Patient Perspectives on Financial Barriers to Home Dialysis Training in BC and Yukon: A Qualitative Survey

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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.

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