Management of rheumatoid arthritis

Incorporating patient perceptions and objective measures

Treat-to-target strategies and new biologic therapies have revolutionized the management of RA. In spite of these advances, treatments are limited in that they are only as effective as the accuracy of the measurement and quantification of the disease activity itself.

To this end, a number of patient-reported outcome measures have been validated to estimate and quantify disease activity, and many are routinely used in clinical practice. These tools have been widely accepted based on their good correlation with physician decision-making and simulation of disease activity [1]. Many of these rely heavily on patient report of pain levels, disability and stiffness. These measures have been presented as a reliable way to assess the activity of disease and influence treatment decisions [2, 3]. However, evidence has suggested that patient and physician perceptions of disease activity are often inconsistent [4, 5]. Furthermore, patient assessments might not always accurately reflect inflammation. We found that exclusion of patient global assessments and tender joint counts from composite disease activity scores improved the correlation with synovitis on MRI and resulted in more accurate prediction of radiographic progression [6]. The development of serum biomarker testing as well as advanced imaging techniques such as musculoskeletal US and MRI may provide physicians with additional objective information regarding the inflammatory burden, improving risk stratification on an individual level in the coming decade [7, 8]. While these assessments may accurately identify inflammation, they can be expected to correlate poorly with the patient’s assessment of their disease, exacerbating divergence between patient and physician assessments.

Patient-centred care is a virtually uniformly appreciated principle in health care today. However, a practical approach to implementing patient-centred care remains elusive for the average provider. Several approaches to incorporating these principles are currently in practice. These include the use of shared decision-making tools—a key feature of the Affordable Care Act in the USA. Another approach is to directly solicit patient preferences regarding treatment options. This approach is better suited to preference-sensitive treatments such as joint replacement in OA. In addition, there is no validated and reproducible way to measure patient preferences over a range of circumstances. Furthermore, patient preferences can be reshaped through educational intervention [9].

The approach to incorporating patient preference that is most often utilized in RA involves the use of patient-reported measures of disease activity to guide treatment decisions. These tools have often been developed in settings where there is little or no objective evidence to guide decisions. As physicians have increasing access to sophisticated technologies, the role of these measures becomes less clear.

Difficult decisions to use or intensify potentially harmful immunosuppressive therapies in RA must be considered carefully. Patients with RA may have a number of underlying causes of joint pain and disability that may elevate disease activity scores but are not necessarily associated with the activity of the inflammatory disease. These include secondary OA, neuropathy and amplified pain, among others. Furthermore, not all patients with active early RA will experience significant pain and disability despite aggressive and destructive disease. Thus attention primarily to patient perspectives might result in both over- and undertreatment of the inflammatory disease, potentially resulting in poorer long-term outcomes.

Similarly, the assumption that patient-reported outcomes are explained by a greater inflammatory burden may result in underrecognition and undertreatment of associated conditions that would be unlikely to respond to immunotherapies alone.

Physicians are now increasingly being asked to consider cost. Accurate assessment of the inflammatory disease burden would allocate resources more effectively to those most likely to benefit from them. Better control of the inflammatory disease may also decrease long-term costs by preventing morbidity from the disease.

The cost to perform clinical trials has also risen steeply due to increased regulation and improvements in the standard of care. Current measures of disease activity require large studies with extended follow-up in order to demonstrate efficacy. Therefore, while the incorporation of patient-reported measures in clinical trials carries face validity, these outcomes are likely not the most efficient and cost-effective way to determine the efficacy of new therapies.

The need to define and incorporate objective measures has been considered in other settings. The investigators as part of the Study of Biologic and Immunomodulator Naïve Patients in Crohn’s Disease (SONIC) trial recently concluded that clinical measures were not adequately predictive of endoscopic or biomarker remission and suggested more objective measures in trials aimed at changing the natural history of the disease [10].

Whether or not patient-reported outcomes are the best way to assess the burden of inflammatory disease, a lack of consideration of patient-reported factors will result in
considerable frustration for the patient and compromise the patient–doctor relationship. Therefore separate measures that assess distinct domains of the disease may play an important role in helping the physician understand the patient experience and tailor therapies accordingly.

Physicians will increasingly be faced with making management decisions that both incorporate individual patient preference and objectively target inflammatory disease. They are therefore tasked with comprehensively assessing patient-reported outcomes while balancing them with available objective measures. Effective communication between patient and physician is therefore paramount and a single composite disease activity score does not help to facilitate this communication.

We therefore suggest that the future of RA management (and clinical trial design) should move away from the all-encompassing clinical disease activity scores. Separate assessments of patient perspectives on pain and functional limitations and efforts at objective documentation of inflammatory burden may have more meaning.

We believe the first step is to encourage funding agencies to support research in the validation of new methods to quantify inflammatory disease. It is important to remain open to considering these measures as primary outcomes when evaluating the efficacy of new therapies in order to improve the efficiency of clinical trials. When pain and physical functioning are of interest as the primary outcome, patient-reported measures specific to these domains are appropriate. In the end, measures that specifically address different facets of disease will positively affect all areas of clinical research in RA by improving the accuracy of the most important covariables.

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