Is self-assessment by patients of disease activity acceptable over the long term in rheumatoid arthritis? A 3-year follow-up of 771 patients

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Key message: Self-assessment of disease activity is feasible in rheumatoid arthritis, but its frequency decreases over time.

Sir,

In rheumatoid arthritis (RA), regular assessment of disease activity is an integral part of a treat-to-target approach.[1] However, repeated, close-in-time consultations with the rheumatologist are not always feasible. In the Comorbidities and Education in Rheumatoid Arthritis (COMEDRA) trial, RA patients were trained to perform a self-assessment of Disease Activity Score on 28 joints (DAS28), termed auto-DAS (they were randomised to have this visit either at baseline, or after 6 months).[2] At the 6-month timepoint, the COMEDRA trial showed the feasibility of auto-DAS, and we found more therapeutic changes had been made in the auto-DAS arm.[2] The present letter reports the results of the open-label follow-up of this trial, after 3 years. The objective was to assess the feasibility over the long-term of auto-DAS assessment, and determine the characteristics of patients adherent to auto-DAS.

This was an open long-term (2-4 years) extension of the 6 month randomized controlled COMEDRA trial of patients with definite, stable RA. Ethical approval (ethical committee CPP Ile de France VI, number 8-14) and informed patient consent were obtained. During a nurse visit, the importance of regular disease activity assessment was explained, as well as the principle of the DAS28. Patients were trained by a nurse to perform auto-DAS, using a video and teaching of self-assessment of joints (the training took approximately 30 minutes). It was suggested to them to perform this self-assessment regularly and to note it in a booklet. In the present follow-up, 2-4 years after the end of the trial, patients were seen in a face-to-face interview with a nurse and the frequency of auto-DAS was assessed through the auto-DAS booklet (N=247) and if unavailable, from patient questioning. Adherence to auto-DAS was defined as the performance of at least one auto-DAS more than 6 months after the end of the trial. Characteristics of adherent versus non adherent patients were compared by univariate and multivariate logistic regression analyses and included demographic and disease activity variables as well as the centre, according to its recruitment in the trial (centres were binarised as higher or lower than median inclusion number).

Of the 970 recruited patients, 771 (79.5%) were followed up 3 years and had available data regarding auto-DAS: mean (±standard deviation) age 61 (±11) years, median [interquartile range, IQR] disease duration 15 [9 - 23] years; 615 (80%) were women and 534 (69%) were currently taking a biologic. There were no notable differences between those followed-up or not (data not shown). The mean baseline and 3-year DAS28 scores (calculated by the health professionals) were respectively 3.1±1.3 and 2.8±1.4, the mean mHAQ was 0.38 (±0.45). The inter-rater reliability (measured by intraclass correlation coefficient) of DAS28 between health professional and patient was 0.50 [95% confidence interval 0.43-0.56] at baseline and it was 0.62 [0.57-0.67] at 3 years. After 3 years, 354 (46%) patients were adherent to auto-DAS. For adherent patients the median [IQR] number of auto-DAS performed was 5.4 [1.7 – 12.8] overall, i.e. 2.3 [0.8 – 5.9] per year. However among the adherent population, the number of patients who performed an auto-DAS at least once per year decreased over time (**Figure**) ($p<0.0001$). In the multivariate analysis, only larger inclusion centres were significantly associated to an adherent behaviour (odds ratio 2.9 [95% confidence interval 2.0 – 4.1], $p<0.0001$).

These results confirmed the feasibility of auto-DAS. Auto-DAS may reflect flares and allow the health professional to obtain an overview of health status between visits.[3-5] These results further indicate that after a short training, many of these long-standing, moderately active RA patients continued to perform an auto-DAS, though the performance of auto-DAS decreased over time. It is of course possible that patients who self-reported autoDAS were not accurate. It is noteworthy that in this cohort, most patients did not receive any ongoing positive feedback on their auto-DAS. In the larger inclusions centres, auto-DAS adherence was higher. We hypothesise that a high number of patient inclusion reflected local strong involvement of physicians and nurses in the project. The results are suggesting a less optimal performance of the auto-DAS in the absence of discussion of the results of the auto-DAS with the treating rheumatologist. It is noteworthy that patients in the present study had stable RA, usually in moderate disease activity. It is possible that auto-DAS is felt as worthwhile, when patients are flaring or otherwise doing poorly. Reversely, repeated

assessments may pall for patients in long-term stable disease.[6] The decrease over time of auto-DAS, and previous studies of between-visit assessments (such as e-health tools can provide) indicate a benefit from feedback from the health care providers, to keep patient motivation up.[6,7]. These data emphasize the importance of a clear communication between the rheumatology team and the treating rheumatologist in order to explain clearly the objectives and the potential benefit of this initiative. These results thus suggest the necessity of a regular reinforcement of this initiative; which might be optimally performed by the rheumatology team during the recommended annual systematic and comprehensive review supervised by the rheumatology team. [8]

We conclude that self-assessment of disease activity is feasible in RA but positive reinforcement appears necessary. Further studies should analyse if outcomes are better for patients who perform self-assessments regularly.

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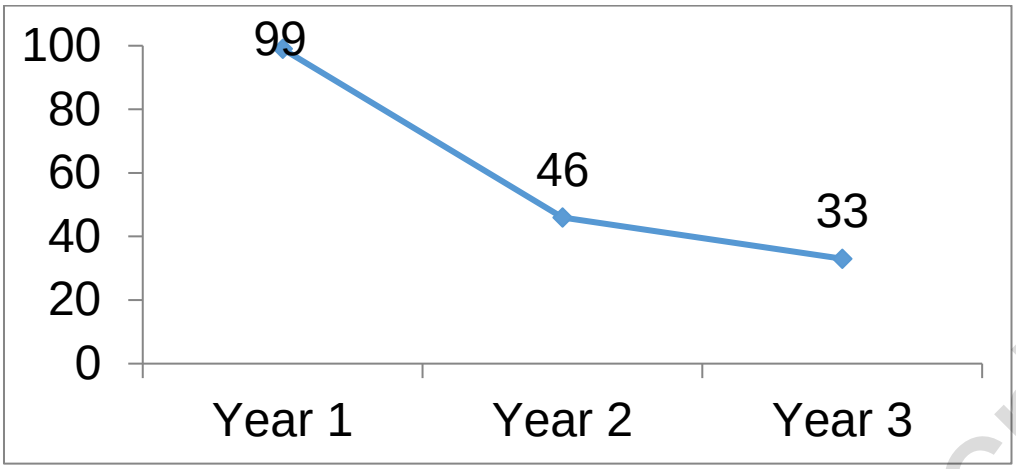
Figure title. Percentage of patients performing at least one auto-DAS per year, over time



Legend

X axis year of follow-up after the trial

Y axis percentage of patients performing at least one auto-DAS each year, among patients considered adherent (i.e., having performed at least one auto-DAS more than 6 months after the end of the trial).