

Promoting Diversity, Equity, and Inclusion for Psoriatic Diseases

Junko Takeshita¹ , Jeffrey Chau² , Kristina Callis Duffin³ , and Niti Goel⁴ 

ABSTRACT. There is increasing evidence of racial and ethnic disparities in the evaluation and treatment of people with psoriasis (PsO) and psoriatic arthritis, and inadequate racial/ethnic diversity in psoriatic disease (PsD) research. At the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) 2021 annual meeting, a program focusing on diversity, equity, and inclusion (DEI) was presented to highlight known health and healthcare disparities in PsD. There is limited understanding of the prevalence and severity of PsD and how it affects quality of life among racial/ethnic minorities with PsD. Educational gaps and lack of diversity in our dermatology workforce may be contributing to challenges in appropriately diagnosing and treating PsO in darker skin types. Racial/ethnic minorities are also inadequately represented in clinical research, including trial recruitment and participation, for PsD. A panel of patient research partners, researchers, and clinicians ended the session with a broad discussion on how GRAPPA can better ensure racial/ethnic DEI in their educational, research, and clinical missions.

Key Indexing Terms: GRAPPA, psoriasis, psoriatic arthritis

Introduction

Diversity, equity, and inclusion (DEI) are important in all aspects of scientific discovery; this applies not only to the populations being studied but also to the scientists conducting the research. Diversity refers to the all the ways in which people and groups differ from one another. Diverse groups are necessary to drive discovery and innovation, and this is particularly true in health disparities research.

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¹J. Takeshita, MD, PhD, MSCE, Department of Dermatology, Department of Biostatistics, and Epidemiology and Informatics, Perelman School of Medicine at the University of Pennsylvania, Philadelphia, Pennsylvania, USA; ²J. Chau, MCS, Patient Research Partner, Hong Kong Psoriatic Arthritis Association, Hong Kong, China; ³K. Callis Duffin, MD, MS, Department of Dermatology, University of Utah, Salt Lake City, Utah, USA; ⁴N. Goel, MD, Patient Research Partner, Chief Medical Officer, Abcurio Inc., and Adjunct Assistant Professor, Division of Rheumatology, Duke University School of Medicine, Durham, North Carolina, USA.

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Address correspondence to Dr. K. Callis Duffin, University of Utah, 4A330 Dermatology, SOM, 30 North 1900 East, Salt Lake City, UT 84132, USA. Email: Kristina.duffin@hsc.utah.edu.

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Health and healthcare equity refers to the fair and just opportunity to be as healthy as possible, and the guarantee of accessible, affordable, and culturally appropriate care among all individuals. Although sometimes conflated, the terms *equality* and *equity* are not the same. Equality refers to the state in which everyone has the same benefits. The difference between equality and equity is illustrated in Figure 1, which depicts equality as giving each person the same bicycles, regardless of their height or ability, and contrasts this with the picture of equity, where the bicycles provided are distributed according to individual need.¹

Inclusion refers to an environment in which groups or individuals with different backgrounds are culturally and socially accepted, welcomed, and equally treated. It brings traditionally excluded individuals or groups into processes, activities, decisions, or policy making in a way that shares power and ensures equal access to opportunities and resources. Inclusion builds a culture of belonging by actively inviting the contribution and participation of all people.²

Health Inequities Among People With Psoriatic Disease

A growing body of literature highlights the existence of racial/ethnic health and healthcare disparities related to psoriatic disease (PsD) in the US. However, even a basic understanding of the burden of PsD among non-White populations remains limited due to existing data collection and measurement challenges. In the most recent analysis of data from the 2011–2014 National Health and Nutrition Examination Survey, the prevalence of psoriasis (PsO) among adults in the US was highest among non-Hispanic White (3.5%) compared to non-Hispanic Black (2.5%), non-Hispanic Asian (2.5%), non-Hispanic other race (3.1%), and Hispanic (1.9%) individuals.³ Importantly, these prevalence estimates relied on receipt of the diagnosis of PsO from a healthcare provider, thereby underestimating

