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Lived experiences of patients receiving hemodialysis during the COVID-19 pandemic: A qualitative study

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Key Points:
*Hemodialysis patients showed resilience in their ability to adapt to the new reality of their hemodialysis treatments.

Abstract:
Background: Hemodialysis patients have faced unique challenges during the COVID-19 pandemic. They face high risk of death if infected, and have unavoidable exposure to others when they come to hospital three times weekly for their life-saving treatments. The objective of this study was to gain a better understanding of the scope and magnitude of the impacts of the pandemic on the lived experience of patients receiving in-center hemodialysis. Methods: We conducted semi-structured interviews with 22 patients who were undergoing dialysis treatments in five hemodialysis centers in Montreal from Nov 2020 to May 2021. Interviews were transcribed and then analyzed using thematic content analysis. Results: Most participants reported no negative impacts of the COVID-19 pandemic on their hemodialysis care. Several patients had negative feelings related to forced changes in their dialysis schedules, and this was especially pronounced for indigenous patients in a shared living situation. Some patients were concerned about contracting COVID-19, especially during public transportation, while others expressed confidence that the physical distancing and screening measures implemented at the hospital would protect them and their loved ones. Some participants reported that masks negatively impacted their interactions with healthcare workers, and for many others, the pandemic was associated with feelings of loneliness. Finally, some respondents reported some positive impacts of the pandemic, including use of telemedicine, and creating a sense of solidarity. Conclusion: Patients undergoing hemodialysis reported no negative impacts on their medical care, but faced significant disruptions in their routines and social interactions due to the COVID-19 pandemic. Nevertheless, they showed great resilience in their ability to adapt to the new reality of their hemodialysis treatments. We also show that studies focused on understanding the lived experiences of indigenous patients and patients from different ethnic backgrounds are needed in order reduce inequities in care during public health emergencies.

Disclosures: M. Fortin reports the following: Advisory or Leadership Role: I am a member of the ethics committee of Transplant Quebec, the Collège des médecins du Québec, and the Canadian Society of Transplantation. I am also a member of different committees of the Canadian Blood Services. A. Affdal reports the following: Advisory or Leadership Role: Scientific Director - Canadian Journal of Bioethics. W. Beaubien-Souligny reports the following: Honoraria: Baxter. D. Blum reports the following: Honoraria: Astrazeneca; Otsuka. A. Nadeau-Fredette reports the following: Other Interests or Relationships: Current Scholarship from Fonds de la recherche du Québec en Santé (FRQS). R. Suri reports the following: Honoraria: Otsuuka; Amgen; and Advisory or Leadership Role: Canadian Society of Nephrology; Canadian Institutes of Health Research Institute of Circulatory and Respiratory Health. M. Vasilevsky reports the following: Ownership Interest: Bank of America; Inovio Pharmaceuticals; Eli Lilly; Microsoft; Stellantis N.V.; Precigen Inc; Sirius XM Holdings; Bircliff Energy Ltd; Brookfield Infrastructure Partners; CCL Industries Inc; CAE Inc; Canadian National Railway; Cenovus Energy; Enbridge inc; Parkland Corporation; Teck Resources Ltd; Toronto Dominion Bank; West Fraser Timber Co Ltd; Yamana Gold Inc; and Research Funding: GSK/PPD Investigator Services; CIHR via Sunnybrooke Research Institute. The remaining authors have nothing to disclose.

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Lived experiences of patients receiving hemodialysis during the COVID-19 pandemic: A qualitative study from the Quebec Renal Network

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KEY POINT

• Hemodialysis patients showed resilience in their ability to adapt to the new reality of their hemodialysis treatments.

ABSTRACT

Background

Hemodialysis patients have faced unique challenges during the COVID-19 pandemic. They face high risk of death if infected and have unavoidable exposure to others when they come to hospital three times weekly for their life-saving treatments. The objective of this study was to gain a better understanding of the scope and magnitude of the impacts of the pandemic on the lived experience of patients receiving in-center hemodialysis.

