Accessing hemodialysis clinics during the COVID-19 pandemic

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A B S T R A C T

Transportation is a key element of access to healthcare. The COVID-19 pandemic posed unique and unforeseen challenges to patients receiving hemodialysis who rely on three times weekly transportation to receive their life-saving treatments, but there is little data on the problems they faced. This study explores the attitudes, fears, and concerns of hemodialysis patients during the pandemic with a focus on their travel to/from dialysis treatments. A mixed methods travel survey was distributed to hemodialysis patients from three urban centers in Montréal, Canada, during the pandemic (n = 43). The survey included closed questions that were analysed through descriptive statistics as well as open-ended questions that were assessed through thematic analysis. Descriptive statistics show that hemodialysis patients are more fearful of contracting COVID-19 in transit than they are at the treatment center. Patients taking paratransit, public transportation, and taxis are more fearful of COVID-19 while traveling than those who drive, who are driven, or who walk to the clinic. In the open-ended questions, patients reported struggling with confusing COVID-19 protocols in public transport, including conflicting information on whether paratransit taxis allowed one or multiple passengers. Paratransit was the most used travel mode to access treatment (n = 30), with problems identified in the open-ended questions, such as long and unreliable pickup windows, and extended travel times. To limit COVID-19 exposure and stress for paratransit users, agencies should consider sitting one patient per paratransit taxi, clearly communicating COVID-19 protocols online and in the vehicles, and tracking vehicles for more efficient pickups.

1. Introduction

Hemodialysis (dialysis) is a life-saving treatment for people experiencing kidney failure, which involves cleaning the patient's blood of toxins and excess fluids through a machine (Canadian Institute for Health Information, 2019). Over 23,000 Canadians are currently receiving hemodialysis at a cost of over $2 billion annually (Canadian Institute for Health Information, 2019). Though essential, the treatment is lengthy and arduous, as most patients must travel to the treatment center three times weekly for treatments that last four hours each

(Canadian Institute for Health Information, 2019). Previous research has found that the majority of dialysis patients do not travel to dialysis treatments independently: they either rely on someone else to drive them, or use public transport or paratransit, a form of public transport that provides individualized rides to certain segments of the population that are scheduled ahead of time (Yazawa et al., 2019). Therefore, though transport can be a barrier for accessing many different types of healthcare (Corcoran et al., 2012; Cui et al., 2020), the frequency of hemodialysis trips and their tendency to be made using social networks or public transport make access to transport a particularly important determinant of healthcare access for hemodialysis patients.

Few studies have examined the role of transport in hemodialysis patients' access to healthcare, and even less attention has been paid during the COVID-19 pandemic. Because dialysis patients tend to be older (in Canada, their average age is 64 years), are immunocompromised, and have multiple comorbidities such as diabetes or cardiovascular diseases, many experience a higher risk of complications and death if exposed to COVID-19 (Blake, 2020). In fact, a Canadian study found that patients undergoing dialysis who were diagnosed with COVID-19 had a case fatality rate almost four times higher than the general population (Taji et al., 2021). Yet unlike other high-risk populations, hemodialysis patients must leave their homes regularly. This study aims to understand the attitudes, concerns, and fears of hemodialysis patients during the COVID-19 pandemic while they travel to and from treatment, as well as problems experienced in accessing transportation during the pandemic. Through the Québec Renal Network, an electronic survey was distributed to hemodialysis patients from three urban centers between November 2020 and January 2021. The closed questions of this survey are analysed herein through descriptive statistics while an open-ended question are assessed through thematic analysis. Results derived from this study are used to formulate recommendations for transit agencies and companies on how to manage future disruptive events related to hemodialysis patient transport.

2. Literature review

Past research has found that transport impacts dialysis patients' health and wellbeing. For instance, past research has found that dialysis patients taking independent transport modes, such as driving a car, walking, or biking to their appointments have higher physical and mental composite health scores than those taking dependent modes such as getting a ride in another person's vehicle or using public transport (Yazawa et al., 2019). In another study, the level of control and comfort during a trip were found to be the main determinants of a person's transit stress (Legrain et al., 2015). Though this study did not focus on dialysis patients, the level of control for dialysis patients is known to be low as many take dependent modes of transportation such as public transport, paratransit or taxis (Yazawa et al., 2019). Therefore, it is important that comfort, both physical and mental, is considered while traveling to treatment

Many dialysis patients use paratransit. One study found that dialysis patients who took paratransit to medical appointments were most likely to miss appointments than any other mode of transport mode (Chan et al., 2014). The same study also noted that patients who missed a dialysis appointment were three times more likely to go to the hospital for an emergency, again indicating how important reliable transport is regarding the health of dialysis patients. The literature on paratransit more broadly has found that a key challenge of managing this door-to-door public transport service is scheduling and routing vehicles to satisfy customers (Aldaihani and Dessouky, 2003). This may be especially challenging given that predicting the growth of new paratransit passengers is very difficult (Bearse et al., 2004). Though this form of transport has its challenges, a cost-benefit analysis found that the benefits of paratransit far exceed its costs (Nguyen-Hoang and Yeung, 2010). This analysis also found evidence suggesting that most paratransit users have few other available options, further highlighting the

importance of this service.

