



Crying out for equity: outcomes of rheumatic diseases confounded by ethnicity

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Recently, COVID-19 has put the spotlight on ethnicity and disparities in outcomes; an issue of great urgency which preceded the COVID pandemic. Particularly within rheumatology, these differences in outcomes have been known for a couple of decades [1]. In January 2022, the publication of a special report from the British Society for Rheumatology (BSR) relating to the National Early Inflammatory Arthritis Audit (NEIAA), further demonstrated worse outcomes for patients from BAME (Black, Asian, and ethnic minority) backgrounds at 3 months in England and Wales, despite these patients having equal access to care [2]. This study also showed that these patients were more likely to be seropositive, and less likely to be smokers suggesting that they have a more severe disease compared to White patients. This directly contrasts with previous perceptions that some ethnic minority groups, such as South Asians developed less severe diseases with rheumatoid arthritis (RA). Adjustment for the social class has not changed the differences in outcomes [3]. There have been multiple other studies over the last decade in the UK demonstrating poorer outcomes in BAME patients [4, 5]. In those earlier studies, delays in presentation and referral for specialist care would explain some of the differences, although the latest NEIAA study does not demonstrate these differences. There have also been other studies suggesting divergent, often culturally influenced views relating to medication, which might

explain some of the variation in outcomes [6, 7]. Regrettably, BAME patients are under-represented in research studies and drug trials, and there is a lack of good quality data for common treatments as well. Relatively smaller numbers of ethnic minority patients are included in rheumatology disease registries, thereby reducing the generalisability of findings from these sources. For example, the UK BSR biologics register has less than 5% BAME patients (personal communication) although the proportion of the UK BAME population is around 14%, and the NEIAA study (which is mandatory) reported around 13% BAME patients [2]. Sadly, this is not unique to rheumatology [8]. Education and health literacy were considered important factors leading to worse outcomes, and hence we developed resources such as Apni Jung (our fight) to improve the level of understanding of disease mechanisms and treatments in RA [9] and osteomalacia information [10] for South Asian patients. There has been scant comparable data coming out from mainland Europe with no clear explanation for this.

In Asia, an observational cohort study using data from a Singaporean early RA registry demonstrated patients of Malay origin were more than twice as likely to be in ‘high disease activity’ groups at presentation as compared with Chinese patients [11]. A Malaysian multi-ethnic cross-sectional study of 371 patients comparing patients with RA who achieved treatment targets against those who did not identified Malay ethnicity as an independent predictor of failure to achieve the target after confounder adjustment (OR 2.96; 95% CI 1.4 to 5.96) [12]. A prospective cohort study from the USA found that Native American populations were more likely to be seropositive and have higher inflammatory markers compared to White American patients [13]. Further data from US cohorts have revealed more adverse disease activity, disability, and pain scores among minority ethnic groups such as African Americans. These only remain statistically significant for higher pain scores after adjustment for confounding factors [14]. A US cohort using registry data

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from 2010 to 2012 showed higher disease activity among minority ethnic patients compared to White patients [15].

There are significant ethnic differences in other rheumatological diseases as well. Ethnic differences in systemic lupus erythematosus have been long recognised. The findings have been fairly consistent in recognising the higher incidence and greater severity with more renal disease and serositis in Black, Hispanic, and Asian populations compared to Whites [16–18]. Data from Africa suggest that the prevalence and severity of RA and SLE show similarities to data on African Americans [19]. In contrast, Giant cell arteritis (GCA) is much less common (risk reduced to about a quarter) in patients of South Asian descent [20, 21]. In psoriatic arthritis, South Asian ethnicity appears to be associated with worse clinical phenotype and worse patient outcomes [22]. Ankylosing spondylitis and axial spondyloarthritis are more common in White patients and associated with higher rates of HLA B27 positivity compared to Blacks, but Blacks have increased severity and worse functional outcomes [23]. Takayasu's arteritis is more common and presents earlier in Asian and Black populations compared to Whites [24]. Kawasaki disease appears to be more common in children of Asian ancestry, whilst Behcet's disease occurs most commonly along the ancient silk road between Europe and China [25]. Outcome data across various ethnic groups within vasculitis are sadly lacking (Table 1).

