


BMJ Open Impact of the COVID-19 pandemic on Canadian transplant journeys: a mixed methods study

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ABSTRACT

Background Navigating the organ donation and transplantation system in Canada can be challenging for individuals on transplant journeys. Although it is likely that the COVID-19 pandemic has further contributed to these challenges, the experiences of individuals during the pandemic in Canada have not been well elicited.

Objective To illuminate how the COVID-19 pandemic has impacted individuals on transplant journeys in Canada.

Design Convergent parallel mixed-methods study.

Setting Canada.

Participants Adult patients, caregivers, and donors on transplant journeys across Canada.

Data collection Eight focus groups and an online survey between May and November 2021. Focus group transcripts were analysed using an inductive conventional content analysis approach. Survey data were analysed using descriptive statistics. The study was guided by individuals with lived experience of organ donation and transplantation.

Results A total of 830 participants completed three COVID-19 related survey questions, with 21 participating in the focus groups. *Survey results:* over 50% of patients and caregivers reported that the pandemic impacted their access to their healthcare team, their mental health (60% and 65%, respectively) and their comfort going out in public (80% and 75%, respectively). Although many donors reported several factors that impacted their transplant journey, the impact appeared to be greater for patients and caregivers. *Qualitative results:* three themes emerged from the qualitative data that contextualise participant's experiences: compounding isolation, disruption amid uncertainty and unforeseen benefits.

Conclusion The COVID-19 pandemic has exacerbated many of the challenges that individuals on transplant journeys experience. It will be critical for transplant programmes to consider these factors in future care provision.

INTRODUCTION

Organ transplantation is not only a life-saving treatment for many individuals with end-stage organ failure but can lead to better outcomes than alternative treatments, including increased quality of life and significant health system savings.^{1–3} Although transplantation has benefits, transplant recipients will

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Selection bias, including a predominantly white, English speaking and female study cohort, limited the generalisability of the findings.
- ⇒ The data were collected as a secondary objective from an overarching study.
- ⇒ Our study highlighted the important experiences of a relatively large cohort of adults on transplant journeys across organ groups in Canada.
- ⇒ Qualitative focus groups enabled the research team to garner further context into survey findings.

experience lifelong follow-up and management, including managing the side effects of immune suppressing medications, navigating a lifetime of check-ups and invasive monitoring, and fears that they may 1 day lose their transplant and begin the journey over again.^{4–6}

The organ donation and transplantation system in Canada is publicly funded and managed by a complex network of provincial, multi-jurisdictional, and national organisations and health authorities, each with varying practices and responsibilities. This can make navigating multifaceted transplant journeys challenging. Like many health sectors, the organ donation and transplantation system in Canada was further impacted by the COVID-19 pandemic in various ways, including re-deployed transplant workers, surgical lockdowns, reduced critical care capacity and transplantation safety concerns.^{7–9} This resulted in individuals on transplant journeys experiencing additional challenges, including transplant delays, reductions in transplantation rates, increased fear and anxiety, and significant changes in transplant care to accommodate shifting healthcare landscapes.^{10–15} Transplant recipients have further experienced higher rates of morbidity and mortality due to their immunocompromised state and underlying health conditions.^{16–18} Public health measures and

other elements that impacted their safety (eg, vaccine availability and efficacy) were also constantly changing and often uncertain.^{19 20}

Between May and November 2021, we conducted a mixed methods study using a survey and focus groups to explore the experiences of individuals on transplant journeys in Canada to garner a greater understanding of how health services delivery could be improved. The study dates coincided with the third and fourth wave of the COVID-19 pandemic and just followed COVID-19 vaccine availability, which began to be available in Canada in December 2020.²¹ The detailed public health measures that were in place were not captured during our study (eg, masking requirements, visitor restrictions, surgical delays, staff re-deployment), however, were likely to have varied across jurisdictions and throughout the study period. It was indeed likely that factors related to the COVID-19 pandemic had further contributed to the challenges individuals faced navigating the organ donation and transplantation system in Canada. However, the experiences of individuals on transplant journeys in Canada had not been well elicited in relation to the pandemic. A better understanding of these experiences was needed to improve supportive transplantation care provision within the COVID-19 landscape and beyond. As such, we included questions specific to understanding the impact of the COVID-19 pandemic, with the aim of this secondary analysis to shed light on how the COVID-19 pandemic impacted individuals on transplant journeys in Canada.