While most research on the role of transport in patients' health and wellbeing was conducted before the COVID-19 pandemic, a 2020 cross-sectional study in Toronto and Vancouver found that certain transit riders decided to avoid public transport out of fear of contracting COVID-19 (Palm et al., 2021). Further, people from marginalized groups were found to defer accessing healthcare due to this fear in public transport (Palm et al., 2021). Hemodialysis treatments, on the other hand, simply cannot be avoided in many cases, as many patients cannot survive more than a week without treatment (O'Connor et al., 2013). Dialysis patients may expose themselves to COVID-19 when traveling to their necessary, routine in-person treatments. Only one study to the best of the authors' knowledge examined access to hemodialysis treatment during the pandemic and found that transport is a prominent, but often overlooked, area of COVID-19 exposure for dialysis patients. Indeed, along with living in a nursing home and being admitted to the hospital in the past 2 weeks, taking shared transport to hemodialysis appointments is a key risk factor for COVID-19 exposure (Rincón et al., 2020).

Taken together, we know that dialysis patients are at higher risk of serious illness and death from COVID-19, are at risk of contracting the virus while travelling, and must continue to travel to treatment during the pandemic. However, little is known about the experience of travelling to treatment during the pandemic. This is an important research gap given that stress and anxiety have negative effects on the health-related quality of life of dialysis patients (García-Llana et al., 2014). In fact, research shows that anxiety is a significant predictor of mortality in peritoneal dialysis patients (Griva et al., 2016). Therefore, this paper explores dialysis patients' attitudes, concerns, and fears during the COVID-19 pandemic with a focus on their experiences travelling to/from treatment. Results can be used to inform policies that ensure that hemodialysis patients are safe and at ease while they travel to care, regardless of which mode they use.

3. Data and methods

3.1. Data

The data used for this study was collected in collaboration with the "Impact of COVID-19 on Patients Receiving Hemodialysis: The Quebec Renal Network (QRN) COVID-19 Study". A bilingual (French and English) online survey was developed, and pilot tested by the research team. The survey was approved by the McGill Research Ethics Board (REB) and was distributed from November 2020 to January 2021 at three Montréal dialysis clinics, which have adequate research infrastructure support to conduct the study. An REB approved advertisement was posted in each of these three units inviting all patients to complete the survey. Additionally, research coordinators approached English or French speaking patients during their treatments notifying them of the study and inviting them to participate. The survey took approximately 25 min to complete. Participation was free and voluntary, and all information collected was anonymized. Research coordinators assisted patients who had difficulty with the online tool, and respondents had the option of completing the survey at home or at the treatment center. Participants were not directly compensated but were entered in a draw to win a $50.00 prepaid credit card.

3.2. Analysis

Two analyses were completed on the survey. First, an exploratory analysis of respondents' answers to the survey's closed questions was conducted. Patients were asked contextual question, such demographic questions (age, gender, etc.), dialysis location, and health status. They were also asked a series of questions about transport, including travel mode, punctuality, and changes in travel mode. With regards to respondents who indicated walking as a mode of transport, only those who selected walking as their sole mode of transport to dialysis were

considered walkers. Those who walked to public transport, on the other hand, were considered public transport users.

Questions included in the survey also pertained to healthcare access (e.g., missed appointments), as well as COVID-19, including rating their fear of contracting the virus and their views toward prevention protocols. Finally, patients were asked questions to assess travel satisfaction, quality of life, and health status. Descriptive statistics were computed to explore relationships between these variables, including cross tabulation.

This was complemented by an analysis of the following two open-ended questions included in the survey:

"We'd love to hear any other thoughts or experiences you would like to share. For example, do you have any suggestions for the public transport agency to improve your experience traveling with them for your medical appointments? Or have you had any experiences to or from the dialysis unit that you want people to know about?"

"Do you have any additional thoughts or comments that you would like to share?"

A total of twenty-eight responses were recorded. Braun and Clarke's Thematic Analysis approach (Braun and Clarke, 2006) was used to analyze the data. First, all comments were read and initial ideas about themes were jotted down. Because the answers to both questions did not differ greatly in content, responses to both questions were combined. However, the respondents' answers to both questions were analyzed side by side to ensure that when their content overlapped it was not counted twice. Next, Initial codes were created after reading all comments, these codes were then re-arranged into larger themes. Examples of themes include "COVID-19", "Fatigue", "Fear", and "Cleanliness". A table was then created with each respondent's answer as rows, and these themes as columns. Each idea expressed in a respondent's answer was noted in the table and frequencies of these ideas were tabulated. The themes were then reviewed and, when needed, redefined. The final themes along with key sample quotes are reported herein.

4. Results

A total of 92 people began the survey, but only 43 completed it. Table 1 provides on overview of the survey sample. Of the 43 respondents, approximately two thirds identified as male (63%; n = 27) while a third identified as female (37%; n = 16). The respondents were between 41 and 95 years old, and the sample has an average age of 61.8 years. Because this study has a small sample, it likely is not statistically representative of all hemodialysis patients. However, past research on hemodialysis patients with larger samples has also identified a slight overrepresentation of male patients with an average age similar to that in this study (64.7 years) (Villar et al., 2007). Concerning transport, 58% (n = 30) of dialysis patients took paratransit (either a van, a taxi or both) to their appointments, 19% (n = 8) drove themselves in a car, and 14% (n = 6) took a taxi. Only 7% rode as a passenger in a car (n = 3) and took fixed-route public transportation (n = 3). Again, tendency for dialysis patients to travel to their treatments using dependent modes has also been found in previous work (Yazawa et al., 2019).

