Relocation of remote-dwellers living with hemodialysis: A time tradeoff survey

Marcello Tonelli[1], Anita E Molzahn[2], Natasha Wiebe[3], Sara N Davison[3], John Gill[4], Brenda R Hemmelgarn[1], Braden J Manns[1], Neesh Pannu[3], Rick Pelletier[5], Stephanie Thompson[3], Scott W Klarenbach[3]

for the Alberta Kidney Disease Network

(1) Department of Medicine, University of Calgary
(2) Faculty of Nursing, University of Alberta
(3) Department of Medicine, University of Alberta
(4) Department of Medicine, University of British Columbia
(5) Department of Renewable Resources, University of Alberta

No reprints will be available. Correspondence to:
Marcello Tonelli
3051 RTF, University of Alberta
8308 112 St NW, Edmonton, Alberta, Canada T6G 2V2
Phone: 780 407 3235 Fax: 780 407 7864
celloadmin@ualberta.ca

Running Title: Relocation of remote-dwellers on HD

Keywords: end-stage renal disease, hemodialysis, remote-dwellers, health care services

Word Count: 2119 (Abstract 327)

Abstract

There has been little research exploring the experience of dialysis therapy for people living in remote communities. Remote residence location has previously been associated with excess mortality in hemodialysis patients, suggesting that relocation to a referral centre might improve outcomes. It is unknown whether patients view this approach as acceptable. We studied 121 remote-dwelling chronic hemodialysis patients using the time tradeoff method applied to hypothetical scenarios. Participants indicated that they would trade a median of 6 years of life in their current location (including current social supports) (IQR 1-9) for 10 years of life in a referral centre without any of their existing social supports (meaning they would be willing to forgo four years of life to remain in their current residence location). When current social supports were assumed to continue in both locations, people were only willing to forego a median of two years of life (IQR 0-9) to remain in their current location. Older participants were much less willing to accept relocation than younger participants; the median time tradeoff associated with relocation and without social supports was 2 years for participants aged <50 years, 3 years for those aged 50-69.9 years and 9 years for those aged ≥70 years. In summary, we found that hemodialysis patients currently living remotely were willing to forgo much of their remaining life expectancy rather than relocate – especially among older participants. These findings suggest that decisions about relocation should be accompanied by discussion of anticipated changes in quality of life and life expectancy.

Introduction

There has been little research exploring the experience and outcomes of dialysis therapy for people living in rural and remote communities. In the DOPPS study with nearly 20,994 participants, longer travel time to dialysis was associated with a greater relative risk of death and significantly lower quality of life.[1] Similarly, hemodialysis (HD) patients who live further away from their nephrologist were found to have an increased risk of death compared to those who live closer, even after controlling for confounding variables.[2] One possible explanation for the excess risk of death among remote-dwellers is that reduced access to nephrologists and other health services leads to lower quality of care.[3] This finding is worthy of further consideration because residence location is potentially modifiable.

Although patients can change their location of residence, moving is time-consuming, potentially costly, and often disrupts employment and social and support networks[4] – which may be especially important among elderly or chronically ill individuals,[5] such as those with kidney failure. These financial and social consequences could have a substantial negative influence on quality of life.

Nonetheless, assuming that the relation between residence location and excess mortality is causal, patients might be willing to relocate in exchange for longer life expectancy, even if it meant reduced quality of life. Using a utility measure, the Time Trade-Off, we used hypothetical clinical scenarios to ascertain (1) whether remote dwelling hemodialysis patients would find

relocation acceptable; and (2) their strength of preference to avoid relocating closer to a referral centre (with on-site nephrology support).

Results

We approached 192 remote-dwelling hemodialysis patients about participation in this study (Figure 2). Of these, 71 were excluded (48 due to lack of interest, and 23 who were not eligible to participate). Characteristics of the 121 participants are shown in Table 2; the majority (51.2%) were between 50 and 69.9 years of age. Participants resided, on average, 120 km from the closest referral centre (range 20-900 km).

Overall, participants indicated that they would trade 10 years of life in their current state of health for a median of 7 years of life in "excellent" health (IQR 4.5-8), representing median utility of 0.7 associated with treated ESRD (Question 1). Utility values ranged from 0.5 (patients aged ≥70 years of age) to 0.8 (patients aged <50 years of age) (Table 3).

Overall results of the scenarios relevant to relocation are presented in Table 3. Participants indicated that they would trade a median of 6 years of life in their current location (including current social supports) (IQR 1-9) for 10 years of life in a referral centre (without any of their existing social supports) -- meaning that they would be willing to forgo four years of life to remain in their current residence location. When current social supports were assumed to continue in the referral centre, participants indicated that they would trade a median of 8 years

of life in their current location (including current social supports) (IQR 1-10) for 10 years of life in a referral centre.

