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Original article

Disease impact of rheumatoid arthritis in patients not treated with advanced therapies; survey findings from the National Rheumatoid Arthritis Society

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Abstract

Objective. The aim was to reveal the everyday impact of living with RA in people not treated with advanced therapies (i.e. biologic or targeted synthetic DMARDs).

Methods. People with RA, with disease duration >2 years, not currently treated with advanced therapies, completed an online survey promoted by the National Rheumatoid Arthritis Society. Items covered demographics, current treatment, RA flare frequency, the Rheumatoid Arthritis Impact of Disease (RAID) tool and questions reflecting work status and ability. Descriptive and multivariable regression analyses were performed.

Results. There were 612 responses from patients having a mean age of 59 years, 88% female, 37.7% with disease duration 2–5 years and 27.9% with disease duration 5–10 years. In the last year, 90% reported an RA flare, with more than six flares in 23%. A RAID patient acceptable state was recorded in 12.4%. Each of the seven domains was scored in the high range by >50% respondents; 74.3% scored sleep problems and 72% fatigue in the high range. A need to change working hours was reported by 70%. Multivariable analyses revealed that increasing difficulties with daily physical activities, reduced emotional and physical well-being in the past week were all significantly associated with pain, number of flares and ability to cope ($P < 0.005$). The RAID score was significantly predictive of the number of flares.

Conclusion. Patients not currently treated with advanced therapies experience profound difficulties in everyday living with RA, across a broad range of measures. We advocate that patient-reported measures be used to facilitate holistic care, addressing inflammation and other consequences of RA on everyday life.

Key words: rheumatoid arthritis, impact of disease, patient-reported outcomes

Key messages

- In established RA patients not on advanced therapies, patient-reported outcomes indicate high levels of suffering.
- The Reumatoid Arthritis Impact of Disease acceptable state is very uncommon.
- High levels of pain, physical disability, sleep difficulties and fatigue are prominent symptoms.

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CLINICAL SCIENCE

Introduction

It is widely established that prompt and effective treatment in RA using treat-to-target (T2T) strategies [1] improves disease outcomes. A range of therapies are available, including conventional synthetic, targeted synthetic and biologic DMARDs (csDMARDs, tsDMARDs and bDMARDs, respectively). The principles of T2T incorporate treatment escalation, using all available therapies, to achieve and maintain a chosen target, usually remission or a low disease activity state. A variety of composite DASs are used, capturing specific objective measures of inflammation and broad patient-reported subjective measures of disease impact.

The 28-joint count DAS (DAS28) is used in the UK to determine eligibility for advanced therapies (tsDMARDs and/or bDMARDs). However, there is a discrepancy between the least stringent T2T outcome, a low DAS28 score ($\leq$3.2; LDAS), and the minimum threshold of a high DAS28 score ($\geq$5.1; HDAS) required in some guidelines to permit the use of tsDMARDs and/or bDMARDs [2]. This means that people with moderate disease activity, between these thresholds (DAS28 $>$ 3.2 and $<$5.1; mDAS), are not eligible for advanced therapies. Eligibility is also restricted by the National Institute for Health and Care Excellence (NICE) biologics pathway in England and Wales because it limits the maximum number of advanced therapies a patient can ever receive, denying a trial of all possible options [2]. Reflecting restrictions such as these, huge variations are reported in DMARD use globally [3].

Patients with RA who have not achieved remission, or at least LDAS, have poor outcomes from the consequences of unsuppressed inflammation on their joints, including function and requirement for orthopaedic surgery, in addition to the cardiovascular consequences of accelerated atherogenesis [4–6]. Yet when patients in the mDAS category receive advanced therapies, they respond as well as those in HDAS and better than those remaining on csDMARDs [7, 8], in terms of T2T goals of remission or LDAS and functional outcomes. This confirms that substantial benefits can be gained by treating patients in mDAS with advanced therapies.

