

NOTES FROM THE FIELD

Widening Disparities Among Patients With Rheumatic Diseases in the COVID-19 Era: An Urgent Call to Action

Candace H. Feldman¹  and Rosalind Ramsey-Goldman² 

Recent data from multiple public health departments across the US emphasizing the disproportionate burden of coronavirus disease 2019 (COVID-19) infections in vulnerable populations serve as an urgent call to action (1,2). As rheumatologists, we are acutely aware of the higher morbidity and mortality rates, and for a number of the diseases we treat, the higher incidence and prevalence among racial/ethnic minorities and individuals of lower socioeconomic status (SES) (3–6). Comorbidities are frequent, timely access to subspecialty care is limited, receipt of high-quality care is less common, and care is more often fragmented, with frequent, avoidable acute care use (7,8). Among patients with systemic lupus erythematosus (SLE), where these disparities have been shown to be particularly pronounced, prolonged glucocorticoid use and delayed or lack of standard-of-care immunosuppressive use is common, and hydroxychloroquine (HCQ), the backbone of SLE therapy to prevent flares and organ damage, is underprescribed and adherence is suboptimal (9). In addition, despite an at least 2–3-fold higher prevalence of SLE and significantly poorer outcomes, African American individuals are much less likely to be enrolled in clinical trials compared to white individuals (10,11). Structural racism, historic injustices in research, implicit bias by health providers, and ongoing experiences of discrimination contributing to patient distrust all contribute to this under-enrollment (10,11). As a result, we often recommend treatments that have not been well-studied in the populations that may need them the most. Experiences of racial discrimination have also been associated with increased rheumatic disease activity and greater organ damage (12).

A significant proportion of individuals with systemic rheumatic diseases receive immunosuppressive therapy at some

point during their disease course, and these medications combined with patients' underlying autoimmune conditions increase their susceptibility to severe infection. Among patients with SLE, particularly those insured by Medicaid (the largest public health insurer of low-income Americans), serious infections requiring hospitalization are common and African Americans are more likely than white individuals to experience them (13). The COVID-19 pandemic has already begun to disproportionately affect African American, Hispanic, and American Indian individuals, and individuals of lower socioeconomic status, and we expect that among patients with rheumatic diseases, the disparities will be even more pronounced (1,2). Many of these individuals have more severe manifestations and less well controlled rheumatic diseases at baseline and may not be able to follow social distancing recommendations due to crowded or unstable living situations and financial constraints. In addition, more frequent glucocorticoid use among patients who lack sustained access to high-quality outpatient care not only heightens the risk for infection, but also causes cardiovascular disease and diabetes, known risk factors for poorer outcomes from COVID-19 (9,13,14). These factors raise significant concern for our most vulnerable patients in terms of short-term infection risk and both short-term and long-term control of their rheumatic disease.

HCQ is now being promoted as a potential treatment for COVID-19, which has resulted in medication shortages for our rheumatologic patients. Medicaid limits patients to 1-month supplies of their medications. This means that our most vulnerable patients are also those least likely to have a sufficient supply. Recently, MassHealth, Massachusetts' Medicaid organization which covers

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¹Candace H. Feldman, MD, ScD: Brigham and Women's Hospital and Harvard Medical School, Boston, Massachusetts; ²Rosalind Ramsey-Goldman, MD, DrPH: Northwestern University Feinberg School of Medicine, Chicago, Illinois.

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Address correspondence to Candace H. Feldman, MD, ScD, Brigham and Women's Hospital, Division of Rheumatology, Inflammation, and Immunity, 60 Fenwood Road, Office 6016P, Boston, MA 02115. Email: cfeldman@bwh.harvard.edu.

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nearly 2 million residents, waived this 1-month supply limit, and other states including Illinois, Indiana, and Ohio have attempted to preserve HCQ access for rheumatology patients. An insufficient supply of essential medications, combined with potentially more severe disease and delays to initial care at the outset, will likely result in significantly poorer outcomes and widening disparities in future months when these same patients are unable to obtain refills of this medication.

