COVID-19 and Palliative Care
Observations, Extrapolations, and Cautions

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Life is no brief candle to me. It is a sort of splendid torch, which I have got a hold of for the moment, and I want to make it burn as brightly as possible before handing it on to future generations. —George Bernard Shaw

As our nation reaches the 2-year mark in the battle against coronavirus disease 2019 (COVID-19) and the delta and omicron variants, the death toll now stands at over 870,000 dead Americans (1). Some experts expect the toll to climb to over 1 million dead near or shortly after St. Patrick’s Day (2). The future seems uncertain, and there is little consensus on whether the year ahead will bring a respite from the virus and its grip on daily life and the economy or usher in a more sinister variant.

Patients with kidney disease and their doctors, unfortunately, have long understood mortality and death. No matter how stable a patient is or how efficiently a current therapy works, death casts a familiar shadow across private moments of contemplation and prayer. Yet, rarely do we as patients describe our circumstances as a burden. We are too busy managing life’s responsibilities and pursuing aspirations, fighting to maintain our own lives, or working to improve future kidney care to engage in esoteric exercises or assign simple descriptors to the highly complex issues we navigate.

COVID-19 is a daily reminder of life’s fragility. Each day, the virus continues its horrific and unprecedented burn through immunocompromised and immunosuppressed patients with kidney disease. Equally disturbing is the effect that severe COVID-19 cases have had on Americans and families unfamiliar with life-threatening events, like AKI and life-sustaining KRT or dialysis. Their introduction to the world we know, often through an intensive care unit, is bewildering and shocking. COVID-19 has expanded the ranks of the kidney community in a way no one wished. All of this has caused tremendous stress among frontline kidney professionals whose noble and first instincts and years of training are honed toward keeping their patients alive. As patients, we are indebted to these unsung heroes because we know their expertise has extended our lease on life and capacity to pay it forward.

Amid sudden illness and death, great hope and inspiration are found among the researchers and medical professionals examining the national response to COVID-19 over the past 24 months. Their efforts have uncovered unique insights that have accelerated treatment innovations and led to practice changes that have saved tens of thousands of patients and slowed the national death count. Other research efforts are targeted toward addressing issues that existed well before COVID-19, including the lack of treatment care choice among high-risk patients on dialysis, barriers to quality care and transplantation among underserved communities, and the utilization (or supposed underutilization) of palliative care. The paper titled “Utilization of Palliative Care for Patients with COVID-19 and Acute Kidney Injury during a COVID-19 Surge,” published in this issue of CJASN, addresses this issue on the basis of research findings within the New York Langone Health System (3).

Scherer et al. (3) are honest in stating that their aspirational goal is to facilitate earlier use of palliative care and to encourage consideration of an AKI diagnosis as a trigger for system-based approaches that flag patients at risk for high mortality and suffering and for whom palliative care may have some appeal. They provide comparative data and observations related to the start of palliative care among patients with COVID-19 with and without AKI and among patients with AKI undergoing KRT, including data related to discharge to home, hospice, and death. Among their objectives, the authors seek greater consideration of potential palliative care effects on what they contend are unnecessary medical interventions and high medical costs among patients whose outcomes, more than likely, will be death.

This study was approved by the New York University Grossman Institutional Review Board as an expedited review with a waiver of informed consent. Its weaknesses include reliance on data sources subject to misclassification, limited focus on one health system, and a patient population that was limited to mostly White, non-Hispanic patients in New York City. As the authors state, the implications of their findings are unknown and “should be generalized cautiously to other settings,” but they do express hope that their work may be potentially applicable beyond the.
COVID-19 pandemic, within other medical systems, and across broader chronically ill populations (3).

As members of the national patient and policy leadership team for the American Association of Kidney Patients, we offer strong caution against the generalization or extrapolation of this research, which lacks quantitative or qualitative patient insight data and patient and family perceptions of palliative care. The study does not meet the minimum standards of justification to support any systemwide changes that could interfere with the perceived viability of patients with kidney disease, including patients with AKI, and expected care norms during a medical crisis.

COVID-19 revealed to patients that some medical systems needed an aggressive federal reminder to protect our rights under the Americans for Disabilities Act and other proposed inhumane, discriminatory practices (4–6). Patients trust kidney professionals with our lives, and any other parties seeking to inject themselves into that relationship or influence our intensely private discussions would be wise to earn our trust first.

Disclosures

P.T. Conway is chair, policy and global affairs and immediate past president of the American Association of Kidney Patients (AAKP). P.T. Conway also reports roles with the following entities: chair, Patient Engagement Advisory Committee, US Food and Drug Administration; cochair, Global Innovations in Patient-Centered Kidney Care Summit, AAKP/George Washington University School of Medicine and Health Sciences; board member, Kidney Health Initiative; external expert panel, Kidney Precision Medicine Project, National Institutes of Health/National Institute of Diabetes and Digestive and Kidney Diseases (NIH/NIDDK); Contract Management Board, NIH/NIDDK, United States Renal Data System; member, nephrology specialty board, American Board of Internal Medicine; member, patient advisory board, Center for Dialysis Innovation, University of Washington; reviewer, US Department of Defense Congressionally Medical Research Program; moderator/participant, KidneyX 2019–2021 summits; Novartis Patient Advisory Council for Patient Reported Outcome Measures; and patient voice editor, CJASN editorial team. E.V. Hickey III, USMC, is Vice President and chair, Veterans Health Initiative of AAKP. E.V. Hickey III also reports roles with the following entities: patient advisory board, the Intensity of Statin Therapy in Veterans with CKD study, Veterans Administration Pittsburgh Healthcare System; reviewer, US Department of Defense Congressionally Medical Research Program; member, project advisory board, The Kidney Project; and kidney stakeholder, US Food and Drug Administration Medical Device User Fee Amendment V Reauthorization Planning Team.

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The authors dedicate this editorial to all Americans and their families who have suffered the effects of COVID-19 and to the innocent people who have lost their lives to the virus. Further, we honor the selfless sacrifices of frontline kidney professionals and medical specialists who risk their own lives and safety in the daily struggles to save lives, maintain respect for the dignity of human life, and offer their immeasurable comfort to patients and their families at the end of life.

The content of this article reflects the personal experience and views of the author(s) and should not be considered medical advice or recommendation. The content does not reflect the views or opinions of the American Society of Nephrology (ASN) or CJASN. Responsibility for the information and views expressed herein lies entirely with the author(s).

Author Contributions

P.T. Conway and E.V. Hickey III wrote the original draft and reviewed and edited the manuscript.

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