

Transportation Burden Associated With Hemodialysis in Canada: A Qualitative Study of Stakeholders



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Rationale & Objective: For patients requiring in-center hemodialysis, suboptimal transportation arrangements are commonly cited as a source of ongoing stress and anxiety and have been associated with a reduced quality of life and increased mortality risk. Transportation-related problems are especially pronounced in Canada given its size, low population density, and long, often snowy winters. We aimed to identify and better understand transportation options for hemodialysis patients in Canada and to describe stakeholder experiences.

Study Design: We used a qualitative descriptive research design to explore stakeholder experiences and perspectives of transportation to and from dialysis facilities.

Setting & Participants: We recruited participants from a large urban hemodialysis program in Western Canada and included 11 participants from a project group, 45 participants from an open forum, and a survey of 8 social workers. Data collection occurred at a series of project group meetings and an open forum (n=45). In addition, we asked 8 renal social workers based in major

cities across Canada to comment on the provision of transport for patients in their area via email or telephone consult.

Analytical Approach: We used conventional content analysis to explore stakeholder experiences.

Results: Traveling to and from dialysis facilities remains a source of stress and anxiety for many patients and their families. Patients described several factors contributing to these feelings including: the challenges of physically getting to the treatment center, particularly in adverse weather conditions; being a burden on family and friends; difficulties accessing the treatment facility; issues with public transport; and financial worries related to high costs.

Limitations: Findings may not be relevant in low- and middle-income countries and those with a warmer climate.

Conclusions: Without a concerted and collaborative approach to address the barriers identified here, it is likely that travel to and from in-center hemodialysis will continue to adversely affect patients' quality of life.

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Canadians benefit from a universal health care system, often termed 'Medicare.' Despite providing a relatively comprehensive range of clinical services, Medicare has several limitations and inconsistencies that may adversely affect the patient experience. One such limitation is transportation for people traveling to medical appointments, as the costs incurred are not covered by the health care system. Although similar challenges may be experienced by patients in other countries, transportation-related problems are especially pronounced in Canada, given its large size, low population density, and long, often snowy winters.

In 2017, over 24,000 Canadians were treated with maintenance hemodialysis; of these, 76% used in-center facilities including hospitals or satellite units.¹ Facilities are typically situated in urban and suburban areas. Patients living outside of these areas are required to organize their own travel arrangements, which can involve journeys of several hours. In some instances, patients relocate to be closer to a facility; however, this can be prohibitively expensive. Unlike travel related to the care of acute or most other chronic conditions, travel to attend hemodialysis treatments is often lifelong and is required 2-4 times a week. This represents a high treatment burden that often compounds a typically high illness burden and comes with

a financial cost. Many hemodialysis patients are older, are likely to have other chronic medical conditions including diabetes, cerebrovascular disease and coronary disease, and are affected by reduced mobility, frailty, and impaired cognition.^{2,3} Patients can also experience severe symptoms during and after hemodialysis such as changes in cognition, cramps, extreme fatigue, and hypotension, which can affect their ability to drive or to use public transport.⁴ Further, patients on maintenance hemodialysis are likely to be in lower socioeconomic groups, retired, or unable to work, resulting in a low income. Fifty-five percent of respondents on maintenance dialysis reported a household income of less than \$35,000 annually and 22% an income of less than \$20,000. In the same Canadian survey, 21% of respondents indicated that they had forgone food or basic necessities to be able to afford their treatment.⁵

Suboptimal transportation arrangements are commonly cited as a reason for patients not adhering to their dialysis treatment,^{6,7} and although delays in transportation may be somewhat tolerable in the short term, for many patients, transport issues are a source of ongoing stress and anxiety. Moist et al⁸ found that longer travel times were associated with a reduction in patient-reported quality of life because of reduced time available to socialize with family and friends. In addition, those traveling longer distances are

PLAIN-LANGUAGE SUMMARY

Patients treated with in-center hemodialysis must travel to a dialysis facility 2-4 times a week for a treatment. Patients find travel to and from dialysis sessions stressful, and it is known to adversely affect their quality of life. Factors that contribute to this are: the challenges of physically getting to the treatment center; being a burden; difficulties accessing the facility; issues with public transport; and financial worries related to high costs.

