

ORIGINAL ARTICLE

Suspension and resumption of kidney transplant programmes during the COVID-19 pandemic: perspectives from patients, caregivers and potential living donors – a qualitative study

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SUMMARY

Many countries have suspended kidney transplantation programmes during the COVID-19 pandemic because of concerns for patient safety and the shortage of healthcare resources. This study aimed to describe patient, family member and potential donor perspectives on the suspension and resumption of kidney transplant programmes due to COVID-19. We conducted seven online focus groups involving 31 adult kidney transplant candidates ($n = 22$), caregivers ($n = 4$) and potential donors ($n = 5$). Transcripts were analysed thematically. We identified five themes: cascading disappointments and devastation (with subthemes of shattering hope, succumbing to defeat, regret and guilt); helplessness and vulnerability (fear of declining health, confronted by the threat of and change in dialysis, disconnected from health care, susceptibility to infective complications); stress from uncertainty (confusion from conflicting information, unable to forward plan), exacerbating burdens (incurring extra financial costs, intensifying caregiver responsibilities), and sustaining health through the delay (protecting eligibility, relying on social support, adapting to emerging modalities of care). During the suspension of kidney transplantation programmes, patients felt medically vulnerable because of declining health, susceptibility to infection and reduced access to care. There is a need to address health vulnerabilities, disappointment, uncertainty and additional burdens arising from the suspension of kidney transplantation programmes.

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Key words

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Introduction

The COVID-19 pandemic has impacted on kidney transplant programmes globally [1–4]. Many countries have restricted or suspended kidney transplantation programmes due to concerns for patient safety and the shortage of healthcare resources during the pandemic [2,4–9]. There are some data to suggest that kidney transplant recipients are at an increased risk of severe COVID-19 because of immunosuppression and comorbid conditions [7,10–13].

Decisions to limit or suspend transplantation activity in the context of this pandemic are fraught with medical, logistical and ethical challenges [1,7,9]. Delays in transplantation can be detrimental for patients receiving dialysis because of deterioration in health. Additional screening, need for isolation and protection for the transplant team (e.g. those travelling to high-risk areas for donor procurement) also need to be considered [5]. Challenges identified in a recent global transplantation report include hospital facilities and workforce being diverted from transplantation to manage COVID-19, uncertainties of the risks of transmission from COVID-19 positive donors and lack of agreement about immunosuppression strategies in the context of the pandemic [7]. Prioritization of resources is difficult as the balance between equity and utility shifts with the increased risks imposed by COVID-19 [1,5].

However, the impact of the suspension of transplant programmes on patients, caregivers and potential donors may be underrecognized. This study aims to describe the perspectives of kidney transplant candidates, caregivers and potential donors on the suspension and resumption of kidney transplant programmes.

Patients and methods

Context

Kidney transplantation was classified as an elective surgery and was suspended (31st March 2020 to 27th April 2020) by hospital jurisdictions in a coordinated response, in consultation with State Governments and the Chief Medical Officer, following receipt of advice to do so from a peak body of transplantation and donation experts convened by the Federal Government and the Transplant Society of Australia and New Zealand as the “National Transplantation and Donation Rapid Response Taskforce – COVID 19”. Kidney transplantation was suspended during the initial log-phase of incident cases of COVID-19 in Australia, at which time Australia predicted a far higher number of cases and

greater burden of COVID-19 than has been experienced to date. Regarding the recommencement of transplant programmes, the Communique released by the COVID-19 National Transplantation and Donation Rapid Taskforce (13 May 2020) stated that “Deceased donor transplantation has resumed cautiously and any changes in community infection rates and transmission will be followed closely before a decision is made to resume full transplant activity. Processes need to be in place to ensure that patients can be safely managed through the operative and post-operative periods with as little time spent in hospitals and waiting rooms as possible, acknowledging that the safest place for immunosuppressed people being at home with no visitors. Units need to be as well prepared as possible for potential further outbreaks and clusters of infection” [14].

According to the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA), for patients receiving dialysis and waitlisted for kidney transplant, survival from time of waitlisting (censored at transplantation) is 99% and 94% at 1 and 3 years, respectively [15]. The mortality rate is 1.9 deaths per 100 patient-years (95% CI: 1.5–2.5) [15]. The average waiting time for a kidney transplantation is 2–3 years, but can be up to 7 years [1]. As of 17th June 2020, there were eight cases of COVID-19 in transplant recipients and 4 cases in patients receiving dialysis in Australia [16].