MATERIALS AND METHODS

In this study, we analysed a subset of data from a larger programme of research examining the lived experiences of transplant patients, living donors and caregivers on transplant journeys in Canada. The larger study was a patient-oriented convergent parallel mixed-methods study that used a 60-question survey and garnered qualitative data through focus groups and written responses about transplant experiences more generally. This study was planned prior to the COVID-19 pandemic, however, was ultimately carried out during the pandemic. The research team thus realised that it would also be imperative to capture data on transplant experiences related to the COVID-19 pandemic. The survey was thus adjusted to include three questions about the COVID-19 pandemic, including what areas the COVID-19 pandemic has impacted, whether the participants felt they had adequate access to the information they needed, and whether they visited a hospital during the pandemic. The survey was administered online and developed in conjunction with a survey design specialist and with those with lived experience of the transplant system. The survey underwent several rounds of review to establish content and face validity. Participants were recruited primarily through virtual promotion via project collaborators, including

The Kidney Foundation of Canada and the Canadian Organ Donation and Transplantation Research programme.

To help contextualise the survey data we conducted four focus groups with five to six participants in each who had lived experience with transplantation in Canada. Participants primarily included patients across different organ groups (n=19), one kidney donor, and a spouse of a patient who had received a kidney transplant. Focus groups were conducted in French and English over the Zoom platform and facilitated by an experienced moderator from the Kidney Foundation of Canada, at least one member of the patient advisory committee, and a member of the research team. After preliminary data analysis, the same focus group participants were invited to take part in a second focus group, resulting in a total of eight, 2-hour focus groups with five to six participants in each. During the first round of focus groups, participants frequently brought up COVID-19 related topics and issues related to transplantation. In the second round of focus groups, we thus asked targeted questions related to the COVID-19 pandemic to garner further insight into participants experiences (survey questions can be found in online supplemental file 1). All data collection occurred between May and November 2021.

Survey data were analysed descriptively using the Qualtrics platform using frequencies and percentages. Differences between participant groups (patients, caregivers, donors) on COVID-19 impacts were analysed by comparing observed and expected values using the Pearson χ^2 statistic. χ^2 assumptions for expected counts were assessed. We compared proportions between groups using a Bonferroni correction. We were also interested in examining differences based on patient organ type (kidney, liver, lung, other). We combined heart, pancreas and other into one 'other' category and excluded those who selected multiple answers or multi-organ due to small samples sizes and cell counts.

Focus groups were transcribed verbatim, translated into English, and imported into NVivo (QSR International Pty Ltd, V.12, 2018) for data analysis. We used a conventional content analysis approach for qualitative data analysis wherein after reviewing the transcripts and audio files, an initial list of codes was generated and organised into an overarching list of categories which was used as a coding framework to derive themes. Themes were refined through iterative rounds of group discussion and analysis, ensuring each represented a range of participant views. Quantitative and qualitative data were then compared, contrasted and integrated to offer a more comprehensive depiction of the participant's experiences with their transplant journey during the COVID-19 pandemic. The research team comprised individuals with varied experience with organ donation and transplantation. Each team member reflected on and discussed the impact of their unique positionalities throughout the research process.

Patient and public involvement

The Improving Engagement and Empowering Patients on Their Transplant Journey project was co-led by the Patient/Advocate Advisory Committee (PAAC) of the Organ Donation and Transplantation Collaborative. Members of the PAAC provided critical project input and direction from project inception to completion.

RESULTS

Quantitative results

A total of 830 participants completed three COVID-19 related survey questions. Most survey participants were female (69.6%), English speaking (92.7%) and white (88.8%) (table 1). Participants reported various ways in which the COVID-19 pandemic impacted their transplant journey (table 2).