Patient and rheumatologist perceptions of what constitutes a successful treatment outcome can differ [9], with patients using a broader definition than that provided by DAS28, leading to discordance in the understanding of disease severity between patients and physicians [9]. In this large Korean survey, more than half of patients with RA thought their disease more severe than their physicians did, with pain, fatigue and sleep disturbance being some of the factors associated with discordance. The widely used composite outcome scores DAS28 and the Simple Disease Activity Index (SDAI) are derived from observer, patient and laboratory assessments. Patient assessments in these scores are limited to a tender joint count and a subjective global assessment of disease. A variety of composite patient-reported outcome measures (PROMs) assess the impact of RA on a broader range of aspects of living with RA, such as the Rheumatoid Arthritis Impact of Disease (RAID), the Rheumatoid Arthritis Disease Activity Index (RADAI) and the Routine Assessment of Patient Index Data-3 (RAPID3). The RAID score is a patient-derived differentially weighted seven-item validated and reliable tool, sensitive to change and EULAR adopted [10]. It is well correlated with RADAI, patient global measures, short form-36 (SF-36) physical and mental subscales, EuroQol-5 Dimension (EQ-5D) health status questionnaire and the DAS28 score [10, 11]. On an individual patient level, a score below two is deemed a patient acceptable state [12, 13], and both absolute and relative minimally clinical important improvements are also defined [13].

This study focuses on the everyday impact of RA in patients not receiving advanced therapies with tsDMARDs and/or bDMARDs. It aims to assess in detail a wide range of aspects of quality of life and everyday living using the RAID score and other measures of the impact RA. The work has been instigated by the National Rheumatoid Arthritis Society (NRAS; https://www.nras.org.uk/), the UK RA patient organization.

Methods

Survey design and dissemination

Patients with RA were invited by NRAS to complete a survey (available from NRAS on request). This was hosted using the NRAS Health-Unlocked online peer support forum and shared more widely through NRAS social media channels, including Facebook, Instagram, LinkedIn and Twitter. A landing page explained the rationale behind the survey, emphasizing the aim to understand the experiences of patients of living with RA. This was followed by screening questions to identify the target population based on current therapies.

Target population

The target population was people with RA, $>$16 years of age, with a disease duration of $\geq$2 years and living in the UK. Included patients were allowed to be on analgesics, NSAIDs, CSs and csDMARDs but not on advanced therapies, defined as bDMARDs and tsDMARDs.

Survey components

Items recorded sociodemographic information, including age, gender, ethnicity, highest educational achievement and employment status. RA-specific information included disease duration, current therapies and access to advanced therapies.

The frequency of RA flares in the last year was recorded, based on the definition: an episode of increased RA disease activity accompanied by worsening symptoms, functional impacts, and clinical indicators of sufficient magnitude and duration to place individuals at greater risk of joint damage and poorer outcomes when left untreated.

The impact of RA on quality of life in the last week was assessed by completion of the RAID patient-reported outcome score covering seven domains: pain, functional disability, fatigue, sleep, coping/self-efficacy, physical and emotional well-being. Each of the seven domains is scored on an 11-integer numerical rating scale (NRS), with 0 representing a good low activity score and 10 a high severe activity score. A patient acceptable state is defined as a RAID score of <2. In the absence of guidance, we arbitrarily classified the NRS scores for each individual domain into the following ranges (low range 0–<5, high range ≥ 5, mild 0–2 and severe 8–10) to gain an idea of which domains scored particularly poorly or well.

Difficulties at work were measured using a selection of questions extracted from the Work Productivity and Activity Impairment (WPAI) questionnaire (http://oml.eular.org/sysModules/obxOML/docs/id_98/WPAI-GH_English_US_V2.pdf).

Statistical analysis

Descriptive data analyses were undertaken after data collection, followed by univariable and multivariable regression analyses. Independent variable selection for multivariable model building was based on their face validity for prediction of dependent variables and considerations of correlational coefficients, significance levels and collinearity. Age and gender were maintained in the models as an *a priori* decision. Independent variable inclusion in logistic backwards stepwise regressions (as informed by univariable analyses) was conducted to examine associations with key PROMs. Multivariable regression models were created separately for the following dependent variables: pain in the last week, ability to cope with their RA in the last week, and the number of RA flares experienced in the past 12 months. The SPSS statistical package 26 (SPSS, Chicago, IL, USA) was used for all data analyses (https://www.ibm.com/support/pages/downloading-ibm-spss-statistics-26).

Results

Six hundred and twelve patients completed the survey. The mean age was 59 years, 88% were female and 98.5% were of White ethnicity. RA disease duration was 2–5 years in 37.7%, 5–10 years in 27.9% and >10 years in 34.2%. Full sociodemographic characteristics are shown in Table 1.