We used the Consolidated Criteria for Reporting Qualitative Studies (COREQ) to report this study [17].

Participant selection

Kidney transplant candidates age 18 years and over, their family members, and potential donors who had commenced workup were eligible to participate. All participants had to be English-speaking and able to give informed and voluntary consent. We took an inclusive approach and invited participants through Transplantation Society of Australia and New Zealand (TSANZ) Patient Network (this was open to all with registration available on the TSANZ website), social media and news media. This also enabled the inclusion of a wide diversity of demographic and clinical characteristics. Ethics approval was provided by The University of Sydney (2020-217). Due to the multi-pronged method of recruitment, we could not apply a purposive sampling strategy.

Data collection

The one-hour focus groups were convened from April to May 2020 using ZOOM videoconferencing. To

Table 1. Participant characteristics (*N* = 31).

Characteristic	<i>N</i> (%)
Role	
Transplant candidate on the waiting list	14 (45)
Transplant candidate with a potential living donor	8 (26)
Family member/caregiver	4 (13)
Potential living kidney donor	5 (16)
Sex	
Male	14 (45)
Female	17 (55)
Age (years)	
18–30	3 (10)
31–40	3 (10)
41–50	3 (10)
51–60	9 (29)
61 or older	13 (42)
Ethnicity	
White European	28 (90)
Other*	3 (10)
State of residence	
New South Wales	15 (48)
Victoria	9 (29)
South Australia	4 (13)
Queensland	3 (10)
Employment	
Full time	11 (35)
Part-time/casual	11 (35)
Student	1 (3)
Not employed	2 (6)
Retired	6 (19)
Highest level of education	
High school	6 (19)
Professional certificate/University	25 (81)
Marital status	
Single	6 (19)
Married/partnered	23 (74)
Divorced/separated	2 (6)
Cause/type of kidney disease (refers to patient)	
Polycystic kidney disease	5 (16)
Hypertension	4 (13)
Diabetes	4 (13)
Glomerulonephritis	5 (16)
Infection	3 (10)
Other†	12 (39)
Not known/not reported	2 (6)
Current treatment (refers to patient)	
None	4 (13)
Haemodialysis	17 (55)
Peritoneal dialysis	10 (32)
Time on waiting list (years) (refers to patient)	
<1	9 (29)
1–2	10 (32)
3 or more	7 (23)
Patient's transplant cancelled/postponed	
Yes	14 (45)
Relationship with potential donor (reported by patients only)	
Spouse	4 (13)

Table 1. Continued.

Characteristic	<i>N</i> (%)
Child	2 (6)
Parent	2 (6)
Sibling	2 (6)
Friend	2 (6)
Other‡	5 (29)
Relationship with recipient (reported by donors only)	
Spouse/partner	4 (13)
Child	1 (3)
Parent	4 (13)
Sibling	2 (6)
Friend	2 (6)
Other‡	4 (13)

Total may not sum to 31 as multiple responses were possible; were not reported or were not applicable. For patient characteristics, donor and caregivers could provide a response regard the characteristics of the patient.

*Other, Middle Eastern, Indian, Chinese.

†Other included Alport Syndrome *n* = 2, FSGS *n* = 1, Reflux nephropathy *n* = 1, immune-related *m* = 1, genetic *n* = 2, scleroderma *n* = 1 (3%), lupus *n* = 1.

‡Other, brother/sister in law, paired kidney programme.

maximize attendance rates (participants could select their preferred session) and to support diverse discussion, focus groups were mixed and included transplant candidates, family members and potential donors. The question guide was developed from the literature and discussion with the investigator team. We asked questions about: the impact of the suspension programmes (including on health, treatment, emotional and mental wellbeing, family, finances, and access to care, self-management), access to care, resumption of transplant activity (knowledge, expectations, decision-making, information and communication; Appendix S1). An investigator (CG, AB, NSW, AT) facilitated each group, and a co-facilitator took field notes. We convened groups until we reached data saturation, when little or no new concepts were arising. All groups were recorded and transcribed.