more likely to experience transportation problems that contribute significantly to their treatment sessions being shortened and missed, and this is associated with an increased mortality risk.⁸⁻¹⁰

Issues related to transportation to and from in-center hemodialysis facilities frequently challenge patients and can adversely affect their experiences of health care and quality of life. However, there are limited studies that examine this issue among contemporary hemodialysis patients. The purpose of this research is to identify and better understand the current options for transportation to and from hemodialysis facilities and to describe stakeholder experiences. Improving our knowledge and understanding of the burden of transportation in relation to the different transport options and its effect on patients and their families may help policy makers and service providers to reconfigure and invest in services that better meet these patients' particular needs.

METHODS

We used a qualitative descriptive design to explore patients, families, and health provider experiences and perspectives of transportation. Qualitative description research is primarily aimed at gaining insight and understanding of a phenomenon through the perspectives of those participants who have direct experience of it.¹¹ During the process, the researchers aim to stay close to the “surface of the data and events”¹² and to provide an account of “experiences, events and process that most people (researchers and participants) would agree are accurate.”¹³ This type of research is usually undertaken with a view toward stimulating a change or improvement, rather than to improve conceptual knowledge.¹¹ The advantage of this approach is in gaining information directly from participants rather than using preconceived categories or theoretical perspectives.

Participants and Setting

The Patient interest in Kidney Services (PiKS) group (Table 1) was initiated to provide a forum through which people using and providing hemodialysis services could identify and address aspects of the service that could be improved on. During the 18-month duration of the

research, a small project group of patients, family members, and health care workers (8-11 participants) met monthly. The group worked on a number of small projects aimed at improving patients' experience of hemodialysis. These meetings were recorded on a digital recorder and transcribed. A monthly summary was produced to track the progress of the group. Recruitment to the PiKS group occurred on World Kidney Day at a public information event in a local hotel. A researcher (RAL) gave out flyers inviting people with an interest in improving services for patients on hemodialysis. In addition, an overview of the research was presented to the hemodialysis administrative team, including the executive director and the senior managers, who cascaded the information to their clinical teams. Both patients and health care staff were advised to contact the researcher by email or telephone if they were interested in participating. The PiKS group organized an open forum to which the wider hemodialysis community was invited. Flyers were posted in hemodialysis facilities across the city inviting patients and their families to a 1-day open forum to explore aspects of living with hemodialysis, in particular, focusing on issues relating to transportation. Participants (Table 1) in both these groups were recruited through a combination of purposive sampling and

Table 1. Demographics of Research Participants

Characteristic	No.
Demographics of PiKS monthly meetings (n=11)	
Participants	
Patient	5
Family member	2
Social worker	1
Manager	1
Nurse practitioner	1
Researcher	1
Patient sex	
Male	2
Female	5
Patient dialysis vintage	
<1	1
1-5	2
>5	2
Patient employment status	
Full-time/part-time	0
Retired	3
Medically retired	2
Demographics of participants open forum (n=45)	
Participants	
Patient	20
Family member	17
Social worker	1
PhD candidate	3
Researcher	1
Nurse	3

Abbreviation: PiKS, Patient interest in Kidney Services.

