Embracing Diversity: The Imperative to Represent the LGBTQIA+ Community in Rheumatology Research

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In recent years, medical and scientific communities have made commendable progress in acknowledging gender identity and sexual orientation in research. However, the medical and scientific communities must ensure that research efforts reflect the needs and experiences of the lesbian, gay, bisexual, transgender, queer, intersex, asexual, and many other individuals that belong to the LGBTQIA+ community. More than 1 in 13 adults in the United States identify as lesbian, gay, bisexual, and/or transgender.¹ The plurality of this community is 25 to 39 years of age (41%), and almost 17% are 55 years or older.¹ Among adults over 50 years of age, lesbian, gay, and bisexual individuals report more low back and neck pain than heterosexual peers.² Further, lesbian women are more likely to report being diagnosed with arthritis than heterosexual women.² ³ Transgender Medicare beneficiaries (37%) are more likely to have fibromyalgia than cisgender beneficiaries (21%).⁴ This latter finding is particularly salient since transgender individuals may use gender-affirming hormone therapy (eg, exogenous estrogen or testosterone) to affirm their gender identity. The therapy could influence immune response and rheumatic diseases; however, we lack sufficient evidence to infer whether gender-affirming hormone therapy can modify rheumatic diseases for better or worse.⁵ ⁶

Despite the size of the LGBTQIA+ community and the high prevalence of rheumatic and musculoskeletal diseases, fewer than 1 in every 2000 rheumatology-related publications indexed in PubMed over the past 15 years reference this population. More specifically, as of 2022, only 11 studies in PubMed report on transgender patients with rheumatic diseases.⁵ These studies and a recent retrospective study reported on 20 transgender patients with rheumatic diseases—all on gender-affirming hormone therapy.⁵ Hence, there is an absence of data to establish the epidemiology within this population and to define the effects of gender-affirming hormone therapy or surgery on rheumatic diseases.⁵ In this editorial, we focus on the imperative to represent the LGBTQIA+ community in rheumatology research and avoid old heuristics.

Let’s stop muddying the water

Sex, sexual orientation, and gender identity represent 3 unique constructs, and too often, sex and gender are incorrectly used interchangeably in our literature. Sex (male, female, or intersex)—assigned at birth—represents bodily characteristics (eg, chromosomes, internal and external reproductive organs), whereas gender is a social construct. To avoid confusion, authors should clearly state whether participants were asked about sex, gender, gender identity, or sexual orientation. To demonstrate a source of confusion, we searched PubMed titles and abstracts for the “Osteoarthritis Initiative”—a widely used cohort with publicly available data—and “sex” or “gender.” A PubMed search for “sex” yields 185 publications, and a search for “gender” yields 61 publications (including 7 that use both “sex” and “gender”). In reality, the interview question in the Osteoarthritis Initiative was, “What is your gender, male or female?” The interview form included an option for “refused,” but no one refused. Investigators need to ensure we report that these participants were asked about gender and primarily given 2 options (male or female). Though our example relied on the Osteoarthritis Initiative, we encourage all investigators to review how they have asked about gender or sex and ensure accurate and detailed reporting.

Collecting needed data

To address the underrepresentation of the LGBTQIA+ population in rheumatology research, we need appropriate data collection, research design, and recruitment strategies. The inclusion of sexual orientation and gender identity as demographic variables in research studies is vital for capturing the unique experiences and health concerns of LGBTQIA+ individuals, as well as...
for participants to feel “seen” and fully engaged in our research. Moreover, sexual orientation and gender identity intersect with other important demographic factors such as national origin, age, race, ethnicity, and socioeconomic status. Together, these factors can lead to a more comprehensive understanding of how arthritis is experienced and managed.7,8

Best practices for assessing sexual orientation and gender identity include asking these as separate items and including an assessment of sex at birth.9,10 However, the exact wording used depends on the context and population.9,10 For instance, research restricted to sexual or gender minority populations should include a wide range of terminology and options for self-definition, whereas population-based research involving predominantly cisgender respondents requires clear wording to reduce respondent confusion and resulting misclassification.11,12 In almost all cases, open-ended options will allow respondents not only to best represent themselves but also to feel included.13 Although some researchers have expressed theoretical concern that older populations may take offense at being asked these demographic items, this has not been the case in practice, with low levels of item refusal, even in older populations. Only 7% of adults 80 years and older declined to answer an item on sexual orientation, and 3% a gender identity item,14 with nonresponse rates in all groups declining rapidly in recent years.15

Representation matters
By including sexual orientation and gender identity in research studies, we can gain valuable insights into the unique healthcare needs and challenges faced by LGBTQIA+ individuals with or at risk for rheumatic or other musculoskeletal diseases. This inclusion may promote trust, enhance patient-provider communication, and improve patient outcomes. Further, by exploring the experiences of LGBTQIA+ individuals, researchers can identify potential environmental and social determinants of health, thereby facilitating the development of tailored interventions, treatment approaches, and improved communication and education strategies.

REFERENCES