Barriers to Home Hemodialysis Across Saskatchewan, Canada: A Cross-Sectional **Survey of In-Center Dialysis Patients**

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Abstract

Background: Despite clinical and lifestyle advantages of home hemodialysis (HHD) compared with in-center hemodialysis (ICHD), it remains underutilized in our province. The aim of the study was to explore the patients' perception and to identify the barriers to use of HHD in Saskatchewan, Canada.

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Objectives: The primary objective of the study was to evaluate and explore patient perceptions of HHD and to identify the obstacles for adoption of HHD in Saskatchewan. The secondary objective was to examine variations in the patients' perceptions and barriers to HHD by center (main dialysis units vs satellite dialysis units).

Design: This is a cross-sectional observational survey study.

Setting: Two major centers (Regina and Saskatoon) and 5 associated satellite units attached to each center across the province of Saskatchewan.

Patients: We approached all prevalent ICHD patients across Saskatchewan, 398 agreed to participate in the study. **Measurements:** Self-reported barriers to HHD were assessed using a questionnaire.

Methods: A questionnaire was designed to determine the patients' perceived barriers to HHD. Descriptive statistics was used to present the data. Chi-square and Mann-Whitney U test were used to compare the patients' responses between main and satellite units

Results: Satisfaction with current dialysis care (91%), increase in utility bills (65%), fear of catastrophic events at home (59%), medicalization of one's home (54%), and knowledge deficits toward treatment modalities (54%) were the main barriers to HHD uptake. Compared with patients dialyzing in our main units, satellite patients chose not to pursue HHD more frequently because they had greater satisfaction with their current dialysis unit care (97% vs 87%, P < .001), felt more comfortable dialyzing under the supervision of medical staff (95% vs 86%, P < .007), could not afford additional utility costs (92% vs 45%, P < .001), were unaware of the risks and benefits of HHD (83% vs 33%, P < .001), had concerns over time commitments for training to HHD (69% vs 32%, P < .001), and had concern for family burnout (60.8% vs 40.6%, P < .001). Limitations: We used questionnaires to quantify known barriers, and this prevents inclusion of additional barriers that individual patients may consider important. Cross-sectional data can only be used as a snapshot. Only 398 patients agreed to participate, and the results cannot be generalized to 740 prevalent HD patients. We did not capture data on demographics (age, income, and literacy level), comorbidities, and dialysis vintage, which would have been helpful in interpretation of the results.

Conclusions: Satisfaction with in-center care, lack of awareness and education, specifically in the satellite population, concerns with family burnout, expenses associated with utilities, and training time will need to be addressed to increase the uptake of HHD.

Trial Registration: The study was not registered on a publicly accessible registry as it did not involve any health care intervention on human participants.

Abrégé

Contexte: Malgré les avantages sur le plan clinique et sur le mode de vie du patient, l'hémodialyse à domicile (HDD) demeure sous-utilisée en Saskatchewan comparativement à l'hémodialyse en centre hospitalier (HDCH). Nous souhaitions explorer les perceptions des patients à l'égard de l'HDD et déterminer les obstacles qui en limitent l'utilisation dans cette province.

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Objectifs: Dans un premier lieu, l'étude visait à connaître les perceptions des patients à l'égard de l'HDD et à cerner les facteurs limitant son adoption comme modalité en Saskatchewan (Canada). On souhaitait ensuite analyser les différences entre les perceptions des patients et les obstacles limitant l'utilisation de l'HDD selon le centre (service de dialyse principal ou cliniques satellites).

Type d'étude: Une étude transversale et observationnelle sous forme de sondage.

Cadre: Deux importants centres hospitaliers (Régina et Saskatoon) et cinq cliniques satellites associées à chacun des centres et réparties dans toute la province.

Sujets: Nous avons approché tous les patients suivant des traitements d'HDCH en Saskatchewan et 398 personnes ont accepté de participer à l'étude.

Mesures: Un questionnaire a permis de déterminer les obstacles des participants à l'utilisation de l'HDD.

Méthodologie: Un questionnaire a été élaboré pour déterminer les barrières perçues par les patients en ce qui concerne le choix de l'HDD comme modalité. La statistique descriptive a été employée pour la présentation des données. Le test du Chi carré et le test U de Mann-Whitney ont été utilisés pour comparer les réponses des patients entre les centres de dialyse et les cliniques satellites.