More than half of the sample (65%; n = 28) said that their general health was "Good" or better. Dialysis patients were also asked about other comorbidities. Given that diabetes is the leading cause of kidney failure in Canada (approximately 36% of cases being caused by diabetes) (Canadian Institute for Health Information, 2019), it is perhaps unsurprising that diabetes was reported by 49% (n = 21) of the sample. The other notable comorbidities were arthritis (23%; n = 10), heart disease (19%; n = 8) and peripheral vascular disease or other circulation problems (19%; n = 8). This presence of comorbidities in the sample is similar to that in hemodialysis patients across Canada (Blake, 2020).

Fig. 1 shows the locations of the dialysis clinics included in this study. The majority (58%; n = 25) of patients received dialysis the

Table 1
Summary statistics.

Gender	n	%	Dialysis Clinic	n	%
Male	27	64%	CHUM (clinique externe de Gaspé)	16	37%
Female	16	38%	MUHC (Lachine site)	25	58%
			MUHC (Glen Site)	2	5%
Age			**Highest level of education obtained**		
40–49	6	14%	Primary/Elementary school diploma	4	9%
50–59	11	26%	Secondary school diploma	15	35%
60–69	13	30%	Trade/Technical school or college diploma	12	28%
70–79	10	23%	Undergraduate degree	2	5%
80–89	2	5%	Graduate degree	8	19%
90–99	1	2%	Prefer not to answer	1	2%
			I don't know	1	2%
In general, would you say your health is:			**Marital Status**		
Excellent	4	9%	Single (never married)	11	26%
Very Good	10	23%	Married (or common law partner)	18	42%
Good	14	33%	Separated or divorced	10	23%
Fair	14	33%	Prefer not to answer	4	9%
Poor	1	2%			
Mode of transport to dialysis			**Illnesses diagnosed**		
Paratransit van or shuttle (STM, RTL, EXO, STL)	12	28%	Diabetes	22	51%
Paratransit Taxi	18	42%	Arthritis	10	23%
Taxi	6	14%	Heart Disease	8	19%
Bus (STM, RTL, EXO, STL)	1	2%	Peripheral Vascular Disease/ Circulation Problems	8	19%
Metro (STM)	2	5%	Stroke or Transient Ischemic Attack (TIA)	5	12%
Passenger in a car	3	7%	Cancer	5	12%
Driver of a car	8	19%	Heart Failure	4	9%
Walk	4	9%	Chronic Lung Disease, Chronic Bronchitis or Chronic Obstructive Lung Disease	4	9%
			Liver disease, Hepatitis C, or Hepatitis B	3	7%
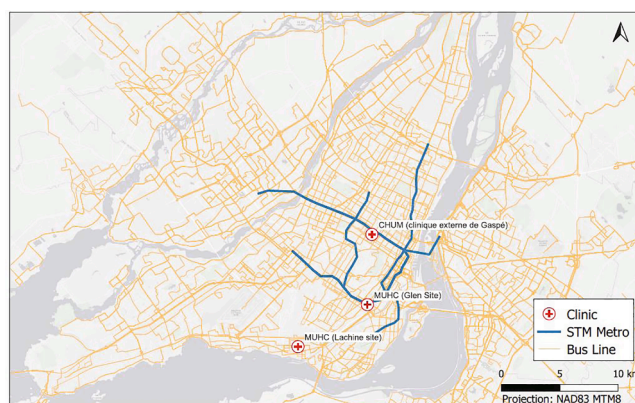
Fig. 1. Hemodialysis clinic locations.

MUHC Lachine site, followed by the CHUM Clinique Externe de Gaspé (37%; n = 16) site, and the MUHC Glen site (5%; n = 2). The MUHC Lachine site was a satellite unit located in a hospital far from Montreal's underground Metro system, and most respondents from this site took paratransit to get to their appointments (72%; n = 18). All public transport users (n = 3) participating in this study received their treatments at the CHUM Clinique Externe de Gaspé site. A larger sample in

these clinics could offer more insight into attitudes of dialysis patients towards public transport.

The remainder of the results is organized in two sections. The first outlines the results of the quantitative analysis of closed survey questions. Fear of contracting COVID-19 while traveling emerged as a major theme. Because this concern was more pronounced amongst paratransit users, an analysis on these users' travel satisfaction is then presented. The second section presents the results of the thematic analysis of open-ended questions.

4.1. Quantitative results

4.1.1. Safety

When asked to indicate their level of agreement with safety-related statements, respondents felt safer from traffic, crime, and unwanted attention than from contracting COVID-19 (Fig. 2). In fact, 92% (n = 40) felt safe from crime and unwanted attention and 79% (n = 34) felt safe from traffic while 62% (n = 27) felt safe from contracting COVID-19. The statement with the fewest Agree or Strongly Agree responses was "I felt that the driver took all necessary precautions to keep me from contracting COVID-19". Only 52% (n = 13) of respondents provided a positive response to this statement.