Table 2. Illustrative Quotes and Emergent Themes

Themes and Subthemes	Illustrative Quotes/Examples
<p>Challenges of traveling to dialysis sessions Adverse traveling conditions particularly during the long winters: wind; snow, and ice Living several hours away from their nearest facility Medical conditions that affect patients' ability to drive, particularly fatigue Frailty and impaired vision, cognition, and reflexes, which can affect ability to drive Stress of feeling like there is no alternative to self-driving, even when fatigued</p>	<p>"I'm usually the first one out of our street in the morning, so I have to clear the snow to the end of the road, it's a work out before I've even got there" (Male, 61 y, patient). "Sometimes we just have to miss it [dialysis session], the roads can be closed for hours." (Female, 66 y, patient). "I counted once and there were 14 cars that had been blown off the road, it puts you off." (Female, 57 y, patient). "I won't drive on a dialysis day, I just can't do it, I have done it but it's not good, I think I am alright but then it hits me and I feel floored, I worry I will fall asleep and drive off the road." (Male, 70 y, patient). "I'm feeling it now [the effects of hemodialysis] ...sometimes I have to crawl from the car to get to the house [after dialysis], I know I can't go on like this...I live with my mom, she's 89, and [she is] probably the only reason I keep coming [...] but there will be a time, and it's coming soon, where I won't be able to get out the car, then I'm done." (Male, 70 y, patient). "When I was on regular dialysis, there was no way I could drive afterwards, I think it was too much for my body. Doing it slowly [over 8 hours] I didn't feel so wiped out afterwards [...]. I also didn't want to keep relying on my wife to drive me, it was too much for her, she works full-time as well." (Male, 61 y, patient).</p>
<p>Burdening family and friends Patients' guilt from inconveniencing family and friends who provide transportation 3 times a wk Emotional burden of worrying about patients becoming unwell during the ride Physical burden of helping older or frailer patients get to and from the house/car Family members' guilt about not being able to help with transportation</p>	<p>"There can be real anxieties around driving patients home following dialysis. People are worried that the patient will become unwell and they won't know what to do". (Social worker). "My wife works her shifts around my runs, I feel bad that she has to do that but it takes too long on the handi bus [...] you never know exactly when they are going to come." (Male, 70 y, patient). "I do wonder about some patients [ability to drive], you see them walking out of here following a run and I'm thinking...not sure you should be driving." (Social worker). "I've had family members phone and tell me their worried about whoever driving, but it's very difficult, especially if the patient has capacity." (Social worker).</p>
<p>Accessing facilities No 'disabled' or designated parking Long distance from car parks to facility entrance Slippery surfaces difficult, unsafe, and stressful for patients with poor vision, balance, weakness, and frailty</p>	<p>"I collapsed getting into my car, it was icy but I don't remember falling [...] I woke up on [on the ground] with a broken wrist." (Male, 70 y, patient). "You can't park anywhere near the entrance and so you end up with a bit of a trek and you're not always feeling the best." (Male, 61 y, patient). "Yeah, parking is not an issue for us, it is right outside [the facility] and free." (Female, 57 y, patient)</p>
<p>Difficulties associated with public and mobility-assisted transport Transport schedules inconvenient, not on time Long transportation times Difficulty applying for services No forum for feedback to transport company</p>	<p>"I got fed up of waiting for mobility-assisted transport, so I started using the Transit, which was okay for a while but then they changed the schedule and I had to catch 2 buses and then it just didn't work with my runs and everything [dialysis schedule]." (Male, 70 y, patient). "[Mobility-assisted transport] is not always on time and then it messes up dialysis because the bus won't wait and then it needs to be</p>

(Continued)

Table 2 (Cont'd). Illustrative Quotes and Emergent Themes

Themes and Subthemes	Illustrative Quotes/Examples
<p>High financial cost of transportation Costs for both vehicle and parking Home dialysis as a solution</p>	<p>rescheduled." (Male, 81 y, patient). "Thank goodness I only have to use Calgary Access once a week, but even then, I live a 10-minute drive from the unit, it can take an hour and a half to get home." (Male, 60 y, patient). "I applied for [mobility-assisted transport] because I often struggle to walk from the car to dialysis because I am so breathless, but they didn't think this was a good enough reason". (Female, 49 y, patient). "There's lots of paperwork if you want to use [patient transport] and it's very difficult to get approved". (Female, 66 y, patient). "There's an 8 page application, which the social worker helps with, and then you have to go for an interview down town so they can check you really can't use transit... why they can't just trust what the social worker tells them I don't know... and it is a real pain to get there." (Male, 70 y, patient). "You have to turn up in person for the interview, someone gave me a tip and said don't arrive on public transport because they'll say, well you managed it today [to use public transport]. They don't take into account how awful you feel before and after dialysis." (Female, 66 y, patient). "I'd had an operation and I couldn't drive myself to dialysis, I'd asked at the [nurses] but they could only suggest [patient transport]. Well, if you've traveled in one of those, you know it is not very comfy, I still had the stitches in. In the end, my elderly father (74 y old) came from Saskatoon to help." (Male, 52 y, patient). "I've made a number of complaints [about mobility assist] but never heard anything back, I wouldn't be surprised if they didn't pass them on." (Male, 60 y, patient).</p> <p>Male, 73 y old, has been on home hemodialysis for 7 y. He lives with his wife in Strathmore, a town 50 km outside of Calgary. They have 1 daughter who resides in another province. He and his wife are retired and live on a fixed income. One of the reasons he chose home dialysis was the difficulties in traveling to his nearest facility in Calgary. Although he drives and has a car, the cost of traveling 300 km a week, in addition to the cost of parking, even with a subsidy, would be too expensive: "When I visit with my nephrologist, I have to make sure it's at the beginning of the month, 'cause otherwise I am waiting for my [monthly check]." "Costs associated with operating and maintaining a car. Parking charges, income threshold is low (\$24 000 CAD at time of this research) to qualify for assistance with costs associated with transportation to dialysis facilities. To qualify, patients have to disclose their finances which many patients find humiliating." (Social worker).</p>