Résultats: Les principaux freins à l'adoption de l'HDD étaient la satisfaction avec la modalité actuelle (91 %), l'augmentation des factures des services publics (65 %), la peur qu'un incident catastrophique survienne à la maison (59 %), la médicalisation du domicile (54 %) et le manque de connaissances sur les différentes modalités de traitement (54 %). En comparaison des patients dialysés en centre, les patients des cliniques satellites décidaient plus souvent de ne pas adopter l'HDD parce qu'ils se disaient davantage satisfaits de leurs traitements actuels (97 % [cliniques satellites] c. 87 % [centre]; p<0,001). Ces patients se disaient également plus confortables de suivre leurs traitements sous supervision médicale (95 % c. 86 %; p<0,007), mentionnaient davantage leurs craintes face à une augmentation des coûts en services publics (92 c. 45 %; p<0,001), s'avéraient moins bien informés sur les risques et les bienfaits de l'HDD (83 % c.33 %; p<0,001), étaient plus préoccupés par l'investissement de temps requis pour se familiariser avec les procédures de l'HDD (69 % c. 32 %; p<0,001) et s'inquiétaient davantage des conséquences sur leur famille (60,8 % c. 40,6 %; p<0,001).

Limites: Nous avons quantifié les facteurs limitant l'adoption de l'HDD à l'aide d'un questionnaire, ce qui a empêché l'inclusion d'obstacles supplémentaires considérés comme importants au plan individuel. Les données transversales ne peuvent être utilisées que comme un instantané. Seulement 398 patients ont accepté de participer à l'étude et ainsi, les résultats ne peuvent être généralisés aux 740 patients dialysés dans les établissements choisis. Nous n'avons pas colligé les données démographiques des patients (âge, niveau de revenus, littéracie), les maladies concomitantes, ni les antécédents de dialyse, ces données auraient été utiles pour l'interprétation des résultats.

Conclusion: Les freins à l'adoption de l'HDD comme modalité de dialyse, soit la satisfaction envers les soins reçus en centre, le manque de connaissances et de formation pour cette modalité — particulièrement chez les patients des cliniques satellites — et les préoccupations en regard des conséquences sur la famille, des dépenses associées aux services publics et de l'investissement de temps requis pour se familiariser avec les procédures, devront être abordés si on souhaite que l'HDD soit adoptée par un plus grand nombre de patients.

Enregistrement de l'essai: L'étude n'a pas été inscrite dans un registre accessible au public puisqu'elle n'implique aucune intervention sur les participants.

Keywords

barriers, patients, end-stage renal disease, home hemodialysis, in-center hemodialysis

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What was known before

Home hemodialysis (HHD) is underutilized in Saskatchewan, Canada (2.5%), compared with some jurisdictions. With identifying barriers to utilizing HHD, we can better design center-specific programs to address the unique barriers leading to low utilization of HHD.

What this adds

Our findings add further to the existing literature on this topic. In our jurisdiction, we identified the following: a lack of awareness and education, specifically in the satellite population, concerns with family burnout, expenses associated with utilities, and training time will need to be addressed to increase the uptake of home hemodialysis.

Introduction

Intermittent hemodialysis (HD) is an expensive, intrusive, and physiologically inadequate treatment, as most uremic toxins are only partly removed with the aid of dialyzers. Home hemodialysis (HHD) offers a potentially superior solution yet remains underutilized as penetration rates remain low across the world. There are multiple clinical advantages to dialyzing frequently at home. The most obvious ones include reduced left ventricular hypertrophy,^{1,2} better blood pressure control,² less myocardial stunning,³ lower interdialytic fluid gains,⁴ liberalization in diet and fluid restrictions,⁴ improved phosphorus control,⁵ and middle to large molecule clearance.⁶ These benefits may translate to improved mortality.^{7,8} Additional advantages are reduced duration of postdialysis fatigue,9 improved sleep quality,10 and improved sexual satisfaction.¹¹ The result is improved quality of life, energy, reduced travel costs, ability to return to part-time or full-time work, and increased productivity.¹²⁻¹⁴