Methods

We conducted semi-structured interviews with 22 patients who were undergoing dialysis treatments in five hemodialysis centres in Montreal from Nov 2020 to May 2021. Interviews were transcribed and then analyzed using thematic content analysis.

Results

Most participants reported no negative impacts of the COVID-19 pandemic on their hemodialysis care. Several patients had negative feelings related to forced changes in their dialysis schedules, and this was especially pronounced for indigenous patients in a shared living situation. Some patients were concerned about contracting COVID-19, especially during public transportation, while others expressed confidence that the physical distancing and screening measures implemented at the hospital would protect them and their loved ones. Some participants reported that masks negatively impacted their interactions with healthcare workers, and for many others, the pandemic was associated with feelings of loneliness. Finally, some respondents reported some positive impacts of the pandemic, including use of telemedicine, and creating a sense of solidarity.

Conclusion
Patients undergoing hemodialysis reported no negative impacts on their medical care but faced significant disruptions in their routines and social interactions due to the COVID-19 pandemic. Nevertheless, they showed great resilience in their ability to adapt to the new reality of their hemodialysis treatments. We also show that studies focused on understanding the lived experiences of indigenous patients and patients from different ethnic backgrounds are needed in order to reduce inequities in care during public health emergencies.
INTRODUCTION

Patients receiving hemodialysis have been particularly vulnerable during the COVID-19 pandemic. Their impaired immunity and high burden of comorbid diseases puts them at increased risk of death and severe complications from COVID-19.\textsuperscript{1-6} To reduce transmission of COVID-19, public health agencies quickly mandated physical distancing and self-isolation measures\textsuperscript{7}. However, patients receiving in-center hemodialysis cannot self-isolate: uniquely, they must come to the center three times weekly for life-saving treatments which can last several hours\textsuperscript{8}, resulting in unavoidable and regular exposure to health-care workers and other patients. Many patients also use public transportation or ride share to get to the dialysis unit\textsuperscript{9-10}. Further, hemodialysis units are often crowded, making physical distancing difficult to achieve\textsuperscript{11}, increasing the probability of patients exposure to COVID-19.

In the Canadian province of Quebec, a public health emergency and a general lockdown were declared on March 13, 2020. During the first wave of COVID-19, Quebec was considered a hot spot, with the city of Montreal being particularly affected with very high rates of community transmission\textsuperscript{12}. Numerous protective measures were quickly implemented in dialysis units\textsuperscript{11}, like symptom assessments before entering the treatment area, isolating suspected or confirmed cases, sanitizing, social distancing, and mandatory mask wearing\textsuperscript{13}. Infection rates approached 25\% in patients receiving in-centre hemodialysis in Montreal\textsuperscript{11,14}.

Patients’ experiential knowledge is key to improving their care\textsuperscript{15,16}. Very few studies have examined the experiences of in-centre hemodialysis patients during the COVID-19 pandemic. The purpose of this study, which is part of a larger study documenting the impact of COVID-19 hemodialysis clinics in Quebec\textsuperscript{17,18}, was to gather hemodialysis patients’ perspectives and experiences following the first wave of COVID-19 infections. A better understanding of the scope and magnitude of the
disruptions faced by hemodialysis patients during the pandemic would help to inform interventions during public health emergencies.

METHODS

This exploratory study relied on semi-structured interviews with dialysis patients. We used the consolidated criteria for reporting qualitative research checklist. Recruitment and interviews were carried out between November 2020 and May 2021 during the second and third waves of COVID-19 infections in Quebec. Convenience and purposive sampling were used to recruit hemodialysis patients from five hemodialysis centres in the Montreal area. Purposive sampling consisted in recruiting participants with varying socio-demographic characteristics (age, sex, type of work, ethnic origin, etc.). Patients were recruited by a local coordinator at each site and were referred to the research team. Participants received $30 as compensation for their participation.

Interviews were conducted in English or French over the telephone (9) or by videoconference (13). Two different experienced interviewers (AA and FB) carried out the interviews; they had no involvement with the care provided in the dialysis units, nor were they in any way connected with the participants. The interviews lasted between 20 and 78 minutes and were digitally recorded and transcribed. The Centre hospitalier de l’Université de Montréal Research Ethics Board approved the study (CE 20.065, MP-02-2021-9006), and all participants provided informed consent. The interview transcripts were sent for approval to the participants we were able to reach.

