healthcare provider, key reasons for PD failure include “improper training and not enough people looking after them” (Healthcare provider 26).

Unsuitable housing conditions can be a decisive factor on the choice of a modality. In our sample, seven patients had experienced PD. PD was considered for two more patients but not pursued. In one case, the patient reported being advised that PD was not a suitable option, but the rationale was not documented (Patient 007). In contrast, PD would have been the option of choice for Patient 407, but this was not possible because of substandard housing:

[H]ome dialysis: I could do that at home. But I don't have running water in my house at home. I've got those options still and I'm still thinking about – trying to make up my mind ... I'd go home first chance I get (Patient 407).

This patient reflected that “I used to want to come to the city a lot,” but that his priority was to get home. At the time of the interview, he reported that he had been waiting for two years for an ICHD bed in a site closer to his home community.

A healthcare provider contributed the following scenario:

A good example is one person who'd be perfect for [PD] up North but wants to live with their daughter. But the housing won't be provided for both of them together ... So that person didn't sign the papers or could have had an apartment by themselves that was big enough for PD but ended up having to move to Winnipeg to start [ICHD] because they wanted to live with their daughter. They wanted to live in a family group, which isn't always something that the system, then, is sensitive to and provides. So, they don't always provide the unique circumstances or for the extended family that, often, people want to live with or the context of the extended family (Healthcare provider 40).

The successful use of PD in an FN community is thus linked to a number of factors beyond clinical suitability. These factors are largely structural and contextual.

Discussion

Expanding access to home-based options in rural and remote communities is evidently complex, because of the limited local support available (support group, renal clinics, limited local primary care) and the distance required to access more complex care if needed. Our results show that barriers to home modalities in rural and remote FN contexts include intrinsic and extrinsic factors. Intrinsic factors include medical suitability and patients' fear in their ability to manage a complex disease previously only treated by doctors and nurses. There appears to be an important lack of trust in home modalities.

Extrinsic factors include the support of family and friends and lack of appropriate housing (space for storage and running water). These findings echo those on patients' perspectives documented in the CADTH report (CADTH 2017), although the context and the scale are different. The housing crisis in FN communities has been well documented (Carriere et al. 2017; Lacombe et al. 2011; Wearmouth and Wielandt 2009; Webster 2015). A 2017 Canada Mortgage and Housing survey documented that one in three houses on-reserve was below acceptable standards. This percentage was as high as one in two in the prairie region, which counts as the highest number of FN families living on-reserve (Canada Mortgage and Housing Corporation 2011). Likewise, the lack of access to safe drinking and running water in many communities has attracted the attention of James Anaya, the Special Rapporteur on Indigenous Human Rights to the United Nations (Anaya 2014).

Finally, the devastating impact of former and current policies on FN families continues to undermine some families' ability to support individual members, as is the case for those on home dialysis (McKenzie et al. 2016), leaving those family members to depend more readily on public services, which in turn may be prejudiced towards FNs (Browne et al. 2010, 2011; 2015; Nelson et al. 2016).

To date, most research works documenting models of APD have related the existence of urban-based models, which function primarily on the basis of home visits (Bevilacqua et al. 2017; Brown and Wilkie 2016; Dimkovic et al. 2009; Giuliani et al. 2017; Lobbedez et al. 2012). We found no evidence of patient engagement in the development of the model. Further, no attention has been paid to the need of patients from rural and remote settings and to the specific needs of FN patients.

Conclusions

Our analysis suggests that developing APD sites in FN communities might expand options for eligible FN patients. The mutual support of a group of patients undergoing PD together, assisted by a healthcare professional, with a central and temperature-controlled location to house supplies, could create opportunities that help to not only overcome the infrastructure and housing issues but also mitigate the intrinsic barriers of the patient's concerns and fears associated with current PD models.

Our decades of experience working in FN communities, and providing renal healthcare services to FN patients, suggest that success will require a) developing a service with strong coordination, b) wrap-around supports in terms of the mental, emotional, spiritual and physical care; and c) a strong culturally appropriate education and empowerment components. These are, in our view, essential to successfully support the individual and their family through the adjustment to APD.

Implementing an APD program within an Indigenous context would also help build local expertise in this complex disease. Expanding local expertise may prove to be the most important factor in not only expanding local knowledge of treatment but also preventing the disease and could perhaps also shift current trends towards increased CKD and ESKD diagnoses at very early ages. Fundamentally, effective models of APD must build on the needs and wants of FN patients themselves and be context-relevant.

Australia and New Zealand have successfully implemented models of APD in rural and remote Indigenous contexts. An APD pilot was also successfully implemented in BC non-FN communities (Bevilacqua et al. 2017). An urban APD site exists in Winnipeg. Although we readily admit that greater research in this area is needed, and will be undertaken by our team over the next five years, APD appears promising.

Note

¹ The Assembly of Manitoba Chiefs (AMC) was formed in 1988 to act as an advocate on issues that commonly affected all First Nations of Manitoba. The First Nations Health and Social Secretariat of Manitoba was established in 2014 with the staff from AMC's Health and Social Secretariat.

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