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Resuming Deceased Donor Kidney Transplantation in the COVID-19 Era: What Do Patients Want?

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Background. The rapidly evolving novel coronavirus 2019 (COVID-19) pandemic bought many kidney transplant (KT) programs to a halt. Integral to resuming KT activity is understanding the perspectives of potential transplant candidates during this highly dynamic time. **Methods.** From June 1 to July 7, 2020, a telephone survey of KT candidates on the deceased donor waiting list at Imperial College Renal and Transplant Centre in West London was conducted. The survey captured ongoing COVID-19 exposure risks and patients' views on waitlist (WL) reactivation and undergoing transplantation. **Results.** Two hundred seven responses were received. Of the respondents, 180 patients (87%) were happy to be reactivated onto the WL; with 141 patients (68%) willing to give consent to transplantation currently, while 53 patients (26%) felt unsure, and 13 patients (6%) would decline a KT. The vast majority of patients had no concerns. In the responses from those who were uncertain or who would decline a KT, concerns about COVID-19 infection and the need for reassurance from transplant units dominated. Universally patients wanted more information about COVID-19 infection risk with KT and the precautions being taken to reduce this risk. **Conclusions.** The majority of surveyed patients are in favor of reactivation and receiving a KT despite the ongoing COVID-19 pandemic. Reactivation of candidates cannot be assumed and should take an individualized approach, incorporating clinical risk with patient perspectives. Improved communication with KT candidates is highly requested.

(*Transplantation Direct* 2021;7: e678; doi: 10.1097/TXD.0000000000001126. Published online 5 March, 2021.)

INTRODUCTION

For much of the United Kingdom and particularly in London, the novel coronavirus 2019 (COVID-19) brought many kidney transplant (KT) programs to a halt. In early April 2020, at the height of the pandemic in the United Kingdom, only 4 out of 23 adult KT centers remained open, some running with restrictions in place.[1] Concern related to patient safety, increasing pressure on acute healthcare resources, diversion of services and staff to support frontline efforts, and uncertainty over the risks associated with immunosuppression during this time, all contributed to these actions. Unsurprisingly, the number of KT performed globally has therefore declined dramatically during the pandemic.[2] Resuming transplant activity is proving challenging due to logistical issues, service reorganization, and creation of "COVID-secure" pathways, all in the context of the ongoing COVID-19 risk and contingency planning for a potential second surge of the virus.

Integral to resuming transplant programs is understanding the perspectives of potential KT recipients during this time and incorporating these views into service planning and delivery. At the Imperial College Renal and Transplant Centre, a large tertiary renal unit serving West London, we conducted a survey of our KT waitlist (WL) candidates to better understand these perspectives.

Received 24 September 2020. Revision received 30 November 2020.

Accepted 2 December 2020.

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The authors declare no conflict of interest.

This work was supported by the National Institute for Health Research Biomedical Research Centre based at ICHNT and Imperial College London.

A.K.T. participated in research design, performance of the research, data analysis, and writing of the article. H.B., R.D., A.D., S.G., P.M., L.R., R.S., and S.S. contributed to the performance of the research. F.D. and E.B. contributed to the editing of the article. M.W. conceived the work, performed data analysis, contributed to the writing and editing of the article, and maintained oversight for the work.

**A list of "ICHNT Renal COVID group" is given in "Acknowledgments" footnote.*

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ISSN: 2373-8731

DOI: 10.1097/TXD.0000000000001126

MATERIALS AND METHODS

In conjunction with multidisciplinary colleagues, a survey was devised (Figure 1). The aim of the survey was to help inform our center's approach to reopening transplant services by obtaining a point estimate of the number of potential transplant recipients wishing to be reactivated on the waitlist and undergo transplantation but also to obtain information via open questions on any concerns patients may have, to help formulate subsequent patient information materials. As prior exposure to COVID-19 or ongoing exposure risk may influence individual views, additional sociodemographic data were also captured. The 299 adult patients who were identified as active on the deceased donor WL before the mass suspension of our program on March 18, 2020, were included. The survey was performed between June 1 and July 7, 2020. The survey was registered as a service evaluation at Imperial College Healthcare NHS Trust (ICHNT) and approved by the ICHNT Renal Quality and Safety Committee.

