

# Health Equity in Rheumatology: A Global Health Perspective

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The United Nations Sustainable Development Goals emphasize the importance of ensuring the health and wellbeing of all human beings as a necessary precondition for peace and prosperity in the world. The spread of egalitarian values in the modern era has generated discussions about health disparities, with renewed calls to lessen health inequities for vulnerable and marginalized populations. This article briefly discusses health disparities and inequities in medicine, focusing on rheumatology. It is well documented that rheumatic disorders present differently among patients of different sex, gender, race and ethnicity. Despite this, most educational materials and guidelines in rheumatology use images and treatment regimens best suited for Caucasian patients. These differences are amplified by the limited recruitment of diverse patients in clinical trials, resulting in disease stereotypes that are based primarily on Caucasian patients, and do not represent disease manifestations across patient populations. These disparities create significant health inequities when combined with socioeconomic differences, and are further enhanced by implicit and explicit biases faced by patients from minoritized and marginalized communities when seeking healthcare services. Ultimately, this results in worse health outcomes for minority patients, further driving healthcare disparities and inequities across patient populations. There is an urgent need to address these disparities through multiple strategies including the diversification of the healthcare workforce, the introduction of implicit bias training for clinicians, and the creation of educational materials which accurately portray disease manifestations among patients of all races, genders and ethnicities.

## Keywords

Gender bias, healthcare disparities, health equity, health workforce, implicit bias, rheumatology, rheumatic diseases

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The preamble of the World Health Organization's constitution defines health as "a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity".<sup>1</sup> An optimal state of health is considered a fundamental human right. When each human has the ability and opportunity to attain optimal health, only then can a secure and peaceful world be envisioned. Thus, developing policies to promote an optimal state of health among member countries is an essential component of governance.<sup>1</sup>

Similarly, the United Nations Sustainable Development Goals aim to promote the health and wellbeing of all human beings at every stage of their lives, recognizing the importance of reducing inequities (not just inequality) among social groups within and outside of every nation.<sup>2</sup> The underlying rationale that separates inequity from inequality is the concept of social justice. While equality refers to each individual or group accessing the same resources or opportunities, equity considers differences within these individuals or groups in accessing different resources or opportunities to achieve the same outcome.

In healthcare, discussions around this topic have commonly utilized the terms 'health disparity' and 'inequity'. While health disparity refers to a measurable difference in health status between different population groups, health inequity refers to the situation in which this difference is attributable to differences in the groups' environment, cultural attitudes, social factors or financial resources.<sup>3,4</sup> The spread of egalitarian values in the modern era and data emanating from the global pandemic have highlighted these disparities, and renewed calls to identify and address systemic causes of inequities in order to reduce health disparities. This paper briefly discusses health disparities in rheumatology and shares strategies that foster a culture of health equity.

## Disparities by biological factors, race and region

Health disparities in rheumatology often occur due to differences observed in disease presentation between races, ethnicities and regions. The European Scleroderma Trials and Research Group study revealed a higher prevalence of pulmonary hypertension and diffuse skin involvement among Asian patients with scleroderma compared with their Caucasian counterparts.<sup>5</sup> The study also found significant differences in the clinical presentation and management of systemic sclerosis-induced interstitial lung disease across seven geographic regions in Europe, highlighting variations in management and the need to standardize evidence-based clinical guidelines.<sup>6</sup>

Similarly, disparities are also rooted in the variable incidences and presentation of rheumatic disease in patients of different sexes and genders.<sup>7</sup> For example, several rheumatic diseases show a female preponderance. The female:male ratio for the incidence of rheumatoid arthritis is 3:1, systemic lupus erythematosus is 9:1 and Sjogren's syndrome is 20:1.<sup>8-10</sup> Not only are females more likely to have these conditions, they are more likely to have greater disease severity or poorer outcomes.<sup>11,12</sup> While biological differences in the presentation of the disease represent health disparities, when combined with socioeconomic differences, they create health inequities.

Pregnancy also plays a role in disease severity and activity, and while some autoimmune diseases (such as rheumatoid arthritis) may improve in pregnancy, others (such as systemic lupus erythematosus) may worsen.<sup>13</sup> In fact, many females experience flares of their autoimmune disease during pregnancy, which can cause serious, even life-threatening complications and require management with non-teratogenic drugs.<sup>13</sup> Furthermore, females with rheumatic diseases also face several maternal health challenges, such as difficulties in conception, infertility, spontaneous abortions, preterm births and babies born small for gestational age.<sup>13</sup> Females in Middle Eastern countries hesitate to discuss their rheumatologic symptoms with their providers during pregnancy due to cultural barriers.<sup>14</sup> Taken together, it is no surprise that the average cost of prenatal care for females with rheumatic disorders is almost twice the cost of that for those who do not have the disease.<sup>15</sup> These disparities in disease presentation contribute to health inequities related to financial costs and avoidable maternal and foetal complications.

