

Key priorities for transplant and living donor advocacy during COVID-19

September 4 2020



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In a newly published paper, the authors first paint the vision of what optimal patient advocacy can do to overcome the challenges described by kidney transplant patients and donors, and then describe how to make

that vision a reality, especially during the COVID-19 pandemic. Dr. Amy Waterman, Deputy Director at the Terasaki Institute for Biomedical Innovation and leader of the Transplant Research and Education Center (TREC), assembled a panel of patients to learn their priorities for their care during this unprecedented time.

The authors describe the vision of optimal patient advocacy as patients feeling informed and empowered to make appropriate decisions about their care. The three key areas the patient panel identified for making that vision a reality are: "including the patient voice in all healthcare decisions and [drug development](#), ensuring equitable access to the best evidence-based treatments and educate patients fully in their care decision process, and honoring patient priorities in all care innovations and policies." The way those key areas look in practice are described throughout the paper.

The authors explain that diverse patient voices should be included, especially those from populations at higher risk of contracting and dying from COVID-19. These patient voices should drive outcomes of interest for transplant centers and educators. Patients were once encouraged to bring [family members](#) along with them to care, but due to the COVID-19 pandemic they are no longer able to do so. Patients and their families should strive to find new ways to engage in care and provide support, while also recognizing there may be increased burden on caregivers for immunocompromised kidney recipients.

Centers should be providing equitable access to up-to-date information for their patients about how their care is impacted by answering questions like, what precautions is the center taking to prevent the spread of COVID-19? It is vital that this information be health literate, written at a 6th grade reading level, and in multiple languages, so that all patients can be informed and make empowered choices about their care. It also means that educational information should be disseminated through

multiple channels like text messages, [social media](#), and emails so that patients have easy access to the information they need to make empowered decisions.

Lastly, optimal patient advocacy at the policy level includes changes like the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act which makes life-sustaining immunosuppressive drugs covered by Medicare beyond the former 36-month post-transplant coverage period.

Dr. Waterman concludes the paper by writing "Patient empowerment is essential through the COVID-19 pandemic given changes in the healthcare system, and transplant recipients' increased risk of contracting COVID-19 and suffering negative outcomes. Patient advocacy is not simply a moral imperative. If we are acting as true patient advocates and empowering patients in their own healthcare, this commitment will result in more patients being alive and thriving—the entire purpose of healthcare itself."

In addition to the information provided in the body of the article, the authors include a table in the publication with specific action steps to overcome barriers to optimal [transplant](#) patient advocacy.

More information: Amy D. Waterman et al, Amplifying the Patient Voice: Key Priorities and Opportunities for Improved Transplant and Living Donor Advocacy and Outcomes During COVID-19 and Beyond, *Current Transplantation Reports* (2020). [DOI: 10.1007/s40472-020-00295-x](#)

Provided by Terasaki Institute for Biomedical Innovation

Citation: Key priorities for transplant and living donor advocacy during COVID-19 (2020, September 4) retrieved 6 July 2024 from <https://medicalxpress.com/news/2020-09-key-priorities-transplant-donor-advocacy.html>

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