Respondents were also asked to rate their fear of contracting COVID-19 on a scale from 0 to 10 where 0 represented 'not worried' and 10 represented 'extremely worried'. The median fear reported while travelling to/from treatment was 4. This level of fear is twice that reported while receiving treatment (reported fear = 2) (Fig. 3). Therefore, though the lever of fear of contracting COVID-19 was relatively low for both scenarios, this fear while travelling to/from treatment was greater than other fears while traveling and greater than contracting the virus while receiving treatment at the clinic.

Further, travel mode was found to impact levels of fear. Namely, public transportation, taxi, and paratransit van users expressed the greatest fear of contracting COVID-19 while travelling (Fig. 3). Public transport and taxi users reported the highest median fear of contracting COVID-19 overall, with 100% of public transport (n = 3) users and 66% of taxi users (n = 4) reporting a fear level over 5. However, the number of respondents for these two modes was very low (3 and 6 respectively).

Paratransit users also expressed high levels of fear, this time with a larger sample (n = 30). Two types of paratransit services exist: paratransit taxis (i.e., taxis adapted to transport people with wheelchairs) and paratransit vans (i.e., minibuses that have higher passenger capacity than paratransit taxis) and. One third of paratransit van users (33%; n = 4) reported a maximum fear level of 10, a higher percentage than any other mode of transport. Paratransit taxi users were also fearful of COVID-19 while in transit, although not as much as paratransit van users, with only 17% (n = 2) of respondents reporting a fear level of 10 and 42% (n = 5) reporting a fear level above 5.
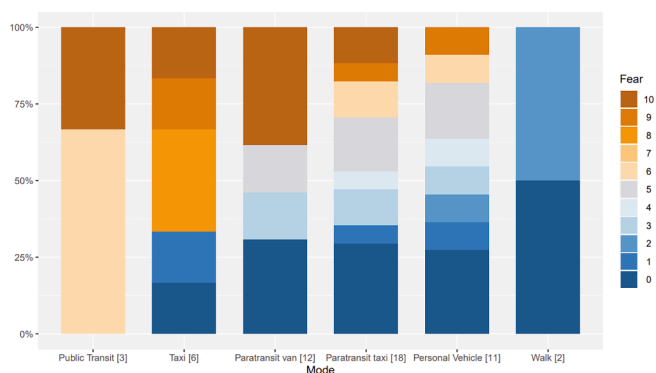

Fig. 3. Fear of contracting COVID-19 on a scale of 0 (not worried) – 10 (extremely worried) and mode of transport.

Meanwhile, respondents who travelled with personal vehicles (n = 11), either as a passenger or a driver, felt safer when traveling to appointments. Indeed, only 18% (n = 2) of these respondents combined reported a fear level over 5 and none reported the maximal fear level. While only 2 respondents walked as their sole mode of transport to dialysis treatment, they expressed the least amount of fear.

Interestingly, though many respondents expressed fear of contracting COVID-19 while travelling, especially those traveling by public transport, paratransit, or taxis, not one respondent changed their mode of transport during the pandemic as they answered to another question in the survey about transport mode change.

4.1.2. Paratransit Users' Travel Satisfaction

The survey also included questions about travel satisfaction. Here, paratransit users were found to be the least satisfied about their travel experience. Because this was the most common mode used to access clinics (used by 56% (n = 24) of respondents), this section explores the reasons behind this low travel satisfaction.

Results indicate that shorter journey times were associated with higher satisfaction. The range for journey length was between 5 and 55 min. These values were separated into 10 min segments for the analysis. Most paratransit users who have travel times under 25 min (86% of those with trips 15 min (n = 6) and 87%of those with travel times under 25 min (n = 13) agree that their travel time is reasonable, while only 33% (n = 2) of travelers with travel times over 25 min agree that the travel time is reasonable (Fig. 4). However, no respondents believed that trips to dialysis clinics that took longer than 35 min were reasonable. It is important to note that only two respondents travelled for 35–45 min and only one did so for 45–55 min. Most respondents' journey times were under this threshold (n = 18). Therefore, though we find that travel times under 35 min are generally perceived as reasonable, future studies
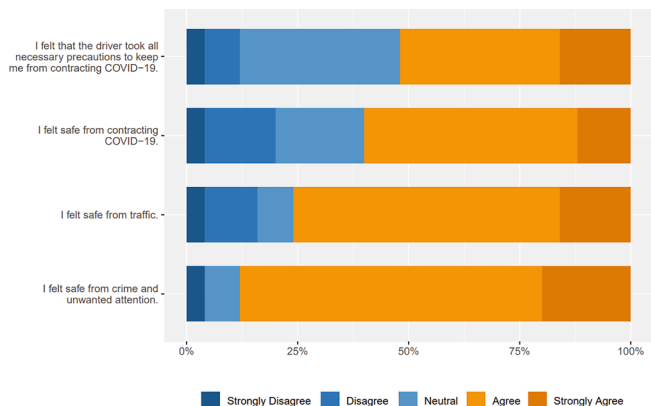