Apart from clinical and lifestyle advantages, there are financial advantages to performing HHD. A comprehensive financial evaluation from Manitoba, Canada, showed that the estimated annual maintenance expenses were \$64 214 (CAD) for in-center facility HD, \$43 816 (CAD) for HHD with the NxStage System One, \$39 236 (CAD) for HHD with conventional dialysis machines, and \$38 658 (CAD) for peritoneal dialysis (PD).¹⁵ Of the 23 305 patients on dialysis in 2018, three quarters were receiving in-center hemodialysis (ICHD), the most expensive treatment option.¹⁶ The proportion of patients receiving HHD in Canada varies by jurisdiction and, in Saskatchewan, is currently 2.5% of the total dialysis population.¹⁶

Despite clinical and lifestyle advantages and reduced travel time in a geographically expansive province with inclement weather, the uptake of HHD in our province remains rather low compared with some jurisdictions.¹⁶ In this study, we wanted to explore the social, economic, educational barriers to HHD uptake in our province. The primary objective of the study was to evaluate and explore patient

perceptions of HHD and to identify the obstacles for adoption of HHD in Saskatchewan. The secondary objective was to examine variations in the patients' perceptions and barriers to HHD by center (main dialysis units vs satellite dialysis units).

Methods

Study Design

We conducted a cross-sectional survey of prevalent ICHD patients within the Saskatchewan Health Authority, across the province of Saskatchewan, Canada, from June 2018 to January 2019. All prevalent dialysis patients from 2 main "hubs" (Regina General Hospital and St Paul's Hospital) and 10 associated satellite units were approached.

A survey was developed collaboratively as part of the provincial internal quality improvement initiative and was based on literature review of known barriers to HHD. The questionnaire was designed to capture the patient-perceived barriers to HHD in Saskatchewan, to identify the most prominent factors impeding uptake of HHD in Saskatchewan. Patients were recruited by the study coordinators at each of the dialysis units. Verbal consent was taken from each participant. The surveys were anonymous, and no individual participant information was requested. The study was approved by the Research Ethics Board of the former Regina Qu'Appelle Health Region (REB-18-64).

Patients

All the 740 prevalent patients in the aforementioned dialysis units were approached by the study coordinators while waiting for their in-center dialysis appointment to complete the survey. Inclusion criteria were age ≥ 18 years, able to read and understand English, receiving HD therapy for at least 3 months, and identified as having end-stage disease. Exclusion criteria were ICHD with acute kidney injury, hybrid therapy (concurrent PD), received HHD treatment in the past, and unsuitable for HHD as per care provider. A total of 398 patients agreed to participate in this study.

The patient questionnaire included 32 questions and comprised 2 sections; the first pertained to patients' characteristics and the second to patients' perceived barriers to HHD. Demographic information collected included living location, resident of assisted living facility, distance to the in-center dialysis unit, level of education, and being followed up by a nephrologist for more than 6 months prior to dialysis initiation. We did not collect any other demographic and dialysisspecific information. Questions addressing barriers to HHD were categorized as knowledge deficits, home constraints, satisfaction with in-center care, and attitudinal barriers. This questionnaire included a combination of yes/no questions, and questions rated using 5-point Likert scales with the following responses (strongly disagree, disagree, uncertain, agree, strongly agree, and not applicable; Supplemental Figure 1).



Figure 1. Study flowchart.

Note. HD = hemodialysis; HHD = home hemodialysis.

Statistical Analysis

Statistical analyses were performed with SPSS Statistics for Windows, Version 22.0 (SPSS Inc, Chicago, Illinois). Descriptive statistics were used to present the data. Values were presented as count (%) or median (interquartile range), as appropriate. For 5-point Likert scale questions, the responses "agree" and "strongly agree" were merged and used in the statistical analysis. Differences across groups (main dialysis units vs satellite dialysis units) were assessed using Mann-Whitney U or chi-square tests as appropriate. The differences were considered significant if the 2-sided Pvalue was less than .05.

Results

Patient Characteristics

All prevalent (n = 740) dialysis patients were approached and 398 agreed to participate in the study. Of the 398 patients, 2 had undergone HHD, 32 were deemed unsuitable for HHD as per care providers (ie, as per response to question 8 in the questionnaire), leaving 364 study patients (217 in main dialysis units and 147 in the satellite dialysis units; Figure 1). The characteristics of study patients are shown in Table 1.

