Individualized Rheumatoid Arthritis Patient Care Means more than Achieving a Number

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The therapeutic scope of inflammatory rheumatic diseases and of Rheumatoid Arthritis (RA) in particular, has increased dramatically over the last twenty years leading to incredibly better chances for the patients. Simultaneously disease activity assessment has become more and more important, not only to document the patient’s disease course, but also for justifying the application of potentially dangerous and expensive remedies. The discussion as to whether and to which extent the patient should be incorporated into disease activity assessment was ever present and is still ongoing in a lively manner. In a very oversimplifying way one may differentiate between the more paternalistic and the other primarily patient orientated party of rheumatologists, though in reality much more disparities may be realized.

The most important question is not the one whether assessment instruments should be applied, but the one whether the instruments preferentially employed, are indeed capable of giving reliable information enough to allow therapeutic decisions. The American College of Rheumatology response criteria for Rheumatoid Arthritis e.g. were prevalingly developed on the basis of studies dealing with oral gold therapy in the late eighties of the last century [1]. Auranofin, though, is now recognized to only have a mall clinically and statistically significant benefit on the disease activity of patients with RA. The beneficial effects appear to be modest compared to drugs such as methotrexate or parenteral gold [2]. Hence, no wonder that high (up to 40 %) placebo response rates regarding ACR 20% improvement after three months have to be acknowledged in placebo controlled trials with biologics. You get the answers you are asking for.

To assess Rheumatoid Arthritis activity composite scores, such as the Disease Activity Score including a 28 joint count (DAS28) [3], the Simplified Disease Activity Index (SDAI) [4], and the Clinical Disease Activity Index (CDAI) [5] are frequently utilized in clinical trials, resulting almost always in mean comparisons. The problem is that the reader learns only little from the average, but of course much more from the extremes. Average values for groups give the reader information, which cannot be transferred into clinical routine directly as extremely seldom groups of patients gain to be treated in a way that their average disease activity, regardless of the individual one, should improve. The normal and challenging enough situations in daily routine is the one that individuals seek for maximum symptom relief. Hence, means can of course not constitute the therapeutic goal for the individual patient.

In addition, all scores, also including patient related outcomes, such as the Health Assessment Questionnaire (HAQ) [6], the Routine Assessment of Patient Index Data 3 (RAPID3) [7], and the Rheumatoid Arthritis Disease Activity Index-Five (RADAI-5) [8], were predominantly developed on the basis of actively diseased patients. The idea behind the development of these instruments never was to denote health, but active disease. That is why the scores’ reliability decreases with an improving disease course. Thus it seems conceivable that the instruments under –or over estimate the amount of improvement, and, for this reason, in daily routine physicians are well advised to listen carefully to their patients. In addition, an urgent need constitutes an instrument designed to characterize the patient in remission, however, what we easily can refrain from are discussions whether patient’s assessment of disease activity or general health may violate the scores’ results and should therefore be replaced by e.g. physician’s assessment of disease activity [9].

Of course it is regarded obligatory to document disease activity. A numerical value, however, must not be regarded as a dogma, it may, though, constitute a landmark. The overall goal must be the best possible outcome achievement for the patient, defined by the patient, who can be regarded the real expert of his individual disease [10]. It is certainly not important that the physician feels well with the disease outcome, but the patient, who in fact is the one to bear the burden of the disease.

We could demonstrate that DAS28, and SDAI/CDAI levels achievable by individual patients differ considerably depending primarily on patient’s pain perception and gender, whereas age, disease duration and RF seem to be indecisive [11,12]. Additionally, it has to be pointed out that the degree of agreement between two instruments does never allow for direct interchange ability [13]. All the scores, whether composite indexes or PROs, constitute useful tools for the monitoring of RA patients. However, only stable low values can be regarded indicators of an uncomplicated course of the disease. Significant fluctuations, however, must be assessed with respect to the changes of the single items and possibly coexisting or newly occurring diseases [14]. And, this leads to another hallmark of
criticism with respect to disease activity assessment. In rheumatology the definition of worsening is lacking, but this is a different story.

Rheumatology as a discipline has to live with the fact that hard and uninfluenced parameters for disease activity monitoring are not available [15]. The application of disease activity assessment instruments cannot substitute for careful clinical patient examination. As a consequence individualised patient care, which commonly is regarded the prerequisite for the best possible outcome, consistently must be based on individualised patient monitoring [16] and is of course far more than achieving a simple numerical value.

References