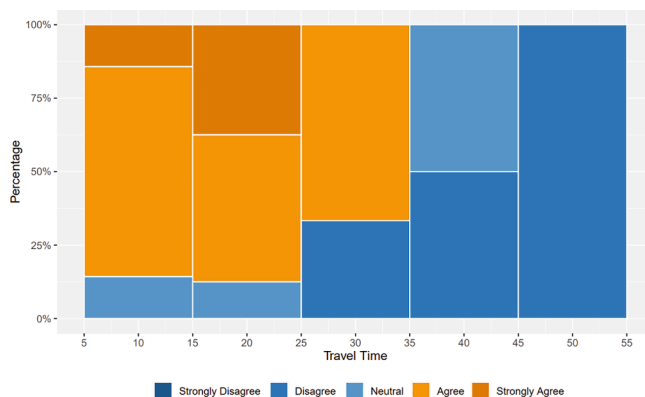**Fig. 2.** Passenger attitudes concerning safety in paratransit.

Fig. 4. Responses to "The time I spend in paratransit is reasonable" and travel time (in minutes).

with larger samples need to be conducted to support this claim.

Three quarters of paratransit users (76%; n = 18) indicated that they were satisfied with their overall paratransit experience (Fig. 5). The data also reveals that paratransit riders are less satisfied with the waiting time for their paratransit vehicle than with the travel times in paratransit, or paratransit in general. Indeed, 32% of respondents (n = 8) disagreed or strongly disagreed with the statement "I am satisfied with the amount of time I waited for my paratransit ride to arrive.". Three respondents (12%) felt this way for the second statement "I am satisfied with how long it took for me to arrive at my destination".

Taken together, drawing from a sample of 43 hemodialysis patients in Montréal, results indicate that fear of contracting COVID-19 while travelling to/from the dialysis clinic was greater amongst respondents than fear of traffic or crime and unwanted attention. Further, though overall levels of fear were relatively low, this fear was greater while travelling to the clinic than while receiving treatment at the clinic. Levels of fear while travelling varied by travel mode where those travelling through communal travel modes with strangers, such as public transport, taxis, and paratransit, expressed greater fear than those traveling through individualized modes, such as driving oneself or walking, or a communal mode with people they know, in this case getting a ride. It is important to note that future work with larger sample sizes is needed to test whether these claims are generalizable to all hemodialysis patients. For instance, only three participants used public transport while only two walked to their treatments. Paratransit riders were also found to have lower overall travel satisfaction, especially with regards to the time they spend waiting for their rides. Based on our very small sample, 35-minutes was identified as a potential threshold for travel satisfaction: self-reported travel satisfaction dropped for trips longer than this amongst the few respondents whose trips took this long.

4.2. Qualitative results

The following two themes emerged from the thematic analysis of open-ended questions: fear of contracting COVID-19 and general dissatisfaction with paratransit services, both of which are detailed below. The focus in most of these comments was on paratransit services, which is likely because most of the respondents to the open-ended question were paratransit users (63%, n = 18).

4.2.1. Fear of contracting COVID-19

In the qualitative responses, COVID-19 was mentioned in eleven (60%) of all paratransit riders' responses. Here, two sub-themes emerged: single occupancy paratransit and COVID-19 protocols. The first sub-theme, the suggestion of riding alone, was mentioned in ten (53%) of paratransit responses. In many cases, the respondents felt strongly about this policy, as is made clear in the following response:

During a certain period at the beginning of the first wave of the pandemic, STM paratransit let patients ride alone in the taxi, which

Fig. 5. Agreement with paratransit time-related statements.

was reassuring. Since the second wave has started, the STM is prioritizing finances instead of the security or the LIFE of dialysis patients (who have a compromised immune system) by making us travel with other people, who are not necessarily dialysis patients. Quebec public health recommends that two masked individuals stay two meters away from each other to protect each other. In a paratransit taxi, the two passengers at the back sit just 30 cm away from each other, which in my opinion, is criminal in a pandemic. […] When I'm traveling to and from dialysis and when another person shares the taxi ride with me, I am always anxious (Translated from French, emphasis original)

This customer's experience highlights the negative impact of forgoing the policy of single-occupancy paratransit vehicles on patient well-being. The respondent interprets this change in policy as "criminal", suggesting that the agency values economic gain over public health and safety. Finally, it hints at the second sub-theme identified in the open-ended questions: dissatisfaction with COVID-19 protocols. In this case, the participant expresses concern that the single-occupancy vehicle protocol was discontinued, especially since this seems to be at odds with public health recommendations.

Indeed, dissatisfaction with COVID-19 protocols was frequently mentioned in the open-ended questions. Specifically, respondents commented on their lack of clarity or on their improper execution. For instance, 4 (20%) of paratransit riders who answered the open-ended question mentioned the cleanliness of vehicles as an issue. Some expressed concerns about the sanitation of the vehicles, while others mentioned that that they did not know when the vehicle was last cleaned, something which caused them worry. For instance, one respondent wrote: "*I don't know if van cleaned before me. I see people getting off and driver doesn't clean van […]*". Although it is now known that COVID-19 spread through surfaces accounts for only a small percentage of transmissions (CDC, 2021), these results highlight the importance of frequent cleaning as well as proper communication of cleaning protocols. These low-cost measures may lower the anxiety of dialysis patients.