RA treatment

Five hundred and twenty-nine patients (86.4%) were taking at least one csDMARD, and 15.4% were on CSs. csDMARDs were used as monotherapy in 262 patients (42.8%) and as combination therapy in 267 patients (43.6%). The majority of patients were on MTX (61%), followed by HCQ (37%). Other medication included SSZ (30%), LEF (9%) and AZA (0.5%). The most frequent combination csDMARD therapy regimen was MTX with HCQ ($n = 151$, 25%), followed by MTX and SSZ ($n = 95$, 16%).

Most respondents (76%) indicated that advanced therapies had not been offered or discussed with them. Of these, 8% reported not being eligible for these therapies. 3% reported that they had experienced side effects, implying previous use of at least one advanced therapy, and only 0.3% reported that they were not on advanced therapies because they were in remission.

RA flares

In the last 12 months, 140 (23%) respondents indicated having experienced six or more flares, 111 (18%) reported three flares, and 60 (10%) indicated that they had experienced no flares. Of those who had experienced flares, 215 (39%) indicated that, on average, a flare lasted 3–7 days, and 73 (13%) indicated that it lasted for >5 weeks.

Impact of disease in the last week

Responses to all seven RAID domains were completed in the majority of cases ($n = 587$), with one domain missing in 24 additional cases. The missing domain was emotional well-being in all 24 cases and was substituted with the mean of the submitted responses to the other six domains. A total RAID score was therefore calculated for 611 respondents. The mean was 4.79 (S.D. 2.04, range 0.24–9.10). A RAID score <2, deemed a patient acceptable state [12, 13], was recorded in 12.4% of participants.

Table 2 shows, for each domain, the proportion of respondents scoring low range (<5), high range (≥ 5), mild (0–2) and severe [8–10] scores. In each of the seven RAID domains, $>50\%$ of respondents recorded a score in the high range in the last week. Sleep and fatigue were the domains with the highest proportion of respondent scores in the high range and severe categories, with 74.3%/40.8% and 72%/38.7% of respondents scoring in these categories, respectively. Ability to cope was the lowest scoring domain, with least disability among respondents; however, even here 51.2% scored in the high range and only 28.9% in the mild range.

The full spread of scores in each domain is shown in Table 3.

Impact on occupation

A total of 371 respondents answered questions on current employment. Fifty-seven of these (15%) reported ≥ 7 days off work in the last 6 months. However, 427 individuals responded to a question assessing whether they had had to change their working hours owing to their condition, indicating that a larger number of participants had been employed at some point since RA diagnosis. Of these, 298 (70%) indicated that their RA had caused them to change their working hours.

Table 1 Sociodemographic characteristics of individuals participating in the survey

Characteristic	Value [*n* (%) or mean (S.D.)]	Missing [*n* (%)]
Age, years, mean (S.D.)	59 (11.84) Range: 69 (minimum = 19, maximum = 88)	N/A
Gender, *n* (%)	Female, 540 (88.2) Male, 68 (11.1)	4 (0.7%)
Time since diagnosis, years, *n* (%)	2–5, 231 (37.7) 5–10, 171 (27.9) 10+, 209 (34.2)	1 (0.2%)
Ethnicity, *n* (%)		
White	603 (98.5)	N/A
Mixed[a]	3 (0.5)	
Black[b]	1 (0.2)	
Asian[c]		
Education, *n* (%)		
University education/professional/vocational equivalents	262 (42.8)	N/A
A levels or equivalent	60 (9.8)	
GCSE/O level grade or equivalent	108 (17.6)	
Vocational, NVQ, BTEC or equivalent	91 (14.9)	
No qualifications	57 (9.3)	
Other/prefer not to say	34 (5.6)	
Work, *n* (%)		
Employed 1–39 h per week	188 (30.7)	N/A
Employed ≥40 h per week	58 (9.5)	
Not employed or seeking work	49 (8.0)	
Job seeking	10 (1.6)	
Disabled and not able to work	79 (12.9)	
Retired	228 (37.3)	
Geographical spread, *n* (%)		
Southern England (includes London SHA, South Central SHA, South East Coast SHA, South West SHA)	228 (37.3)	1 (0.2)
Northern England (includes North East SHA, North West SHA, Yorkshire & the Humber SHA)	132 (21.6)	
Midlands (includes East & West Midlands SHA, East of England SHA)	155 (25.3)	
Wales	26 (4.2)	
Northern Ireland	10 (1.6)	
Scotland	60 (9.8)	

[a]Includes mixed White and Asian, and any other mixed background. [b]Includes Black/Black British-Caribbean. [c]Includes Asian/Asian-British, Asian/Asian British-Pakistani, and any other Asian background. SHA Strategic Health Authority.