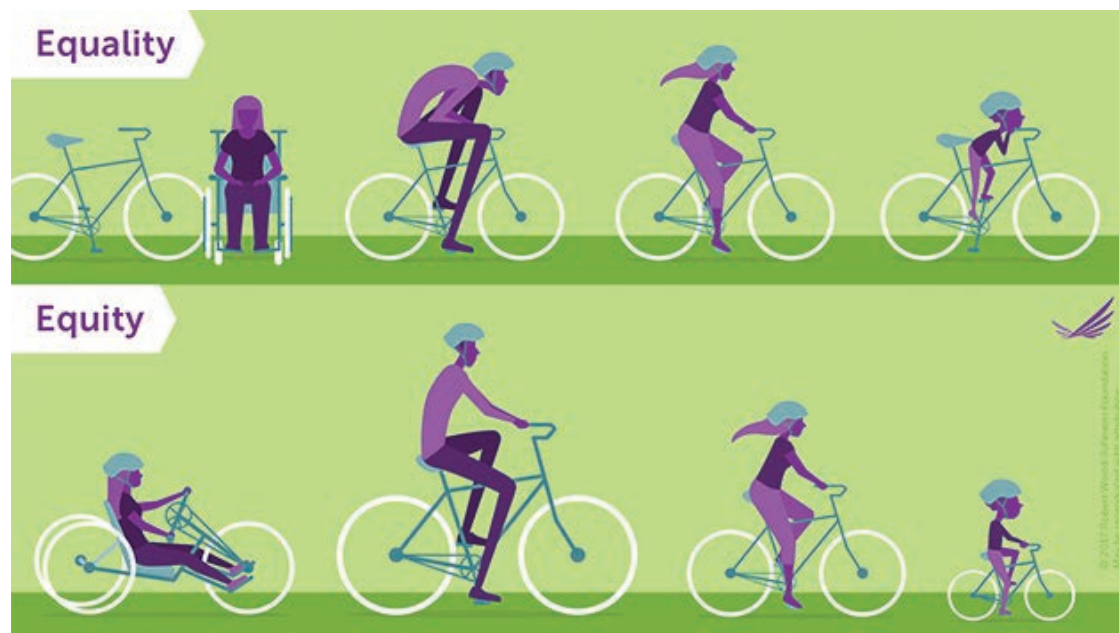


Figure 1. Illustrating the difference between equality and equity. Reproduced with permission from the Robert Wood Johnson Foundation, Princeton, New Jersey, USA.¹

the prevalence in populations that have less access to health-care and are more likely to have undiagnosed disease who are, notably, often disproportionately non-White.^{4,5} Few studies have measured the prevalence of psoriatic arthritis (PsA) in racial/ethnic minority populations. One clinic-based study of 153 individuals with PsO or PsA found that Black patients were less likely to have a diagnosis of PsA (30%) compared to White patients (64.5%).⁶ Additional studies are needed to better understand the burden of PsA among different racial/ethnic groups.

PsO severity and quality of life (QOL) burden are also suggested to differ by race/ethnicity. In a US population-based study that included 27 Black and 541 White adults with PsO, Black individuals reported greater body surface area (BSA) involvement compared to White individuals.⁷ Other studies of clinical trial populations and individuals presenting to an academic center for PsO have also found Asian and Hispanic patients to have more severe disease at baseline or clinical presentation, respectively, compared to White patients.^{8,9} Additionally, Black, Asian, and Hispanic patients with PsO were found to report greater QOL burden due to their skin disease as measured by the Dermatology Life Quality Index in 2 separate studies of a clinical trial population and a real-world population enrolled in the Psoriasis Longitudinal Assessment and Registry.^{9,10} Racial/ethnic differences in QOL burden due to PsO persisted after accounting for differences in objective measures of disease severity (eg, BSA involvement, physician global assessment) across the groups.

There are many potential causes for the racial/ethnic differences in PsD burden, including racial/ethnic disparities in healthcare utilization for and treatment of PsO.^{4,11} Another contributing factor is diagnostic uncertainty among clinicians evaluating PsO in people of color.¹² A survey study of practicing

dermatologists in the US found that dermatologists were less confident in the diagnosis of PsO when presented with standardized head shots and clinical photos of PsO in a Black individual compared to a White individual with otherwise identical characteristics.¹² Further, diagnostic uncertainty was associated with a lower likelihood of a dermatologist recommending appropriate treatment for severe PsO (ie, phototherapy, oral systemic, or biologic therapy). Educational activities aimed at improving the diagnosis of PsO in skin of color are an important component in addressing racial/ethnic disparities in PsO disease burden.

