

Living Organ Donor Health Care Priorities During the COVID-19 Pandemic



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At the onset of the coronavirus disease 2019 (COVID-19) pandemic, the majority of transplant programs in the United States suspended living donor kidney and liver transplant surgeries.¹ Although many programs have since resumed these procedures, the cumulative number of living donor kidney and liver transplants between March 13, 2020 (the date of the COVID-19 emergency declaration) and June 1, 2020 was almost 70% lower than the cumulative number over the same timeframe in 2019.² In a recent national survey study of transplant programs, 56% of respondents cited donor and transplant candidate concerns as a substantial barrier to living donor transplant during the pandemic.³ Although transplant programs have focused on steps to mitigate COVID-19 transmission risk to living donors (e.g., by using telemedicine for clinical evaluations and requiring predonation self-quarantine),^{3,4} more knowledge is needed on donor concerns and attitudes about donation during the pandemic to improve processes of shared decision-making and donor-centered care.

As transplant programs in the United States and across the world continue to face dynamic conditions due to the COVID-19 pandemic, the goal of this study was to elucidate the perspectives of previous and prospective organ donor members of an online support group ([Supplementary Methods](#)) about preferred information sources, priorities for mitigating donation-related risks, and excess health-related and other burdens experienced during the pandemic. We also

assessed whether donor perspectives differed by local COVID-19 burden, relationship to recipient, and donor organ type.

Among approximately 550 active support group members, 157 individuals responded to the survey study (28%), of which 148 met the inclusion criteria ([Supplementary Methods](#)). The majority of respondents were previous or prospective kidney donors ($n = 111$, 75%). The cohort was 94% non-Hispanic white and 91% female. Compared with prospective donors, previous donors were older (51–70 years of age: 13% vs. 33%, $P = 0.04$), whereas other demographics were similar ([Table 1](#)). Respondents resided in 40 U.S. states and the District of Columbia.

Respondents rated personal doctors as their most important information source (median importance 90 [interquartile range {IQR} 72–100]), followed by transplant programs (86 [IQR 65.5–100]) and official websites (79 [IQR 58–92]). Social media was the least important source of information (26 [IQR 11–54]). Ratings on sources of information did not differ by respondents' relationships with transplant recipients, donor organ type, previous or prospective donor status, or COVID-19 case burden in their state on the date of survey response.

Nearly one-third (28%) of respondents reported that COVID-19 changed the way that they think about the risks of living donation. The following themes arose from open-ended responses about donor perceptions of pandemic-related risks: (i) concerns about kidney

Table 1. Study respondent characteristics

Characteristic	Overall cohort (<i>N</i> = 148)	Previous donor (<i>n</i> = 101)	In work-up to donate (<i>n</i> = 47)	<i>P</i> value
Age group, yr, <i>n</i> (%)				
18–30	16 (10.9)	10 (9.9)	6 (13.0)	0.04
31–50	92 (62.6)	58 (57.4)	34 (73.9)	
51–70	39 (26.5)	33 (32.7)	6 (13.0)	
≥71	0 (0)	0 (0)	0 (0)	
Missing	1 (0.006)	0 (0)	1 (2.1)	
Race/ethnicity, <i>n</i> (%)				
Non-Hispanic white	139 (93.9)	94 (93.1)	45 (95.7)	0.70
Non-Hispanic black	1 (0.7)	1 (1.0)	0 (0.0)	
Non-Hispanic Asian	2 (1.4)	1 (1.0)	1 (2.1)	
Hispanic	3 (2.0)	2 (2.0)	1 (2.1)	
Other race/ethnicity	3 (2.0)	3 (3.0)	0 (0.0)	
Male, <i>n</i> (%)				
Missing	2 (0.01)	1 (1.0)	1 (2.1)	0.49
Educational attainment, <i>n</i> (%)				
High school or GED	15 (10.2)	8 (7.9)	7 (15.2)	0.13
Some college or graduate	84 (57.1)	63 (62.4)	21 (45.7)	
Beyond college	48 (32.7)	30 (29.7)	18 (39.1)	
Liver donor, <i>n</i> (%)				
Missing	37 (25)	24 (23.8)	13 (27.7)	0.61
Timing of donation, <i>n</i> (%)				
Within the past year		53 (52.5)		
Within the past 5 years		29 (28.7)		
>5 years ago		19 (18.8)		
Recipient or intended recipient family member, <i>n</i> (%)				
Missing	64 (42.2)	45 (44.6)	19 (40.4)	0.64
Cumulative cases in state, median (IQR)				
Missing	33,210 (13,878–63,411)	33,193 (13,530–71,563)	33,912 (15,961–49,232)	0.66
Cases per million in state, median (IQR)				
Missing	3422 (1643–5217)	3521 (1569–6415)	3145 (1899–4028)	0.24

