

BACKGROUND

- Home modalities offer advantages over in-centre dialysis, including reduced overall health care spending.
- Patients face significant out-of-pocket costs to train at St. Paul's Hospital if they live outside the Lower Mainland.
- BCPRA assists with equipment and utilities, but not travel or accommodation costs related to training. Government financial support varies across provinces and health authorities.
- A recent Kidney Foundation survey reported that 50% of patients' household income decreased after commencing dialysis, and 41% were below the Canadian low-income cutoff.
- The reported annual out-of-pocket costs ranged from \$1400-2500 depending on dialysis modality.
- The report recommended increasing efforts to subsidize transportation costs and expand access to travel grants, especially for rural areas.
- Patients and their families face financial challenges as income decreases and incurred costs increase.
- This can create a financial burden and a barrier to dialysis access, particularly for those of low socioeconomic status.
- Societal costs of CKD are high due to lost work productivity, costs to disability insurance, and Canadian pension plan payouts in excess of \$200 million per year.

OBJECTIVES

This study aims to understand patient perspectives on the costs incurred for home dialysis training in BC and Yukon.

METHODS

- Letters of invitation were sent to 32 patients who have completed training in a home-based method of dialysis and are currently followed by the kidney program at St. Paul's Hospital.
- Patients were invited to complete a telephone survey which included demographic information, open, and closed-ended questions related to the costs they experienced while training.
- Each telephone interview was transcribed verbatim, analyzed and emergent themes were identified from the data including representative quotes.
- Participation in the study was voluntary. Informed consent was obtained at the beginning of each interview and in writing.
- Ethics approval was obtained from the Providence Health Care Research Ethics Board.

RESULTS

Survey Demographics:

- response rate 15/32 (47%)
- mean age 63.5 years, 60% male
- 11 BC and 4 Yukon residents
- 73% on peritoneal dialysis



- 67% primary household income earners
- majority incomes between \$25,000 to \$100,000
- 8/15 (53%) were reimbursed
- Most expensive aspect was accommodation
- All supported creation of a funding program



Fig. 1: Survey Participant Locations

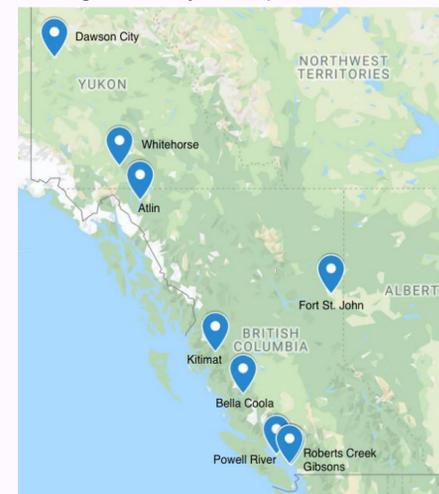
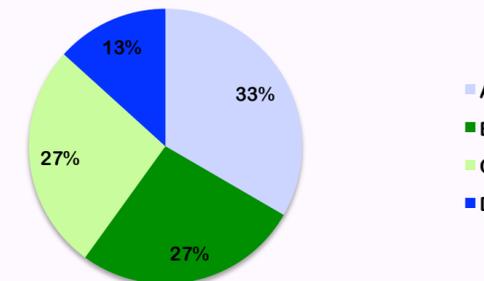


Fig. 2: Which would best describe your experience with training costs?



- A. Costs were not a barrier to my selection of home modalities
- B. Costs were a burden for my household, but we were able to manage
- C. Family or others helped me cover costs
- D. Costs related to my training created a financial hardship for me

Representative Quotes:

When you chose your current dialysis method, were costs for training a factor in your decision?

- No, not costs per se, no. I didn't really have a choice.

What out-of-pocket costs did you incur for your training?

- We stayed in a hotel right next door to hospital. \$4200 cost...We had to pay out of pocket.
- I found a place to rent...travel money to and from hospital, taxi money and living costs and hard to set up a new place to live in.

Would financial assistance for training have been a benefit for you?

- Yes for housing because it's huge. I was absolutely blown away (by costs).
- Anything would be good... I was very lucky everyone donated money. I don't know what I would have done without family support.
- By the time we were down going to Vancouver for two treatments. We were broke and maxed out our credit cards. MHSD did help us find a place for home hemo training and a little for gas and food \$150 for five weeks. So it got us started.

Were you reimbursed for any out-of-pocket costs related to your training?

- They (Yukon government) pay airline ticket and reimburse \$75 per day.
- Only travel reimbursed \$30 for accommodation was the only benefit we got. It comes out of pocket and it still comes out of pocket.

Would you recommend the creation of a program to support patients with the out-of-pocket costs of training?

- If I had to pay everything myself I never would be able to afford it. I would have probably strapped together the money...
- The accommodation is often the biggest barrier, if there's some way it can be offset.

CONCLUSION & NEXT STEPS

- Our patients incur a significant personal cost during the training period for peritoneal dialysis and home hemodialysis, including transportation, food, accommodation, and other expenses, as well as lost income.
- Reducing the financial burden of training for patients outside urban centres has important implications for increasing uptake of home modalities.
- There is potential to expand the use of simulation to assist dialysis training, though this would not fully replace the need for travel.
- We have secured funding for one patient to train in the Vancouver area. This includes:
 - accommodation for PD tube insertion (3 nights)
 - accommodation for 2 weeks of training (12 nights)
 - one return flight
 - total amount: \$1875.17
- Moving forward, we plan to continue with the pilot project of reimbursement for SPH patients living within Vancouver Coastal Health region, greater than 50km outside the city.

ACKNOWLEDGEMENTS

We thank the St. Paul's Foundation for their generous support in funding the pilot program.

REFERENCES

1. The Kidney Foundation of Canada. The burden of out-of-pocket costs for Canadians with kidney failure. <https://www.kidney.ca/burden>. September 2018.
2. Manns B, Hemmelgarn B, Tonelli M, et al. The cost of care for people with chronic kidney disease. *Can J Kidney Health Dis* 2019; 6: 1-11.
3. Klarenbach S and Manns B. Economic evaluation of dialysis therapies. *Semin Nephrol* 2009 Sep; 29(5): 524-532.
4. Barnieh L, King-Shier K, Hemmelgarn B et al. Views of Canadian patients on or nearing dialysis and their caregivers: a thematic analysis. *Can J Kidney Health Dis*. 2014, 1:4.
5. Mathew AT, Park J, Sachdeva M et al. Barriers to Peritoneal Dialysis in aboriginal patients. *Can J Kidney Health Dis*. 2018; 5:1-9.
6. Chan CT, Wallace E, Golper TA et al. Exploring barriers and potential solutions in home dialysis: an NKF-KDOQI Conference outcomes report. *Am J kidney* 2018; 73(3): 363-371.