snowballing. Travel expenses and parking passes were provided for the monthly meetings and the open forum (patients and family participants). Most of the data relating to transportation was collected at the open forum. Volunteer

scribes were recruited from our wider research team via email. Participants were included if they were patients on long-term hemodialysis (longer than 3 months), family members or staff working within kidney services, English

speaking, and over the age of 18. Written, informed consent was obtained at the first PiKS meeting and at the open forum. A third data source was a number of renal social workers (n=8) who worked in cities across Canada. An initial invitational email was sent through the Canadian Society of Renal Social Workers, who were invited to respond either by email or by telephone. This study was approved by the Conjoint Health Research Ethics Board at the University of Calgary, REB17-1599. The names of patient participants have been changed to protect anonymity.

Data Collection

The open forum workshop was held in a local, further education college and included 6 focus groups with 45 participants. A preidentified facilitator (members of our PiKS group) directed discussions in each group and a volunteer scribe made detailed notes at each table. A secondary part of the study involved renal social workers, based in 14 major cities across Canada (Calgary, Edmonton, Hamilton, Halifax, Kitchener, London, Ottawa, Saint John, Saskatoon, Thunder Bay, Toronto, Vancouver, Winnipeg, and Yarmouth). Social workers were invited to comment on the provision of transport for patients in their area, specifically in relation to the following questions: how do patients travel to dialysis if they are unable to drive themselves; how much does this cost them; who provides the transport; and how is it funded? Transcripts from the PiKS meetings were reviewed for data relating to transport.

Data Analysis

Patient, family, and health care workers' perspectives and experiences recorded at the open forum, the PiKS meetings, and those of the social workers were transcribed, aggregated, summarized, and organized by RL using NVivo software. Conventional content analyses¹⁴ were used to inductively identify codes directly from the text, and these formed the emergent subthemes and themes. These themes were reiterated a number of times as transcripts were reread and further analyzed. Two other members of the research team (JH and NV) independently reviewed a number of transcripts and the data display in relation to the codes and themes. The researchers discussed the themes to confirm the consistency of the data analysis and the appropriateness of the resultant findings (investigator triangulation). Codes and themes were also reviewed for feedback by the PiKS group and considered to be an accurate reflection of patient experiences and discussions during the open forum. Data provided by the social workers was organized into a display matrix and analyzed for similarities and differences in transport provision. All social work participants were sent an early copy of this article to check that the findings included resonated with their and their patients' experiences.

RESULTS

Forty-five people participated in the open forum: 37 patients and family members, a social worker, 3 PhD candidates, a researcher (RAL), and 3 nurses. In addition, 6 volunteer scribes were present (Table 1). Patients recognized that travel to and from hemodialysis facilities was an inevitable part of accessing life-sustaining treatment, but nearly all participants reported feelings of frustration and anxiety, irrespective of their mode of transport and/or the distance to their facility (Table 2). These were related to the challenges they faced in physically getting to and from their treatment center several times a week, but also included feelings of being a burden, difficulties in accessing the facility, issues with public transport, and financial worries related to the high costs of transportation.