DEI Challenges in PsD Research

To ensure the equitable advancement of scientific knowledge for PsD, clinical research participants must adequately represent our increasingly diverse population. Although the US National Institutes of Health and the U.S. Food and Drug Administration have published guidance on the need for greater diversity among human participants in research studies, race and ethnicity information, in particular, continues to be underreported, and the racial/ethnic diversity of research participants remains poor.¹³

Specific to PsO, a comprehensive review of 26 randomized clinical trials for PsO published between 2010 and 2015 and performed exclusively in the US found that either race or ethnicity was reported in 76.9% of studies.¹⁴ In another review of 35 PsO clinical trials published between 2014 and 2019, it was found that race was not reported at all in 5 studies (14%) and only reported as “White vs non-White” in 23% of studies.¹⁵ Reporting of ethnicity was worse, with nearly 66% of studies not reporting ethnicity at all. Among the studies reporting race and ethnicity, White individuals were overrepresented and Black and Asian individuals were underrepresented relative to the 2019 US population in PsO clinical trials. Even if we accept the PsO

prevalence estimates that differ by race/ethnicity and account for these differences, Black participants are still underrepresented in PsO clinical trials.

To fully understand the burden of PsD, address health disparities, and advance scientific knowledge, we must promote diverse, equitable, and inclusive participation in PsD research. Many compounding barriers to this exist, including challenges with access to healthcare and research opportunities; limited availability of culturally or health-literacy sensitive, patient-facing research documents; and study procedures that ignore social barriers to research participation (eg, time off from work, transportation, internet access). Most investigator- and patient-reported outcome instruments have not been developed or validated among diverse populations, and trials are often designed in a manner that excludes diverse and inclusive participation based on strict inclusion/exclusion criteria and study procedures. For example, people with more comorbidities or those with less social support, who are also more often not White, are often excluded from participating in research. The development and implementation of initiatives to address these many barriers are necessary to meaningfully advance research that is applicable to our increasingly diverse population.

Panel Discussion on DEI

During the panel discussion, additional DEI topics were explored. Globally, in cultures where doctors are seen as authority figures, a relative absence of shared decision making can bias treatment selection and inclusion into clinical studies. Age, socioeconomic status, health literacy, disabilities, place of residence (eg, rural, suburban, urban), among many other factors and social determinants, were highlighted as affecting healthcare access and being important considerations in medical management and health promotion.

Panelists also discussed efforts to improve the diversity of the workforce and appropriate educational resources for dermatologists and trainees. The proportion of Black or Hispanic physicians in the US remains unacceptably low (< 6% each), and a diverse workforce is necessary to support the provision of culturally mindful and equitable healthcare.^{16,17} Efforts are underway to improve the diagnosis and treatment of skin diseases in people of color, such as the inclusion of more photographs of skin diseases in darker skin types in medical textbooks and other training materials.¹⁸ Institutions are prioritizing efforts to promote equitable admissions, recruitment, promotion, mentorship, and retention practices to improve the diversity of medical students, residents, and faculty. Organizations are also working to increase the diversity of research teams as well as developing best practices to promote the recruitment and enrollment of diverse populations.^{19,20}

Conclusions

GRAPPA is committed to equity, diversity, and inclusion. One of the primary educational missions of GRAPPA is to provide expertise and training on assessing joint and skin disease, and efforts will be made to address the lack of photographic examples of joint and skin inflammation in darker skin types in the

rheumatology and skin training modules. Most disease severity assessments use descriptive language that is centered around light skin (eg, use of “redness” to describe the visual appearance of psoriatic inflammation). Disease severity instruments need to be modified or newly developed to be inclusive of the full spectrum of skin tones.

Additional opportunities for GRAPPA to address DEI include promoting membership and leadership diversity, being more inclusive in selecting patient research partners, supporting a diverse group of researchers, recruiting diverse or historically underrepresented populations in studies, ensuring awarded pilot grants address DEI, and implementing implicit bias training. A DEI taskforce will be instrumental in addressing the many challenges highlighted in this session and achieving health equity.

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