Table 2 Summary scores across seven patient-reported outcomes in the past week

Domain	Score <5 (%) Low range	Score ≥5 (%) High range	Score 0–2 (%) Mild	Score 8–10 (%) Severe
RAID total score	50.2	49.8	12.4[a]	4.6
Pain	40.9	59.1	19.4	16.6
Functional disability	40.7	59.3	24.1	21.0
Fatigue	28.0	72.0	14.5	38.7
Sleep	25.7	74.3	11.3	40.8
Physical well-being	36.5	63.5	17.8	16.9
Emotional well-being	44.8	55.2	24.1	20.7
Coping	48.8	51.2	28.9	12.6

[a]Percentage of respondents with Rheumatoid Arthritis Impact of Disease (RAID) total score 0–<2, defined as a patient acceptable state.

Table 3 Participant reporting of key RA symptoms experienced in the past week

Pain in the last week (range 1–10, with 10 being indicative of extreme levels of pain)			Difficulties doing daily physical activities in the last week (range 1–10, with 10 being indicative of extreme difficulties in doing daily physical activities)		
Scale	**Frequency**	**Valid percentage**	**Scale**	**Frequency**	**Valid percentage**
0 = no pain	30	4.9	0 = no difficulties	50	8.2
1	40	6.5	1	44	7.2
2	49	8.0	2	53	8.7
3	67	10.9	3	54	8.8
4	65	10.6	4	48	7.8
5	71	11.6	5	75	12.3
6	95	15.5	6	81	13.2
7	94	15.4	7	79	12.9
8	61	10.0	8	69	11.3
9	17	2.8	9	25	4.1
10 = extreme pain	23	3.8	10 = extreme difficulties	34	5.6
Missing	–	–	Missing	–	–
Total	612	100.0	Total	612	100.0
Score $<$ 5	251	40.9	Score $<$ 5	249	40.7
Score $\geq$ 5	361	59.1	Score $\geq$ 5	363	59.3
Fatigue in the last week (range 1–10, with 10 being indicative of being totally exhausted)			**Sleep difficulties in the last week (range 1–10, with 10 being indicative of extreme difficulties sleeping in the last week)**		
Scale	**Frequency**	**Valid percentage**	**Scale**	**Frequency**	**Valid percentage**
0 = no fatigue	26	4.2	0 = no difficulty	0	0.0
1	24	3.9	1	34	5.6
2	39	6.4	2	35	5.7
3	35	5.7	3	34	5.6
4	48	7.8	4	54	8.8
5	56	9.2	5	55	9.0
6	51	8.3	6	59	9.6
7	96	15.7	7	91	14.9
8	108	17.6	8	89	14.5
9	66	10.8	9	53	8.7
10 = totally exhausted	63	10.3	10 = extreme difficulties	108	17.6
Missing	–	–	Missing	–	–
Total	612	100.0	Total	612	100.0
Score $<$ 5	172	28.0	Score $<$ 5	157	25.7
Score $\geq$ 5	440	72.0	Score $\geq$ 5	455	74.3
Physical well-being in the last week (range 1–10, with 10 being indicative of being very bad)			**Emotional well-being in the last week (range 1–10, with 10 being indicative of very bad)**		
Scale	**Frequency**	**Valid percentage (n = 611)**	**Scale**	**Frequency**	**Valid percentage (n = 586)**
0 = very good	32	5.2	0 = very good	49	8.4
1	34	5.6	1	40	6.8
2	43	7.0	2	52	8.9
3	58	9.5	3	66	11.3
4	56	9.2	4	55	9.4
5	116	19.0	5	72	12.3

(continued)