Challenges of Traveling to Dialysis Sessions

All participants mentioned the weather in relation to traveling to hemodialysis. Canadian winters are long and can last from October to April, with snow, wind, and ice making driving conditions treacherous and stressful. Most patients and staff could recall at least one occasion when storms prevented travel to or from dialysis, and occasions were described when patients, traveling home, were stranded in their cars for several hours or even overnight. For most patients, dialysis days are 'long days,' typically including a 4-hour treatment session with travel time in addition. Patients who self-drive described reclaiming a certain amount of control over their treatment schedules and lives. However, this can also present challenges, and patients described not always feeling well enough to drive, "Sometimes I just have to pull off the road and give it a while" (76-year-old male patient). Others changed their dialysis modality to home dialysis so they could avoid driving on dialysis days or to nocturnal dialysis (a gentler form of dialysis). Even though self-drive was the preferred mode of transport, patients still experienced it as a burden. Generally, it was the regularity of it and monotony of it, with no end in sight: "Same old, same old... here we go again, it's depressing...really depressing" (58-year-old male patient). As patients aged and became less independent, they found they had to rely more on family and friends to transport them to hemodialysis sessions.

Burdening Family and Friends

Patients reliant on family or friends for transportation described feelings of guilt in burdening their family with driving them to dialysis, "It's a lot to ask someone, they've got their lives too [...] it's like you're both on dialysis" (84-year-old male patient). Family members also expressed concerns, mainly in relation to situations where patients become unwell on the journey home.

Difficulties Accessing the Facilities

Parking and getting from the car to the dialysis facility were also identified as problems. Inner city health care

Table 3. Pros and Cons of Different Transport Modes

Self-drive	
Pros	Cons
<p>More control: Patients feel more in control when they can drive.</p> <p>Less time: No waiting for transport.</p>	<p>Less safety: Patient fatigue postdialysis and chronic medical conditions can affect their ability to drive.</p> <p>More stress: Patients experience stress from worrying about their ability to drive, particularly in inclement weather.</p> <p>More financial costs: of the vehicle, maintenance, and parking.</p> <p>Difficult access: Car parks can be some distance from the facility.</p>
Driven by family and/or friends	
Pros	Cons
<p>Easier access: Can be dropped near to the facility door.</p> <p>Less stress: Patients do not have to worry about their ability to drive.</p>	<p>Patient guilt: Patients sometimes perceive that they are already a burden to their family and friends; relying on them for transportation 3 times a week accentuates this perception and can create feelings of guilt.</p> <p>Difficult access: As patients become older or frailer, family members report increasing difficulties for patients getting to and from the house/car. Also, no 'disabled' designated parking or 'drop off' zone in some units.</p> <p>More stress: Many relatives/friends driving patients to hemodialysis worry about the patient becoming unwell during the journey home.</p> <p>Family member guilt: Family members can feel guilty about not being able to help with transportation</p>
Public transport	
Pros	Cons
<p>Lower cost: Can be cost-effective if patient lives close to facility.</p> <p>Less stress: Less stressful for patients as professional drivers are familiar with driving in adverse weather conditions.</p> <p>Less time: Perceived to be associated with less waiting than government provided transport on shorter routes.</p> <p>More control: Those able found it liberating not to be reliant on disability transport.</p>	<p>Difficult access: Distance to walk to catch bus, tram, train. Requires a certain amount of mobility to walk to the transit stops and from the transit stop home. Waiting at transit stops can be extremely cold in winter as very few are heated. Not door to door.</p> <p>More time: Most trips across the city involved at least one change of bus/tram prolonging travel time.</p> <p>Higher cost: Expensive for those living outside the city.</p>
Mobility-assisted transport	
Pros	Cons
<p>Easier access: Service from patient's door-to-door facility</p> <p>Lower cost: Most inner cities provide a subsidized transport system with concessions for seniors and those on a low income. The fares for people traveling with mobility-assisted transport typically pay the same rates as those using regular transport.</p>	<p>Difficult access: Drivers are obliged to ensure door-to-door service. However, this does not mean to the internal doors of the dialysis unit, just to the entrance of the facility, which may be a hospital or a mall.</p> <p>Less convenient schedule: Patients will often shorten their dialysis session if they think they will miss their booked bus/transport. Arriving late for dialysis treatment because of transport delays or bad weather can mean a shortened or missed treatment, and/or a wait of several hours to be rescheduled.</p> <p>More time: Multiple drop offs can mean a patient living within 10 min of their unit can be the last to be dropped off, which can take up to 2 h.</p>
Private hire	
Pros	Cons
<p>Easier access: service can be door to door.</p> <p>More convenient schedule: Patients report it is a generally reliable and direct service.</p>	<p>Less safety: Drivers not able to help patients get in and out of vehicle.</p> <p>Higher cost.</p>