Data analysis

All transcripts were imported into HYPERRESEARCH software (version 3.7.5; ResearchWare Inc, Randolph, MA, USA) to facilitate data analysis. Using thematic analysis, author CG inductively identified initial concepts related to the participant perspectives on the suspension and resumption of kidney transplantation programmes. Similar concepts were

grouped into preliminary themes and subthemes, which were discussed with the facilitator team, and sent to participants for comment. This ensures that the final analysis reflects the full range and depth of the data obtained. A thematic schema was developed to summarize and depict conceptual links among the themes.

Results

In total, 22 kidney transplant candidates, four caregivers and five potential donors participated across seven focus groups ($N = 31$). Of the 49 participants confirmed to attend, 31 (63%) participated in the focus groups. Participant characteristics are shown in Table 1. Of the 22 patients, three had chronic kidney disease not yet requiring kidney replacement therapy, 12 were receiving haemodialysis, and seven were receiving peritoneal dialysis; 17 were female. Fourteen participants had their transplant cancelled during the time of the suspension.

We identified five themes, which are described in the following section. Concepts specific to those on the waiting list or with a living donor are detailed accordingly. Selected quotations to support each theme are provided in Table 2. The thematic schema is provided in Fig. 1.

Cascading disappointments and devastation

Shattering hope

Patients were “traumatized” when the programme was stalled because a transplant was their hope. The suspension was “one more event” on top of every other disappointment (including previous cancellation of transplant). Those who had their transplant cancelled felt like the “rug was pulled out from under them”. Some were frustrated as they feared having to start the workup over again.

Succumbing to defeat

Patients felt powerless having to wait in the “deathly silence” and in limbo because there could be no communications or decisions made about their transplant for an indefinite period of time. One patient expressed that he felt depressed and struggled to remain optimistic about their health.

Regret and guilt

Some potential donors had an initial transplant date prior to the suspension and felt guilty and that they had

let the patient down when the rescheduled surgery had to be cancelled. One patient who “estimated” that he had about ‘20 years’ of life left said “I just could see my prime whittling away” due to the suspension. He felt he “owed to himself and his wife [a potential donor]” to be well and now “there’s the sort of sense of disappointment this possibly may not come about”.

Helplessness and vulnerability

Fear of declining health

Some patients were concerned about their health deteriorating in terms of disease progression or because of dialysis. The stress related to COVID-19 was thought to “accelerate the loss of their kidney function”. Some questioned, “will I even make it to survive to get to this transplant. Because it keeps being pushed later and later”.

Confronted by the threat and change in dialysis

Some patients who were preparing for pre-emptive transplantation now faced the dreaded possibility of needing dialysis because of the delay. They encountered additional barriers in accessing the preferred mode of dialysis, for example having to do in-centre haemodialysis rather than home haemodialysis because of the costs – “because I’m down on the transplant list, the costs for setting up a home dialysis for short-term, they didn’t want to do, so they just told me to stick with hospital dialysis”.

Disconnected from healthcare

Patients appreciated being contacted about the suspension personally by phone or email, rather than a generic mailed letter, which was regarded as perfunctory. Some felt neglected when appointments with their nephrologists were cancelled. Others were still waiting for a follow-up call after the initial news of cancellation. Some did receive general information from their specialist but also sought information from other sources including news media – “I didn’t hear very much about it. My specialist did ring me to let me know that they were going to start redoing it. I think I got most of my information from the news”.

Susceptibility to infective complications

Some patients understood the decision to suspend transplantation was for their own safety – “I understand the reasons why the transplant programme was

Table 2. Selected illustrative quotations for each theme.