Most patients (95%), caregivers (96%) and donors (71%) reported that the COVID-19 pandemic had impacted their transplant journey. The overall Pearson χ^2 was significant ($p < 0.001$) for between group differences, with observed versus expected counts indicating that patients were impacted more and donors were impacted less. Specifically, patients (80%), caregivers (75%) and donors (29%) indicated that the COVID-19 pandemic impacted their level of comfort going out in public, with significant between group differences ($p < 0.001$) being attributed to a higher proportion of patients being impacted. Patients, caregivers and donors also indicated that the COVID-19 pandemic impacted both their access to their healthcare team (52%, 54% and 29%, respectively; $p = 0.002$) and their mental health (60%, 65% and 35%, respectively; $p < 0.001$). Significant between group differences were attributed to living donors being less impacted by the pandemic. Although the impact of COVID-19 on the ability to attend work or school was found in less than 30% of each participant group, the overall difference was significant ($p = 0.010$), with a higher impact on patients. No between group differences were found regarding accessing medications. When examining COVID-19 impacts between patient organ types, there was a difference between groups in terms of access to the healthcare team ($p = 0.020$) and mental wellness ($p = 0.015$). Interestingly, this difference was attributed a greater proportion of lung patients reported being impacted. Although the other impacts were not statistically significant between patient organ types, it is interesting to note that for all impacts the proportion of lung patients affected was higher than the other groups (table 3). Twenty-seven per cent of respondents also felt that they did not have adequate access to the information they needed to make decisions about their health and had not visited the clinic or hospital during the pandemic. Several other impacts were also identified by survey respondents (figure 1).

Qualitative results

Twenty-one individuals participated in one of eight focus groups, including nineteen patients, one caregiver and

one living donor. Most focus group participants were male (52%), and under 55 years of age (71%) (table 1). Three themes emerged from the qualitative data that help to contextualise participant's experiences: compounding isolation, disruption amid uncertainty and unforeseen benefits.

Compounding isolation

Many of the challenges that Canadians experienced because of the pandemic were magnified for those on a transplant journey. Participants described feeling isolated and worried about getting COVID-19 and fearful of its unknown impact on their health. Many also described frustrations in changing rules and regulations and often felt that regulations did not adequately protect them.

I'm frustrated by government decisions and inaction with implementing restrictions. I never was a political person but the pandemic and the indifference of the government towards people with co-morbidities is maddening.

Many participants described ways in which they would take extra precautions to keep safe given their immunocompromised state and how difficult and isolating this could be. Some participants also spoke of hospital restrictions, where family or friends were not able to visit which was very difficult given that many hospital stays were long and complex.

Anytime I do have to go out or be around people, I just minimize the risks at all costs, you know, like shopping early, shopping online, just not being around people. I haven't seen my kids in two years.

These additional precautions impacted the ability of many participants to connect with their social network as well as to meet other needs (eg, get groceries, work). The additional precautions needed by the transplant recipient/patient also impacted their family who needed to take additional precautions to protect them. Their worry and isolation often exacerbated their pre-existing mental health concerns.

For me certainly going through transplant during a pandemic was crazy. Being in the hospital for two months [...] without my support system was atrocious. Nobody could see me. My husband couldn't come, my mom, my sister. Very hard.

Disruption amid uncertainty

The COVID-19 pandemic highlighted existing disjunctures across the transplant continuum. Participants explained that many of the difficulties that they encountered on their transplant journeys were exacerbated due to the COVID-19 pandemic. For example, continuity of care and access to accountable care were impacted as a lot of information about the COVID-19 pandemic and how it would impact them was often unclear, inaccessible or differed across providers. Many participants further