GED, General Education Development; IQR, interquartile range.

damage from COVID-19; (ii) worries about risks of COVID-19 transmission; (iii) increased need to be hypervigilant about health after donation; (iv) mental health and stress; (v) availability of medical care; and (vi) difficulty making decisions given the volume of information and misinformation about the pandemic (Table 2).

Donors and prospective donors ranked transplant candidate medical needs to be the most important pandemic-related concern (median importance 90 [IQR 78–100]). Compared with prospective donors, previous donors had higher importance ratings for emotional/mental burdens of donation during the pandemic ($P = 0.04$) and risks of the loss of health insurance ($P = 0.02$; Figure 1). Furthermore, donors in states with the highest cumulative COVID-19 cases rated recipient health as a more important concern than those in states with lower cumulative cases ($P = 0.03$), whereas kidney donors rated hospital resource strain as more important concern than liver donors ($P = 0.003$). Qualitative comments from prospective donors included concerns about returning to work if they were to donate. With respect to factors for decision-making about the acceptability of living donation during the pandemic, transplant program advice about safety was rated more important by

donors to nonfamily members versus family members ($P = 0.03$) and by those in states with the highest COVID-19 cumulative cases compared with other states ($P = 0.046$). Transplant candidate risks of dying were rated a more important decision-making factor by liver donors than by kidney donors ($P = 0.02$; Table 3).

In this survey study of living organ donors and prospective living organ donors from across the United States, respondents suggested that the decision to donate during the pandemic should depend strongly on factors such as transplant candidate medical need and availability of testing for COVID-19. Donors rated several burdens as being important during the pandemic, including medical risks, mental and emotional strain, and economic impacts including the possibility of losing employer-based health insurance. Physicians were the preferred information source about COVID-19. However, donors also gleaned pandemic-related information from a variety of other sources. Given rampant misinformation about the pandemic and a relationship between viewership of news sources and variation in perceived severity of the pandemic,⁵ transplant programs should augment decisional support by guiding donors to trusted information sources about the pandemic.

Table 2. Illustrative quotes from living organ donors and prospective living organ donors contrasting different perspectives and concerns during the COVID-19 pandemic

