

# PATIENTS' AND PHYSICIANS' PRIORITIES FOR IMPROVEMENT. THE CASE OF RHEUMATIC DISEASES

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## Abstract

**Objectives:** To compare the health priorities elected by patients with rheumatic diseases and by their attending rheumatologists.

**Patients and Methods:** We undertook a cross-sectional study among patients and rheumatologists in Portuguese rheumatology outpatient clinics. 75% of all Portuguese Rheumatology Departments agreed to participate. Rheumatologists from non-participating hospital departments were asked to collaborate through their private practices. All patients were eligible for inclusion except if they were under 18 years of age or had a mental disorder that would affect their participation. Data were collected through dedicated questionnaires. Patients were asked to indicate 3 priorities for improvement out of 12 health domains (Arthritis Impact Measurement Scale 2) regarding their rheumatic disease. Rheumatologists were asked similar questions focused around rheumatoid arthritis (RA) and osteoarthritis (OA).

**Results:** 1,868 patients and 56 rheumatologists entered the study. The most commonly selected priorities by patients with rheumatic diseases were: "Rheumatic pain" (70%), "Walking and bending" (45%), and "Hand and Finger Function" (40%). The main priority for improvement among patients with RA was "Rheumatic Pain" (69%), while rheumatologists more commonly elected "Work" (55%) as their main priority for these patients. Among patients with OA, "Rheumatic Pain" was the first priority for both patients and doctors (elected by 75%, and 55% of respondents, respectively).

**Conclusions:** Our study showed discordance between the priorities for improvement elected by patients and by their respective physicians. This

was more pronounced in RA than in OA. Studying and addressing such differences may support physicians and institutions to better achieve the prime goal of incorporating and responding to patients' needs and preferences.

**Keywords:** Patients report priorities; Pain; Function.

### «What this paper adds» box

- Physicians seem to have a tendency to focus on markers of biological processes and long-term structural prognoses rather than patients' needs and preferences. There is a consistent call by diverse international groups and regulatory bodies towards the development and regular use of patient-reported outcomes in clinical research. However, current knowledge on patients' preferences is scarce.
- This paper finds that priorities elected by Portuguese patients with rheumatic conditions are quite consistent with those observed in different European countries; however, there is considerable discordance between patient and their rheumatologists' elected priorities. Such studies may assist physicians in giving appropriate consideration to patients' values and expectations when designing their clinical strategies.

## Introduction

Physician and patient assessment of patients' health status and health priorities may diverge<sup>1</sup>. Physicians may have a tendency to focus on markers of biological processes and long term structural prognosis rather than patients' needs and preferences<sup>2</sup>. In a recent study, the International Classification of Functioning, Disability and Health (ICF) of WHO was used to contrast patient and physician's views. Patient focused groups confirmed 74 out of 76 ICF

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categories previously selected by physicians to be included in the Comprehensive ICF Core Set for RA. However they identified 62 additional categories which should be considered, mainly related to bodily functions, environmental factors, activities and social participation<sup>3</sup>.

Shared patient and physician decision-making in disease management ranks very high among patients' concerns and inclusion of patients' views in assessment and research can contribute to better doctor-patient communication, leading to more appropriate therapeutic options<sup>4-7</sup>. Workshops at OMERACT (Outcome Measures in Rheumatoid Arthritis Clinical Trials) reviewed outcome measures used in rheumatoid arthritis<sup>5</sup> and suggested the inclusion of patients' perspectives including their priorities for treatment, using measures like the Arthritis Impact Measurement Scale 2<sup>3,8</sup>. The same group has recently promoted the concept of PLIMs (Personal Life Impact Measures)<sup>9</sup>. The Food and Drug administration of the USA has recommended that patient reported outcomes should be developed and used to incorporate patients' perspectives in clinical trials<sup>10</sup>. The National Institutes of Health of the USA are actively promoting an ambitious program to address the same needs (PROMIS – Patient Reported Outcomes Measurement Information System)<sup>11</sup>.

Literature on patient's preferences is scarce and few studies have been specifically applied to the rheumatic diseases. Patients with rheumatic diseases tend to prefer treatments that increase their degree of independence<sup>12,13</sup>. However, cultural diversity in patients' preferences in some particular aspects of health care has been demonstrated and several other factors might be influential<sup>6,14-16</sup>. Portuguese patients, for instance, seem to be less proactive and more dependent on their physicians' views and tend to give more importance to an individualized approach with a focus on emotional and personal issues rather than on shared decision-making regarding their treatment<sup>6</sup>.