Table 3 Continued

Physical well-being in the last week (range 1–10, with 10 being indicative of being very bad)			Emotional well-being in the last week (range 1–10, with 10 being indicative of very bad)		
Scale	**Frequency**	**Valid percentage ($n = 611$)**	**Scale**	**Frequency**	**Valid percentage ($n = 586$)**
6	74	12.1	6	54	9.2
7	95	15.5	7	76	13.0
8	69	11.3	8	70	11.9
9	15	2.5	9	23	3.9
10 = very bad	19	3.1	10 = very bad	29	4.9
Missing	1	–	Missing	26	–
Total	612	100.0	Total	612	100.00
Score $<$ 5	223	36.5	Score $<$ 5	262	44.8
Score $\geq$ 5	388	63.5	Score $\geq$ 5	324	55.2

Ability to cope with their RA in the last week (range 1–10, with 10 being indicative of people feeling their ability to cope is not good)		
Scale	**Frequency**	**Valid percentage ($n = 611$)**
0 = very well	69	11.3
1	51	8.3
2	57	9.3
3	62	10.1
4	60	9.8
5	99	16.2
6	78	12.8
7	58	9.5
8	48	7.9
9	13	2.1
10 = very poorly	16	2.6
Missing	1	–
Total	612	100.0
Score $<$ 5	299	48.8
Score $\geq$ 5	312	51.2

Stepwise backwards regression analyses

In multivariable analyses (Table 4), for every unit increase in the scores of daily physical activities and of emotional well-being in the past week, there was a significant increase in pain experienced in the past week and worsening in the ability to cope ($P < 0.005$). Increasing difficulties with daily physical activities and reduced emotional and physical well-being in the past week were all significantly associated with all three outcomes of pain, number of flares (in the last 12 months) and ability to cope ($P < 0.005$). The RAID score was significantly predictive of the number of flares in age- and gender-adjusted models, whereby for every unit increase in the score, there was an increase in the number of flares by 0.5 units (β-co-efficient 0.52; 95% CI 0.45–0.58).

Discussion

This survey, led by the NRAS, has focused on the impact of disease in patients with established RA currently not receiving advanced therapies. It shows that RA flares are extremely common, with 90% of patients experiencing at least one flare and nearly a quarter reporting six or more flares in the last year. Only 12.4% of respondents were currently in a patient acceptable state, as defined by a total RAID score less than two. The high impact of RA on everyday life is further emphasized by the finding that in all seven domains, >50% respondents recorded scores in the high range, indicating a significant burden in the last week. This is supported by impact on work data from the survey, with 70% of respondents reporting a change in working hours owing to their RA. Difficulties with daily physical activities and worsened physical and emotional well-being were significantly associated with higher pain, a greater number of flares and worsened ability to cope. Thus, across all assessed PROMs, RA patients currently not taking advanced therapies experience an interrelated burden of adverse outcomes from their disease.

These findings argue for a detailed interpretation of DAS28 or SDAI scores when considering treatment escalation to achieve T2T goals. Unsuppressed

Table 4 Multivariable models with pain, number of RA flares and ability to cope as dependent outcomes

Independent variable	Model 1: pain in the last week Coefficient (95% CI) *n* = 584	Model 2: number of RA flares experienced in the last 12 months Coefficient (95% CI) *n* = 607	Model 3: ability to cope with their RA in the last week Coefficient (95% CI) *n* = 393
Gender	−0.120 (−0.445, 0.206)	0.040 (−0.372, 0.452)	0.039 (−0.397, 0.476)
Age	−0.009 (−0.018, 0.000)	−0.009 (−0.020, 0.002)	0.020** (0.008, 0.031)
Number of RA flares experienced in the last 12 months	0.167** (0.103, 0.230)	–	–
DMARDs: take LEF	–	0.499* (0.053, 0.945)	–
Pain in the last week	–	0.302** (0.222, 0.381)	–
Difficulties with daily physical activities in the last week	0.474** (0.403, 0.545)	–	0.323** (0.234, 0.412)
Physical well-being in the last week	0.188** (0.104, 0.272)	0.154** (0.072, 0.237)	0.206** (0.098, 0.314)
Emotional well-being in the last week	−0.068* (−0.129, −0.006)	–	0.336** (0.258, 0.414)
Ability to cope with their RA in the last week	0.130** (0.056, 0.204)	–	–
Model information			
Model fit	0.000**	0.000**	0.000**
R	0.876	0.574	0.861
R^2	0.767	0.329	0.741

Other variables adjusted for in the models included difficulties with working with the hands, DMARD use and feeling that RA is controlled enough to allow daily life. The *R* value represents the simple correlation. The R^2 value indicates how much of the total variation in the dependent variables can be explained by the independent variable(s). *$P < 0.05$; **$P < 0.005$. LEF: leflunomide.