Themes covered during the interviews were outlined in an interview guide with open-ended questions that are summarized in Table 1. The interview guide was developed by the research team and pre-tested by a patient partner. The interview guide was modified as new topics emerged from the interviews.
Patients were identified by self-identified gender. We used a qualitative descriptive approach to describe hemodialysis patients’ experiences during the COVID-19 pandemic. The goal of this pragmatic approach is to stay close to the data and provide a comprehensive summary of the topic studied, using thematic and content analysis. The latest version of the NVivo (QSR International) software was used to facilitate the analysis. All members of the research team developed the coding frame. MFM coded the interviews, and no new codes were created after the twelfth interview. The number of participants allowed for data saturation. AA coded 31.8% of the raw data with the rate of coding agreement assessed at 88.2%, and disagreements were discussed. Coded quotes were then organized by theme and subtheme.

RESULTS

Participants’ characteristics
Over the study period, 39 patients were approached, 32 agreed to participate, and 22 were interviewed. Two patients declined after being contacted, three declined because of personal and health issues, and five could not be reached. There were thirteen male and nine female participants, with a mean age of 60 years (table 2). They had spent an average of six years in dialysis, and ten were listed for a transplant. Fourteen identified as Caucasian and four patients were members of Indigenous communities (table 2).

Qualitative interviews
The themes identified during the interviews are presented in Table 3 with interview excerpts.

Effects of the COVID-19 pandemic on hemodialysis care and routine
Majority of patients mentioned that the protective measures and changes implemented at the start of the pandemic “didn’t really affect the treatments themselves.” (P19, female).
However, one significant impact were the changes in their routine related to infection prevention and control measures. Four patients had to change dialysis units, two of whom were from Indigenous communities: “we don’t have a dialysis clinic, [...] and before the COVID, they went to different dialysis clinics [...]. So, they were all different, different areas where they went, but ever since the COVID happened, we have, we’ve all been placed at the same time, at the same hospital.” (P14, male). Some patients mentioned having difficulty coping with a modification of their dialysis schedule: “I was doing in the morning. I was liking the mornings, so I don’t really like it in the evenings doing my hemodialysis because I cannot sleep well when I go home.” (P15, male). The other changes were requested by patients who felt safer in another unit or who had to change after being infected by COVID-19.

Another change reported was the modification in their transportation to the unit. Two participants stopped using public transit because they feared being infected: “Since March or April, I’ve been getting there myself by car, and I make sure to be in the outdoor parking lot to avoid being in the elevators.” (P10, male).

Although switching from in-centre to home hemodialysis would limit exposure to COVID-19 in the hospital, no participants had considered it: “I prefer going to the hospital even if we’re in the middle of a COVID-19 pandemic than doing this at home.” (P22, male).

**Impact of COVID-19 infection risk and mitigation measures**

**Concerns related to their own infection risk**

Patients expressed different attitudes about the risk of being infected with COVID-19. Some stated that they were “not afraid of the COVID” (P15, male). One patient had a fatalistic attitude about being infected: “if I have to catch it, it’s because the good lord wanted it this way.” (P14, female). On the other hand, some patients reported being afraid of dying of COVID-19. Others were more concerned
than afraid: “I was, I wouldn’t say afraid, I wasn’t in fear, but I was, you know, uneasy that I may catch the coronavirus.” (P4, male). The idea of going to the hospital multiple times a week and being infected in their unit seemed to concern some patients, especially those who “knew a person that got the COVID while at the hospital, [...] so that [...], added a little bit more paranoia.” (P10, male).

**Impact of infection control and prevention measures in the hemodialysis unit**

In order to prevent COVID-19 infection within dialysis units, strict infection prevention and control measures were rapidly implemented. This included: wearing masks, physical distancing when possible, use of plexiglass between stations, and screening questionnaires with regular nasopharyngeal swabbing at each treatment. Despite those onerous measures, most patients reported being satisfied, believing that “these measures are good” (P15, female) and being “very enthusiastic about what’s happening in that unit.” (P08, male). They also had good words for healthcare workers (HCWs) in their units and their ability to adapt.