Understanding such diversities will be pivotal to incorporate patients' perspectives and fine tuning therapeutic strategies towards endpoints that are relevant to patients<sup>5</sup>. We determined and compared the aspects of rheumatic diseases where Portuguese patients and physicians would most like to see improvements. We investigated whether these priorities were affected by sex, age, profession, and educational level, type of rheumatic disease, pain or emotional status of patients.

## Patient and Methods

**Setting and patients.** This cross-sectional multicenter study was carried out between March 2007 and January 2008 in outpatient clinics of Portuguese rheumatology departments. Rheumatologists from non-participating hospital departments were asked to collaborate through their private practices.

**Patients.** All patients attending the rheumatology outpatient clinics of the collaborating hospitals were invited to participate. Patients were only excluded if they were aged under 18, refused to participate, presented any mental disturbance which could affect the interview or if they were attending their first appointment, as no diagnosis or therapeutic management could be assigned to the visit. The number of patients included from each hospital was proportional to the hospitals' affluence, varying from 60 to 300. Private practices included 30 to 50 patients per rheumatologist.

Patients were interviewed in the waiting room and questionnaires included demographic variables, diagnoses, drug treatments currently used, pain level, and the identification of the rheumatologist responsible for their treatment.

**Rheumatologists.** All rheumatologists working at the collaborating Hospitals were invited to participate. Rheumatologists from non-participating hospitals were invited to allow access to patients from their private practices. Information from physicians was collected by a self-administered questionnaire, which included physician's demographic characteristics (age and gender), and a self-reported measure of "aggressiveness" in the treatment of pain.

**Assessment of priorities for health improvement.** Patients were asked to elect three priorities for improvement in their disease by answering question 60 of Arthritis Impact Measurement Scale 2 (AIMS2). This includes 12 areas of health (level of mobility, walking and bending, hand and finger function, arm function, self-care tasks, household tasks, social activity, support from family and friends, rheumatic pain, work, level of tension and mood). Rheumatologists were asked to answer the same question, separately considering their patients with rheumatoid arthritis (RA) and with osteoarthritis (OA).

**Other variables of interest.** Since many factors may influence patients' priorities, we registered patients' age, gender, educational level, marital

and work status, profession, diagnosis, disease duration, pain severity and emotional status. Rheumatologists' age and gender were also recorded.

**Profession.** We used the national classification of professions (Portuguese Institute for National Statistics) and grouped them into two categories: non-active (unemployed, domestic, retired and students), and active. The latter included: non-qualified workers, manual workers (services and sales; farmers and qualified workers of the agricultural and fishing industries; workers, artifices, and installations and mounting workers) and intellectual workers (armed forces; public administration senior managers, company leaders and senior managers; intellectual and scientific professions specialists and scientific professionals; technicians and professionals of intermediate level; administration personnel).

**Diagnoses:** Patients' self-reported diagnoses were used and a main diagnosis was attributed. These included RA, systemic lupus erythematosus (SLE), psoriatic arthritis (PA), other seronegative spondyloarthropathies (SpA), fibromyalgia (FM), localized soft-tissue disease (STD), osteoporosis, and osteoarthritis (OA). Other diagnoses were grouped into 3 categories: 1) Other Connective Tissue Diseases (OCTD), including systemic sclerosis (Scl), Behçet's disease (BD), Sjögren's syndrome (SS) and overlapping syndromes; 2) Peripheral/Axial joint pain (PAJP): cervical pain, low back pain, spine disturbances and non-specific arthralgia; 3) Other diseases, including gout, Paget's disease (PD) and diverse rare diagnoses. Whenever patients referred having more than one disease, the main diagnosis was established in accordance with the highest of the following hierarchy: RA, SLE, OCTD, PA, SpA, OP, OA, FM, PAJP, STD and other diseases.

**Patients' self-reported bodily pain.** The bodily pain dimension of health status from the Short-Form-36 was chosen. Bodily pain is scored as a continuous variable ranging from 0 to 100, where 0 indicates worst pain. It is constructed based on 2 variables, each assessed by a question – Pain Intensity (“How much bodily pain have you had during the past 4 weeks?”) and Pain Interference with Work (“During the past 4 weeks, how much did pain interfere with your normal work?”). The construction of these instruments is explained in detail elsewhere and they have been validated for the Portuguese population<sup>17,18</sup>.