inflammation, and its consequences for individual component scores within DAS28/SDAI, should be addressed with an escalation of immune suppression. However, a high patient global score or tender joint count might reflect factors other than inflammation. Composite PROMs, such as RAID, provide a detailed analysis of the breadth and severity of the impact of RA on patients' everyday lives. When a failure to reach a RDAS or LDAS T2T goal is driven by non-inflammatory factors, it would be appropriate to target high-scoring domains from the responses to PROMs, with interventions such as cognitive behavioural therapy for fatigue, poor sleep and mental health or neurogenic agents for pain sensitization. A positive impact on these will then be reflected in a lower patient global score and a higher likelihood of achieving the desired DAS28 or SDAI T2T goal. There is also scope for greater use of non-pharmacological interventions in patients in remission. A study of 140 patients with early RA who had achieved rapid and sustained remission within a year revealed that one in five had discordant poorly controlled pain and/or fatigue [14]. Likewise, of 134 RA patients with established disease in remission or low disease activity, RAID was at least two in 51.5% [15]. In a holistic model of care, these important measures of quality of life should be recorded and addressed, as advocated by the NICE [16]. In support of our findings, recent data from the Rheumatoid Arthritis Medication Study (RAMS) demonstrate that despite a 'satisfactory' rating of their condition, early RA patients with high PROM scores are less likely to respond to therapy, calling for high vigilance to optimize care and outcomes [17].

Although this survey specifically targeted patients not on advanced tsDMARDs and/or bDMARDs, it was not possible to determine the current DAS28 score or the treatment history for each patient. The minimum disease duration of 2 years means that it is likely that those with HDAS (i.e. DAS28 > 5.1) up to that time point would already have been treated with advanced therapies and therefore excluded from the survey. Some might have been in the HDAS range and not on advanced therapies because they were about to start or were in transition to a second or third tsDMARD or bDMARD. Only 3% indicated previous adverse events in response to bDMARDs, suggesting very few might have been in transition between advanced therapies for this reason. We believe it likely that the majority of respondents had never received advanced therapies, and in UK practice this means they would have had a DAS <5.1. Regardless of the current DAS28 score, our findings

indicate a very high impact of RA on everyday quality of life. The dominance of fatigue and sleep domains recording the greatest disability is also supported by previous studies including patients who were in remission or LDAS [15, 18–20].

The strengths of this survey are its size, with 612 respondents, with age and gender as expected for an established RA population, and its ecological validity, with broad geographical reach across England, making the findings largely generalizable, although Northern Ireland, Scotland and Wales were under-represented. The frequency of csDMARD use is reflective of common treatment approaches in the UK. Limitations of this study include the survey-based nature of data collection at a single time point, with potential selection bias, ethnicity being primarily White, and the high proportion of female respondents. Although the last of these is expected in RA, the results are limited in generalizability of findings to other ethnic groups and males. The disproportionally high number of respondents achieving the highest levels of education (university degree or similar) will have introduced bias. These respondents are more likely to understand complex information, access resources for self-help and adhere to therapies, thus maximizing opportunities to maintain their quality of life. This means that our findings are a likely to be underestimation of the burden of RA across all patient groups. The strict eligibility criteria for advanced therapies in the UK might have influenced the impact of disease on our respondents, because all had established RA for $\geq$2 years, and $>$10 years in 34%. It would be interesting to reproduce our findings in similar people with established RA not on advanced therapies from countries where the disease activity threshold to escalate therapy is lower. Finally, identification of flares by subjective report might have been biased if there was difficulty in distinguishing an RA flare from other causes of short-term pain, such as intercurrent infection or a loss of long-term control of RA.

In conclusion, this study highlights the extensive impact that RA exerts on everyday quality of life in patients not treated with advanced therapies, extending previous work demonstrating the poor long-term function and orthopaedic outcomes in similar patients. PROMs represent a valuable source of information to facilitate holistic care, combining suppression of inflammation with other interventions to minimize the impact of disease on important aspects of daily life, including fatigue, sleep and well-being. We advocate routine collection of PROMs in daily practice to provide insights into disease severity and impact otherwise not captured in composite scores, such as DAS28.

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Data availability statement

Questionnaire and data are available from National Rheumatoid Arthritis Society on request.

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