Theme	Quotations
Cascading disappointment and devastation	
Shattering hope	I got the call [about the transplant suspension] ... my heart sunk. Every time I get close to something, someone seems to pull the rug from underneath me. (P, FG4) I was devastated. I feel like I've had a really hard few years. . . This is my light at the end of the tunnel . . . This is where I'm putting all my hopes. I'm trying to get back to a normal life and get back to a job . . . and be a proper mum and carer to my children and I was devastated. (P, FG6)
Succumbing to defeat	You've got no hope. . . You're waking up to go to dialysis to come home and hope that you don't catch this infections. (P, FG5)
Regret and guilt	[On hearing the news of transplant suspension] I must admit I did go into a state of depression (P, FG7) I let [the patient] down because I could have had the three prior [chances to donate]. . . So he was disappointed, and he knew that I felt guilty, but he reassured me that it was probably for the best at the time. (D, FG4) I may not ever get to being back up [due to transplant suspension] . . . and I think I owe it to myself and my wife that . . . I feel there's the sort of sense of disappointment this possibly may not come about. (P, FG7)
Helplessness and vulnerability	
Fear of declining health	Having a restaurant and having it closed down is a massive financial burden, which has led to a lot of stress that in the past is what's accelerated my loss of function, kidney function. (P, FG1) I was unhappy and concerned, and worried about how long it was going to go because in the news they were reporting about how long six to 12 months, how long am I going to last, I didn't know what to do. (P, FG2) Another thing that came to my head when they said about the suspension was, my health has really, really declined in the last year and a half probably. I'm now worried, will I even make it to survive to get to this transplant. Because it keeps being pushed later and later. It's definitely . . . been a huge fear, since finding that out that, will I ever get there? (P, FG6)
Confronted by the threat of and change in dialysis	I'm trying my best to avoid dialysis, so that's why I wanted to be pre-emptive. I'm just lucky enough that we've had eight people so far put their hand up, so hopefully we can get a match sooner than later. (P, FG1) I don't think that 12 h of dialysis a week is enough to maintain my kidney and my body function. It's enough to keep me alive, but that's about it. I would much prefer if I didn't have the transplant to be doing home dialysis where I could get 40 h. (P, FG1)
Disconnected from healthcare	All of our nephrology appointments have been cancelled over here. . . they're not doing even telehealth. . . we have a doctor come in once a fortnight to once a month. So, I haven't really seen a nephrologist or a renal doctor since this happened. (P, FG5) My son's gone into the paired exchange. Now, what does that mean? I don't know. We had several rounds of this, relatives being tested. Then there is deathly silence. (C, FG4)
Susceptibility to infective complications	When I first heard about it, I was a little bit disappointed, but then I have a scientific background I could then look put a bit of logic into it. Yes, I think it is a good preventative measure, suspend them all while this virus is going around. (C, FG2) My first initial reaction was well, they're doing it in our best interests. It's certainly not for their own, it's mainly for us, to keep us safe. (P, FG3) I would prefer to wait a bit, I am quite concerned about some sort of infection after I have the surgery, as long as I'm feeling still able to cope and not on dialysis, I would prefer to wait a bit longer. (P, FG3) We're all trying to get our transplants, but the stress of after the transplant. . . you start to wonder if it's going to be worth it, but if COVID-19 is still around after you've had your transplant. . . It's just put extra stress on everything. I don't think the transplant process is going to be as simple as it would have been if this damn disease wasn't around. (P, FG1) [I watched] Facebook Live about how COVID affected kidney patients and I thought that was really good because my doctor obviously told me that we're more at risk than the general community. (P, FG3)
Stress from uncertainty	
Confusion from conflicting information	If a doctor has some information, unless they're really sure of the facts, just don't say anything at all because they're just setting us up for excitement to then get [hopes crashed] afterwards. Stick to the facts if you know the facts say it, if you don't, don't say it. (P, FG6)

Table 2. Continued.