Reasons that living donation should/should not continue during the pandemic	Perspectives that donations should continue:	Perspectives that donation should be postponed:
New/heightened risks of living donation during the pandemic	<p>Perspectives that donations should continue:</p> <p><i>"Just because there is a pandemic doesn't stop people from needing organs. But I do feel donors and recipients need to be watched, taken care of, and isolated much more right now."</i></p> <p><i>"People still need donations to live. I believe hospitals are doing everything in their power to stay sterile and clean. I am not worried about continuing my donation during this time."</i></p> <p><i>"If the physicians feel the transplant cannot wait and that the donor and recipient are as safe as possible and that the benefits outweighed the risks, I'd trust my transplant team."</i></p> <p><i>"Our recipients already lead difficult lives, and trying to navigate a pandemic while also managing failing health simply doesn't seem fair or sustainable. As long as care teams feel equipped to perform the surgery and the related aftercare, donors and recipients should be able to choose to proceed."</i></p> <p>Previous donors:</p> <p><i>"Just a little more nervous than I've been before. This was obviously an unknown and I like making decisions with all the facts. And I don't like that every one initially completely dismissed any chance this could impact our community more. It makes me nervous that the data is not inclined our way."</i></p> <p><i>"Since healthcare insurance is so often linked w/job/employer and there is so much financial strain w even historically successful companies laying folks off or closing, I can understand where a potential donor may have concerns. As a recent donor"... "I would certainly choose Cobra on day 1, rather than rolling the dice w the 60 day window to get it, if I lost my coverage."</i></p> <p>Reported that transplant program postponed donor surgeries:</p> <p><i>"Being in a hospital is risky now - having surgery is risky - and the recipient's immune system will be compromised after surgery - that adds a whole other layer of concern during the pandemic."</i></p> <p><i>"I worry for those who are continuing to visit the hospitals for donation."</i></p> <p><i>"I want to help but it was a relief when the doctors put everything on hold. I am worried about my health and ability to recover financially."</i></p> <p>Kidney donor:</p> <p><i>"Experience has shown that some patients who get COVID can go into renal failure. Having given away 50 per cent of my nephrons I add that to my list. I knew going in that in the event I get cancer of some kind, I might not be able to tolerate a full chemo regimen without damaging my kidney. We share our spare so to speak. I think of it more like we drive on our spare."</i></p> <p>Liver donor:</p> <p><i>"More cautious about germs. Washing hands more."</i></p>	<p>Perspectives that donation should be postponed:</p> <p><i>"Given the potential risk to the recipient who will be immunocompromised for the donation and afterwards, and to minimize use/wastage of sparse healthcare resources, it's prudent to postpone all elective living donor surgeries till after the pandemic is over."</i></p> <p><i>"I think that it puts both parties at such an increased risk that it doesn't seem appropriate. However, the person I am donating to is not yet on dialysis and her health is holding. I may feel differently if her health was more critical."</i></p> <p><i>"If it is something that can wait a few months then it should be postponed, as having family around for support is also important too."</i></p> <p><i>"I want to wait until we understand the virus a bit more."</i></p> <p>Prospective donors:</p> <p><i>"On one hand, my recipient needs my kidney. On the other hand, if we both come down with COVID that would only add to further complications."</i></p> <p>Reported that transplant program did not postpone donor surgeries:</p> <p><i>"I will not donate until I can have my caregiver with me in the hospital to act as my advocate."</i></p> <p><i>"Life goes on and if important surgeries are not going on, then life may not go on."</i></p> <p>Considering kidney donation:</p> <p><i>"I have had to change every aspect of my life. My employer thinks of me as high risk as do I. Protecting my kidneys has become a top priority."</i></p> <p><i>"Now I'm nervous to donate. I know the virus can affect what would be my one kidney."</i></p> <p><i>"Conflicting reports about damage to the remaining kidney scares me."</i></p> <p>Considering liver donation:</p> <p><i>"I wonder what additional precautions are being taken."</i></p>
Concern for those in need of transplants vs. concern for self	<p>Family recipient:</p> <p><i>"I was told by our surgeons, after the fact, that my father would not have lived through the rest of the week if we hadn't had our surgeries at that very time. I would have been devastated if I had been deemed a perfect match and couldn't proceed with the lifesaving surgeries because of the pandemic and my father, would be dead."</i></p> <p>High-COVID prevalence in state of residence:</p> <p><i>"My concern for transplant during the pandemic is more about the recipient and their low immune system post-surgery as well as a taxed hospital not having adequate resources to staff COVID and a transplant floor at the same time."</i></p> <p><i>"More than ever, the recipients need access to healthy organs to help them combat any further illness."</i></p> <p><i>"Pre-emptive donations should be put on hold...they are not yet in kidney failure."</i></p>	<p>Nonfamily recipient:</p> <p><i>"I just ask, 'what if that was my mom, dad, sister, or brother,' and the answer is easy: Yes, to save a life!"</i></p> <p><i>"As a non-directed donor, I don't think it's worth the health risks (for myself) at the moment."</i></p> <p>Lower COVID prevalence in state of residence:</p> <p><i>"Recipients do not stop needing a transplant because there is a global pandemic."</i></p> <p><i>"If the recipient can wait, wait."</i></p>