Another COVID-19 protocol suggestion that was brought up by two paratransit riders (13%) was to insert a transparent separator (e.g., plexiglass) between the driver and the patients. A further respondent raised concerns about drivers not wearing masks or wearing them incorrectly, which would both help to diminish rider anxiety and protect them from COVID-19 exposure. Some respondents brought up both protocols, for instance one respondent stated: "*It is important to make sure that all drivers have their masks on during travel time. It is crucial that all cars have a separation glass or plastic.*".

4.2.2. General dissatisfaction with paratransit service

The second theme discussed in the open-ended questions was general dissatisfaction with paratransit services. Here, the two issues that were mentioned frequently were pickups and travel times. The most common issues raised was the extended and sometimes unreliable pickup window of 30 min: ten (53%) paratransit users mentioned that this 30-minute pick up window was too long or that it was tiring to wait outside. Furthermore, four paratransit respondents reported that the drivers were late during pickups, which contributed even more to their fatigue and dissatisfaction, as evidenced by this patient's quote: "*The half hour that they are allowed to make you wait to pick one up is very long. You are standing waiting for them. Very tired*".

Another four paratransit users who answered the open-ended question mentioned extended driving time as an issue in their answers. To alleviate these longer travel times, one paratransit taxi user noted that the drop-off and pickup system could be more efficient: "*My problem is I live in the East end of mtl [Montréal] and the taxi goes sometimes west to pick up a pt [patient] and then and only then he turns to drop me off home.*".

Though these two specific challenges were discussed most frequently, some quotes provided insight into larger issues that exist
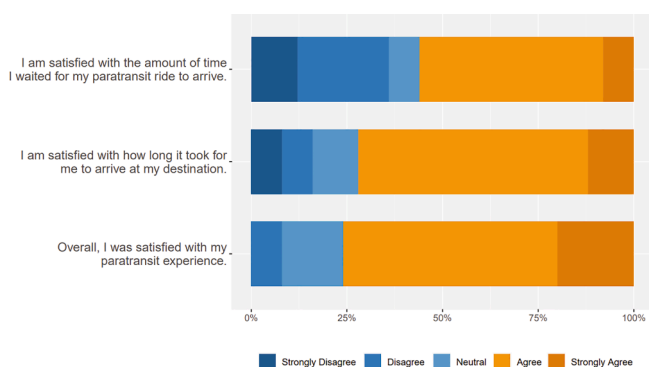
with the City's paratransit service. For instance, one participant wrote:

> A driver told me the other day that if I wanted good service I should call a real taxi, because they [paratransit drivers] are doing charity work by transporting us free of charge, even though I pay my paratransit fee every month …" (Translated from French)

Although this quote describes just one patient's experience, it highlights how conflicting views might exist between drivers and customers about the purpose of paratransit. While paratransit may be seen as an essential service for hemodialysis patients and other high-risk populations during the pandemic, such as this research participant, drivers who are also putting themselves at greater risk by completing this essential work may view their labour as underpaid or dismiss it as "charity work". Because this quote is from a paratransit user who is recalling an event, future research should examine the experience of paratransit drivers to further explore this dynamic.

Collectively, the responses of the open-ended questions corroborate the results of the quantitative analysis. Two key themes were identified: fear of contracting COVID-19 and dissatisfaction with paratransit services. Though most of the comments focused on paratransit services, the most common travel mode of the sample, other insight was gained from these responses. For instance, one participant who drove themselves to the clinic expressed how exhausting this journey was with the following quote:

> Driving myself, to and from Lachine clinic, from Montreal East, the drive is much longer & exhausting. Also, the walk to my car from the clinic to the parking lot is not clear. There are no lights outside & after the first snowfall the path to the parking lot is not cleared, cleaned, or salted

This response also highlights how the design of clinics can be improved to make this journey less tiring (e.g., lighting, winter maintenance, and nearby priority parking for dialysis patients). Others shed light on the unpleasantness of dialysis treatment in general. For instance, one participant simply wrote: "*I wish I didn't have to do dialysis*".

5. Conclusion and discussion

This paper presents the results of a mixed-methods analysis of a survey distributed to dialysis patients during the COVID-19 pandemic. Looking across the quantitative and qualitative analysis, two main concerns were expressed: fear of potential COVID-19 exposure while traveling to treatment, as well as general dissatisfaction with paratransit services.

This study found that fear of contracting COVID-19 is greater while traveling to dialysis treatment than while receiving treatment in the clinic. Further, mode choice impacted patients' levels of fear whereby those traveling by public transport, paratransit, and taxi expressed greater fear than those traveling by car (either as the driver or a passenger) or by foot. Therefore, those traveling alone or with people they know voiced less fear than those travelling with the public. A larger sample size would have helped strengthen these claims, as the sample for certain modes was very low (e.g., 3 people used transit and 2 walked). Interestingly, none of the research participants changed their travel mode. Future research can examine why those who expressed fear of contracting the virus while travelling did not change their travel mode. Perhaps they lived too far from the clinic to walk, could not afford their own personal vehicle, or have physical impairments that result in the need for paratransit services to travel.