### Disparities by social roles and factors

Differences observed in disease progression and outcomes between sexes can also be attributed to differences in care-seeking behaviours and care received, which alters disease course and management. Although females are more likely to seek healthcare services, symptoms such as chronic pain are not properly diagnosed or managed in the same manner among females compared with males.<sup>16,17</sup> For example, female patients with spondylarthritis are more likely to be misdiagnosed with fibromyalgia or psychosomatic disorders than males, and experience longer delays in receiving a correct diagnosis.<sup>18,19</sup> Contrastingly, regardless of the rheumatic disease, males tend to utilize healthcare services less often than female patients and tend to present at later stages of the disease, potentially leading to the worse health outcomes observed.<sup>20</sup> Unfortunately, very few studies explore the role of the sex and gender moderator on the natural history and progression of these diseases. Nonetheless, shared decision-making between rheumatologists, patients and other healthcare providers can help optimize sex and gender-based priorities, leading to more efficient delivery of healthcare services.<sup>21,22</sup>

Recently, there has been widespread discussion about the experiences of lesbian, gay, bisexual, transgender and queer (LGBTQ+) individuals in the healthcare system, the implicit and explicit biases many face, and difficulties in accessing necessary medical services. Educational materials often have biased representations of LGBTQ+ patients, which may contribute to social stigma.<sup>23</sup> A systematic review revealed significant implicit bias among medical, dental and nursing students in their interactions with LGBTQ+ patients.<sup>24</sup> LGBTQ+ patients, in a recent study described their interactions with healthcare providers as transactional, and experienced a sense of power imbalance in the healthcare system.<sup>25</sup>

In rheumatology, it is known that transgender women have a higher immune-mediated inflammatory rheumatic disease incidence than other

LGBTQ+ patients.<sup>26</sup> Although the impact of hormonal changes on the progression of rheumatic diseases is well documented, there is a lack of information on the impact of gender affirming hormone therapy utilized by transgender individuals on the progression of their rheumatologic disease, due to their exclusion from clinical trials.<sup>27</sup> A recent systematic literature review highlighted the lack of relevant clinical evidence and stressed the need for gender-diverse recruitment of participants in clinical trials to fill in the gaps in our knowledge.<sup>28</sup> Further research needs to be conducted to understand the experiences of such patients in rheumatology clinics.

### Disparities in systemic policies and infrastructure

Clinical trials are also an important area to consider, as there can be prevalent healthcare disparities given that minority populations based on sex, gender and race/ethnicity are underrepresented in clinical trials. Disparities can also occur when specific populations are excluded from clinical trials, as seen in excluding patients with an autoimmune disease from the coronavirus disease 2019 vaccine and drug trials.<sup>29</sup> For example, there is an underrepresentation of males in clinical trials of musculoskeletal disease and trauma, despite having a similar burden of disease to females.<sup>30</sup> However, generally females are underrepresented (or unable to enroll) in clinical trials for biologic drugs.<sup>30</sup> There is an urgent need to foster feelings of trust among minoritized communities through community-based participatory research, to ensure equitable participation in clinical trials.<sup>31,32</sup> The recruitment of diverse participants in clinical trials can minimize the amplification of disease stereotypes based on demographics. The recent *Lancet* Summit on sex and gender in rheumatology highlighted this often-ignored sex-based disparity in clinical research and highlighted the need to address and appropriately report sex and gender differences in clinical trials.<sup>33</sup>

Looking at the healthcare system, differences in socioeconomic factors significantly impact patients' ability to seek, navigate, access and afford medical care. During the coronavirus disease 2019 pandemic, patients with poor language proficiency, lower educational attainment and inadequate access to reliable internet services exhibited hesitation in receiving healthcare services via telemedicine, leading to delays in care and further worsening of their disease.<sup>34</sup> Low-income neighbourhoods, such as Wolverhampton in the UK, exhibit disparities due to a lack of high-quality and reliable broadband services that significantly reduce access to telemedicine services.<sup>35</sup> Furthermore, historically marginalized and segregated communities suffer from significant disparities at the intersection of poverty and race. Based on evidence in the literature spanning time frames of 2011–2016 and 1997–2015, respectively, African American and Hispanic patients had worse disease manifestations and outcomes than Caucasian patients with rheumatoid arthritis in the USA, which persisted even after adjusting for age and gender.<sup>36,37</sup>

