



EDITORIAL

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Improving patients' quality of life: a new challenge for clinical practice

Mejorar la calidad de vida de los pacientes: un nuevo reto en la práctica clínica

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"When we thought we had all the answers, the questions suddenly changed."

Mario Benedetti

The advent of the 21st century XXI has heralded the so-called post-modern era, characterized by hyperproduction, hyperconsumerism and individualism. According to philosopher Gilles Lipovetsky¹, the new trend in the realm of healthcare is subjectivation of disease, i.e., a holistic view of health by the subject together with a mental exploration of their body. This obviously contrasts with the rigidity of hospital practice. Patients no longer consider that they must passively accept their condition. On the contrary, they feel they must participate in the management of their own health and in the decisions concerning their disease. Within the context of our diehard health system, these changes have further strained the doctor-patient relationship. In this new era, health is correlated with quality of life in a rather obsessive way. In this regard, disease stigmatizes the individual as it implies lack of health and therefore of productivity and resources to be consumed. For these reasons, preservation of quality of life in the face of disease has become a priority for many patients.

The term health-related quality of life (HRQL) came about over thirty years ago in the United States as a result of a confluence of clinical research in the realm of functional capabilities with and psychological studies on wellbeing. Since then and up to the present, multiple definitions have been proposed without a consensus being reached regarding a new conceptual model. However, all such definitions are of a multidimensional and subjective nature. The most important aspects covered by HRQL are social, physical and cognitive functioning; personal mobility and personal care; and emotional wellbeing. Several measurement tools have been implemented, especially within the area of pharmacoeconomics, to assess the cost-effectiveness of the different interventions and, to a lesser extent, of clinical research².

Although determination of HRQL has established itself in the last few years as an essential prerequisite for the adoption of decisions related to the management of chronic conditions as it reflects the patient's perception on the overall impact of the disease on their life, implementation of such measurements in clinical practice has been scarce. In a theoretical hierarchy of health outcomes, signs and symptoms would be at the base of the pyramid and HRQL would be at the top as it measures the impact of disease and

of the treatment applied on the physical, psychological, social and somatic domains of functioning and wellbeing³.

A series of both generic and specific instruments are currently available to measure the impact of disease. Measurements are subdivided into preference-based health profiles, which assign a value (known as utility) on a scale from 1 (full health) to 0 (death). In some cases, scales may include values lower than 0 (worse than death). The most commonly used scales in observational studies and clinical trials are the Short-Form-36 Health Survey and the EuroQol-5 Dimension Questionnaire (EQ-5D). Utility measurements are based on the preferences or utilities assigned to different health statuses and which, divided by the number of years in a person's life, provide us with the so-called Quality-Adjusted Life Years (QUALY) index, frequently used in cost-efficacy studies to evaluate health technologies⁴. These generic questionnaires have the advantage that they come in different versions for different kinds of conditions and different populations, they have been thoroughly time tested, and they allow for comparisons to be made across diseases or with the general population.

In the field of rheumatology, inflammatory articular diseases such as rheumatoid arthritis (RA), psoriatic arthritis (PA) and spondyloarthritis (SA) are chronic diseases associated with severe disability, decreased quality of life and higher morbidity and mortality⁵. Their management depends on whether there is any inflammatory activity present as determined by indices made up of variables based on pain, function, inflammation of the joints, biological inflammation parameters, and an patient-reported overall assessment of the disease. These indices are used to determine whether the disease is active or in remission, with treatment being initiated or modified based on clinical recommendations or guidelines.



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Several recent studies have brought to light certain discrepancies between the physician's appraisal of the disease and the perceptions of the patient as measured by means of specific HRQL questionnaires. For example, a study on 460 patients with PA demonstrated that lower fatigue levels, lower self-perceived coping and impaired social participation, as evaluated using the PsAID (Psoriatic Arthritis Impact of Disease) questionnaire, were associated with a discordance between the overall assessment of the disease by the physician and by the patient⁶. In a similar study on patients with RA, the self-perceived overall perception of over 30% was significantly different from that of their rheumatologist's appraisal⁷. In a survey of 274 patients with RA from eight countries, when subjects were asked about their appraisal of remission, the most commonly invoked domains were pain (67%), fatigue (33%) and independence (19%)⁸.

The foregoing shows that measuring quality of life in patient with inflammatory arthropathy using tools that reflect the patient's own perspectives and experiences, Patient Reported Outcome and Patient Reported Experience (PROs and PREs) may provide a detailed insight into the impact of these diseases and, consequently, the information required for shared decision-making. In his definition of value-based healthcare (patient-relevant outcomes/cost), Porter⁹ argues that patient self-reported outcomes and experiences should be integrated into clinical practice as they are essential to understand variables such as functional status, pain, anxiety, and other factors that the patient are easier for the patient to judge, and which cannot be detected by biological markers.

Several recent clinical trials analyzing the effectiveness of certain biological drugs have looked into quality-of-life outcomes, mostly as a secondary variable. The heterogeneity of the endpoints used in the different trials makes it difficult to interpret their correlation with the effects of the disease and the body's response to treatment. Only 16 of the 96 clinical trials on RA analyzed in a systematic review in 2015 included HRQL-related PROs¹⁰.

Sarobe M *et al.*¹¹ analyzed the effect of biological drug certolizumab pegol on HRQL using the EQ-5D questionnaire in 59 patients with chronic inflammatory arthritis. The significance of this article lies in the fact that, in

spite of a small sample size, it was conducted in real world conditions. A comparison with the health status of the Spanish population shows a significantly poorer health condition across all groups. It is worth noting that only 13.56% of patients claimed they were in perfect health and, although the pain domain was the most clearly affected one, 68% of the sample also obtained a low score in the anxiety/depression domain, and 78% in the self-care domain.

The perception of the different HRQL domains varies across different populations. An international study where a specific questionnaire was administered to 1,200 patients from eight countries with PA found that articular, enthesitic and skin symptoms were most common in the United States, where the most prevalent symptoms in Spain and in France were social embarrassment and disapproval, and fatigue, respectively¹². Articular inflammatory diseases are highly heterogeneous and these variations could be the result of the social and cultural differences existing between countries.

Although there is a growing interest in incorporating HRQL measurements to evaluate different rheumatological conditions, such determinations are not considered to be one of the goals of therapeutic interventions, i.e., they are not regarded as a significant health outcome. In this regard, the General Principles of the 2019 guidelines of the European League against Rheumatism (EULAR) for the management of PA¹³ state that "the primary goal of treating patients with psoriatic arthritis is to maximize health-related quality of life". Nonetheless, it is recommended that treatment "should seek remission or, alternatively, low disease activity by regular disease activity assessments and appropriate modifications of therapy".

Coming back to the beginning of this editorial, patients —and society at large— are changing at a faster pace than scientific research, clinical practice and healthcare itself, which are still anchored in a biomedical model. The challenge for this new century is therefore to promote higher quality lifestyles ensuring that HRQL measurements are systematically used to gain a better understanding of the wide range of sequelae caused by different conditions. In this way, clinical decisions will be based on a broader consensus, increasing their relevance to all our patients.

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