Special consideration was given to paratransit riders, as 56% (n = 24) of hemodialysis patients surveyed take a paratransit shuttle and/or a paratransit taxi to their appointments. Although paratransit users were not as fearful as public transport or taxi users of COVID-19 exposure while in transit, there was still a significant proportion (37%; n = 9) of

riders that had a fear of 6 or higher our of a maximum of 10 while in paratransit, and 26% (n = 6) of riders reported a maximum fear value of 10. The qualitative responses also reinforce and illustrate this fear. To address COVID-19 related concerns, the public transport agency of Montréal, the STM, has outlined the following protocols in paratransit vehicles on the "Coronavirus prevention" page of their paratransit website: sitting 2 masked passengers in a vehicle, making face coverings mandatory, installing protective screens in vehicles and cleaning vehicles between each trip. However, their website also mentions that minibuses and taxis will only transport one passenger at a time (Société de Transport de Montréal, 2020). This information is confusing and should be clarified so that paratransit can make informed decisions about how they travel to and from treatment. The cleaning of paratransit vehicles should also be better communicated and better executed, as many respondents were not entirely satisfied with the cleanliness of paratransit vehicles. Communicating how often vehicles are cleaned, both online and in the vehicles, may reduce riders' anxiety. Furthermore, because hemodialysis patients have a much higher risk of serious illness and death if they contract COVID-19 (Valeri et al., 2020), allowing them to travel alone in paratransit would both limit COVID-19 exposure and reduce anxiety. In fact, single-occupancy in paratransit vehicles was enacted in other cities during the pandemic, resulting in higher customer well-being (Ravensbergen and Newbold, 2020).

Pre-pandemic issues with paratransit, the most used travel mode by patients in this study, were also reported in both the closed and open-ended questions. Two issues were mentioned frequently: The unreliable and long 30-minute pickup window, and extended travel times. Although 76% of paratransit users (n = 33) are satisfied overall with their overall experience, satisfaction levels are significantly lower when it comes to waiting time and travel time. Further, it became apparent that paratransit users with a travel time over 35-minutes do not think their travel time is reasonable. However, few respondents fell beyond this time fame making it difficult to generalize the results. Although the nature of paratransit pickups makes it difficult to shorten travel time, it is possible to make waiting times shorter by offering real-time vehicle tracking so users can plan their travel accordingly. Paratransit agencies could consider implementing real-time tracking in paratransit vehicles that can be followed through an app like Transit or Chrono. This has already been done with STM bus and metro lines (Société de Transport de Montréal, 2021).

A general policy recommendation emergent from these results include developing tracking apps for paratransit services. During future pandemics or similar public health crises, we also recommend single-occupancy rides in paratransit vehicles, separation between riders on all forms of public transport, enforcement of mask-wearing policies, and clear and consistent communication of COVID-19 precautions, including vehicle cleaning. It is important to note that single-occupancy rides could result in longer waiting times. Given that long travel times were found to be a source of dissatisfaction, public transit agencies must weigh the benefits of public health to those of convenience.

This study has certain limitations, the most important one being the small sample size of completed responses (43 survey respondents) from three dialysis clinics. This might be due to the small amount of dialysis patients in general. Given that approximately 50% of surveys were incomplete, perhaps the survey was long and tiring for patients to complete while receiving dialysis. The online format may have hindered participation as well. Indeed, it was noted that respondents often required help completing the survey. Selection bias may exist as well, as patients who are more tech-savvy (who may also tend to be from higher income households or be more highly educated) may have been more inclined to complete the survey. Future survey-based research on dialysis patients may want to consider paper formats or investing in more research coordinators to help respondents complete the survey. Though the sample is small, this study still contributes to the very limited knowledge on dialysis patients' experiences traveling to/from their burdensome, but essential appointments three times per week. The

richness of the qualitative answers provided by the respondents, and the fact that these responses support the quantitative analysis, also helps to offset the small sample size. A larger sample size would not only allow for the generalization of the results, it would have also allowed for different types of analyses. For instance, future research could examine hemodialysis patient's transport experiences across social factors such as gender, income, personal characteristics (e.g., social support or health consciousness). Another limitation is that paratransit and car users were heavily represented because one of the three clinics, the Lachine MUHC, is not very accessible using public transport. Targeting more patients from clinics along the Metro lines in future studies might provide better insights into attitudes towards public transport.

CRediT authorship contribution statement

References

Aldaihani, M., Dessouky, M., 2003. Hybrid scheduling methods for paratransit operations. Comput. Ind. Eng. 45 (1), 75–96. https://doi.org/10.1016/S0360-8352(03)00032-9.

Bearse, P., Gurmu, S., Rapaport, C., Stern, S., 2004. Paratransit demand of disabled people. Transp. Res. Part B: Method. 38 (9), 809–831. https://doi.org/10.1016/j.trb.2003.10.004.

Blake, P. 2020. Global dialysis perspective: Canada. *Kidney360*, *1*(2), 115. https://doi.org/10.34067/KID.0000462019.

Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. Qual. Res. Psychol. 3 (2), 77–101. https://doi.org/10.1191/1478088706qp063oa.

Canadian Institute for Health Information. 2019. Annual Statistics on Organ Replacement in Canada: Dialysis, Tranplantation and Donation, 2009 to 2018. (Ottawa, ON).