The West London renal population is highly diverse, both ethnically and socioeconomically. To reach as many patients as possible and provide equal access to this survey, telephone consultations were performed. The survey was conducted by nephrology fellows, who usually undertake the deceased donor organ offering consultations within our unit. The survey format, questions, and how to record responses were explained to all trainees conducting the survey.

The survey responses were collected and recorded in a shared electronic document, together with sociodemographic data. Of the 299 patients on the WL, responses were received from 207/299 (69.2%) patients; 8/299 (2.7%) had died, 5 (1.7%) were being worked up for a living donor KT in the independent sector, 3 (1.0%) declined involvement, 6 (2.0%) were unable to participate due to language barriers, and 70 (23.4%) were unavailable. In those patients who were unavailable, this was either due to incorrect telephone numbers being listed within the hospital records, or in most cases, the patient did not answer the telephone calls when multiple attempts were made. The results presented therefore reflect the views of the WL patients who did respond, representing 76.6% of the WL population in West London.

Data Analysis

Statistical and graphical analyses were performed with MedCalc v1.9. The Chi-squared test was used for proportional assessments. Data are reported as median and interquartile range. The 2-sided level of significance was set at $P < 0.05$.

RESULTS

The patient characteristics of the 207 respondents are shown in Table 1. Thirty-six patients (17.4%) had previously tested positive for COVID-19 through viral detection on a nasopharyngeal swab, and a further 8 patients (3.9%) reported symptoms suggestive of a COVID-19 infection but did not have a confirmatory test.

Current and Ongoing Exposure Risk

One hundred sixty-five patients (80%) reported they were living with others, of whom 41 patients (25%) were living with children under the age of 16. Ten patients reported household contacts who had displayed symptoms suggestive of COVID-19; 9 of these patients had been symptomatic or tested positive themselves, whereas 1 patient had neither.

Before the pandemic, 75 patients (36%) were working. For most participants, their work status had changed significantly with the pandemic, with 29 patients (38.7%) no longer working, 25 (33.3%) working from home, 15 patients (20%) furloughed (government job retention scheme), and 6 (8%) patients continuing to attend their workplace. For those patients who were no longer working, this meant either they

Exposure Risk

1. Have you had COVID-19 infection?
2. Do you live alone?
    a. Do you live with any school age children (≤16 years of age)?
    b. Has anyone in your household had COVID-19?
3. Were you working prior to the COVID-19 pandemic?
    a. What is the current state of your work?
    b. Are you travelling to work using public transport?
4. In-centre haemodialysis patients: how do you travel to haemodialysis?

Transplantation Views

1. Would you like to be activated on the deceased donor transplant wait list, when the transplant programme re-opens?
2. Would you like to have a kidney transplant at the moment?

Open Questions

1. Do you have any specific questions or concerns related to COVID-19 and kidney transplantation?
2. Any other comments

FIGURE 1. Outline of telephone survey. COVID-19, novel coronavirus 2019.

TABLE 1.

Characteristics of survey responders

Characteristic		Number (%)
Gender	Male	130 (63)
	Female	77 (37)
Age	17–30	9 (4.3)
	31–40	24 (11.6)
	41–50	35 (16.9)
	51–60	53 (25.6)
	>61	86 (41.6)
Ethnicity	White	54 (26.1)
	Black	44 (21.2)
	Indo-Asian	92 (44.4)
	Other	17 (8.2)
RRT modality	In-center hemodialysis	168 (81.1)
	Home hemodialysis	7 (3.4)
	Peritoneal dialysis	32 (15.5)

RRT, renal replacement therapy.

had chosen to stop working themselves or their employer was no longer expecting them to perform any employment-related activities. Of the 6 patients who were still going out to work, only 1 patient reported using public transport to do so, whereas the rest were using a private form of transport.

Further exposure risk was associated with attendance for in-center hemodialysis. The majority of respondents were receiving in-center hemodialysis (168 [81.2%] patients), of whom 98 (58.3%) used private transport to attend dialysis, 49 patients (29.2%) used public transport, 17 (10.1%) used hospital transport, and 4 (2.4%) patients used a combination of hospital and public transport.