**Table 1** Demographic characteristics (n=830 survey respondents; n=21 focus group participants)

Variable	Total n (%)	Patients n (%)	Donors n (%)	Caregivers n (%)	Focus groups n (%)
Organ type					
Kidney	493 (59.4)	392 (47.2)	50 (6.0)	51 (6.1)	8 (38.0)
Liver	231 (27.8)	176 (21.2)	13 (1.6)	42 (5.1)	3 (14.3)
Heart	54 (6.5)	42 (5.1)	0 (0.0)	12 (1.4)	4 (19.0)
Lung	55 (6.6)	47 (5.7)	0 (0.0)	8 (1.0)	1 (4.8)
Pancreas	30 (3.6)	26 (3.1)	0 (0.0)	4 (0.5)	1 (4.8)
Multi-organ	5 (0.6)	4 (0.5)	0 (0.0)	1 (0.1)	2 (9.5)
Other	16 (1.9)	10 (1.2)	3 (0.4)	3 (0.4)	2 (9.5)
Gender					
Male	248 (29.9)	215 (25.9)	17 (2.0)	16 (1.9)	11 (52.4)
Female	578 (69.6)	435 (52.4)	47 (5.7)	96 (11.6)	10 (47.6)
Other	2 (0.2)	0 (0.0)	1 (0.1)	1 (0.1)	0 (0.0)
Prefer not to answer	2 (0.2)	1 (0.1)	0 (0.0)	1 (0.1)	0 (0.0)
Province/territory					
Alberta	120 (14.5)	96 (11.6)	9 (1.1)	15 (1.8)	1 (4.8)
British Columbia	158 (19.0)	120 (14.5)	15 (1.8)	23 (2.8)	2 (9.5)
Manitoba	42 (5.1)	27 (3.3)	3 (0.4)	12 (1.4)	1 (4.8)
Newfoundland & Labrador	13 (1.6)	10 (1.2)	0 (0.0)	3 (0.4)	1 (4.8)
New Brunswick	22 (2.7)	16 (1.9)	3 (0.4)	3 (0.4)	0 (0.0)
Northwest Territories	1 (0.1)	1 (0.1)	0 (0.0)	0 (0.0)	0 (0.0)
Nova Scotia	31 (3.7)	23 (2.8)	3 (0.4)	5 (0.6)	3 (14.3)
Nunavut	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Ontario	301 (36.3)	240 (28.9)	23 (2.8)	38 (4.6)	8 (38.0)
Prince Edward Island	4 (0.5)	3 (0.4)	1 (0.1)	0 (0.0)	0 (0.0)
Quebec	116 (14.0)	101 (12.2)	4 (0.5)	11 (1.3)	4 (19.0)
Saskatchewan	18 (2.2)	11 (1.3)	3 (0.4)	4 (0.5)	1 (4.8)
Yukon	4 (0.5)	3 (0.4)	1 (0.1)	0 (0.0)	0 (0.0)
Age					
18–24	8 (1.0)	7 (0.8)	0 (0.0)	1 (0.1)	1 (4.8)
25–34	61 (7.3)	38 (4.6)	9 (1.1)	14 (1.7)	2 (9.5)
35–44	147 (17.7)	101 (12.2)	17 (2.0)	29 (3.5)	6 (28.6)
45–54	197 (23.7)	149 (18.0)	15 (1.8)	33 (4.0)	6 (28.6)
55–64	232 (28.0)	196 (23.6)	12 (1.4)	24 (2.9)	4 (19.0)
65–74	172 (20.7)	148 (17.8)	11 (1.3)	13 (1.6)	1 (4.8)
75 or over	11 (1.3)	10 (1.2)	1 (0.1)	0 (0.0)	1 (4.8)
Prefer not to answer	2 (0.2)	2 (0.2)	0 (0.0)	0 (0.0)	0 (0.0)
Ethnicity					
White	737 (88.8)	583 (70.2)	57 (6.9)	97 (11.7)	Data not collected
Hispanic, Latino or Spanish	6 (0.7)	4 (0.5)	0 (0.0)	2 (0.2)	
Black or African	4 (0.5)	4 (0.5)	0 (0.0)	0 (0.0)	
Asian	34 (4.1)	27 (3.3)	2 (0.2)	5 (0.6)	
Middle Eastern or North African	9 (1.1)	4 (0.5)	1 (0.1)	4 (0.5)	
Indigenous	15 (1.8)	9 (1.1)	3 (0.4)	3 (0.4)	
Other	19 (2.3)	15 (1.8)	2 (0.2)	2 (0.2)	
Prefer not to answer	6 (0.7)	5 (0.6)	0 (0.0)	1 (0.1)	

Continued

Table 1 Continued

Variable	Total n (%)	Patients n (%)	Donors n (%)	Caregivers n (%)	Focus groups n (%)
Language					
English	769 (92.7)	594 (71.6)	65 (7.8)	110 (13.3)	Data not collected
French	159 (19.2)	129 (15.5)	10 (1.2)	20 (2.4)	
Other	88 (10.6)	68 (8.2)	6 (0.7)	14 (1.7)	

Participants could 'select all that apply' for organ type and language questions.

reported delays in their transplant workups among other resources and services being delayed or cancelled.