On the other hand, some patients did criticize measures in their unit, as some felt inconsistent. “[...] wearing the mask and washing the hands is adequate, [...] everybody touches the same scale, everybody uses the same washroom, everyone uses the same waiting room, so I don’t think that’s very effective. Yes, we’re using the same pen to write our weights, we’re touching the scale to weigh ourselves, how is that helping?” (P20, female).

The prohibition of visitors was also a well-accepted by most patients. That said, it appeared to disproportionately affect elderly patients from indigenous communities who could no longer communicate with HCWs due to language barrier which previously their visitors helped to bridge: “when the COVID first happened, they were not allowed to bring their escorts and there was this lady, she only speaks her native tongue, and there was no translator for her. [...]”
elderly and you can’t speak the language that they’re using to communicate you with at the dialysis, it’s kind of scary for her.” (P10, male)

Finally, some patients mentioned the positive impact of health measures in their social lives and in the hospital, and hoped it will last well beyond because “it’s good for newer generations. It’s showing young people [...] some good, hygienic habits to maintain.” (P7, female).

Fears of infecting their loved ones
Several patients reported fears of infecting their families and putting them at risk. Some decided to “stay away from them.” (P13, female). Patients from indigenous communities feared for their communities once allowed to return to their remote villages and took the decision to not “see anybody.” (P13, female). The health measures implemented by dialysis units and the government overall helped to reduce patients’ stress and were viewed by patients as a way to protect themselves and their families. They were also willing to take every step necessary to minimize their risk of exposure while “avoiding situations that was in higher risk.” (P7, male).

Impact of COVID-19 pandemic on relationships

Interactions with healthcare workers
Patients who had been in hemodialysis for a long time reported that the HCWs, particularly doctors, were more distant than before and that they would “do everything they can to avoid being closer.” (P3, male). Patients also had fewer interactions with HCWs and would “chat less and less.” (P1, male), and masks prevented patients from seeing HCWs’ non-verbal expressions. Other patients, mostly female, mentioned that physical distancing had an impact on their relationships with HCWs, and that they found it “a little bit hurtful.” (P19, female). On a more positive note, telephone appointments “have been very welcome.” (P4, male).
COVID-19 pandemic and isolation from loved ones

Patients reported “feeling down sometimes” (P11, male) during the COVID-19 pandemic and missed interactions with family members and friends. “It gets depressing sometimes. But there have been times where I have cried in my room missing my family.” (P14, female). Social media was used as a way to cope with isolation from their loved ones. Some would even “see each other everyday through FaceTime.” (P17, male). Other participants accepted this distance, inevitable in the context, affirming: “What we’re hoping is that we all get through it and be able to give each other hugs later.” (P11, male). The feeling of loneliness and isolation was reported more often by female than male participants. Despite that, others mentioned that the pandemic fostered a sense of solidarity and support and that “in terms of helping each other, going to help neighbours, making something to eat then bringing it next door, [...] stopped to think that everything is a given.” (P18, female).

DISCUSSION

Our study documents hemodialysis patients’ lived experiences during the COVID-19 pandemic in the Canadian province of Quebec, which was particularly affected by COVID-19 in the first and second waves of the pandemic. Fortunately, the pandemic did not appear to alter patients’ experiences related to their hemodialysis care. However, patients were profoundly affected by changes to their overall routine, which included changes in their mode of transportation to and from the unit due to fear of contracting COVID-19, transfers to another unit, and imposed changes to their schedules. These two last factors particularly affected the four indigenous patients we interviewed. These patients were originally from northern remote regions in Quebec, and despite already being in a shared living situation in Montreal from before the pandemic began, all patients in this shared living situation were cohered to receive their dialysis treatments together after the pandemic began. While most patients were fearful of contracting COVID-19 and were appreciative of the implemented infection prevention and control measures which they felt would protect them and their loved ones,
some felt the measures made them distant from their HCWs and experienced isolation from loved ones. Interestingly, patients who were in hemodialysis the longest were least affected by the changes as a result of the pandemic. Hemodialysis patients demonstrate exceptional resilience, and it may be that more time spent in hemodialysis increases this resilience.