Theme	Quotations
Unable to forward plan	I just find it really inconsistent and frustrating sometimes. . .you've talked to the different doctors, and you've all got different opinions and that's great. But to have someone that you trust is really important to me. Because I find it hard when I'm hearing so many different advice from different nephrologists, and they're saying different things. (P, FG5) 'Also, mention of the risks of why the suspension has occurred and that's one of the points because I think more information of why it has happened will make people go "Oh, they're looking after my health before doing the transplant". (P, FG3) My life is still on hold, I can't really plan a whole lot more, because I want obviously. . .to donate the kidney. And I don't know when that is, and then after that, I can get on with my life again. (D, FG5) My wife is a donor. . .It takes a bit for us to organize things, and not having a date or not having a timeframe in the future [for the transplant]. . .so it's just lots of the unknown puts a lot of stress on you. (P, FG1)
Exacerbating burdens	
Incurring extra financial costs	Because I'm semiretired, but I'm too young to get the pension, and so the amount of money that I've spent to get the workup done to get the transplant, and then it was postponed, and if I've got to go through all of that again in six months' time it's still going to cost me. (P, FG1) I work part-time, I told my boss, 'I don't feel safe here, I don't want to work here at the moment while this is happening. I'm going on unpaid leave'. So financially it hit harder because my business didn't close down, I wasn't able to get any of the COVID payments. (P, FG5)
Intensifying caregiver responsibilities	I find it really hard for him [caregiver], . . . he's sort of had to take on a lot more. (P, FG4) He's [patient] unable to work because he doesn't want to put himself in a situation to get the COVID-19. And therefore, his wife. . . she's had to put her work on hold as well so they can just keep themselves safe. (D, FG5)
Sustaining health through the delay	
Protecting eligibility	We're just waiting here because of this virus; everything is on hold. It could backfire, it takes one of us to get sick or in paired exchange rotation group something happens and we are all out of whack again. (D, FG6) I feel a level of responsibility . . . that I actually mentally have something that I used to think was mine, you know? I hardly thought about the kidneys, to be honest. But now I have a kidney that's for somebody else, And it's a gift . . .and I want to look after that gift. And . . .keep fit. (D, FG5)
Relying on social support	In this critical time of COVID, . . . I think it's where families step in. And you can't do kidney disease as an island, it's got to be a community, and all of your relatives. (C, FG4) That's the best thing. Having the support of the family. (P, FG4)
Adapting to emerging modalities of care	Telehealth I think is a great way to go and that's probably one of the pluses that's come out COVID-19 I think. . .down the track I think doctors are going to be more used to doing things like telehealth, because it's a lot easier. (P, FG1) One of the issues in bringing the medicos into the 21st Century and teaching them what FaceTime is or what Zoom is or something like that, because it would be much easier than talking over the phone to talk face to face. You can do that now with technology. (P, FG2)

C, caregiver; D; potential donor; FG, Focus group ID; P, patient.

suspended for these patients going on immunosuppressants. It's just not worth the risk. But it doesn't take the trauma away from being on hold". They also considered the increased risk of infection in hospital settings – "I was disappointed that elective surgeries were cancelled, [I saw] on our Facebook groups, before I got official letter. It's to stay on the safe side I guess, the risk of infection in hospital maybe outweighs it, or leaving the team to be available to the COVID patients". Another patient expressed, "I was very scared to catch it (COVID) so I was happy that it was

postponed". Some patients felt conflicted about whether to proceed with transplant once programmes resumed because of the potential risks of severe COVID-19 infection after surgery while on immunosuppressants. Potential donors worried about being carriers of the virus. Participants questioned whether deceased and living donors would be screened for COVID-19. However, others wanted to proceed with transplantation immediately because they trusted the decision of their medical team and their efforts to minimize such risks.