**Patients' mental health status.** This was assessed

through the SF-36 Mental Component, ranging from 0 to 100, where 0 indicates worst mental health status. The mental health subscale of SF-36 is composed of 5 questions: “How much of the time during the past 4 weeks”: 1) “have you been a very nervous person?”; 2) “have you felt so down in the dumps that nothing could cheer you up?”; 3) “have you felt calm and peaceful?”; 4) “have you felt downhearted and blue?”; 5) “have you been a happy person?”.

**Confidentiality and ethical approval:** Patients' confidentiality was assured by the non-existence of personal identifiers. Patients identified their rheumatologist but this information was only used if the physician expressed the wish to receive a personalized analysis regarding his group of patients (with no patient identifiers, since these were non-existent). This option was introduced with the aim of contributing to physicians' education. Otherwise, data was confidential. The study was approved by each Hospital's Ethics Committee.

**Statistical analyses.** Descriptive statistics were used to describe demographic and clinical characteristics. Continuous data were presented as means and standard deviations (SD). Categorical data were described as percentage (number).

Logistic regression models were used to determine which sociodemographic and clinical factors were associated with the choice of health priorities by patients. We present *Odds Ratios* (OR) and respective 95% confidence intervals. Univariate and age and sex-adjusted models were carried out. Statistical significance was considered at the 5% level.

Data were analysed using the statistical software package Stata version SE 10.

## Results

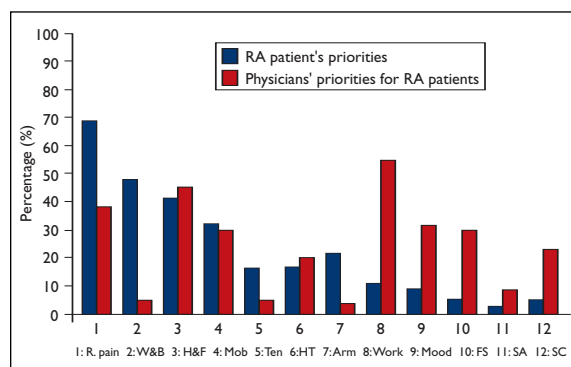
### Socio-demographic and clinical characteristics.

Nine of the twelve Portuguese public hospital rheumatology departments agreed to participate. Demographic and clinical characteristics of patients are shown in Table I. Data from 1,868 patients, 79% women, with a mean age of 56.8 years and a mean educational level of 7.1 (SD 4.5) years, were analyzed. Eighty-one percent were followed in outpatient clinics of nine public hospitals and 19% were recruited in private practices. Thirty-six percent of the patients were professionally active, and 64% were non-active, 41% being retired. RA was the most commonly reported main diagnosis (37%),

**Table I. Socio-demographic and clinical patient characteristics**

| Variables                              | Mean (SD) or % (n)<br>(N=1868) |
|--|--------------------------------|
| Sex, female                            | 79 (1468)                      |
| Age, years                             | 56.8 (14.2)                    |
| Level of Education, years              | 7.1 (4.5)                      |
| Retired                                | 41 (770)                       |
| Active                                 | 36 (671)                       |
| Married/living together                | 73 (1354)                      |
| Duration of rheumatic disease, years   | 11.4 (10.9)                    |
| SF-36 Mental health (0-100,0 is worst) | 53.5 (24.3)                    |
| SF-36 Bodily Pain (0-100,0 is worst)   | 37 (23)                        |
| Main Diagnosis:                        |                                |
| RA                                     | 37 (667)                       |
| SLE                                    | 5 (94)                         |
| OA                                     | 19 (336)                       |
| OCTD                                   | 5 (96)                         |
| FM                                     | 7 (125)                        |
| SpA + PA                               | 4 (71)                         |
| OP                                     | 12 (209)                       |
| Other diseases                         | 2 (32)                         |

Note. Missing data: age – 3 cases; gender – 4 cases; Education – 20 cases; Mental health – 2 cases.



**Figure 1. Rheumatoid arthritis: patients and physicians' priorities.** Columns represent the percentages of RA patients (n=667) and physicians who included the respective area among their three main priorities for improvement in RA. (R. pain: Rheumatic pain; W&B: Walking and bending; H&F: Hands and finger function; Mob: Mobility; Ten: Psychological tension and anxiety; HT: Household tasks; Arm: Arm function; FS: Family support; SA: Social activities; SC: Self care)

followed by OA (19%) and OP (12%). The average duration of the rheumatic disease was 11.4 (SD 10.8) years.