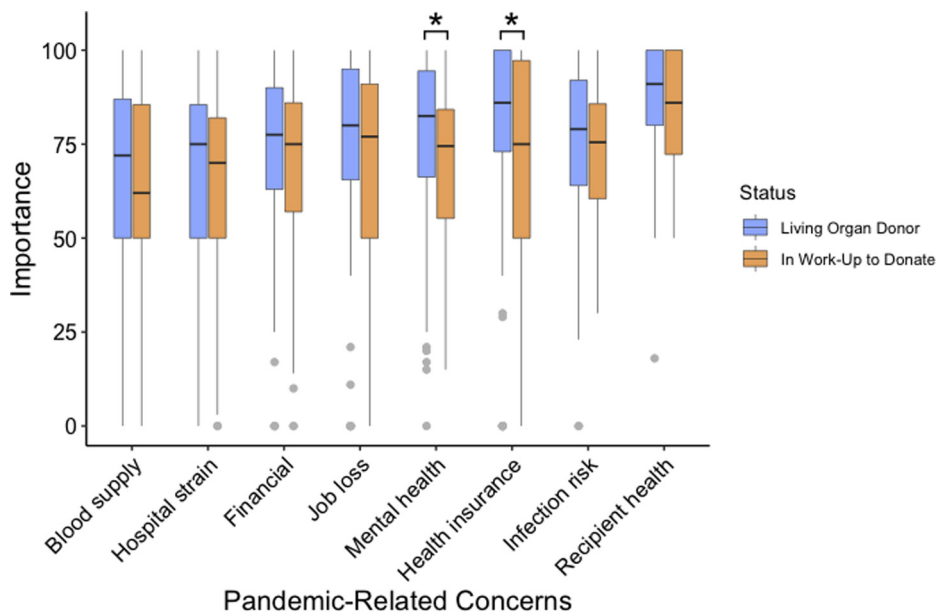


Figure 1. Relative importance of previous and prospective living organ donor concerns during the COVID-19 pandemic. Box-and-whisker plot depicts respondent ratings on the importance of specific concerns during the pandemic. Scale from 0 (not important) to 100 (very important). Blue boxes display ratings from living organ donors, whereas orange boxes display ratings from those in the evaluation process to become living organ donors. Concerns that were rated significantly higher by living organ donors than by those in the donation evaluation process are indicated by asterisks.

Donors' concerns for those in need of transplants were a recurring theme throughout the survey responses. Respondents also rated transplant candidate needs to be the most important consideration when determining whether donation risks are acceptable during the pandemic. While respondents emphasized the need for transplant programs to balance recipient health acuity with donor infection risk and hospital strain, the overall findings suggest that many donors are willing to accept the additional burdens of donation during the pandemic if delaying the donation would endanger the transplant candidate's life.

Donors reported that employment instability and the potential loss of health insurance are major causes for

concern during the pandemic. These findings raise the concern that pandemic-related unemployment and insurance losses are likely to exacerbate the known financial burdens of living organ donation in the United States.⁶ Notably, compared to prospective donors, previous donors assigned greater importance to concerns about health insurance loss and emotional/mental burdens. We can speculate that this difference may be because prospective donors have not yet experienced emotional or financial burdens from living donation. Implementing programs that promote financial neutrality of living organ donation and mental health support for living donors should be heightened priorities during the pandemic.⁷

Table 3. Donor and prospective donor priorities for decision-making about the acceptability of living donation during the COVID-19 pandemic

Conditions	Living donor (n = 101)	In work-up (n = 47)	Kidney donor (n = 111)	Liver donor (n = 37)	Nonfamily recipient (n = 84)	Family recipient (n = 64)	Lower cumulative cases (n = 109)	Highest cumulative cases (n = 39)
Low number of regional cases	71 (50–90)	69 (50–83)	69 (50–89)	75 (60–86)	71 (50–91)	71 (50–84)	71 (50–87)	80 (50–92)
Availability of COVID-19 tests	82 (69–95)	85 (68–95)	83 (68–95)	85 (75–94)	85 (73–95)	82 (60–92)	84 (69–93)	86 (68–96)
Antibody test available	78 (50–92)	73 (50–86)	78 (50–92)	76 (50–90)	77 (50–92)	78 (50–89)	75 (50–89)	82 (50–94)
Vaccine or effective therapy	79 (50–95)	74 (50–88)	75 (50–94)	77 (50–93)	76 (50–93)	76 (50–94)	74 (50–90)	85 (50–95)
Transplant program safety assessment	91 (76–100)	90 (79–98)	91 (78–99)	89 (75–100)	91 (79–100) ^a	89 (73–96) ^a	89 (75–98) ^a	94 (83–100) ^a
Transplant candidate might die	100 (91–100)	98 (90–100)	99 (90–100) ^a	100 (99–100) ^a	100 (90–100)	100 (92–100)	99 (91–100)	100 (95–100)
COVID-19 is eradicated	11 (0–25)	6 (0–25)	9 (0–28)	9 (0–20)	9 (0–24)	10 (0–26)	9 (0–25)	11 (0–28)

COVID-19, coronavirus disease 2019.

Survey rating scale: 0, not important; 100, very important. Ratings displayed as median (interquartile range).