Interestingly, not all participants were interested in closer medical follow-up even at their current location of residence: 20% indicated that they would prefer the status quo to weekly visits from their nephrologist Finally, in scenarios where life expectancy was assumed to be only 1 year if they moved to a referral centre, participants were only willing to forgo one month of life expectancy (IQR 0-11) in exchange for remaining in their current location.

Participant age (but not sex, diabetes status, or distance from the referral centre) significantly modified participant's willingness to relocate (Table 3). Older participants were much less willing to accept relocation than younger participants. For example, the median number of years that a person was willing to forgo rather than move to a referral centre without social supports was 2 years for participants aged <50 years, 3 years for those aged 50-69.9 years and 9 years for those aged ≥70 years. Put differently, participants aged ≥70 years indicated that they would value 1 year of life in their current location (with or without current supports) equally to 10 years of life in a referral centre without their existing social supports.

Discussion

Hemodialysis is associated with poor quality of life; median utility among participants in our study was only 0.7, representing a substantial decrement compared with perfect health.[6] A key finding of our study was that most remote-dwelling hemodialysis patients place a high value on

remaining in their current residence location – even when relocation to a referral centre did not involve loss of existing social supports. Given that reduced access to social supports is an anticipated consequence of nearly all such relocations, it is notable that participants were willing to forgo four years of life to remain in their current residence location. A second key finding was the age-dependence of results: with younger participants placing a lower relative value on avoiding relocation and a higher relative value on longer life expectancy.

The link between remote or rural residence location and increased mortality among hemodialysis patients is based on observational data.[2] The relatively small magnitude of the apparent increase in relative risk (8-20%), the potential for residual confounding, and the lack of trial data mean that causality is uncertain. Data from other studies support the potential benefits of aging in place (remaining in one's own home or community in spite of potential changes in health and functioning in later life).[7] These considerations together with the results of the current study argue strongly against a policy of routinely proposing relocation to remote-dwelling hemodialysis patients as a method of reducing mortality.

Our results may have broader implications for the common practice of transferring ill or failing patients from remote communities to receive hemodialysis in referral centres. The low tolerance for relocation (especially in the absence of social supports) reported by participants in our study suggests that this practice may not always be justified – especially for those aged ≥70 years. In fact, our findings likely support the increased use of peritoneal dialysis wherever possible for such patients – which might avoid the need for relocation to an area served by an in-centre hemodialysis unit. Overall, our findings suggest that the potential benefits of

relocation should be carefully explored with patients and their families, ideally using a decision aid. This may help patients to make a decision about relocation that is consistent with their values and preferences – and potentially to remain in their own communities even if this leads to lower access to care and/or shorter life expectancy. Further consideration could also be given to supporting people in rural and remote areas to remain in their home communities. Research evaluating the outcomes and cost-benefits of local clinics, home visits, and telehealth initiatives could be considered.

Our study has some limitations that should be considered when interpreting results. First, it used hypothetical scenarios rather than real world situations to estimate people's strength of preference for avoiding relocation. Although we used rigorous methods to perform our time tradeoff analysis, the extent to which responses correspond to the true values and preferences of participants is uncertain. Second, all participants were drawn from a single large hemodialysis program in a Western Canadian province. Although the characteristics of patients were broadly similar to the overall Canadian hemodialysis population,[8] our findings require validation in other patient populations and clinical settings. Finally, the default comparator for most scenarios implied a life expectancy of at least 10 years, which may be longer than the life expectancy of many hemodialysis patients. When life expectancy was explicitly limited to one year, participants appeared to be more accepting of relocation. This suggests that any assessment of preferences related to relocation may be most useful to patients if accompanied by a sensitive discussion of anticipated life expectancy.

In summary, in this study of remote-dwelling hemodialysis patients, we found people were willing to forgo a substantial number of years of life rather than relocate to a referral centre – especially among older participants. These findings suggest that decisions about such relocation should be made in the context of a careful discussion of anticipated changes in quality of life and life expectancy.