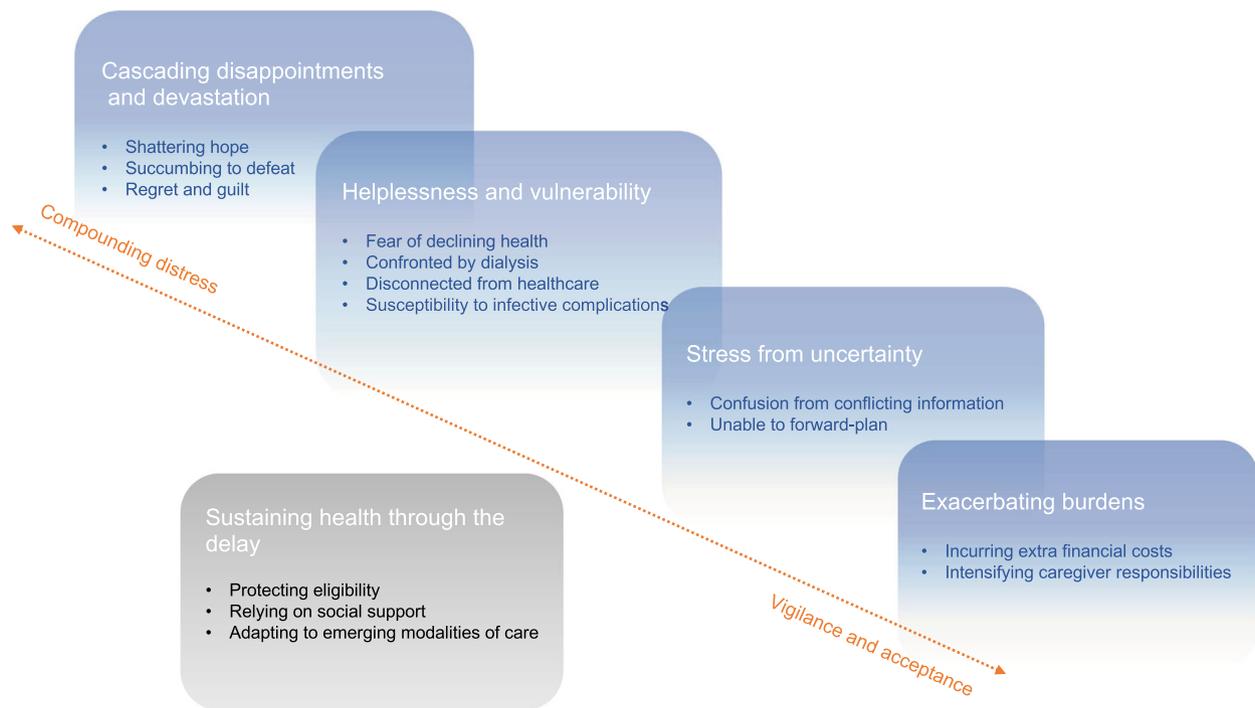


Figure 1 Thematic schema.

Stress from uncertainty

Confusion from conflicting information

Receiving different messages about the suspension of transplant programmes caused some to lose confidence in their doctors – “there has been some trust lost by the doctor in the dialysis unit”. Some patients felt doctors should communicate only “when they have the facts [about resuming transplants]” to avoid giving them false hope. One family member remarked the suspension was for “political reasons ... – how many people died because of the suspension.” Others felt able to only speculate on the reasons for the suspension of kidney transplantation – “It would be kind of nice to know the exact reasoning behind stopping it [kidney transplant programmes], whether it’s for the immunosuppressant side of it or if they need more beds and stuff in the hospital, because I don’t really know the exact reasoning behind why they stopped”. Another family member commented – “How come the USA, they have so many corona[virus] cases, and didn’t stop transplant for the kidneys? They never stopped it...why here we stopped it then?” They suggested that coordinated and consistent communication about the suspension and resumption of transplant programmes was needed.

Unable to forward plan

Being on standby was difficult for donors who wanted to “donate, and get on with their lives”, and some worried about being able to remain healthy enough to donate. Without “having a clear direction of a time frame”, patients were unable to plan for the transplant – “we’ve [patient and donor] got to organize people to look after the house, sit in the house and live there for a month.the lots of unknowns puts a lot of pressure on you”. One patient reported they were contacted by their transplant unit who could not give them a time-frame for the suspension – “He rang and said that due to the number of ICU beds, they couldn’t continue with doing the transplants. It was on hold indefinitely”.

Exacerbating burdens

Incurring extra financial costs

One patient who had hoped to return to work after transplant was concerned about the delay because they were unemployed and had no income. For some patients, the transplant workup had cost “an absolute fortune” and some worried about costs of repeating the screening tests after transplant programmes resumed. One patient who had their transplant cancelled had

purchased AU\$400 (US\$250) worth of immunosuppressants that could not be returned.

Intensifying caregiver responsibilities

With the postponement of transplants, caregivers had to keep up their duties in supporting the patient receiving dialysis. Some changed the way they lived to protect patients during the suspension. A family member who was a healthcare worker had to “leave home” and make separate arrangements to socially distance themselves from the patient during the suspension period.

Sustaining health through delay

Protecting eligibility

Potential donors felt added pressure to keep fit during the suspension because they “didn’t want to be the reason” for jeopardizing the patient’s chance for the transplant.

Those enrolled in paired kidney exchange programmes felt they were in a precarious predicament because everyone in programme had to remain healthy – “it just takes one person in the programme to get sick or if something happens we would be all out of whack”.

Relying on social support

Patients relied on family support to cope with the increased waiting period due to transplant suspension – “family support . . . everyone just ganging together and pushing and encouraging and each day is just a massive battle”.

Adapting to emerging modalities of care

During the suspension, some patients had to use telehealth. They took more responsibility for self-monitoring and checked their blood pressure and blood glucose levels at home. They felt that telehealth used during the suspension period would help them self-monitor and minimize visits to the hospital if they received a transplant during the COVID-19 period.