Centers for Disease Control and Prevention, 2021. Science Brief: SARS-CoV-2 and Surface (Fomite) Transmission for Indoor Community Environments. Retrieved from: https://www.cdc.gov/coronavirus/2019-ncov/more/science-and-research/surface-transmission.html.

Chan, K.E., Thadhani, R.I., Maddux, F.W., 2014. Adherence barriers to chronic dialysis in the United States. J. Am. Soc. Nephrol. 25 (11), 2642–2648. https://doi.org/10.1681/ASN.2013111160.

Corcoran, K., McNab, J., Girgis, S., Colagiuri, R., 2012. Is transport a barrier to healthcare for older people with chronic diseases? Asia Pac. J. Health Manage. 7 (1), 49–56.

Cui, B., Boisjoly, G., Wasfi, R., Orpana, H., Manaugh, K., Buliung, R., Kestens, Y., El-Geneidy, A., 2020. Spatial access by public transport and likelihood of healthcare consultations at hospitals. Transp. Res. Rec. 2674 (12), 188–198. https://doi.org/10.1177/0361198120952793.

García-Llana, H., Remor, E., Del Peso, G., Selgas, R., 2014. The role of depression, anxiety, stress and adherence to treatment in dialysis patients health-related quality of life: a systematic review of the literature. Nefrologia 34 (5), 637–657. https://doi.org/10.3265/Nefrologia.pre2014.Jun.11959.

Griva, K., Kang, A.W.C., Yu, Z.L., Lee, V.Y.W., Zarogianis, S., Chan, M.C., Foo, M., 2016. Predicting technique and patient survival over 12 months in peritoneal dialysis: the role of anxiety and depression. Int. Urol. Nephrol. 48 (5), 791–796. https://doi.org/10.1007/s11255-015-1191-x.

Legrain, A., Eluru, N., El-Geneidy, A., 2015. Am stressed, must travel: The relationship between mode choice and commuting stress. Transp. Res. Part F: Traff. Psychol. Behav. 34, 141–151. https://doi.org/10.1016/j.trf.2015.08.001.

Nguyen-Hoang, P., Yeung, R., 2010. What is paratransit worth? Transp. Res. Part A: Policy Pract. 44 (10), 841–853. https://doi.org/10.1016/j.tra.2010.08.006.

O'Connor, N.R., Dougherty, M., Harris, P.S., Casarett, D.J., 2013. Survival after dialysis discontinuation and hospice enrollment for ESRD. Clin. J. Am. Soc. Nephrol. 8 (12), 2117–2122. https://doi.org/10.2215/CJN.04110413.

Palm, M., Sturrock, S.L., Howell, N.A., Farber, S., Widener, M.J., 2021. The uneven impacts of avoiding public transit on riders' access to healthcare during COVID-19. J. Transp. Health 22, 101112. https://doi.org/10.1016/j.jth.2021.101112.

Ravensbergen, L., Newbold, B., 2020. 'I Wouldn't Want to Get on the Bus': older adult public transit use and challenges during the COVID-19 pandemic. *Findings*. https://doi.org/10.32866/001c.18202.

Rincón, A., Moreso, F., López-Herradón, A., Fernández-Robres, M.A., Cidraque, I., Nin, J., Méndez, O., López, M., Pájaro, C., Satorra, À., Stuard, S., Ramos, R., 2020. The keys to control a COVID-19 outbreak in a haemodialysis unit. Clin. Kidney J. 13 (4), 542–549. https://doi.org/10.1093/ckj/sfaa119.

Société de Transport de Montréal. 2020. *Coronavirus Prevention.* Retrieved 6/30/2021 from.

Société de Transport de Montréal. 2021. *Ways for Viewing Bus Schedules.* Retrieved 30/06/2021 from.

Taji, L., Thomas, D., Oliver, M., Ip, J., Tang, Y., Yeung, A., Cooper, R., House, A., McFarlane, P., Blake, P., 2021. COVID-19 in patients undergoing long-term dialysis in Ontario. Can. Med. Assoc. J. 193 (8), 278–284. https://doi.org/10.1503/cmaj.202601.

Valeri, A.M., Robbins-Juarez, S.Y., Stevens, J.S., Ahn, W., Rao, M.K., Radhakrishnan, J., Gharavi, A.G., Mohan, S., Husain, S.A., 2020. Presentation and outcomes of patients with ESKD and COVID-19. J. Am. Soc. Nephrol. 31 (7), 1409–1415. https://doi.org/10.1681/ASN.2020040470.

Villar, E., Remontet, L., Labeeuw, M., Ecochard, R., 2007. Effect of age, gender, and diabetes on excess death in end-stage renal failure. J. Am. Soc. Nephrol. 18 (7), 2125–2134. https://doi.org/10.1681/ASN.2006091048.

Yazawa, M., Omae, K., Shibagaki, Y., Inaba, M., Tsuruya, K., Kurita, N., 2019. The effect of transportation modality to dialysis facilities on health-related quality of life among memodialysis patients: results from the japanese dialysis outcomes and practice pattern study. Clin. Kidney J. 13 (4), 640–646. https://doi.org/10.1093/ckj/sfz110.