Patient barriers to HHD (responses on a 5-point Likert scale) are shown in Figure 2. The most frequently reported barriers to HHD were satisfaction with current in-center care (92%), having medical supervision at the ICHD unit (90%),

followed by opportunity to socialize with ICHD patients and staff (86%), increased utility bills (65%), fear of a catastrophic health event at home without supervision (59%), and fear of not having doctors/nurses at home (57%). Other prominent barriers to HHD were unwillingness to bring medical supplies into the home, and concerns about landlord disagreement to the home renovations (54% and 53%, respectively). Family burnout (50%), concerns about extended HHD training duration (48%), and home constraints (unsuitability, inability to make modifications to the home, and lack of space) also figured prominently (42%-45%). A total of 33% of patients identified as residing on a reserve, 26% of those residing on a farm, and 12% of urban dwellers stated that they were not on HHD because of unsuitable water in their area (Tables 2 and 3). A significantly higher proportion of respondents residing on a First Nations reserve indicated unsuitable water as a barrier to HHD, compared with those living in cities or towns (P < .001).

Patient Perspectives Towards HHD in Main Versus Satellite Dialysis Units

The satisfaction with HD care was higher in satellite units in comparison with main units (97% vs 88%, P < .001). Significantly fewer patients in satellite dialysis units were aware of HHD as a treatment option (57% vs 88%, P < .001), and this also correlated with fewer satellite patients having attended renal replacement therapy class prior to

Table I. Patients' Characteristics.

Patients' characteristics	Total, n = 364	Main dialysis units, n =217	Satellite dialysis units, $n = 147$	Main vs satellite dialysis units P value
	N (%) Median (IQR)	N (%) Median (IQR)	N (%) Median (IQR)	
Living location				
Town/city	329/346 (69.1%)	161/201 (80.1%)	78/145 (53.8%)	<.001
Aboriginal reserve	62/346 (17.9%)	26/201 (12.9%)	36/145 (24.8%)	
Farm	45/346 (13%)	14/201 (7%)	31/145 (21.4%)	
Distance of home to in-center	n = 358	n = 211	n = 147	.041
hemodialysis (kilometers)	12 (5-76.25)	10 (5-70)	30 (5-80)	
Resident of assisted living facility	62/364 (17%)	19/217(8.8%)	43/147 (29.3%)	<.001
>Grade 12 education	153/363 (42.1%)	99/216 (45.8%)	54/147 (36.7%)	.085
>6months being under care of a nephrologist prior to starting dialysis	215/362 (59.4%)	147/216 (68.1%)	68/146 (46.6%)	<.001

Note. IQR = interquartile range.



Figure 2. Patients' attitude/perspective to home hemodialysis (responses on a 5-point Likert scale).

starting dialysis (31% vs 53%, P < .001). While more respondents in the satellite dialysis units, compared with the main units, stated that they did not understand the benefits and risks of HHD (83% vs 33%, P < .001), nor were they offered HHD by the medical care team (75% vs 44%, P < .001), a higher percentage of satellite unit patients indicated they would not pursue HHD due to the time commitments required for HHD training (70% vs 32%, P < .001). More patients in satellite dialysis units, in comparison with main units, indicated that they would not be able to confidently operate an HD machine at home (68% vs 28%, P < .001), and more felt comfortable receiving dialysis treatment in the presence of medical staff (95% vs 86%, P = .007; Tables 2 and 3).

		Main dialysis units, n = 217	Satellite dialysis units, $n = 147$	Main vs satellite dialysis units	
Patients' perceptions and perceived barriers to HHD	Total, n = 364	N (%)	N (%)	P value	
HHD awareness					
I am aware of HHD as treatment option	273/363 (75.2%)	190/217 (87.6%)	83/146 (56.8%)	<.001	
l attended renal replacement therapy class prior to starting dialysis	146/330 (44.2%)	105/199 (52.8%)	41/131 (31.3%)	<.001	
Knowledge; I am not on HHD because:					
I was never offered HHD by the medical care team	201/356 (56.5%)	92/211 (43.6%)	109/145 (75.2%)	<.001	
I do not understand the benefits and risks of HHD	191/355 (53.8%)	70/210 (33.3%)	121/145 (83.4%)	<.001	
Home consideration; I am not on HHD because:					
The water in my area is unsuitable for HHD	65/350 (18.6%)	40/207 (19.3%)	25/142 (17.5%)	.663	
I have no additional space at home	160/353 (45.3%)	115/209 (55%)	45/144 (31.2%)	<.001	
l would rather not bring medical supplies to my home	191/353 (54.1%)	115/209 (55%)	76/144 (52.8%)	.677	
I am not keen on making changes to my home that may be required to do HHD	151/354 (42.7%)	121/209 (57.9%)	30/145 (20.7%)	<.001	
l do not feel my home is suitable for HHD	147/353 (41.6%)	111/208 (53.4%)	36/145 (24.8%)	<.001	
Satisfaction; I am not on HHD because:					
l am satisfied with the care l receive at my hemodialysis unit and would not want to change	325/355 (91.5%)	184/210 (87.6%)	141/145 (97.2%)	.001	
I feel more comfortable doing dialysis in the presence of medical staff	316/351 (90%)	178/206 (86.4%)	138/145 (95.2%)	.007	
I like socializing with other patients/staff at my hemodialysis unit	306/354 (86.4%)	181/209 (86.6%)	125/145 (86.2%)	.915	
My landlord would not agree to the home renovations that may be required for HHD	81/153 (52.9%)	51/109 (46.8%)	30/44 (68.2%)	.016	

