

Disparities in Pulmonary Arterial Hypertension Care: Challenges and Solutions

Health disparities have a detrimental effect on the clinical outcomes and quality of care received by minorities in the United States. Compared with the rest of the population, minorities with pulmonary hypertension (PH) are at risk for worse outcomes due to difficulty accessing healthcare, lack of or limited insurance, poor socioeconomic status, and distrust of the healthcare system, among other factors. By disproportionately impacting vulnerable patients, the delay to diagnosis and the barriers to introducing therapies has the potential to worsen health disparities in PH, especially when compounded by the challenges facing patients and families during the COVID-19 pandemic. At present, there is a major unmet need for health policy initiatives to protect minorities, likely due to the lack of studies demonstrating the extent of health disparities. This issue of *Advances in Pulmonary Hypertension* is part of an ongoing effort by the Pulmonary Hypertension Association (PHA) to advocate research avenues and changes in health policy in favor of minorities that could have a profound and lasting impact on improving the quality of healthcare experienced by minority populations afflicted with PH.

In “The Impact of Socioeconomic, Racial, and Ethnic Disparities on Pulmonary Hypertension Diagnosis and Treatment”, Talwar and colleagues provide a comprehensive review of available evidence that points at how genetics, sex, age, race and socioeconomic status influence the quality and outcomes directly associated with health care delivery. Most importantly, the authors advocate for the prioritization of research efforts seeking to understand the

individual contribution of these factors and the potential long-term benefit for improving clinical outcomes in vulnerable populations of PH patients across the United States.

In the article “What Rare Disease Patient Advocacy Groups Are Doing to Mitigate the Effects of Disparities”, Drell and her colleagues from National Organization for Rare Disorders (NORD) share case studies that exemplify the current social and health care challenges faced by patients suffering from rare diseases who belong to minority groups. The important role that non-profit advocacy organizations play in helping patients face discrimination and health care inequalities is discussed and recommendations are made to guide clinicians, health care practitioners and caregivers on how to support those patients who are most vulnerable to experience health inequity due to limited resources and access to medical care.

In the article “Hispanic Ethnicity and Social Determinants of health: Harnessing Data from The Pulmonary Hypertension Association registry” Bernardo and Colleagues discuss the interplay between biologic, socioeconomic and racial factors in PAH with special emphasis on the Hispanic population. The authors also point towards the noticeable underrepresentation of minorities such as Hispanics in most PAH registries and even in randomized clinical trials. The implications of underrepresentation in research are far reaching and may further contribute to disparate care of the minority patients.

Finally, in the round table discussion, Dr. Talwar moderates a lively discussion with healthcare providers and members of the PHA centered around their own experiences managing patients at risk for health disparities, their efforts to advocate for wider PH medication access, and their vision for what changes

must be implemented in our health care system to avoid placing PH patients at a disadvantage as a result of socioeconomic status, race/ethnicity and other risk factors associates with disparities. Solutions to address and ultimately eradicate disparities will need to eliminate healthcare bias, increase patient access, and increase diversity and inclusion in healthcare providers.

Addressing health disparities is a challenge that requires the pooling of federal, community, and professional resources to facilitate the development of research projects, interventions, educational materials, and health policy designed to change clinical outcome among vulnerable minority groups. We thank all the authors who provide their time and effort to help prepare this issue of *Advances* and hope that the information herein will serve to spark initiatives to address health inequities and improve health care access for all our PH patients.

Vinicio A. de Jesus Perez, MD FCCP FAHA ATSF

Associate Professor of Medicine, Division of Pulmonary, Allergy and Critical Care Medicine (PACCM)
Co-Director, Stanford Translational Investigator Program (TIP)
Director of Faculty and Fellow Diversity and Inclusion in PACCM
Chair, 3CPR Scientific & Clinical Education Lifelong Learning Committee (SCILL)
Chair, International Pulmonary Vascular Diseases Consortium (iPVD)
Stanford University Medical Center

Arunabh Talwar, MD

Division of Pulmonary, Critical Care, and Sleep Medicine,
Department of Medicine, Donald and Barbara Zucker School of Medicine at Hofstra/Northwell