Concise Methods

Participants

Participants were recruited from the Northern Alberta Renal Program (NARP) from February 2010 to April 2012, specifically from remote dialysis units in Drayton Valley, Fort McMurray, Grand Prairie, Lloydminister, Peace River, Rocky Mountain House, Slave Lake, St. Paul, Stettler, Vegreville, Westlock, and Wetaskiwin, Alberta (Figure 1). The remote dialysis units are managed as satellites of the in-centre programs those in Edmonton, Red Deer, Calgary, Medicine Hat and Lethbridge. In contrast to patients treated in in-centre dialysis units (who are seen in-person by a nephrologist between 1 and 3 times per week), patients in satellite dialysis units are managed by telephone, videoconference and occasional in-person visits.

English-speaking adults (≥18 y), within 8 weeks of commencing hemodialysis, were eligible for inclusion in the study provided that they indicated that they could understand the questions in the study survey. Written, informed consents were obtained. The University of Alberta research ethics board approved the study. The medical charts were reviewed for demographic information and medical history, and verified verbally with the participant.

Survey

The Time-Trade-Off Technique (TTO) is a health utility measure that involves an assessment of the preference of various health states. The individual is asked to choose between two health states, and the time frames are adjusted until they can no longer choose one option over another. We used the TTO to determine participants' relative preference for residence relocation versus remaining in their own home, following recent recommendations.[9] Analyses were aimed at determining how many months or years of life each participant was willing to trade for the opportunity to avoid relocation. The survey was administered during a face-to-face interview with a research assistant, who used a pre-printed questionnaire as a guide. The research assistant asked each question in English and explained further when requested. The participants verbally answered the questions and the research assistant recorded the response on paper.

Each participant was asked to consider scenarios in which they would locate to the in-centre unit that was closest to their current dialysis unit. Analyses were aimed at determining (1) utility for the current health state, where 1 represents perfect health and 0 represents death; and (2) how many months or years of life each participant was willing to trade or forgo for the opportunity to avoid relocation. In general, comparator scenarios assumed 10 years of survival, similar to the median survival for nondiabetic patients with ESRD on dialysis.

As a warm-up task, we evaluated the participants' perception of their current health (vs "excellent health"; Question 1 in Table 1). This question provides insight as to the respondents' perceptions of the burden of illness associated with kidney failure, as well as familiarizing them with the time trade off methodology. We then evaluated participants' willingness to potentially increase life expectancy through more intensive medical care but without relocation (Question 2 in Table 1). We next assessed the relative merit of years of life spent in their current location versus the closest referral centre (close to specialized medical care) where the participant's existing social supports were not available (Question 3 in Table 1). To examine the perceived value of residence location per se, this scenario was repeated but specifying that their social supports would still be available in the new location (Question 4 in Table 1).

While most scenarios used a comparison survival of 10 years, a final question limited the horizon to one year in order to assess the possibility that time preference varied with shorter life expectancy. Worse-than-death states were not considered by our survey. Once an initial response was given, the research assistant adjusted the time frames in subsequent questions using the "ping-pong" method.[10] All participants appeared to understand the survey; we did not exclude participants for "non-trading" behavior or apparent inconsistencies in results between questions.

Distance to referral centre

We calculated distance from the postal code of the participants' residence to the closest referral centre. We determined the geographic coordinates for each 6-digit postal code using

the Statistics Canada Postal Code Conversion File (PCCF; www.statcan.ca). These coordinates were entered into ESRI ArcInfo 10.0 software (www.esri.com) to determine the shortest distance by road (in km) between the residence of each participants and the closest referral centre.

Statistical analyses

All analyses were completed in Stata/MP 13.0 (www.stata.com). Descriptive statistics were reported as counts and percentages, or means, medians and inter-quartile ranges, as appropriate. Differences between subgroups were tested using the Kruskal Wallis test and Fisher's exact test. The following subgroups were explored as potential modifiers: age (<50, 50 to 69.9, ≥70 y), gender, diabetes, and distance to closest referral centre. Distance was dichotomized at ≥150 km as per prior work.[11]

Acknowledgements

The authors of this report are grateful to Nancy Ruholl and Bill Liu for research assistant support, and to Ghenette Houston for administrative support.

This work was supported by the Canadian Institutes for Health Research (200709MOP-178552-PUB-CBAA-62156) and a Leaders Opportunity Fund grant from the Canada Foundation for Innovation. MT is supported by an AHFMR Population Health Scholar award and a Government of Canada Research Chair in the optimal care of people with chronic kidney disease.

Statement of Competing Financial Interests

There are no competing interests.