Fifty-six rheumatologists (27 women), 11 representing private practices, entered the study. This represents over 50% of all rheumatologists practising in Portugal. The average age of these physicians was 42.3 (SD 9.7) years.

### Overall priorities of patients with rheumatic diseases and their relation with pain severity.

Overall, the top 3 priorities for improvement elected by the patients were: "Rheumatic pain" (70%, n=1,315), "Walking and bending" (45%, n=841), and Hand and Finger Function (40%, n=747). These were followed by "Mobility" (29%, n=545), "Level of tension" (21%, n=388), "Arm function" (21%, n=383), "Household tasks" (17%, n=325), "Mood" (12%, n=223), "Family support" (5%, n=101), "Social activities" (4%, n=75), "Self-care" (4% (n=74). To study the impact of pain severity on the selection of priorities we performed a similar analysis restricted to the patients who reported more pain (the top 25%): there were no relevant differences (data not shown).

### Priorities for RA: patients' and rheumatologists' perspectives

Priorities for improvement for RA, by rheumatologists and by patients with this disease (n=667) are presented in Figure 1. Physicians and patients agreed in electing "Hand and finger function" as their second most important priority, with a similar expression in both groups (51% of patients and 45% of physicians). However, the first priority for RA patients, "Rheumatic pain", elected by 69% of patients, was selected by only 38% of physicians (third in rank). The third of patients' priorities, "Walking and bending" was elected out by 48% of patients but only by 5% of rheumatologists.

"Work" was the most commonly elected priority by physicians regarding RA (55%). This was not so important for RA patients (11% of patients elected work, making it the 8<sup>th</sup> priority in ranking). Two other areas showed a greater gap (>10%) between patients and doctors selections. These were "Arm function", selected by 22% of the patients and 4% physicians, and "Self-care" (5% patients and 23% physicians).

Investigating the factors that might be associated with the choice of "Rheumatic pain" as a priority among RA patients, we found that only the severity of pain reported by the patient (by the SF-36 bodily pain) was significantly associated. The election of "rheumatic pain" as a priority was more fre-

Table II. Univariate and age and sex-adjusted logistic models for the first priority of RA and OA patients.

| Independent Variables                           | Rheumatic pain for RA patients |                            | Rheumatic pain for OA patients |                            |
|---|--------------------------------|----------------------------|--------------------------------|----------------------------|
|   | Univariate model               | Age and sex-adjusted model | Univariate model               | Age and sex-adjusted model |
|   | OR (95% CI)                    | OR (95% CI)                | OR (95% CI)                    | OR (95% CI)                |
| Age (ref age>67)                                |                                |                            |                                |                            |
| 58-67   | 0.76<br>(0.49, 1.16)           | n.a.                       | 0.79<br>(0.42, 1.45)           | n.a.                       |
| 48-57   | 1.05<br>(0.66, 1.67)           |                            | 0.74<br>(0.38, 1.45)           |                            |
| 38-47   | 1.20<br>(0.67, 2.14)           |                            | 1.12<br>(0.38, 3.27)           |                            |
| 18-37   | 0.83<br>(0.41, 1.71)           |                            | 0.17*<br>(0.04, 0.75)          |                            |
| Sex (male= 1)                                   | 1.02<br>(0.68, 1.52)           | n.a.                       | 1.09<br>(0.62, 1.92)           | n.a.                       |
| Education (years)                               | 1.02<br>(0.99, 1.07)           | 1.02<br>(0.98, 1.07)       | 0.97<br>(0.92, 1.03)           | 0.98<br>(0.93, 1.05)       |
| Marital status<br>(married/ living together= 1) | 0.97<br>(0.67, 1.40)           | 0.96<br>(0.65, 1.40)       | 1.04<br>(0.59, 1.83)           | 1.00<br>(0.55, 1.82)       |
| Profession<br>(active vs. non active)           | 1.15<br>(0.80, 1.65)           | 1.08<br>(0.70, 1.67)       | 0.50*<br>(0.30, 0.84)          | 0.47*<br>(0.26, 0.86)      |
| Public hospital (yes)                           | 0.74<br>(0.48, 1.16)           | 0.74<br>(0.47, 1.16)       | 1.49<br>(0.84, 2.64)           | 1.58<br>(0.88, 2.81)       |
| Rheumatic disease duration<br>(median >8 years) | 0.84<br>(0.60, 1.17)           | 0.86<br>(0.61, 1.21)       | 1.43<br>(0.87, 2.36)           | 1.41<br>(0.84, 2.38)       |
| Bodily Pain<br>(sub-scale SF-36)                | 0.989*<br>(0.982, 0.996)*      | 0.989*<br>(0.982, 0.996)*  | 0.998*<br>(0.977, 0.999)       | 0.987*<br>(0.975, 0.999)*  |
| Mental health<br>(sub-scale SF-36)              | 0.99<br>(0.99, 1.001)          | 0.99<br>(0.99, 1.001)      | 1.00<br>(0.99, 1.01)           | 1.00<br>(0.99, 1.01)       |