There are a few other studies in this field. Similar to our results, Sousa et al.\textsuperscript{27} reported that some patients found adherence to protective measures as a coping strategy that helped them to accept changes in their routine. Patients also reported that COVID-19 led to a decrease in physical activity, difficulty complying with dietary and fluid recommendations, as well as the need to consult a nephrologist, all of which were not mentioned in our participants’ interviews.

Another American study surveyed 49 in-centre hemodialysis patients to determine the impact of the COVID-19 pandemic on their psychological health.\textsuperscript{10} Their participants were moderately to extremely worried about leaving their homes for dialysis treatment and like in our study, patients feared getting infected in the unit or during their transport to hemodialysis. As in our study, switching to home dialysis therapy was not an option for a majority. The desire to continue to go to the unit could be further attributed to the importance of their routine, or also the desire to break the mandatory COVID-19 isolation. In a survey conducted in Ireland, participants reported changes in their interactions with medical staff.\textsuperscript{23}

Women and men interviewed reported feeling lonely and isolated from their loved ones, but women seemed to be more affected than men. This difference could potentially be explained by a social desirability bias, where men are less prone to discuss their psychological issues.\textsuperscript{28} Participants in our study did not report a major impact on their mental health and increased suicidal ideation. This differs from studies that have shown increased psychological distress and anxiety in different countries and among the Quebec population.\textsuperscript{29-32} In the dialysis population, the impacts of the pandemic on mental
health vary across studies. In the American study mentioned above, participants reported feeling lonely and some developed depressive symptoms. Another study showed that the mental health of dialysis patients appeared unaffected by the pandemic. The authors hypothesized that dialysis patients are used to adapting to various difficulties because of their disease and dialysis treatment and have therefore developed coping mechanisms that could help them face the challenges associated with a pandemic. The need for dialysis patients to report to the hospital three times weekly could have possibly contributed to easing their feelings of loneliness and isolation in that study. This could well be the case for patients interviewed in our study, who, despite social isolation and distance from their HCWs, felt a strong sense of belonging to a community. Another study had similar findings where patients looked forward to their dialysis treatment for social interactions, even if these were limited.

We recognize our study’s limitations. We were only able to interview patients receiving dialysis treatment in an urban region predominantly affected by the first and second waves of the COVID-19 pandemic. Most of our patients were Caucasian and spoke French or English, and thus the results do not reflect the reality of dialysis patients from other ethnic backgrounds. Our ability to draw definitive conclusions regarding the experience of indigenous patients is also limited and requires further study. Finally, the majority of our patients were married or in civil unions, which may have lessened the impact of the pandemic on their mental health.

Some recommendations can be made based on our results in order to improve patient care during a pandemic or other public health emergency. First, as demonstrated in our study, hemodialysis patients seem very attached to their care routine. Maintaining this routine should accordingly be of the utmost importance, in order to minimize patients’ stress in times of uncertainty. If this is not possible, any disruptions should be communicated rapidly with the reasons, and eliminated as soon as feasible. Second, our findings show that dialysis, for patients, is not only a place of care, but also a place of life. Effective communication with HCWs should be prioritized, and efforts
should be made to encourage safe social contacts with other patients and HCWs, when desired. Third, even if our study did not show dire mental health consequences for patients during the COVID-19 pandemic, these results should not be generalized, as mental health is personal to each individual. Units should put protocols in place to monitor patients’ mental health over time. Fourth, special attention should be paid during health emergencies to marginalized populations such as indigenous communities in order to prevent and mitigate inequities in care.