References

1. Moist, LM, Bragg-Gresham, JL, Pisoni, RL, Saran, R, Akiba, T, Jacobson, SH, Fukuhara, S, Mapes, DL, Rayner, HC, Saito, A, Port, FK: Travel time to dialysis as a predictor of health-related quality of life, adherence, and mortality: the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Am J Kidney Dis,* 51**:** 641-650, 2008.
2. Tonelli, M, Manns, B, Culleton, B, Klarenbach, S, Hemmelgarn, B, Wiebe, N, Gill, JS, Alberta Kidney Disease, N: Association between proximity to the attending nephrologist and mortality among patients receiving hemodialysis. *CMAJ,* 177**:** 1039-1044, 2007.
3. Bello, AK, Hemmelgarn, B, Lin, M, Manns, B, Klarenbach, S, Thompson, S, James, M, Tonelli, M, Alberta Kidney Disease, N: Impact of remote location on quality care delivery and relationships to adverse health outcomes in patients with diabetes and chronic kidney disease. *Nephrol Dial Transplant,* 27**:** 3849-3855, 2012.
4. Dupuis-Blanchard, S, Neufeld, A, Strang, VR: The significance of social engagement in relocated older adults. *Qual Health Res,* 19**:** 1186-1195, 2009.
5. Penninx, BW, van Tilburg, T, Kriegsman, DM, Deeg, DJ, Boeke, AJ, van Eijk, JT: Effects of social support and personal coping resources on mortality in older age: the Longitudinal Aging Study Amsterdam. *Am J Epidemiol,* 146**:** 510-519, 1997.
6. Laupacis, A, Keown, P, Pus, N, Krueger, H, Ferguson, B, Wong, C, Muirhead, N: A study of the quality of life and cost-utility of renal transplantation. *Kidney Int,* 50**:** 235-242, 1996.
7. Bacsu, JR, Jeffery, B, S., J, Martz, D, Novik, N, Abonyi, S: Healthy Aging in Place: Supporting Rural Seniors' Health Needs. *Online Journal of Rural Nursing and Health Care,* 12**:** 77-87, 2012.
8. Canadian Institute for Health Information. Canadian Organ Replacement Register (CORR). 2014; http://www.cihi.ca/CIHI-ext-portal/internet/en/document/types+of+care/specialized+services/organ+replacements/corr_directory. Accessed September 17, 2014.
9. Attema, AE, Edelaar-Peeters, Y, Versteegh, MM, Stolk, EA: Time trade-off: one methodology, different methods. *Eur J Health Econ,* 14 Suppl 1**:** S53-64, 2013.
10. Lenert, LA, Cher, DJ, Goldstein, MK, Bergen, MR, Garber, A: The effect of search procedures on utility elicitations. *Med Decis Making,* 18**:** 76-83, 1998.
11. Thompson, S, Bello, A, Wiebe, N, Manns, B, Hemmelgarn, B, Klarenbach, S, Pelletier, R, Tonelli, M, Alberta Kidney Disease, N: Quality-of-care indicators among remote-dwelling hemodialysis patients: a cohort study. *Am J Kidney Dis,* 62**:** 295-303, 2013.

Table 1. Time tradeoff questions used during the survey, including potential responses

Questions	Response
1. If you had to choose between X years of life with **excellent health** **OR** ten years of life with your current health which would you choose?	Median 7 years with excellent health (IQR 4.5-8) For 10 years with current health Median tradeoff = 3 years (IQR 2-5.5)
2. If you had to choose between staying in your current location with your current health, the same medical care and same supports as you have now **COMPARED TO** staying in your current location with your supports, having **weekly kidney doctor visits** and therefore improved health, more access to other specialist. Which would you choose?	Improved health with weekly kidney doctor visits and more access to specialists in current location 92 (80.0%) Current health without further supports in current location 23 (20.0%)
3. If you had to choose between 10 years of life living **in or close to the city*** for improved health but **none of the supports** you have listed **OR** X years of life with your current medical care in your current location and with your supports, which would you choose?	Median 6 years with current health and supports in current location (IQR 1-9) For 10 years of life living in/close to the city with improved health and none of the current supports Median tradeoff = 4 years (IQR 1-9)
4. If you had to choose between 10 years of life moving **to or close to the city with the social supports you have listed** **OR** X years of life with your current medical care in your current location with your supports which would you choose?	Median 8 years with current health and current supports in current location (IQR 1-10) For 10 years of life living in/close to the city with better medical care and current supports Median tradeoff = 2 years (IQR 0-9)
5. Now you only have 12 months to live. If you had to choose between living at your current location with your current health and current supports **OR** moving **closer to the city** to receive **better health care** and you would **also have supports**, which would you choose?	Median 11 months with current health and supports in current location (IQR 1-12) For 12 months of life living in /close to the city with better medical care and current supports Median tradeoff = 1 month (IQR 0-11)

"City" refers to the 5 referral centres: Edmonton, Red Deer, Calgary, Medicine Hat and Lethbridge.