Note. For 5-point Likert scale, the count (%) of patient who agreed or strongly agreed is shown. HHD = home hemodialysis.

Table 3. Patients' Perceptions and Perceived Barriers to HHD (Family Concerns, Risk/Fears).

D	Total, n = 364	Main dialysis units, n = 217 N (%)	Satellite dialysis units, n = 147 N (%)	Main vs satellite dialysis units P value
Patients' perceptions and perceived barriers to HHD				
Family; I am not on HHD because:				
I have no support at home	96/353 (27.2%)	60/208 (28.8%)	36/145 (24.8%)	.404
l am worried about family burnout	157/313 (50.2%)	67/165 (40.6%)	90/148 (60.8%)	<.001
My family would be upset with the sight of blood and needles	76/317 (24%)	40/172 (23.3%)	36/145 (24.8%)	.744
l cannot afford the additional increase in my utility bills	223/364 (64.5%)	92/204 (45.1%)	131/142 (92.3%)	<.001
Risk/fear; I am not on HHD because:				
l have a fear of technology	47/355 (13.2%)	37/210 (17.6%)	10/145 (6.9%)	.003
I would not be able to confidently operate a hemodialysis machine at home	157/354 (44.4%)	59/209(28.2%)	98/145 (67.6%)	<.001
I do not have time for the 2 months of training needed for HHD	169/355 (47.6%)	68/210 (32.4%)	101/145 (69.7%)	<.001
l am fearful of not having doctors and nurses at home	201/253 (56.9%)	123/208 (59.1%)	78/145 (53.8%)	.319
I am scared I would have a major health event at home without supervision	210/356 (59%)	133/211 (63%)	77/145 (53.1%)	.061
l am scared of using needles on myself	33/349 (38.1%)	83/204 (40.7%)	50/145 (34.5%)	.240
HHD is not as good as in-center	108/356 (30.3%)	72/211 (34.1%)	36/145 (24.8%)	.061

Note. For 5-point Likert scale questions, the count (%) of patients who agreed or strongly agreed is shown. HHD = home hemodialysis.

Most satellite dialysis unit patients (92% vs 45%) reported the increased utility bill as a barrier to HHD (P < .001). Family burnout was more frequently reported by satellite unit patients (61% vs 41%, P < .001). Patients in main units more frequently reported a lack of willingness to make changes to their home (58% vs 21%), lack of space (55% vs 31%), and unsuitability of home (53% vs 25%) as barriers to HHD (P < .001; Tables 2 and 3).

Given that proportion of participants living in assisted living was much higher in the satellite units compared with main units, sensitivity analysis (chi-square or Mann-Whitney U test) was performed with exclusion of assisted living to determine if differences between main and satellite units remain significant. The results remained unchanged following the exclusion of participants in assisted living facilities except 3 questions (I feel comfortable performing dialysis in the presence of medical staff, my landlord would not agree for home renovations, and I am scared to have a major health event without supervision; Supplemental Tables 1–3).

Discussion

In this province-wide survey, we aimed to identify barriers to increasing the uptake of HHD by approaching patients on ICHD. Predialysis care in our province is delivered at the 2 main hubs (Regina and Saskatoon) either in clinician offices or in multidisciplinary care clinics. All our incident HD initiation occurs in the main units (acute and chronic). For chronic patients, who live close to a satellite unit, they are expected to dialyze for 6 sessions in the main unit (for clinical stability, dietary education and reconciliation of medications, and needling of fistulas). Once they are deemed to be stable and suitable for transfer, the patients are sent to the closest satellite unit. We train patients for HHD exclusively at the 2 main units via a Fresenius 2008K machine. Majority (85%) of our patients at both sites perform short daily (4 hours) dialysis sessions. There is a higher uptake for HHD at our northern site (geographic reasons) compared with the southern site.