In conclusion, the aim of this study was to report the experiences of in-centre dialysis patients in an urban area heavily affected by the COVID-19 pandemic. The patients interviewed showed resilience and an ability to adapt to uncertainty. Patients were willing to adhere to measures to protect themselves and their loved ones, but expressed opinions on how the disruptions to their lives could be minimized, including improving their interactions with health care. These results highlight the importance of considering patients’ perspectives in the implementation of protective measures in case of a pandemic or health emergency. Further studies are also needed to better understand the experiences and responses of indigenous patients and patients from different ethnic backgrounds in order to reduce inequities in care.

**Disclosures:** M. Fortin reports the following: Advisory or Leadership Role: I am a member of the ethics committee of Transplant Quebec, the Collège des médecins du Québec, and the Canadian Society of Transplantation. I am also a member of different committees of the Canadian Blood Services. A. Affdal reports the following: Advisory or Leadership Role: Scientific Director - Canadian Journal of Bioethics. W. Beaubien-Souligny reports the following: Honoraria: Baxter. D. Blum reports the following: Honoraria: Astrazeneca; Otsuka. A. Nadeau-Fredette reports the following: Other Interests or Relationships: Current Scholarship from Fonds de la recherche du Québec en Santé (FRQS). R. Suri reports the following: Honoraria: Otskuka; Amgen; and Advisory or Leadership Role: Canadian Society of Nephrology; Canadian Institutes of Health Research Institute of Circulatory and Respiratory Health. M. Vasilevsky reports the following: Ownership
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**Author Contributions:** Rita Suri: Conceptualization; Funding acquisition; Writing - review and editing. Marie-Françoise Malo: Formal analysis; Investigation; Writing - original draft; Writing - review and editing. Aliya Affdal: Formal analysis; Investigation; Writing - review and editing. Fabian Ballesteros Gallego: Formal analysis; Investigation; Writing - review and editing. William Beaubien-Souigny: Conceptualization; Funding acquisition; Writing - review and editing. Annie-Claire Nadeau-Fredette: Conceptualization; Funding acquisition; Investigation; Writing - review and editing. Marie-Chantal Fortin: Conceptualization; Formal analysis; Methodology; Writing - original draft. Daniel Blum: Data curation. Marie-Line Caron: Data curation; Investigation. Murray Vasilevsky: Data curation; Investigation. Norka Rios: Data curation; Investigation; Project administration.
References


Table 1: Themes addressed during the qualitative interviews

<table>
<thead>
<tr>
<th>Themes</th>
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</thead>
<tbody>
<tr>
<td>Overall experience of hemodialysis care during the pandemic</td>
</tr>
<tr>
<td>Mode of transportation to the dialysis unit</td>
</tr>
<tr>
<td>Fears and concerns related to the pandemic</td>
</tr>
<tr>
<td>Interaction between HCWs and patients</td>
</tr>
<tr>
<td>Recommendations</td>
</tr>
<tr>
<td>Impact of the pandemic on mental health and feelings of loneliness</td>
</tr>
</tbody>
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Table 2: Participants’ characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N=22 (%)</th>
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<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male/Female</td>
<td>13 (59) / 9 (41)</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td>60.5 ± 16.7 (ranging from 30 to 90)</td>
</tr>
<tr>
<td><strong>Ethnic group</strong></td>
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<tr>
<td>Caucasian</td>
<td>14 (64)</td>
</tr>
<tr>
<td>Indigenous</td>
<td>4 (18)</td>
</tr>
<tr>
<td>Other</td>
<td>4 (18)</td>
</tr>
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<td><strong>Hemodialysis centre</strong></td>
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<td>Centre 1</td>
<td>5 (23)</td>
</tr>
<tr>
<td>Centre 2</td>
<td>6 (27)</td>
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<td>Centre 3</td>
<td>4 (18)</td>
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<td>Centre 4</td>
<td>4 (18)</td>
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<td>Centre 5</td>
<td>3 (14)</td>
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<td>Retired</td>
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<tr>
<td>Unemployed</td>
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<td>Employed full time/part time</td>
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<td>High school</td>
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<tr>
<td>Technical school or College</td>
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<td>University</td>
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<td>Less than $30K</td>
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<td>$30K to $99,999</td>
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<td>Widowed</td>
<td>2 (9)</td>
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<tr>
<td>Separated/Divorced</td>
<td>1 (4)</td>
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<tr>
<td><strong>Number of years on dialysis</strong></td>
<td>6.0 ± 6.2 (ranging from 1 to 27)</td>
</tr>
<tr>
<td><strong>Listed for a kidney transplant</strong></td>
<td>10 (45)</td>
</tr>
<tr>
<td><strong>Tested for COVID-19</strong></td>
<td>22 (100)</td>
</tr>
<tr>
<td><strong>Number of times tested for COVID-19</strong></td>
<td></td>
</tr>
<tr>
<td>(ranging from 2 to 25)</td>
<td>8 ± 6.8</td>
</tr>
</tbody>
</table>