Over the past 3 years, we have engaged in an academic–community partnership in the greater Boston and Chicago areas. We have worked alongside community leaders to better understand the impact of neighborhood factors and social determinants on health, experiences of racial discrimination, and SLE-related health disparities by race within our cities (15). Now more than ever, we recognize the need to partner with our communities to better understand the acute needs of our rheumatology patients, to build trust, and to intervene to reduce the risk of widening disparities due to COVID-19. We propose the following call to action:

Collect and release sociodemographic data in both the clinical and research settings

There are multiple registries both locally and internationally collecting data on the burden of COVID-19 among patients with rheumatic diseases. In addition to collecting and releasing data on race and ethnicity, it is imperative to consider measures of SES (occupation, level of education, income level), as well as neighborhood deprivation, racial residential segregation, and social determinants of health. These include questions about employment, financial and housing stability, food insecurity, neighborhood safety, access to medications and health care, child and elder care, and experiences of racial discrimination. Only by understanding the impact of these factors on the burden and spread of disease, and on access to care, will we be able to develop comprehensive strategies to reduce disparities and improve the health of our entire population. As these factors also directly impact patient care and outcomes, they should be incorporated into routine clinical visits.

Engage in advanced care planning conversations with our patients

While traditionally thought to be in the domain of primary care providers and geriatricians, as rheumatologists we have well-established, long-term relationships with the patients we care for who have complex chronic diseases. Prior studies suggest that African American and Hispanic individuals, as well as individuals with less education and lower income, are less likely to have engaged in advanced care planning (16). Rheumatologists should join the charge and advocate to be part of these essential conversations with our patients, particularly with those who are older and chronically ill, both prior to and during serious acute illness (17).

Ensure racial/ethnic diversity in clinical trial enrollment and understand factors that may bias observational studies

Racial and ethnic minorities are underrepresented in medical research. Particular attention to these populations is essential as we investigate COVID-19 treatments and prophylaxis using rheumatology-related medications and other medications. It is also critical to recognize the role of both historic and current racial discrimination when we promote diverse clinical trial enrollment (11). In addition, when we conduct observational studies examining the effects of rheumatic disease medications on COVID-19 incidence and severity, we need to recognize differences in the burden of comorbidities, prior access to care, and in receipt of HCQ and immunosuppressive medications by race/ethnicity and SES that may bias associations.

Support rheumatology-related disparities research

The National Institute on Minority Health and Health Disparities, the National Institute on Aging, and the National Institute of Mental Health issued a Notice of Special Interest in response to the urgent need for research on the impact of COVID-19 among health disparity populations (18). We appeal to the National Institute of Arthritis and Musculoskeletal and Skin Diseases to similarly recognize the potential for widening disparities caused by COVID-19 in our vulnerable rheumatology patient population and support additional research to intervene quickly to address this.

Recognize and address the inequities in access to care during this pandemic

Telemedicine and virtual visits may not be accessible to patients who do not have reliable phones, computers, or internet access. Unstable or crowded living situations, and lack of childcare may also make these encounters challenging. Patients who may feel less comfortable in the clinical setting due to prior experiences of racial discrimination may not want to visit with a health care provider they do not know and trust, as physicians cover each other's patients. Fears of medical charges and lapses in insurance due to unemployment will also likely delay care for those in greatest need. Frank conversations with patients about these issues, as well as with community leaders, could facilitate adjustments in the way health care is provided right now to ensure that these patients get the care they need.

Advocate for our patients

We need to partner with rheumatic disease–specific organizations as well as city, state, national, and international organizations and community-based networks to ensure that all of our patients, including the most vulnerable, are able to access

the medication and health care that they need during this time of crisis and after. We need to advocate for all states to allow for 90-day supplies of essential medications for our patients whether they are covered by public or private insurance. We need to recognize the importance of access to reproductive care for all of our patients, given the significant impact of pregnancy on systemic rheumatic diseases. As such, we should consider joining with other medical associations, including the American College of Obstetricians and Gynecologists and the American Medical Association, to advocate in support of continued access to abortion as an essential health service and not as a political issue (19). We must fight to ensure that all of our patients, regardless of race/ethnicity, immigration status, income level, employment status, and insurance status, are able to access their medications and timely, high-quality, essential care. Partnerships with community-based organizations are critical to disseminate culturally sensitive education to reduce stigma toward certain racial/ethnic groups, notably persons of Asian descent in the setting of COVID-19. With our community partners, we must also advocate to develop the infrastructure necessary to address our patients' social and economic needs that are exacerbated by this pandemic.

Now more than ever, we need to consider our most vulnerable rheumatology patients and mobilize partnerships across health care providers, academic institutions, community members, and policy leaders to prevent the avoidable widening of racial, ethnic, and socioeconomic disparities in the setting of COVID-19. We need to recognize that as health care providers and researchers, our fight is not just clinical care-based; achieving equity in health now and going forward requires so much more.

AUTHOR CONTRIBUTIONS

Drs. Feldman and Ramsey-Goldman drafted the article, revised it critically for important intellectual content, and approved the final version to be published.

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