Views on Transplantation

One hundred eighty patients (87%) reported they would like to be reactivated as soon as the transplant program restarted, 17 patients (8%) felt unsure and 10 patients (5%) said they would not wish to be reactivated at this stage. However, there was some discordance between wish to be reactivated and wanting to proceed with KT at the present time. In regard to receiving a KT, 141 patients (68%) said they were happy to give consent for a KT currently, 53 patients (26%) were unsure, and 13 patients (6%) said they would not consent (Figure 2). A comparison of the clinical and social characteristics of patients by their consenting preference is shown in Tables 2 and 3.

Concerns, Comments, and Questions

A series of open questions were used to determine patients concerns, comments, and questions regarding reactivation on the waitlist and transplantation. Common themes and topics were identified from the responses received and are described below.

Eager to Have a KT

The majority of participants reported having “no concerns” at all or that they were “happy to proceed if the transplant team were happy to do so.” A common underpinning to these responses were participants describing having a high level of “trust in their nephrology teams,” and therefore feeling “happy to be guided by them.” Specifically, 1 respondent described being “not keen during the peak, but after seeing the additional interventions in the hemodialysis unit and renal service,” they “felt better about having a KT now.” Similar thoughts of “being in safe hands”

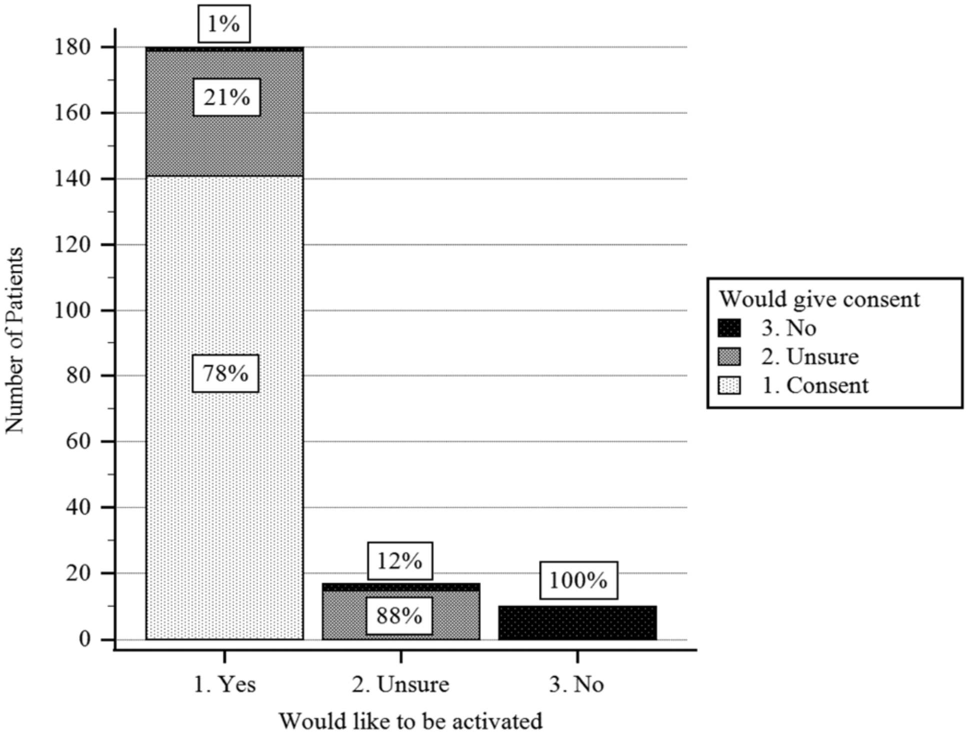

FIGURE 2. Patient views on resuming kidney transplantation: consent for reactivation vs provision of consent for transplantation if called. Although the majority of patients, 180 (87%), wanted to be reactivated for transplantation, 39/180 (21.7%) stated they were either unsure or would not consent for a transplant if offered 1 at the time of the survey. Of the 17 (8.2%) of patients who were unsure whether they wanted to be reactivated on the transplant list, 2 (11.8%) would not consent for a transplant.

TABLE 2.