1. Four patients mentioned during the interviews that they were positive for COVID-19.
Table 3: Themes addressed during the qualitative interviews

<table>
<thead>
<tr>
<th>THEMES AND INTERVIEW EXCERPTS</th>
<th>n = 22</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Effects of the COVID-19 pandemic on hemodialysis care and routine</strong></td>
<td></td>
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<tr>
<td><strong>Impact on hemodialysis care</strong></td>
<td>14</td>
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<td>• I, well not really very greatly, I mean there’s very little difference. (P5, male)</td>
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<tr>
<td>• No, it didn’t, there was no disruption. (P7, female)</td>
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<tr>
<td><strong>Change in their routine</strong></td>
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<tr>
<td>• Yes, before COVID, like I’m situated at […], and we are patients here that come from the North, because we don’t have access to these facilities that we get here in Montreal, we don’t have access to those. [...] Like in my community, we don’t have a dialysis clinic, so I had to be sent here and there’s about eight or nine of us from my community, so we are all situated here. And before the COVID, they went to different dialysis clinics [...]. So, they were all different, different areas where they went, but ever since the COVID happened, we have, we’ve all been placed at the same time, at the same hospital […]. And there is some of them that went to different clinics that say: When are we going back? They want to go back to their old routine, you know? ‘Cause their routine has been changed and they miss where they, where they usually went before the COVID. (P10, male)</td>
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<td>• They don’t want to send people to different clinics because, you know, of contamination or whatever, you know? They don’t want people. If somebody has it, they don’t know right away, so if somebody has it and gets sent to another clinic, they could be spreading it at that other clinic, you know? So, they wanted to keep us all in the same place, same time, you know? So, it will, it’s better if somebody does have the COVID, they know how to trace it, you know? Who we had contact with, it’s easier to track. (P10, male)</td>
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<td>• They switched me to a completely different centre because there was a special centre for those on dialysis who had COVID. (P19, female)</td>
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<tr>
<td>• I requested the change because I didn’t feel safe. (P21, male)</td>
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<tr>
<td><strong>Change in their routine regarding their mode of transportation</strong></td>
<td>9</td>
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<tr>
<td>• But since March or April, I’ve been getting there myself by car, and I make sure to be in the outdoor parking lot to avoid being in the elevators. (P6, male)</td>
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<td>• I’ve stopped taking the metro because you have to wear a mask in order to get into the metro, you know like to get past the turnstiles, but once people are inside, a lot of people take their masks off once the ticket taker doesn’t see them anymore, people take their masks off, they sit in this train with the same air circulating inside with no masks, so I avoid the metro. (P9, female)</td>
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<tr>
<td><strong>Switching from in-centre dialysis to home hemodialysis</strong></td>
<td>8</td>
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<tr>
<td>• No, I have no desire to switch, even if a war broke out, the choice is easy, I would choose: if I can get to the hospital for treatment, perfect. (P2, male)</td>
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<td>• No, no, no, I don’t think I had never imagined doing that. I think the biggest unfortunate aspect is that I don’t live in an apartment large enough to accommodate hemodialysis at the home, but I live so close to the dialysis clinic, I don’t know if it would be a big advantage or not. (P4, male)</td>
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<tr>
<td>• No, not at all, because for me, since my illness began, I have refused to bring my illness home. (P19, female)</td>
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</tbody>
</table>
• Danger of infecting yourself at home. Well, I prefer going to the hospital even if we’re in the middle of a COVID-19 pandemic than doing this at home and risking getting an infection. (P22, male)