Here I'm waiting—it's been two years since I've heard anything from our transplant coordinator on anything from COVID stuff, other than the fact that when I got my shot, I had to let them know that the day that I got my shots.

Others spoke of the significant disruption to their progression to transplant, with needed tests being postponed or cancelled and often encountered less engagement with the healthcare team. Some participants described being frustrated not knowing when their transplant workup and life would get back on track and return to 'normal'.

So his team was sort of like, we're going to stop the workup because you can't get in anywhere for tests. So it just sort of slowed everything down, we actually had a living donor, a friend of ours, who was a match. And, again, going through COVID and her not dealing with it so well and some of her own fears and health issues coming up, she had to back out.

Unforeseen benefits

The pandemic also brought benefits. For example, one participant spoke of how she was able to continue to work as it was now possible to work from home. This may not have been possible prior to the introduction of COVID-19 restrictions. Other participants spoke of the impact of moving to virtual visits, which had previously not been

available. Although introducing their own challenges (eg, poor connection, computer skills), virtual care significantly reduced travel time and life disruption for many.

With the COVID, I only had one in person appointment after I've been discharged. All the rest of the appointment was virtually. They threw phone calls and video calls. And I think even if COVID was not around, I think the option of having the phone/video calls is way helpful.[...] it would have been a nightmare for me if I had to go in person for these appointments.

Other participants spoke of the appreciation they had for their healthcare team in their role for advocating for more information and early access to vaccines.

I think that the transplant team has been proactive. Like for an example right off they started the study about the validity of having a third booster shot and even before that they advocated for us to have the second shot within four weeks period or three weeks period based on the manufacturers advice and not wait the two month period So I feel that they did their part in the biggest extent where they worked for us, they advocated for us that day.

DISCUSSION

We sought to explore the experiences of individuals on transplant journeys during the COVID-19 pandemic in

Table 2 Impact of the COVID-19 pandemic on the transplant journey

	Patients (n=651)	Caregivers (n=114)	Donors (n=65)	Pearson χ^2 significance
Impacted my access to the healthcare team	337 (52%)	62 (54%)	19 (29%)	0.002
Impacted my level of comfort going out in public	524 (80%)	85 (75%)	25 (38%)	<0.001
Impacted my mental wellness (stress, anxiety, depression, etc)	389 (60%)	74 (65%)	23 (35%)	<0.001
Impacted my ability to attend work/school	180 (28%)	23 (20%)	8 (12%)	0.010
Impacted my ability to obtain medications	73 (11%)	15 (13%)	4 (6%)	0.348
There has been no impact because of COVID-19	33 (5%)	5 (4%)	19 (29%)	<0.001
Other	56 (9%)	8 (7%)	10 (15%)	0.140

Participants could have selected multiple responses.

Table 3 Impact of the COVID-19 pandemic based on patient organ type

	Kidney (n=357)	Liver (n=168)	Lung (n=42)	Other (n=44)	Pearson χ^2 significance
Impacted my access to the healthcare team	169 (47.3%)	96 (57.1%)	29 (69.0%)	22 (50.0%)	0.020
Impacted my level of comfort going out in public	275 (77%)	138 (82.1%)	37 (88.1%)	38 (86.4%)	0.154
Impacted my mental wellness (stress, anxiety, depression, etc)	208 (58.3%)	98 (58.3%)	35 (83.3%)	28 (63.6%)	0.015
Impacted my ability to attend work/school	101 (28.3%)	40 (23.8%)	16 (38.1%)	13 (29.5%)	0.301
Impacted my ability to obtain medications	31 (8.7%)	20 (11.9%)	8 (19.0%)	8 (18.2%)	0.065
There has been no impact because of COVID-19	22 (6.2%)	10 (6.0%)	0 (0.0%)	1 (2.3%)	0.290
Other	26 (7.3%)	14 (8.3%)	9 (21.4%)	5 (11.4%)	0.021

Participants could have selected multiple responses.

Canada. We identified that the COVID-19 pandemic has exacerbated many of the challenges that individuals on transplant journeys experience, including impacts to accessing the healthcare team, mental health impacts, compounding isolation and disruption amid uncertainty.