Discussion

The suspension of kidney transplantation programmes due to COVID-19 was devastating for patients who felt medically vulnerable because of declining health, and susceptibility to infection and having to miss in-person appointments and monitoring. The uncertainty in the duration of the delay and conflicting information

exacerbated stress in patients, family members and donors. They were conscious and vigilant about protecting their eligibility for transplant/donation. Some patients experienced added financial burden in paying for immunosuppression that could not be refunded, having to take leave on their employer’s advice and needing to pay for extra tests. The responsibilities on caregivers were also intensified. Decisions to proceed with transplantation after the resumption of programmes were difficult for some because of concerns about increased risks of severe COVID-19, while others believed it was safe to undergo transplant immediately.

There were some differences between candidates on the transplant waiting list and those with a living donor. Patients with a living donor felt a responsibility to remain as healthy as possible to protect their eligibility for living donor kidney transplant, including in the context of paired kidney exchange. Those who were preparing for pre-emptive transplant feared the possibility of having to commence dialysis due to the delay. Some felt unable to forward plan with their donor because of the uncertainty of timing as to when transplant would recommence.

The COVID-19 pandemic has had detrimental impacts on physical, mental and social health in the general population, with fears of infection, frustration, boredom, inadequate information, financial loss and stigma identified as stressors [18]. While these were also identified in our study, additional unique medical and psychosocial challenges faced by patients, caregivers and potential donors were identified that were directly attributed to the suspension of transplant programmes. COVID-19 infection was feared to jeopardize opportunities for transplantation or transplant outcomes. While published data are emerging [10–12], limited and conflicting information available to patients exacerbated stress amidst the disappointment and uncertainty about remaining eligible, or even alive, for transplantation following resumption.

We generated novel and detailed evidence on patient, family and potential donor perspectives on the suspension and resumption of kidney transplant programmes during COVID-19. To our knowledge, their priorities and concerns regarding the impacts of the suspension have not been systematically assessed and documented and may also not always expressed to clinicians involved in their care. We achieved data saturation and the findings were sent back to participants to ensure that the analysis reflected the full range and depth of data. However, there are some potential limitations. The study did not include participants who were non-English-speaking

and would preclude those without access to the internet. Given our multi-pronged method of recruitment, we were unable to use a purposive sampling. However, there was reasonable diversity in the demographic and clinical characteristics among the participants.

We suggest changes to transplant programmes, in particular any cessation of transplant activity, warrant a well-coordinated and consistent approach in communicating this to patients and potential living kidney donors, including the rationale for suspension. This includes the potential risks to kidney transplant recipient and healthcare system, and resource implications. We suggest that centres could provide periodic updates about the pandemic, as available, that includes information about potential plans to restart kidney transplantation programmes. Where feasible, transplant coordinators and other staff could personally inform transplant candidates about the suspension and resumption of transplant programmes. The potential psychological sequelae indicates that access to counselling to manage disappointment, stress and anxiety is needed. We also recommend programmes that support patients in self-monitoring and managing their health to remain fit for transplantation or donation. In considering the resumption of transplant programmes, informed decision-making with patients and their caregivers should include discussion of the potential risks of remaining on dialysis or delaying transplantations versus risks of COVID-19 infection in immunosuppressed recipients. We suggest that further efforts are needed to assess for any changes in how patients are educated and counselled.

Addressing health and emotional vulnerabilities, disappointment, uncertainty and additional burdens arising may help to mitigate the some of the direct consequences of suspending transplant programmes on the lives of patients, caregivers and potential donors.

Authorship

CG: participated in the research design, data collection, data analysis, and drafted the manuscript. AT: participated in the research design, data collection, data

analysis, and drafted the manuscript. AB: participated in the research design, data collection, data analysis, and provided intellectual input on the manuscript and contributed to manuscript writing. NSR: participated in the research design, data collection, data analysis, and provided intellectual input on the manuscript and contributed to manuscript writing. NI: participated in the research design, data analysis, and provided intellectual input on the manuscript and contributed to manuscript writing. JK: participated in the research design, data analysis, and provided intellectual input on the manuscript and contributed to manuscript writing. SC: participated in the research design, data analysis, and provided intellectual input on the manuscript and contributed to manuscript writing. TC: participated in the research design, data analysis, and provided intellectual input on the manuscript and contributed to manuscript writing. SC: participated in the research design, data analysis, and provided intellectual input on the manuscript and contributed to manuscript writing.

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Conflict of interest

The authors have declared no conflicts of interest.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Appendix S1. Interview guide.

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