\* Statistically significant factors; n.a: not applicable

quent among patients with more pain (Table II).

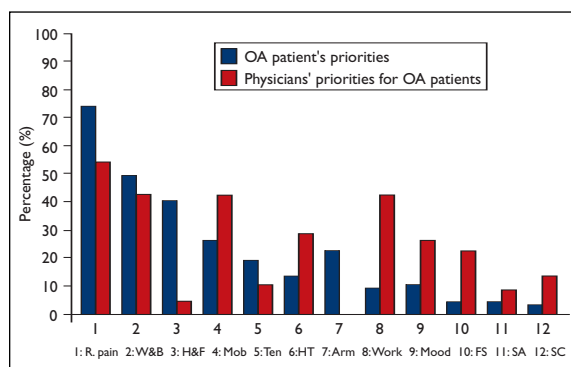
#### Priorities for OA: patients' and doctors' perspective.

Regarding OA (Figure 2), patients (n=336) and rheumatologists agreed on the election of "Rheumatic Pain" as the first priority (elected by 75% patients and 55% physicians). "Walking and bending" was the second choice for patients (50%) and physicians (43%). The third priority for patients, "Hand and Finger Function" was selected by 41% of respondents but was highlighted by only 5% of the rheumatologists. Together with "Walking and bending" physicians elected "Mobility" and "Work" as their second most popular priority regarding their OA patients, but "Mobility" was only chosen by 27% of the patients (4<sup>th</sup> in rank) and "Work" by 10% (8<sup>th</sup> in rank).

Physicians and patients also diverged in the

ranking of other priorities. None of the Rheumatologists chose "Arm function" as a priority while 23% of the patients did. On the contrary, 23% of the physicians' chose "Family support" as a priority whereas only 5% of the patients felt this was among their most pressing problems.

The exploration of factors related to the selection of "Rheumatic Pain" as a top priority among patients with OA (Table II), showed that this was especially common among those professionally "non-active" (twice as much when compared to active patients, OR 0.50; 95% CI 0.30-0.84) even when adjusted for age and sex. Younger patients with OA (below 37 years of age) tended to elect rheumatic pain less often than older patients. Patients with more severe bodily pain also elected pain more often as priority.



**Figure 2.** Osteoarthritis patients and physicians' priorities. Columns represent the percentages of OA patients (n=336) and physicians who included the respective area among their three main priorities for improvement in OA. (R. pain: Rheumatic pain; W&B: Walking and bending; H&F: Hands and finger function; Mob: Mobility; Ten: Psychological tension and anxiety; HT: Household tasks; Arm: Arm function; FS Family support; SA: Social activities; SC: Self care)

## Discussion

Overall, the most commonly selected priorities for improvement among patients with rheumatic diseases were "Rheumatic pain", "Walking and bending", and "Hand and Finger Function". Results showed differences in priorities between patients with RA and OA: as expected, patients with different diagnoses had different health needs.

For patients with RA the most important priorities were "Rheumatic Pain", "Hand and Finger Function", and "Walking and bending". Our results showed relevant and meaningful differences between patients' and rheumatologists' priorities. Doctors' priorities for RA were "Work", "Hands and Finger Function", and "Rheumatic Pain". The election of "Rheumatic Pain" as a priority by RA patients was only associated with the severity of reported pain and it was not related to age, gender, profession, educational level, disease duration or mental health status.