Clinical characteristics by patient’s attitude to undergoing transplantation

Variable		Would consent N = 141 (%)	Unsure N = 53 (%)	Would not consent N = 13 (%)	*P*
Gender	Male	96 (68.1)	27 (50.9)	7 (53.8)	0.07
	Female	45 (31.9)	26 (49.1)	6 (46.2)	
Age	Median (y)	57 (45–65)	55 (44–62)	61 (50–66)	0.28
Ethnicity	Caucasian	38 (27)	12 (22.6)	4 (30.8)	0.77
	Black, Asian, and minority ethnic	103 (73)	41 (77.4)	9 (69.2)	
Cause of ESKD	APKD	8 (5.7)	2 (3.8)	1 (7.7)	0.43
	Glomerulonephritis	32 (22.7)	17 (32)	6 (46.2)	
	Diabetic nephropathy	42 (29.8)	15 (28.3)	0	
	Urological	8 (5.7)	3 (5.7)	0	
	Unknown	36 (25.5)	9 (17)	4 (30.8)	
	Other	15 (10.6)	7 (13.2)	2 (15.3)	
In-center dialysis	Yes	114 (80.9)	42 (79.2)	12 (92.3)	0.55
	No	27 (19.1)	11 (20.8)	1 (7.7)	
	Peritoneal dialysis	22 (15.6)	10 (18.9)	0	
	Home hemodialysis	5 (3.5)	1 (1.9)	1 (7.7)	
Time on waitlist	Median (d)	823 (514–1338)	892 (650–1339)	837 (563–2080)	0.46
Receiving Immunosuppression	Yes	32 (22.7)	8 (15.1)	3 (23.1)	0.50
	No	109 (77.3)	45 (84.9)	10 (76.9)	
Diabetes	Yes	56 (39.7)	21 (39.6)	2 (15.4)	0.22
	No	85 (60.3)	32 (60.4)	11 (84.6)	
Ischemic heart disease	Yes	33 (23.4)	10 (18.9)	4 (30.8)	0.62
	No	108 (76.6)	43 (81.1)	9 (69.2)	
Hypertension	Yes	114 (80.9)	43 (81.1)	7 (53.8)	0.07
	No	27 (19.1)	10 (18.9)	6 (46.2)	
Previous transplant	Yes	37 (26.2)	10 (18.9)	5 (38.5)	0.30
	No	104 (73.8)	43 (81.1)	8 (61.4)	

APKD, adult polycstic kidney disease; ESKD, end-stage kidney disease.

were echoed throughout these responses. Many patients also described an urgency to having a KT, with comments such as being “desperate to proceed,” “feeling brave and ready,” seeing transplantation as their “only chance to get off dialysis” and also many asking, “how soon can the KT program restart.”

TABLE 3.

Social variables by patient’s attitude to undergoing transplantation

Variable		Would consent N = 141 (%)	Unsure N = 53 (%)	Would not consent N = 13 (%)	*P*
Had COVID	Yes	28 (19.9)	6 (11.3)	2 (15.4)	0.37
	No	113 (80.1)	47 (88.7)	11 (84.6)	
Lives Alone	Yes	27 (19.1)	14 (26.4)	1 (7.7)	0.27
	No	114 (80.9)	39 (73.6)	12 (92.3)	
Lives with children ≤16 y	Yes	37 (32.5)	6 (15.4)	0	0.01
	No	77 (67.5)	33 (84.6)	12 (100)	
Household contact with COVID	Yes	5 (4.4)	2 (5.1)	2 (16.7)	0.20
	No	109 (95.6)	37 (94.9)	10 (83.3)	
Employment prelockdown	Yes	50 (35.5)	22 (41.5)	3 (23.1)	0.44
	No	91 (64.5)	31 (58.5)	10 (76.9)	
Type of employment	Not working	90 (63.8)	31 (58.5)	10 (76.9)	0.22
	Business/IT	21 (14.9)	9 (17)	0	
	Education	3 (2.1)	3 (5.7)	1 (7.7)	
	Healthcare	4 (2.8)	1 (1.9)	2 (15.4)	
	Not defined	3 (2.1)	1 (1.9)	0	
	Service/hospitality	20 (14.3)	8 (15)	0	
Travel to in center Hemodialysis	Own transport	64 (56.1)	27 (64.3)	6 (50)	0.37
	Public transport	10 (8.8)	4 (9.5)	3 (25)	
	Hospital transport	38 (33.3)	9 (21.4)	3 (25)	
	Combined transport (public and hospital)	2 (1.8)	2 (4.8)		

COVID, novel coronavirus.