With the diversion of healthcare resources towards COVID-19 related needs, individuals with chronic conditions overarchingly experienced disruptions in ongoing care for chronic disease management, including health services disruption, impacts to their mental health and other reported lifestyle disruptions, and other elements in care provision including medication shortages.²²⁻²⁴

Many Canadians were frustrated by the ever-changing recommendations that surrounded the COVID-19 pandemic (eg, lockdown changes, vaccine eligibility). This was more complicated for people on transplant journeys where their immunocompromised state put them at additional risk.^{19,20} Many participants in our study felt the impact of this, and often described feeling additional fear, uncertainty and isolation as they attempted to manage their underlying health condition, prepare for transplantation and protect themselves or their loved ones. The mental health impact was exceptionally high for many individuals on transplant journeys, yet few participants

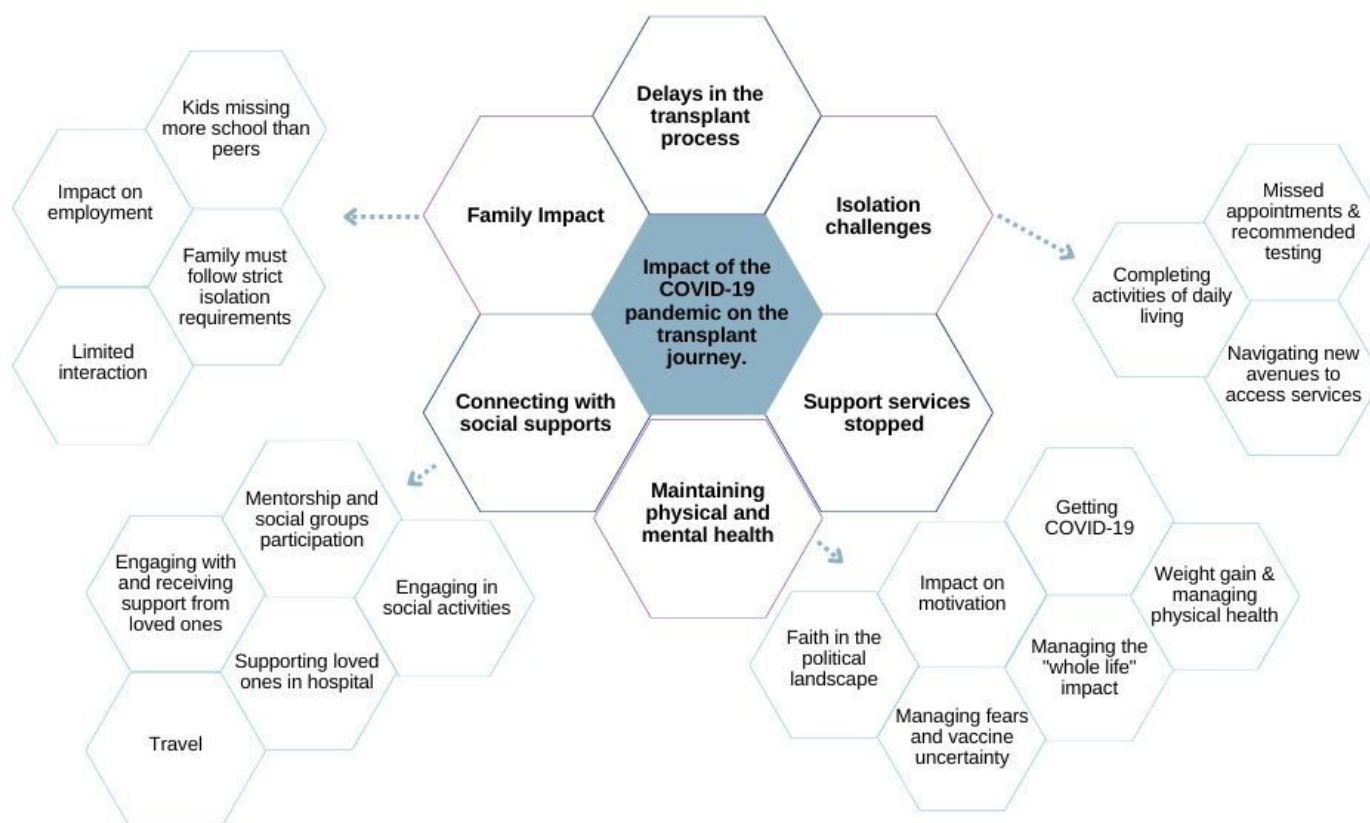


Figure 1 The impact of the COVID-19 pandemic on the transplant journey. Data have been categorised from the written responses in the other category from the survey question 'The COVID-19 pandemic as had an impact on ...'.

spoke of their mental health concerns being prioritised or addressed. Learning and working with individuals on transplant journeys to understand the long-term impacts the pandemic has had on the transplant population and to integrate targeted interventions to support mental health initiatives is an important step forward.