facilities often do not have designated parking situated near the dialysis unit, and where these areas do exist, their layout does not always accommodate the physical limitations many patients have. Where facilities are situated within city limits, parking spaces can be hard to find, and costs can be prohibitive. To save on parking charges, some patients try to use the local street parking but describe

difficulties in getting from their car to the facility due to their physical limitations and/or snow and ice.

Difficulties Associated with Public Transport

Public transport can be an option for younger, fitter patients and is a cost-effective mode of transport for people living within city limits. However, for those living outside

Box 1. Potential Solutions to Improve Stakeholder Experiences**What's new?**

There is evidence that in some areas new ways of providing transport services are being explored. Commissioners and policy makers need to look at which ones show potential in terms of improving patient experiences.

- Interagency partnerships
- Linking with rideshare transportation services
- Apps that provide real-time updates on transportation options

Who is doing it better elsewhere?

Policy makers, providers/commissioners of services need to consider what other health care services are doing to improve stakeholder experiences of transportation.

- Learn and potentially adopt how other systems evaluate patient experiences of transportation
- Identify which services have had the best user experience responses in other systems, why, and whether these findings are applicable to the in-center hemodialysis population

Improve existing services

Process map patients' journeys. Make facility managers aware that patients struggle to access dialysis facility from the car park.

- In multi-occupancy vehicles, group patients according to their zip code
- Allocate parking for patients close to the dialysis facility

Regularly evaluate services

Policymakers, providers and commissioners must solicit stakeholder feedback on transportation services on a regular basis.

- Evaluate the efficiency and effectiveness of the service
- Analyze the experiences of patients receiving hemodialysis services separately; although they represent a small proportion of all users, they are high users of mobility-assisted transport

Consider transportation as integral to accessing treatment and include in care bundle

- Have the cost of travel to dialysis treatment paid for by the health care system

the city, this is not always an option due the absence of direct routes, high costs, and the infrequency of some services. In addition, waiting outdoors for transport in winter is not possible for some people. For those living outside of the city, transport options are limited and expensive.

For patients with a confirmed physical disability who are unable to use public transport, subsidized, door-to-door mobility-assisted services are provided within cities. Although concessionary fares are offered for older citizens,

those with a disability, and those on a low income, the costs of 6 journeys a week for people on a fixed income can still be substantial. Common complaints about the transport system included frequent delays and prolonged travel times. Patient transport is not limited to patients traveling to and from dialysis, and there can be multiple 'drop offs' and 'pick-ups' at different facilities and addresses. These can significantly extend travel time for patients, turning a 10-minute journey into one that takes over an hour, adding extra 'wasted' time to an already long day. Patients and nursing staff recalled numerous occasions when patients reduced their treatment time to avoid rescheduling their transport home: "If you miss your ride because your run's delayed, the [transport] office will tell you it can be anytime within the next hour and a half before the bus comes round again. It can actually be longer than that. [...] I'd rather cut my run time" (41-year-old male patient). Participants shared a general frustration with mobility-assisted transport and felt they had no recourse for poor experiences.

High Financial Cost of Transportation

In addition to the costs of maintaining and running a car, parking can be expensive (Table 2). In some instances, charges varied across the city with patients at one facility paying \$75 for a month's parking and those treated at another only being required to pay \$25 per month. In facilities outside the city limits, parking was often free. Patients on nocturnal dialysis questioned why payment was still required at night when the carparks were largely empty. Although financial assistance is available for patients on a low income, social workers reported a significant proportion of patients are constantly worried about their financial situation. Many patients live within strict financial budgets, and unexpected costs, such as their car breaking down, can be an additional source of stress. One of the patients who attended the forum asked for travel expenses to be paid in advance as his check was not due until the end of the month.