Apprehensive About KT

A proportion of patients remained apprehensive or would decline a KT in the current climate. Commonly raised concerns related to the risk of COVID-19 transmission from the donor and during their hospital stay, and many wanted "reassurance from transplant teams" that it was safe to undergo KT before agreeing to do so. Some patients said they were "not willing to accept a KT until this is all over," describing feeling "very scared" or that currently "it does not feel safe." A small proportion raised concerns about the additional psychological impact having a KT would add when they were already experiencing high levels of stress related to the pandemic and their health and were worried about exposing other vulnerable members of their household to COVID-19 through hospital attendances for the KT. Some were concerned about whether an additional period of shielding and self-isolation would be possible for them, as they would not have their usual levels of social support due to social distancing and shielding instructions. One participant remarked that they were concerned that "the medical follow up afterwards would not be good enough, as the focus of the hospital would be on managing COVID-19."

COVID-19 and KT

Commonly, participants raised queries about how their individual risk of contracting COVID-19 may change by becoming a KT recipient and being immunosuppressed, compared with the risk on their current form of renal replacement therapy. Many were also concerned about how COVID-19 may affect their subsequent success on the KT waitlist, fearing that they would not be reactivated, that the time suspended would affect "their position on the waitlist" and that the program may not restart at all.

General KT Concerns

Patients also raised a number of general KT concerns unrelated to COVID-19, including "fears of the transplant not working and returning to dialysis," feeling "generally scared about KT," and being worried about "accepting the right kidney offer."

Information Requests

When asked what information participants would like from their healthcare team on resuming KT, the following topics were identified:

- Information about COVID-19 transmission risk from the donor and during their hospital stay.
- Information about how COVID-19 has affected existing KT patients and those taking immunosuppression.
- Precautions that would be in place by the healthcare team to reduce COVID-19 transmission risk (including COVID-19 testing of patients and staff).
- The specific precautions they would need to take themselves, both during the hospital stay and following the KT.

DISCUSSION

In this survey of potential KT recipients, the majority of respondents (87%) reported that they would like to be reactivated immediately on to the KT waitlist when local transplant activity is resumed, with only 5% of patients preferring to remain suspended from the WL. Although this does reflect a significant proportion of the respondents, it must be recalled that 70 patients were unavailable, and so their responses were not included, and this perspective may not fully reflect that of the entire WL population. Additionally, there was reported discordance between the wish to be reactivated on the transplant list and providing consent for transplantation, which warrants specific attention. Thirty-nine patients (19%) reported that they were willing to be reactivated on the deceased donor transplant waitlist but were unsure or not willing to undergo kidney transplantation at this time. The comments these patients made were similar to those concerns and queries expressed by the majority of patients, but the discordance between approval for reactivation and consent provides evidence that an individualized approach to reactivation should ideally be taken by transplant units following resumption of transplant services. This would avoid unnecessary offers being made to patients who do not feel ready for transplantation but also provides a platform to explore and resolve individual reasons and concerns as to why this may be. Although blanket reactivation of waitlists may be performed, and discussions had at the time a transplant offer is made, we believe such complex discussions would be better performed electively by the nephrology teams known by the patient.

Analysis of responses by underlying clinical and social factors reveals women were less likely to outrightly provide consent for a KT compared with males; 45/145 (31.9%) of patients who would currently consent were female, compared with 32/66 (48.5%) of those who were unsure or would not consent, $P = 0.02$. Patients who live with school-aged children were also more likely to consent to KT. Despite the ability for patients receiving home dialysis to shield more effectively, we found no association between dialysis modality and willingness to consent. Similarly, no other differences in clinical or social factors were shown to be associated with attitudes to consent.