OA patients referred "Rheumatic Pain", "Walking and bending", and "Hands and Finger Function" as the most important areas in need of improvement, and Rheumatologists also elected "Rheumatic Pain" as the first priority, but this was followed by "Mobility" and "Work" and only then by "Walking and bending". The choice of "Rheumatic Pain", as a priority by OA patients, was more common among those who reported more severe bodily pain, were aged more than 37 years and were pro-

fessionally non-active. This was not related to gender, educational level, disease duration or mental health status. Interestingly, in both diseases, physicians gave higher priority to psychological and social aspects of the disease than patients did.

We are very confident that our results are a good representation of reality in Portugal: we included patients and rheumatologists from the vast majority of rheumatology departments in the country and all patients attending the outpatients department were invited to participate with very limited exclusion criteria. Very few patients refused to answer the questionnaires. However, while interpreting our results it is important to keep in mind that physicians selected their priorities based on a general view of their practice and concerns for RA and OA, but not specific to each patient. Although the inclusion of a large number of patients and physicians can be expected to reduce the influence of individual variations, it is not impossible that priorities of doctors and patients would have been closer if we had asked doctors to respond to this question considering specific cases.

Patients' and physicians' priorities may be expected to differ according to cultural background. Although we did not find a significant influence of educational level on the selection of the main priority by patients and despite a good parallel with published studies from other countries, our results cannot be generalised to other settings without caution. The number of years of formal education (quite low in our case compared with European standards), the universal access to the national health system and to social security are just a few of many confounders that can come into play. Therefore, we do not mean that our conclusions apply elsewhere but rather wish to stress that similar studies may be equally useful in other settings.

Overall, our findings followed a trend also seen in other European countries: the first priorities for improvement were seen among physical aspects of disease and the last choices were made on emotional and social aspects of life<sup>6,13,19</sup>. They may be interpreted in line with Ahlmen et al., who found in a qualitative study, that patients with rheumatic diseases wanted improvements in areas related to increased independence and undertaking of daily living activities<sup>12</sup>.

Our results are in close agreement with those of studies performed in Norway and in the Netherlands where pain was also the major cause for concern among RA patients<sup>13,19</sup>. The second and third

priorities are also similar: "Hand and Finger function" was considered more important than "Walking and bending". It is interesting to note that, in a recent study, patients with RA from 10 different European countries reached very similar conclusions when asked to identify and rank the most important domains of their disease<sup>20</sup>.

Regarding RA, our physicians elected "Work" as their most pressing priority, in clear contrast with patients. The same first priority was elected by four American rheumatologists according to Kwoh and Ibrahim, but this was also the case with 62% of the 79 rheumatic patients included<sup>21</sup>. Regarding OA, "Work" was, again in our study, given a higher priority by physicians than by patients.

The priorities set by physicians and their comparison with those of patients in the present study raise three main considerations:

Physicians may be too focused on classical paradigms of the disease: High rank for "hands and finger function" with low rank for "Walking and bending" in RA. High rank for "Walking and bending" as well as for "Mobility" with low rank for "hands and finger function" in OA. Patients' priorities seem to call physicians for a broader perspective of the disease in terms of anatomical areas of impact.

Physicians rank the ability to work as a much higher priority than patients. Although, this may be related to the reasonable access of our patients to social security support, the reasons behind this remarkable discrepancy cannot be addressed on the basis of this study. However, they certainly deserve attention as efforts to keep patients professionally active can drive physicians into more aggressive therapies whilst not serving the patients' objectives and values.

Physicians gave the psycho-social dimensions of these rheumatic diseases a higher priority than patients did. This may represent a true difference in the representation of the disease, but other factors, including patients' formal educational level and education about the disease, need to be considered before practical implications can be drawn.

Facing the results of this and similar studies, physicians and policy makers may find reasons to reconsider how much (scientific and personal) attention we are paying to the diseases we treat as opposed to the persons we care for. They also give us reason to re-visit our paradigms regarding the main objectives of treatment: disease process and productivity versus quality of life.

We see no reason why these issues would be limited to rheumatic diseases. Similar observations have been made in other areas and more will surely emerge if more studies are performed<sup>10,11,22-24</sup>. This supports the need to promote the incorporation of validated patient reported outcomes in the evaluation of diseases and treatments if physicians are to achieve the most noblest aim of the profession: patient's satisfaction and quality of life.

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## VI Jornadas de Reumatologia e Medicina Familiar do Algarve

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