The current HHD penetration rate in our province is 2.5%. While our rates are better than most US jurisdictions, we lag behind Australia, New Zealand, and a few Canadian provinces.^{16,17} In an attempt to bolster our HHD uptake and to better understand the barriers, we discuss the patient's responses under 4 categories (knowledge deficit, home constraints, satisfaction with in-center care, and risks/fears). The 4 solutions that were identified were as follows: a comprehensive formal education program, compensation for costs borne by the patient, use of transition units, and strategies to prevent burnout of caregivers. While some of the factors can be addressed internally, others will require policy-level changes.

Knowledge-based barriers were identified by the patients as 1 of the major barriers to HHD. A total of 75% of satellite patients claimed that they were never offered HHD as an option, 44% mentioned that they were unaware of the modality as a treatment option, and nearly 50% of patients did not recall ever attending predialysis educational classes. Even after excluding patients residing in assisted living (unlikely to be offered HHD in our jurisdiction), 52% of surveyed patients were unaware of HHD as a treatment modality. It has been shown that appropriate and timely education improves home dialysis uptake. As our province has a significant parachute rate (40%-50%, data not shown), appointing a dedicated home dialysis navigator could help disseminate knowledge and improve uptake among our parachute starts. Ideally, patients could be identified early, before moving out to satellite units, as longer vintage in-center dialysis patients are less likely to adopt HHD.18 Furthermore, implementing a comprehensive education program interwoven with multidisciplinary care clinics has been recognized as crucial in increasing the uptake of home therapies, and our province is making steps toward modifying our current education classes to hopefully make them more impactful.^{19,20} Indeed, de Maar et al have shown that introduction of a structured predialysis education program, "GUIDE," led to an increase in uptake compared with historical controls.²¹

A total of 58% of our patients had less than grade 12 education. Literacy, and in particular, lack of health literacy, is a surrogate marker for low income. In a recent report by the Kidney Foundation of Canada, 22% of HHD patients were under the low-income cut-off compared with 44% of in-center hemo patients.²² While the costs to the taxpayer are lower in patients pursuing HHD, there is a significant financial burden that is borne by the patient. Training is usually provided centrally in the main unit, and our program requires patients and families relocating for 6 to 8 working weeks. There is a requirement to stay in the city for the duration of training with most families heading back home over the weekends. A total of 69% of our satellite patients felt that was a barrier to training. This additional cost is currently not covered by our provincial program. Other jurisdictions such as Denmark, certain states in Australia, and Ontario, Canada, have implemented measures to reimburse patients.²³ While the cost of renovation is borne by our provincial government, the increase in utility bills has been identified as a barrier in satellite communities. The utility costs associated with HHD are significantly higher in rural, compared with urban, municipalities. In our province, rural patients dialyzing 6 days per week (short daily) at home had additional monthly water and electricity bills of \$300 (CAD). This is in contrast to the city dwellers where the cost was an additional \$100 (CAD) per month. The majority (92%) of the rural patients felt that the additional utility cost was a significant barrier to adopting HHD. In jurisdictions where utility costs are covered such as Germany, France, New Zealand (water costs), France (€ 23 per HHD session), and the provinces of Ontario and Manitoba in Canada, the rates of HHD uptake, especially in the rural communities, have been higher.²³ Financial incentives will have to be addressed as initiation on dialysis leads to further loss of income.

