

The Challenge and Opportunity of Capturing Patient Reported Measures of Rheumatoid Arthritis Disease Activity in Vulnerable Populations with Limited Health Literacy and Limited English Proficiency

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KEYWORDS

- Patient-reported outcome measures
- RA patient global assessment of disease activity • Rheumatoid arthritis
- Health outcomes • Limited health literacy • Limited English proficiency

KEY POINTS

- Limited health literacy (LHL) and limited English proficiency (LEP) are widely prevalent and contribute to rheumatoid arthritis (RA) health care disparities.
- The RA Patient Global Assessment of Disease Activity often introduces complexity to the health care encounters of patients and research subjects with LHL and LEP.
- Important work is being done to ensure that patient-reported outcome measures (PROM) are validated and appropriate for diverse and vulnerable populations.

INTRODUCTION

Earlier, more aggressive, and more effective treatments of rheumatoid arthritis (RA) have made remission a realistic target and have greatly improved outcomes compared with past decades.^{1,2} Unfortunately, the therapeutic benefits of the biologic era have not been experienced equally by all patients. There is abundant evidence of ongoing racial and ethnic disparities in RA outcomes in both the United States and abroad (**Box 1**).³

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Box 1**Care disparities in rheumatoid arthritis**

- United States
 - More disability and worse global health among non-whites compared with whites¹¹
 - Higher disease activity and worse functional status in non-whites, non-anglophones, and foreign born¹²
 - Men, non-whites, and persons of lower socioeconomic status are less likely to receive a disease modifying anti-rheumatic drug (DMARD)¹³
 - DMARD therapy is often delayed in ethnic minorities¹⁴
 - Income and ethnicity impact use of biologic therapies¹⁵
- Europe
 - Higher hospitalization rates for RA patients with lower socioeconomic status and manual labor employment¹⁶
 - Worse functional status in patients from deprived socioeconomic areas¹⁷
 - Negative association between disease activity and gross domestic product per capita¹⁸
 - Women are less likely to achieve remission¹⁹
- Latin America
 - Low socioeconomic status is related to high disease activity in early RA²⁰

The widely accepted “treat-to-target” paradigm of RA management guided to remission or low disease activity mandates low scores along a visual analog scale (VAS) on one patient-reported outcome (PRO), the Patient Global Assessment of Disease Activity (PtGA-VAS).^{4,5} PtGA-VAS scores are often discrepant with evaluator assessments of disease activity and may alone prevent patients from being classified in remission.^{6–10} Vulnerable RA patients (defined as elderly, members of racial/ethnic minorities, those with limited health literacy, or non-English speakers) often have difficulty completing the PtGA-VAS. These same RA patients are at the complex intersection of being at risk for health care disparities and having their providers follow guidelines to treat them to a target of low disease activity or remission.

Limited health literacy (LHL) and limited English proficiency (LEP) are variables that may, in part, explain disparities in RA care. This article introduces the reader to these concepts and then reviews the research, which links LEP and LHL to outcomes in RA. The proposed causal pathways responsible for these associations will then be covered, followed by a discussion of the challenges vulnerable populations face completing PROs using the PtGA-VAS as an example. The article concludes with strategies to improve the PtGA-VAS and reduce complexity in the health care system for all patients.

LIMITED ENGLISH PROFICIENCY

Rheumatologists often encounter RA patients with LEP because more than 60 million US residents speak a language other English at home.²¹ LEP is defined based on responses to the US Census and American Community Survey question, “How well do you speak English?” (**Box 2**). Persons that report “very well” are considered English proficient. Persons that report “well,” “not well,” or “not at all” are considered to have LEP.^{21,22} Twenty-five million Americans were self-classified as LEP in the 2011 American Community Survey.²¹

Some of the challenges caring for patients with LEP may be avoidable through the use of professional interpreters as recommended by the Institute of Medicine as a quality and patient safety imperative.²³ Unfortunately, providers often eschew using professional interpreters and opt to “get by” rather than “get help” when caring for

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