Diagnostic Delay in Autoimmune Rheumatic Diseases: A Global Health Problem

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In this issue of The Journal of Rheumatology, Xiang et al.¹ describe the experience and influencing factors of symptom appraisal and help-seeking among patients with various autoimmune rheumatic diseases (ARDs) in a multiethnic urban Asian population. The authors guided the interpretation of this qualitative study based on the social cognitive theory framework to enhance the appraisal of symptoms and help-seeking. This framework includes 3 constructs of symptom appraisal: detection, interpretation, and response, as described by Whitaker et al.²

The study by Xiang et al.¹ leads us to take into account all the aspects that should be considered to observe and understand care-seeking for ARDs as a heterogenous process, given that the conditions encompassed in the ARD label vary in presentation. As such, we must contemplate the diversity of situations that individuals with ARDs face. The contexts of care, such as the healthcare system; the sociocultural contexts of both patients and healthcare professionals (HCPs); and the socio-economic conditions of each country, compel us to reflect from the perspective of global health.³⁻⁴ If factors vary among groups, cultures, and healthcare systems, we must examine how a global viewpoint could define delay or any form of seeking care.

It is important to highlight that the existing theoretical models (ie, symptom appraisal) were developed for diseases other than ARDs, such as cancer and mental health disorders.² This compels those of us studying ARDs to develop a care-seeking model that encompasses the diversity of rheumatic diseases and their specificities, such as pain as an initial symptom or bodily changes, as described in the study by Xiang et al.¹

Sociocultural factors shape symptom interpretation and the resulting decisions for early care, and therefore must be analyzed from the perspective of cultural groups, in dialogue with the biomedical system, without portraying culture as a barrier to care. As the authors mention, ethnic diversity must be regarded as a pivotal aspect of care-seeking and delay.¹ Considering the above, achieving a symptom appraisal model specific to ARDs should also entail proposing a distinct definition of delay that incorporates both clinical and social factors that affect these diseases.

The definition of diagnostic delay is complex and dynamic, since its construction requires consideration of individual, community, sociocultural, and economic aspects, as well as the characteristics of the specific health system. A comprehensive definition of delay should also comprise structural problems such as health inequity, lack of cultural competence, and limited availability and accessibility of HCPs. In most developing countries, healthcare services are inadequate, inaccessible, fragmented, limited, and inequitable in quantity and quality, as described by Peláez et al.⁴ who documented diagnostic delay of rheumatoid arthritis (RA) in Latin America.

Although the study by Xiang et al. was conducted in a multi-ethnic context in Singapore, the aspects highlighted have been replicated in other regions. Indeed, sociocultural diversity is increasingly recognized as a significant element of healthcare globally, particularly regarding noncommunicable chronic diseases like rheumatic conditions. The Latin American Study Group of Rheumatic Diseases Among Indigenous Peoples (GLADERPO) has generated evidence of the deleterious effects of the health of Indigenous communities.⁷⁻⁹ In Argentina,⁴ the Qom people belong to the ethnic group known as Guaycurú. They originally lived in north Argentina and expanded to neighboring countries of Bolivia and Paraguay. The Qom people in this town were forced to leave their natural environment and move to urban areas. These patients with RA belonging to the Qom community experienced an aggressive disease with poor adherence to treatment and inadequate accessibility to healthcare, despite being geographically close to the primary healthcare center. Similarly, a qualitative methodology helped describe...
the health system’s complexity, including the barriers to access and continuity of treatments for patients with ARDs in another community in Argentina. Overall, the healthcare system in Argentina and other Latin American countries excludes ethnic minorities. In Mexico, the impact and barriers of living with arthritis were investigated in a rural Mayan community, showcasing the need to develop culturally sensitive healthcare systems.10,11

One important aspect of the help-seeking process and diagnostic delay, which the study does not mention,1 is how sex and gender influence the experience of symptoms as well as decision making. As previously documented, women are more often affected by ARDs and recognize their symptoms early.12-14 However, they are faced with cultural bias, wherein family members and HCPs question the credibility of their symptoms, which are sometimes perceived as psychosomatic complaints. This results in prolonged searches for care, delays in diagnosis and treatment, more significant systemic impact, and higher morbidity and mortality, as can be seen in systemic lupus erythematosus.12-14

Another limitation is that the different help-seeking models described in the literature and emphasized in this study1 involve only 2 participants—patients and HCPs—who are embedded in a broader context, which includes the patient’s family and a sociocultural network. Additionally, HCPs operate within a care system governed by top-down health policies rather than those being constructed from the bottom up.

We propose an approach based on the need to create culturally sensitive health services to reduce the disabling effects of ARDs, including education among the community and health professionals. In this way, an empowered community will increase accessibility to health services, including specialized rheumatology care.

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REFERENCES