^aP < 0.05. Ratings compared with Wilcoxon rank-sum tests.

This study's strengths include its geographically diverse respondent population and its inclusion of perspectives from both liver and kidney donors and those in the workup process for donation. This study also has limitations. First, our survey had a 28% response rate and the majority of study respondents were female and non-Hispanic white. Respondent demographic characteristics might, in part, reflect the recent demographics of living kidney and liver donors, who in 2019 were 64% female and 71% non-Hispanic white.⁸ However, future research should explore the needs of potential donors who were not reached by the survey, including racial/ethnic minority donors and older donors. Further, although respondents in our study prioritized financial instability as a major concern during the pandemic, research that is focused on the needs of donors with limited financial resources will be crucial to the goal of making organ donation a financially neutral decision in a post-COVID-19 economic environment. Our sample size also limited comparisons between subgroups. Finally, although Facebook is used by a majority (~70%) of U.S. adults and is popular across racial/ethnic groups,⁹ our findings may not be generalizable to donors with limited internet access. Such perspectives will be important to ascertain given an increasing reliance on telehealth by transplant programs.³

As transplant programs continue to adapt to their local pandemic conditions, the findings of this study can inform practices to maximally support donors in shared decision-making and postdonation care. In particular, this study underscores the importance of addressing excess financial and mental health burdens related to COVID-19 in living organ donor evaluation and care processes.

DISCLOSURE

All the authors declared no competing interests.

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AUTHOR CONTRIBUTIONS

ACK, JF, KLL, PPR, MM, RB, and MNH participated in research design. HZ, ACK, JF, KLL, PPR, MM, RB, and MNH

participated in writing the article. HZ, ACK, JF, PPR, MM, RB, and MNH participated in the performance of research. HZ, ACK, and MNH participated in data analysis. HZ, ACK, JF, KLL, PPR, MM, RB, and MNH contributed intellectual content and reviewed and approved the final manuscript.

SUPPLEMENTARY MATERIAL

[Supplementary File \(PDF\)](#)

[Supplementary Methods.](#)

[Supplementary References.](#)

[Sample Full Survey.](#)

REFERENCES

1. Boyarsky BJ, Po-Yu Chiang T, Werbel WA, et al. Early impact of COVID-19 on transplant center practices and policies in the United States. *Am J Transplant.* 2020;20:1809–1818.
2. United Network for Organ Sharing website. COVID-19 and solid organ transplant. Available at: <https://unos.org/covid/>. Accessed September 14, 2020.
3. Lentine KL, Vest LS, Schnitzler MA, et al. Survey of U.S. living kidney donation and transplant practices in the COVID-19 era. *Kidney Int Rep.* 2020;5:1894–1905.
4. American Society of Transplant Surgeons website. ASTS guidance on transplant capacity and testing in the COVID-19 era. Available at: <https://asts.informz.net/informzdataservice/onlineversion/ind/bWFpbGluZ2luc3RhbmNlaWQ9OTI5ODgyNiZzdWJzY3JpYmVyaWQ9MTA2NzU4NDI4OQ==>. Accessed April 28, 2020.
5. Jamieson KH, Albarracin D. The relation between media consumption and misinformation at the outset of the SARS-CoV-2 pandemic in the US. Available at: <https://misinforeview.hks.harvard.edu/article/the-relation-between-media-consumption-and-misinformation-at-the-outset-of-the-sars-cov-2-pandemic-in-the-us/>. Accessed March 7, 2021.
6. Dew MA, Jacobs CL. Psychosocial and socioeconomic issues facing the living kidney donor. *Adv Chronic Kidney Dis.* 2012;19:237–243.
7. Mittelman M, Bertha R, Sutha K. Challenges, innovations, and next steps in achieving financial neutrality for living donors. *Curr Transplant Rep.* 2020;7:215–222.
8. U.S. Department of Health and Human Services website. Organ procurement and transplantation network data. Available at: <https://optn.transplant.hrsa.gov/data/>. Accessed November 2, 2020.
9. Perrin A, Anderson M. Share of U.S. adults using social media, including Facebook, is mostly unchanged since 2018. Available at: <https://www.pewresearch.org/fact-tank/2019/04/10/share-of-u-s-adults-using-social-media-including-facebook-is-mostly-unchanged-since-2018/>. Accessed November 2, 2020.