All these studies were conducted prior to the recent COVID-19 pandemic. The UK NEIAA data collection stopped due to a pandemic-induced lockdown. During the pandemic, huge inequalities have become apparent for COVID-19 outcomes, with worse outcomes for BAME patients in the UK. Rheumatology studies during the pandemic suggest that ethnic minority patients found the messaging around shielding and restrictions difficult to understand and there were important differences in their behaviours [26]. It is therefore likely that the pandemic has led to further divergence in outcomes. Sadly, this means that, as Percy Bysshe Shelley has said, 'the rich get richer, and poor get poorer.' This applies to health as well as to

economic outcomes, with a resultant widening in health inequalities.

With the overwhelming data on adverse health outcomes in ethnic minority patients, what are the successful interventions to address these inequities? Unfortunately, little is known for a variety of reasons. Appropriate studies have either not been done or not been published. Funding for ethnicity-based research is not sufficiently prioritised or provided. Furthermore, not enough is being done to identify and eradicate discriminatory behaviour or practices. Based on the limited data available, as well as our extensive experience in BAME health matters, we believe that ethnic health inequalities are associated with an increased prevalence and severity of long-term conditions or multimorbidity, poor experiences of negotiating health care systems in primary and secondary care, insufficient support from local services, low patient self-confidence in managing their own health, increased educational and health cognition needs and high area-level social deprivation, compared with White populations. From a health economics perspective, we believe that worse BAME health will lead to higher costs, as adverse outcomes lead to increased hospitalisation and loss of earnings. These individual and societal costs make a strong health economic argument for early intervention with the provision of the right support and management to ensure better outcomes, leading to reduced productivity loss and pressures on healthcare systems.

Further research into the field of ethnicity within rheumatology is urgently required. Important differences in aetiopathogenesis and genetics need more focus, and interventional studies with appropriate support and funding infrastructure are also desperately needed. Data on health outcomes by ethnicity needs to be routinely collected with a view to better understanding health disparities, and this should be made mandatory. Prospective studies focusing on key questions are needed to understand the underlying differences better so that specific targeted interventions (not just for patients, but also for clinician behaviour) can be studied to assess their benefit. One issue that should be relatively easier to address is that of adherence to medication

Table 1 Common rheumatological conditions and influence of ethnic background

Condition	Impact of ethnicity
Rheumatoid arthritis	Outcomes are worse in ethnic minority groups such as Black and Asian patients in UK and US
Ankylosing spondylitis	More common in whites compared to Blacks in the US, but more severe in Blacks
Psoriatic arthritis	One report suggests worse outcomes for South Asian pts in the UK
Systemic lupus erythematosus	More severe in Africans and Asians, with worse outcomes
Giant cell arteritis	Much less common in Blacks and Asians
Behcet's disease	More common in the ancient silk route regions
Takayasu's arteritis	More common in Black and South Asian populations
Kawasaki disease	More common in children of Asian descent

[27]. With a significant reduction in the costs of advanced therapies, there seems little reason for not escalating treatment if current strategies are not proving effective. Precision medicine requires research into which treatments work best for which ethnicities and which treatments are likely to be ineffective or cause significant side effects. We believe that the issue of improving health literacy for BAME patients needs to be taken seriously by national and international rheumatology bodies. A centralised platform with support from patient organisations is urgently needed in countries with large ethnic minority patients, and American, European, and British rheumatology bodies ought to take the lead on this. Patient organisations ought to be key collaborators, and social media can be a powerful ally for the dissemination of information. Some social media tools such as translation into various languages can be of immense benefit, provided cultural adaptation is also taken into account. We have recently created a set of educational videos for patients with early inflammatory arthritis (EIA) in the UK [28]. The increasing availability of smartphones means that there is the possibility of reaching out equally and effectively with educational materials to virtually all population groups.

In conclusion, there is a significant body of work attesting to worse outcomes for BAME patients across various rheumatological conditions, including RA, PsA, SLE, and osteomalacia, among others. Regrettably, these important issues regarding rheumatology and ethnicity have been largely ignored within the rheumatology community and beyond. Further work is urgently needed to understand patient and physician behaviour, differences in disease, treatment response and drug tolerance, role of comorbidities, as well as the impact on the individual and family in order to adequately address the needs of the ethnic minority populations. Above all, we have a moral imperative to address this issue and ensure equitable care for all our rheumatology patients.

Author contributions Both authors have contributed to the critical revision of the manuscript and agreed on the final version.

Declarations

Disclosures None.

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Key messages

1. Black, Asian, and minority ethnic (BAME) patients have worse outcomes in a number of rheumatological diseases.
2. There is a paucity of good-quality data on the scientific explanations for these discrepancies.
3. These issues need urgent redressal through appropriate resource provision for suitable studies.