Individuals in our study were often unable to access reliable and consistent forms of information about how to manage their condition within the pandemic and often experienced disruptions in accessing care, especially as it pertained to their transplant workup. Couzi *et al* identified that during the lockdown, only 10% of kidney transplant recipients in France attended outpatient visits, which aligned with recommendations from transplant societies.¹² Although this may benefit to patients and their families in reducing the risk of getting and spreading COVID-19, it is also important to understand the challenges that may arise from less frequent and alternate forms of connecting with the healthcare team. Indeed, Couzi *et al* also identified the challenges to patient communication from transplant centres with limitations to disseminating recommendations.¹² Further, despite being concerned about COVID-19, most patients from a sample of participants in France wanted to receive a transplant despite the risks.¹² It is thus important to keep individuals on transplant journeys informed and to engage in conversations that identify their needs and wishes and advocate for care that supports them.

Although exacerbated during the COVID-19 pandemic, many of the challenges in care provision identified in our study were present before the pandemic.^{25–27} These elements emphasise existing disjuncture within the organ donation and transplantation system in Canada and highlight the importance of building appropriate structures to address them, both during the COVID-19 pandemic and beyond. Knowledge mobilisation and communication across care settings and jurisdictions must continue to be a priority, as is continuing to work on improving the care experiences of this population. Our study also identified opportunities that arose from the pandemic, including the integration of virtual care, which alleviated the travel burden of many participants. Although alternate forms of healthcare delivery such as virtual care are important avenues to expand and explore, challenges to their use remain.^{28–29} The focus should thus be to understand and support the unique healthcare delivery needs of the individual.

It is important to acknowledge that participants in this study were predominantly white, English speaking, female and accessed the study online which may potentially be indicative of higher technological literacy. We also did not capture all important demographic data including disease stage and education level. This selection bias may have resulted in the diverse experiences of individuals with demographic characteristics that more accurately reflect the transplant population in Canada not being represented, impacting the generalisability of the study findings. The data were also a secondary focus

to a primary study. Despite these limitations, the study results help to highlight important patient experiences during this time.

Our study highlighted the important patient experiences on transplant journeys that have been shaped by the COVID-19 pandemic. These experiences highlight both areas of improvement that can be targeted to improve care provision, as well as areas such as virtual care that could continue to be in place to support individuals on transplant journeys.

CONCLUSION

The COVID-19 pandemic has exacerbated many of the challenges that individuals on transplant journeys experience. It is imperative that knowledge mobilisation and communication across care settings and jurisdictions continue to be a priority, as is continuing to work on improving care experiences of this population and understanding the long-term impacts the pandemic has had on the transplant population. Should similar circumstances arise in the future, proper communication channels must remain open with individuals on transplant journeys, including sustained access to their healthcare team. Efforts to reduce delays in transplant progression and enhanced mental health support should also be a priority. Finally, the healthcare community should continue to leverage the unforeseen benefits of the pandemic, including the integration of virtual care. It will be important for transplant programmes to consider these factors in future care provision.

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Patient consent for publication Not applicable.

Ethics approval This study was approved by the Conjoint Health Research Ethics Board at the University of Calgary (REB19-1555). All Tri-Council Policy Statement 2 (TCPS2) guidelines were followed for obtaining consent, protecting confidentiality, and securely transferring and holding data. All participants gave informed consent prior to participation. We followed the Standards for Reporting Qualitative Research and the Strengthening of Reporting Observational Studies in Epidemiology Statement (online supplemental file 2).

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Data availability statement No data are available. Our dataset is not available due to the potential to identify individual participants from our qualitative data and survey responses.

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