Exploration of the rationale behind patient perspectives revealed that for the majority of patients, there were no concerns and instead an "eagerness," even "desperation," to continue with the option of KT irrespective of COVID-19. Many patients described the confidence they had in their nephrology teams and were happy to defer the decision to the healthcare professionals. For those patients feeling uncertain about KT currently, the recurring theme was related to the risks of contracting COVID-19 with KT and the need for additional information about precautions being put in place and reassurances from their nephrology team. For those patients who preferred to stay suspended and did not want to undergo transplantation, the predominant theme was of "waiting until COVID-19 is all over." Many described being worried about "upsetting their current health" and how their COVID-19 risk may change with KT. This was best described by one respondent: "I've been shielding this whole time and remained well, I would not want to undo this hard work or expose myself to getting the virus by having a transplant right now."

Professional guidance from NHS Blood and Transplant, the National Institute for Health and Care Excellence and the British Transplant Society on resuming KT programs has been released and continues to be updated.[3-5] Although the focus of much of this guidance and wider research has been on the practicalities of resuming KT activity safely, data on patient perspectives are limited. Ghua et al interviewed 31 adults, a group consisting of potential live donors, KT recipients, and caregivers in Australia and New Zealand, to determine the impact of KT suspension on these participants.[6] Many of the themes they reported are echoed in the responses from our survey, including patients' mixed feelings on restarting transplant programs, the loss of hope in being suspended, and the desire for improved communication and information from their nephrology teams.[6] This survey adds value by focusing specifically on the recipient's perspective and their exposure risks.

Although our survey has shown that information about risk appears integral to patient decision making, accuracy over risk prediction is going to be challenging. Large registry data from NHS Blood and Transplant, comparing outcomes between all solid organ WL candidates and transplant recipients, reports higher mortality rates with COVID-19 infection in the transplant recipients.[7] However, these data are limited to patients presenting with symptomatic infection and likely to underestimate mild or asymptomatic infection in transplant patients, who have less contact with healthcare services.[8] The attributable risk of immunosuppression on patient outcome at an individual level is currently not known and therefore cannot be quantified for patients. Despite the highly uncertain environment created by the pandemic, effective communication with WL candidates is still of paramount significance.[9] This will ensure patients remain informed of service changes, receive up to date information, and improve their personal experience as well as maintain their confidence in the care provided by their nephrology teams.

Limitations of this work include that it is a service evaluation project rather than a formal research study, and the inclusion of only patients who were available via telephone. This has limited the input of patients with significant language barriers and excluded those patients who were unavailable during the survey period. Similarly, our cohort has not captured any patients listed pre-emptively for KT in whom the perspectives and motives behind KT may be very different. Furthermore, this survey describes patient perspectives at a given timepoint; however, patients' perspectives are likely to vary with time, with the evolution of the pandemic, and changes in local social distancing restrictions. It is also important to highlight that our survey does not represent the informed consent process and was aimed to collect information on patient perspectives rather than disseminate information; whether patient's views would have changed with a more didactic approach cannot be clarified. However, understanding the concerns of patients is important to help inform the transplant community of the evidence we need to support patient management through this unprecedented period.

In conclusion, with COVID-19 infection likely to remain a risk and concern for healthcare systems for the foreseeable future, safely resuming and maintaining KT activity in this climate is a priority for all renal departments. Understanding the perspectives of potential transplant recipients, addressing their concerns, and building these views into KT services is key and will enable appropriate, individualized relisting of patients, alongside safe and effective delivery of KT programs.

ACKNOWLEDGMENTS

The authors would like to thank the patients who have contributed. The authors would also like to thank the contribution of the ICHNT Renal COVID Group (senior clinicians at the Imperial College Renal and Transplant Centre engaged in the care and management of patients during this period: Ashby DR, Cairns T, Charif R, Condon M, Corbett RW, Duncan N, Frankel A, Griffith M, Herbert P, Hill P, Goodall D, Kousios A, Levy JB, Loucaidou M, Lucisano G, Mclean A, Medjeral-Thomas N, Muthusamy A, Palmer A, Papalois V, Parsons D, Salisbury E, Sandhu E, Storey R, Tanna A, Tansey K, Tomlinson J, and Webster P).

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