

Social Determinants of Health in People with Kidney Disease

An Introduction

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The papers that follow derive from talks delivered at the 2020 Alison Norris Symposium at the New York Academy of Medicine (NYAM). The program title was Social Determinants of Kidney Health, the fifth in a biennial series established to memorialize the life and work of Dr. Norris. Dr. Norris was a nephrologist with a practice in Bethesda, Maryland. She maintained a lifelong interest in issues related to patient advocacy. This interest had been articulated most clearly in 2008 in a preface, coauthored with Laurie Norris and Clarence Pearson, to an edited volume of *Patient Advocacy for Health Care Quality: Strategies for Achieving Patient-Centered Care* (1). Norris and her coauthors identified a “public health and medical continuum,” in essence, a spectrum extending from a broad view of disease prevention and provision of resources to the specific prescription and delivery of care on the basis of the values and expectations of an individual patient. Whether the frame of reference was societal or personal, the physician was expected to assume the role of a patient advocate. After Dr. Norris died an untimely death in 2009, these symposia at NYAM were established in her honor. The audience for each symposium was composed of nephrologists and trainees, nephrology nurses and social workers, and patients with kidney disease.

Consistent with the breadth of the mission, themes of the symposia have varied from the intensely personal to the societal. The inaugural event in 2011 was dedicated to examining psychosocial issues attendant to the dialysis experience: embarking on dialysis, dealing with the emotional stresses of dialysis, and withdrawing from dialysis. In the second symposium in 2013, the subject was kidney transplantation, and the focus was on allograft shortage and practical barriers to transplantation within the ESKD population. In 2015, the program organizers acknowledged the growing importance of palliative care principles for patients with CKD and patients with ESKD. This movement appeared to capture the spirit of the Norris charge in sensitizing practitioners to the patient voice in configuring care plans, designing the treatment environment, and weighing patient-identified priorities in allocation of research resources. The fourth symposium in 2017 turned to societal issues, examining the effect of health

care policy on the patient experience. Policy preferences could be manifest as direct economic incentives (what aspects of care were reimbursable) or, more subtly, as quality of care metrics. The symposium reviewed opportunities for advocacy groups to influence these policies.

The most recent symposium, Social Determinants of Kidney Health, was anchored in the public health arena but with speakers who had the depth of focus to show how systemic barriers have personal consequences.

It has slowly become increasingly apparent that psychosocial issues play a role in the survival and, more recently understood, the well-being of patients with ESKD and CKD, as a result of research performed over the last 40 years. In 1981, uncontrolled studies demonstrated that depression was associated with mortality in patients treated with home hemodialysis in the United Kingdom (2). The scope of research on psychosocial issues grew to include various factors linked to socioeconomic status (such as income, occupation, and education).

Race, however, became a key factor in evaluating outcomes from the very earliest investigations into ESKD treatment. Port (3) showed, startlingly, that Black patients with ESKD had improved survival on hemodialysis compared with White patients, an extraordinary finding that is not present in any other major chronic illness. This finding has also held up for more than 3 decades, although it has not been completely explained. Observational data from studies in the ESKD population and the Medicare population suggest that the role of poverty is also independently linked to mortality in these instances (2).

Port's team, in 1987, reported differential survival by race in US patients with transplants as well (4), a finding corroborated recently in several more contemporary populations by Reeves-Daniel *et al.* (5) and others.

These old findings illustrate several key points. Race, although a social construct, matters. An important biologic factor, a gene variant found almost exclusively in people of recent African descent, conveys great susceptibility to the development of several types of kidney disease and to more rapid progression of established disease (2,6). These gene variants have been linked to poorer survival of kidney transplants harvested from