Impact of COVID-19 infection risk and mitigation measures

Concerns related to their own infection risk

• I was, I wouldn’t say afraid, I wasn’t in fear, but I was, you know, uneasy that I may catch the coronavirus. (P4, male)
• If I see somebody, if the elevator door opens and there’s somebody standing there with no mask, I let them go by, by themselves, I don’t go in with them. So, if they’re not prepared to protect themselves, you know, I protect myself. (P9, female)
• I knew a person that got the COVID while at the hospital, [...], so that became you know, added a little bit more paranoia for my part. (P10, male).
• I’m always afraid, wherever I go, anywhere I go, I’m afraid of the virus. I try to be careful as much as I can and I know, and I don’t go anywhere unless I have to. (P13, female)

Risk management in the hemodialysis unit

Appropriate measures

• Oh yes, they’re necessary, they’re absolutely necessary, I understand why it’s being done, but it’s an inconvenience for the patients, that’s all. I understand that it’s for our protection, but it’s an inconvenience. (P9, female)
• Yes, I think they are appropriate, they were really taking care of us good. (P13, female)

Mixed feelings

• I thought it made no sense that if a nurse takes you from the inner door because you have an emergency, yes you can go. But if you ask to go, you can’t go. Oh no, the access is closed, while they go in and out, I don’t understand. I’m already on dialysis, I’m finishing my dialysis, so I’ve followed all the precautions, all the stuff—hand washing, mask and everything I’ve been asked, temperature and everything—why can’t I go to the ER? I have to walk around the hospital from the outside to go when I’ve finished four hours of dialysis. (P19, female)
• I don’t understand why now with the COVID and we have to be screened outside the waiting room, instead of waiting in our chairs which is separated with the plexiglass and everything, and we’re definitely you know X amount apart. They fill up the waiting room screening everybody and then they let everybody go in. It would seem better to me if, you know, everybody could just go sit in their chairs. They’re not in the way, they are distanced, they don’t have to worry about anything, and the person doing the screening can still screen anyway. I don’t see what the difference is between being screened in the waiting room to come into your chair, you know? It just doesn’t make sense. (P21, male)

Prohibition of visitors

• But, but it’s better because they come from outside, it might be them who are most at risk, because there’s a bunch of sick people, many, many people, even if there’s two metres, because then if you spread it to your family, that’s no better. (P7, female)

Fear of infecting their loved ones
• That’s what, that’s what I’m worried about, but thank God at least, I told you, as I told you, I get to have my safety measures, so as long as you know you keep yourself, you know, protected, so yes, but it’s still scary, yes. (P8, female)
• I stay away from them, we talk on the phone, but there’s, there’s no physical interactions at all. (P9, female)
• Yes. It really scares me when I go to my community. (P11, male)
• No, I very rarely see my family, so I don’t have to worry. (P16, male)

Impact of COVID-19 pandemic on relationships

Interactions with healthcare workers

• The doctors, we hardly ever see them. Unless there’s a new patient, and then they come, otherwise, not at all. (P1, male)
• COVID requires them to do other tasks that they would not have normally done. (P2, male)
• The doctors would not come in, we spoke through the window. (P7, female)
• Even the doctors when they pass, at least they don’t approach you like that, they keep their distance. (P8, female)
• It’s hard, you know, to see their faces and the interaction you know is like when you interact with your nurses you know there’s the facial expressions that you see. (P10, male)
• So, we no longer have contact, they do everything they can to avoid being closer to you, even if they still have to get closer because when they have to connect you, they can’t keep a distance of two metres and connect you, they would have to get closer to connect you, but still well protected. (P3, male)
• The staff is kind of freaked out. (P21, male)

COVID-19 pandemic and isolation from loved ones

• I would have really liked to reach out to people, I would have really liked to see my colleagues, I would have really liked to be happy with everyone, but instead, we’re wary, we keep our distance from each other, all that... It’s not... it’s not very pleasant, it’s often said! (P3, male)
• It’s obvious that we feel really isolated. (P7, female)