Another recent literature review, published by researchers from Nigeria and the UK, studying the diagnosis and management of rheumatoid arthritis among low-income populations in resource-poor countries, particularly in Sub-Saharan Africa, demonstrated significant health inequities.<sup>38</sup> Patients in these countries lacked the necessary resources (including financial resources, social support and availability of specialists) for the timely diagnosis and management of their disease, leading to disease worsening, disability and an inability to work.<sup>38</sup> African nations face a growing burden of rheumatologic disorders without necessary resources, such as trained providers, expensive medical tests and drugs available, indicating an urgent need to tailor treatment guidelines to suit their unique socioeconomic situation.<sup>39</sup> Individuals with systemic sclerosis face a partial or complete inability to work, with health

outcomes reported to be worse for those patients with lower educational attainment, diffuse skin involvement and longer disease duration.<sup>40</sup>

### Disparities in the healthcare workforce and training

Several plausible reasons may underpin disparities in the healthcare workforce and provided training. Despite the steady rise in women rheumatologists, particularly in the USA and European Union, there is still a lack of equitable representation of women in leadership positions in rheumatology.<sup>41</sup> Women in the rheumatology profession are less likely to enroll in MD/PhD programmes and tend to have fewer scientific publications compared with their male peers.<sup>42</sup> Furthermore, few women have held editorial positions in rheumatology journals.<sup>43,44</sup> Gender norms and stereotypes have played an important role in shaping women's academic and professional advancement.<sup>45</sup> This gap has narrowed in recent years but persists in the workplace, and leadership roles in academia and research. Similarly, there is a shortage of healthcare providers from underserved and minoritized communities who can deliver culturally competent care and develop feelings of trust in communities where Caucasian physicians are hesitant to practice.<sup>46</sup> There is a need to increase diversity in the workforce and promote individuals from such backgrounds to leadership positions.<sup>47,48</sup>

The lack of culturally competent training of healthcare providers can create health disparities in medicine. A recent study examining the use of images in training materials found a significant underrepresentation of images from dark-skinned patients, leading to a lack of adequate training and increased chances of misdiagnoses and improper management based on the patient's race.<sup>49</sup> Similarly, an analysis of clinical practice guidelines published by the American College of Rheumatology and the European Alliance of Associations for Rheumatology between 2010 and 2020 revealed that one-fourth of the guidelines used race-based terminology and applied findings from research on White patients to patients from other ethnicities.<sup>50</sup> Individuals from minoritized and marginalized communities often suffer from implicit or explicit bias from their healthcare providers, leading to missed diagnoses, inappropriate treatment and patient mistrust of the healthcare system and providers, thus worsening patient-provider relationships.<sup>51</sup> As such, there is an urgent need to develop educational materials on race and gender-conscious training. Healthcare providers should be able to recognize disease manifestations better and appropriately manage rheumatic diseases among patients of all races, ethnicities and socioeconomic backgrounds.

### Driving change towards health equity

Recently, there has been a much-needed push towards introducing implicit bias training in simulation-based teaching strategies, such as using mannequins, standardized patient actors from different ethnicities and patient names representing diverse identities in clinical vignettes.<sup>52</sup> Digital tools such as telemedicine, electronic health records and mobile health applications can also play a significant role in helping patients connect with culturally competent care providers, understand their medical diagnosis, and engage in shared decision-making with their healthcare providers.<sup>53</sup> They can also help collect information from patients about their symptoms, response to treatment regimens and social determinants of health to create a novel database of bias-free information that can empower patients, and guide clinical diagnosis and management of rheumatic diseases.<sup>54</sup>

The European Alliance of Associations for Rheumatology has recently announced the creation of a workforce to bridge this gap by incorporating evidence-based guidelines to promote health and gender equity in the field.<sup>55</sup> Another vital effort to create change is the institution of the Coalition of Health and Gender Equity in rheumatology group, which hopes to bridge some of these gaps through evidence-based consensus on remedial measures. We must ensure that our workplaces reflect our society to lessen health disparities and foster a culture of health equity.

### Conclusion

The existing health disparities based on sex, gender, race and ethnicity have contributed to significant differences in the appropriate management of patients leading to poor health outcomes. They generate health inequities that exacerbate socioeconomic differences among these groups. There is an urgent need to recognize these differences and take remedial measures to bridge these gaps. We need to diversify the workforce and increase the use of gender and race-diverse educational materials during training. We need to promote the delivery of culturally competent care to build rapport with historically marginalized communities and encourage their participation in clinical trials. The journey towards health equity will ultimately require the participation of all members of the healthcare ecosystem: patients, providers, payers, clinical trialists, drug manufacturers and legislators. Only then will we be able to decrease the disparities patients face, and the impact on societies around the world. □

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