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Black donors, regardless of the race of the recipients. These and other biologic factors play important roles, in tandem with societal and psychosocial factors, in determining outcomes, but it is often difficult to quantify effects and establish causality in observational studies. Social factors can determine treatment effects. Cooper-Patrick and others (7) showed that race concordance and trust play important roles in the doctor-patient relationship and in affecting outcomes (8). In another example, experts in hypertension in the 1980s suggested, perhaps for plausible physiologic reasons such as group differences in serum renin levels but in absence of solid outcome studies, that calcium channel blockers should be used for Black patients and angiotensin-converting enzyme inhibitors should be used for White patients (2). This well-intentioned and well-publicized but poorly supported approach to treatment assuredly contributed to the death of untold Black patients until the publication of the results from the African American Study of Kidney Disease and Hypertension trial confirmed that angiotensin-converting enzyme inhibition would be salutary for all groups. Depression and anxiety, linked to death in patients on dialysis, are related in different ways to poverty, lack of access to health care, limits in educational opportunities, and achievements (2). Over the last several years, residential segregation and perception of racial discrimination have been linked to poor outcomes in those with CKD and ESKD (2,9). Subsequent to the work of Barker and colleagues, and Brenner and colleagues, maternal/fetal health, race, and socioeconomic status have been implicated in the development of kidney disease as well (2). More recent data suggest that race is a proxy for discrimination and racism in maternal-fetal outcomes (2). These factors all interact in a vicious circle that contributes to patients' morbidity and mortality.

These social determinants of health are powerful predictors of mortality and morbidity—shown in numerous studies in the general population. Social determinants of health are critical factors in determining patient adherence and ability to receive medical care—as well as morbidity and mortality—demonstrated in both ESKD and CKD populations (2). Over the past few months, the coronavirus disease 2019 pandemic has revealed these issues to be intrinsically linked to our nation's history and current institutions, policies, work environments, and medical practice (9–11). Structural and systemic racism (11,12)—a complex web affecting all aspects of our national life—has been associated with poorer physical and mental health of minority populations (9–12) and may be viewed as a theme of the most recent Norris symposium.

The first half of the 2020 symposium took a national perspective. Dr. Keith Norris of the University of California, Los Angeles opened the program with an examination of CKD care for our poorest patients, for whom the purchase of preventive health services of all kinds must take a back seat to the demands of the day. This was followed by consideration of CKD care in the Black community by Dr. Neil Powe of University of California, San Francisco and in the Latinx community, including its contingent of immigrant workers, by Dr. Lilia Cervantes of the University of Colorado. Where the rubber meets the road in CKD care and prevention lies in the myriad personal decisions each person makes in deciding who to see for care and what to follow through. The quality of the examination room communication can be

pivotal, for better or worse, in its influence on such decisions, an issue that was considered by Dr. Ebony Boulware of Duke University. Finally, a 180-degree assessment was provided in a forum led by Dr. Daniel Cukor of the Rogosin Institute, in which patients with CKD and patients with ESKD issued a report from the front on their views as recipients of kidney care.

Given the events of these last few months, during which the world has tried to cope with a pandemic and in which New York City fought for its life, a report of this symposium from January 2020 appears now as a warm remembrance of a gentler time. Beyond that, the crosscurrent of racial injustice with respect to basic personal and economic survival may seem to render discussion of CKD treatment disparities as a communication from an ivory tower. That being said, our personal path forward as nephrologists can only begin from where we live within the kidney community.

Now, the novel coronavirus pandemic—affecting people of color preferentially for a variety of reasons (with psychosocial factors perhaps most prominently involved)—has exposed the important roles that race differences can play in acute health outcomes, as well as the role of structural racism, in direct and indirect ways. This symposium sought to bring together prominent experts in the field and focuses on the social determinants of health in patients with CKD and ESKD, which are as important to patients and outcomes as fluid and electrolyte balance, loss of nephron mass, anemia, and inflammation. Our patients cannot survive and thrive in environments characterized by poverty, racism, violence, and lack of access to proper food and shelter. To benefit the health of the nation, racism must be ended and poverty exterminated if the health of all, including patients with CKD and ESKD, is to improve.

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See related Perspectives, “The Pathogenesis of Race and Ethnic Disparities: Targets for Achieving Health Equity,” “Social Determinants of Kidney Health: Focus on Poverty,” “The Seen and the Unseen: Race and Social Inequities Affecting Kidney Care,” “Reducing the Burden of CKD among Latinx: A Community-Based Approach,” and “Personal Experiences of Patients in the Interaction of Culture and Kidney Disease,” on pages xxx–xxx, xxx–xxx, xxx–xxx, xxx–xxx, xxx–xxx and xxx–xxx, respectively.