Table 2. Characteristics of participants (N=121)

	N (%) or Median (IQR)
Age	
<50 y	31 (25.6)
50 to 69.9 y	62 (51.2)
≥70 y	28 (23.1)
Male	65 (53.7)
Weight, kg	83.5 (69.6,102.5)
BMI, kg/m^2	29.1 (24.5,35.1)
Distance to referral centre	120 (100,240)
Smoker	33 (27.3)
Angina	12 (9.9)
Diabetes	67 (55.4)
Hypertension	74 (61.2)
Systolic blood pressure, mmHg	137 (121,153)
Diastolic blood pressure, mmHg	70 (58,79)
Cancer	13 (10.7)
Coronary artery disease	19 (15.7)
Heart failure	16 (13.2)
Liver disease	6 (5.0)
Lung disease	24 (19.8)
Peripheral vascular disease	1 (0.8)
Psychiatric illness	22 (18.2)
Stroke	14 (11.6)
Substance misuse	23 (19.0)
Dialysis vintage, y	1.4 (0.5,2.9)
Vascular access	25 (20.7)

BMI body mass index, IQR interquartile range

Table 3. Time tradeoff: subgroup analyses

		Question				
	N	**1**	**2**	**3**	**4**	**5**
Overall	115	Median 3 y IQR 2-5.5	80.0%	Median 4 y IQR 1-9	Median 2 y IQR 0-9	Median 1 m IQR 0-11
Age: **<50 y**	29	Median 2 y IQR 1-4	69.0%	Median 2 y IQR 0-5	Median 0 y IQR 0-2	Median 1 m IQR 0-2
50 to 69.9 y	61	Median 3 y IQR 1-5	89.8%	Median 3 y IQR 1-9	Median 2 y IQR 0-9	Median 1 m IQR 0-11
≥70 y	28	Median 5 y IQR 2.5-8	70.4%	Median 9 y IQR 4-9	Median 9 y IQR 2-9	Median 11 m IQR 0-11
		P=0.02	P=0.02	P=0.004	P=0.001	P=0.007
Gender: **Male**	63	Median 3 y IQR 2-6	80.3%	Median 4 y IQR 0-9	Median 4 y IQR 0-9	Median 1.5 m IQR 0-11
Female	54	Median 2 y IQR 1-5	79.3%	Median 5 y IQR 2-9	Median 2 y IQR 0-9	Median 1 m IQR 0-11
		P=0.24	P=1.00	P=0.19	P=0.15	P=0.69
Diabetes: **Yes**	65	Median 3 y IQR 2-6	82.8%	Median 4.5 y IQR 1-9	Median 3 y IQR 0-9	Median 1.5 m IQR 0-11
No	51	Median 3 y IQR 1-5	76.5%	Median 4 y IQR 1-9	Median 2 y IQR 0-9	Median 1 m IQR 0-11
		P=0.43	P=0.48	P=0.57	P=1.00	P=0.96
Distance to closest referral centre: **≥150 km**	56	Median 3 y IQR 2-8	73.6%	Median 5.5 y IQR 1-9	Median 4 y IQR 0-9	Median 1 m IQR 0-11
<150 km	65	Median 2.5 y IQR 1-5	85.5%	Median 3 y IQR 0-9	Median 1.5 y IQR 0-7	Median 1.5 m IQR 0-11
		P=0.19	P=0.16	P=0.27	P=0.06	P=0.76

1. If you had to choose between X years of life with excellent health OR ten years of life with your current health which would you choose?

2. If you had to choose between staying in your current location with your current health, the same medical care and same supports as you have now COMPARED TO staying in your current location with your supports, having weekly kidney doctor visits and therefore improved health, more access to other specialist. Which would you choose?

3. If you had to choose between 10 years of life living in or close to the city* for improved health but none of the supports you have listed OR X years of life with your current medical care in your current location and with your supports, which would you choose?

4. If you had to choose between 10 years of life moving to or close to the city with the social supports you have listed OR X years of life with your current medical care in your current location with your supports which would you choose?

5. Now you only have 12 months to live. If you had to choose between living at your current location with your current health and current supports OR moving closer to the city to receive better health care and you would also have supports, which would you choose?

Figure 1. Map of study sites

Edmonton, Red Deer, Calgary, Medicine Hat and Lethbridge are the 5 referral centres that patients would relocate to in the hypothetical scenarios.

Figure 2. Participant flow

TTO time tradeoff