A total of 92% of surveyed participants were satisfied with current in-center care, 90% felt comfortable dialyzing in the midst of medical staff, and 87% liked socializing with other patients and staff members. Time spent on dialysis, travel times, and frequent admissions interfere with participation at work and home. It impacts social interactions and frays interpersonal relationships. Dialysis by its very nature (scheduled days with consistent times) enables people to socialize with others in the waiting room or adjacent pods and allows an opportunity to form strong bonds with health care providers. This bond is the strongest in satellite units with smaller numbers and primary nursing. However, it also enables them to get into a state of learned helplessness. In addition, with dialysis being performed by qualified trained nurses in institutions, patients often feel unqualified, and often fear catastrophic complications at home in an unsupervised setting.^{24,25} These issues can further be mitigated by establishing formal support groups, one-on-one pairing, and peer mentoring.²⁶ The introduction of transition units has been seen as a way to reduce this crucial barrier to adoption to HHD utilization. Transition units, where patients are treated in a separate part of the dialysis unit for the first 30 to 60 days post-initiation, focus on education and are staffed by dedicated nurses with the intent of promoting and grooming self-care and home therapies.²⁷ The goals of the program are to improve the education deficits, increase home therapy uptake, and reduce hospitalizations in the first 90 days.²⁷ In an article by Morfin et al, they demonstrate that by focusing on continuity, reliability, empowerment, and wellness, the uptake rate of home therapies can be increased.²⁷

Patients desire a sense of freedom over their lives and control over their treatment, but they do not want to be a burden to their caregivers and family members. It is well recognized that caregivers face a significant and ongoing burden associated with caring for a loved one, irrespective of modality choice.²⁸⁻³⁰ There was a reluctance to inflict caregiver burden in our survey. A total of 50% of the total participants and 60% of the rural recipients were worried about burnout of their loved ones. This is a recognized barrier that features prominently across all surveys. The reported solutions include inclusion of family members in education and training, paid models of support (family members or support staff), enhanced technical support, use of telemedicine for troubleshooting, and use of community houses for relief.^{13,14,31-33} Couples therapy for improved spousal relationship has been reported in patients with advanced cancer and can be tried in patients on home therapies.^{34,35} Respite therapy at home following minor surgical procedures and hospitalizations also go a long way in reducing burnout.

Ideally, all able and independent patients should consider home-based therapies. Hemodialysis should by extension be a surrogate for the remainder. The barriers to uptake are multilayered and multidimensional. Identifying appropriate patients will take effort and time and will need to be cut across the silos that exist in renal care delivery (office, ICHD, chronic kidney disease, HHD, and PD). It will require planning by comprehensive education programs, while patients are still being monitored predialysis with sequential frailty assessments, along with a careful review of home support mechanisms, cognitive scores, employment status, partner employment, vision, peripheral neuropathy, and comorbidities to identify patients who will truly benefit from dialyzing at home. Jayanti et al report that each unit will need to invest in understanding local barriers, using a systematic framework, in "real-time" and not as a one-off exercise. This would involve capturing microlevel (practitioner-level and patient-level), mesolevel (group and team factors, unit culture), and macro-level (process and resource barriers) information.³⁶ A total of 17% of the surveyed recipients were of First Nations heritage. The challenges faced by patients in First Nations reserves are different and well reported in the literature and were not the focus of our survey. However, 32.8% of patients residing on a reserve, in contrast to 12.1% of residents living in a town/city, stated that they were not on HHD because of unsuitable water in their area. These remote locales often have issues with water quality, and, in our province, we do not have a single reserve where the water quality based on the current standards was sufficient to pass the minimum levels needed for home therapies.

The present study has several limitations. The current survey needs to be viewed with caution. We used questionnaires to quantify known barriers, and this prevents inclusion of additional barriers that individual patients may consider important. Only 398 patients agreed to participate, and the results cannot be generalized to 740 patients. Cross-sectional data can only be used as a snapshot. The data were anonymous, and we did not collect detailed demographic information, and hence, patient-specific microsolutions cannot be proposed based on this survey.

Conclusions

The results of our survey indicate that satisfaction with incenter care, lack of awareness and education specifically in the satellite population, concerns with family burnout, expenses associated with utilities, and training time will need to be addressed to increase the uptake of HHD. Some of these issues can be addressed as a program (education and awareness), but others will require policy-level changes (creation of transition units and reimbursement of costs borne by the patient).

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Ethics Approval and Consent to Participate

The study was approved by the Research Ethics Board of the former Regina Qu'Appelle Health Region (REB-18-64).

Consent for Publication

Not applicable as there is no patient identifying information in this manuscript.

Availability of Data and Materials

The data sets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Author Contributions

B.P. conceived and designed the study and assisted with the drafts and edited the final manuscript. L.D. wrote the initial draft. M.J. assisted with manuscript drafts and performed the statistical analysis. S.S., C.D., and C.M. assisted with manuscript drafts. All authors read and approved the final manuscript.

Declaration of Conflicting Interests

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Supplemental Material

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