Social Workers' Perspectives on the Transportation Burden

The social workers confirmed transport issues as an ongoing source of frustration, distress, and depression for many patients, particularly those who require mobility-assisted transport (Table 3). All provinces funded/subsidized transportation systems for seniors and those on a low income, as well as mobility-assisted systems for patients unable to use regular transport. A small number of travel grants are available, particularly for people in rural areas. However, financial support and government coverage varies, leading to inequities across jurisdictions. In addition, to qualify for financial assistance, patients have to disclose their finances, which many find humiliating. Several social workers expressed concerns about individual patients' ability to drive after a dialysis session but felt

helpless in the absence of an alternative that would be palatable to the patients. Social workers also confirmed the prolonged traveling time required for some patients. For example, some patients in Alberta travel for 1-2 hours to their nearest facility, whereas in Manitoba, travel times for some could be as long as 2-3 hours.

DISCUSSION

We found that patients treated with hemodialysis in Canada find travel to and from dialysis sessions stressful because of physical, logistical, emotional, and financial challenges. The findings of our study resonate with previous work. An international study by the Dialysis Outcomes and Practice Patterns study (DOPPS)⁸ concluded that longer travel times were associated with reduced health-related quality of life and greater mortality risk. Similarly, traveling in a 'transportation van' or during inclement weather adversely affects adherence to treatment schedules and contributes to worse outcomes.⁷ To access their life-sustaining treatment, in-center hemodialysis patients face significant challenges related to fitness to drive, waiting times for public transport, long travel times, and the costs of travel. Canadian hemodialysis patients face all these challenges and are further disadvantaged by inclement weather and the low population density, which means longer journey times.

A recent study in Japan indicated that patients able to drive themselves had higher health-related quality of life scores than those reliant on public/mobility-assisted transport.⁸ However, there are many nonmodifiable barriers to self-driving, including chronic medical conditions, side effects from hemodialysis treatments, and the inability to afford a car.²

In recognition of these issues, many health care systems are deploying various strategies to improve patient access to transportation including: interagency partnerships, linking with rideshare transportation services such as Uber, and apps for patients that provide real-time updates on transportation options (Box 1).¹⁵⁻¹⁷ In response to patient-reported experiences of transport in the United Kingdom, the Dialysis Transport Working group has published a number of recommendations⁴ including that the cost of travel to dialysis sessions should be paid by the health care system and be included in the patient's plan of care. In addition, key performance indicators of services should include patient experiences and feedback to assure the ongoing quality of services.

Despite patient transportation to and from hemodialysis centers being repeatedly associated with poorer outcomes for patients in Canada and elsewhere, this topic has attracted relatively little ongoing interest from researchers or policy makers. Although one might expect that publicly funded transportation services would be regularly assessed for quality, no provincial or national standards exist to facilitate this objective. A change in policy is required to shift the responsibility for patient transportation from the

patient to the medical system. A comprehensive assessment of transport options in each province is needed, which should include user experiences (Table S1). In addition to identifying problems, this exercise would provide a baseline from which future improvements can be measured. A collaboration of key stakeholders could develop minimum standards, key performance indicators, and patient-reported experience measures to evaluate transport services on a regular basis.

Our study had limitations. We did not use random sampling and some of the findings may not be relevant to low- or middle-income countries or those with a warmer climate. Its strengths include diverse participants, input from programs across the country, and an in-depth qualitative approach that reflects stakeholder experiences.

In summary, patients requiring transportation to access in-center hemodialysis treatment are unlike any other service users in health care. No other patient group is required to attend a facility 2-4 times a week for treatment, usually for the rest of their lives. This suggests that their health care needs, including transportation to treatment, cannot be met in the same way as other patients with short-term needs. Without a concerted approach to address the barriers identified in this study, it is likely that travel to and from dialysis will continue to adversely affect patients' quality of life and willingness to continue treatment.

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Table S1: Social Workers' Perspectives on Transport Provision for Patient Requiring In-Center Hemodialysis in 14 Canadian Cities.

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