

NEAR STUDY: NEEDS AND EXPECTATIONS IN RHEUMATOID ARTHRITIS – DO WE KNOW OUR PATIENTS NEEDS?

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Abstract

Introduction: Rheumatoid arthritis is a chronic systemic inflammatory rheumatic disease whose characteristics have a clear impact on the life of the patient and his/ her family. Doctor-patient relationship is increasingly based on communication and information transfer. In the case of chronic diseases and especially in RA, that information is fundamental for a better compliance, but also for the prevention of problems and the patient's better management of the disease on a daily basis.

Objectives: To determine in a population of RA patients which are the principal sources of information about the disease, what unmet needs exist and the level of patient involvement in therapeutic decision.

Methods: We applied a questionnaire in person and by telephone to a population of patients with rheumatoid arthritis fulfilling the criteria of the ACR, which were followed at several departments of rheumatology in mainland Portugal, about their expectations, the degree and type of information they expected, and their unmet needs.

Results: A total of 223 RA patients filled in the questionnaire, 82.5% of which were female, mean age 55.13 +/- 14.49 years and whose mean duration of disease was above 5 years in 69.5% of the individuals. Of these, 17.5% found that RA had an impact on quality of life, 15.7% felt that RA affected their ability to enjoy life and 14.3% had difficulties in performing activities of daily living.

Some activities were found to be more difficult for a patient with RA (on a scale of 0 to 10), such as gardening (6.36) and practicing sports (5.79). Other basic tasks were also considered difficult, as are the case of household chores (5.76) sleeping (5.08) walking (4.99) and working (4.86). Regarding

the clinical impact of RA, as expected pain is almost a universal factor (87.9%), although the majority of patients also refer arthritis (78%), pain when moving (65.5%), fatigue (60.1%) and joint deformities (58.3%) as very common symptoms.

Diminishing pain (81.2%), a general improvement of symptoms (73.1%) in a lasting way (57.4%) and reducing arthritis (59.2%) appeared as the main concerns of patients with RA. Regarding quality of information, 68.2% of patients consider they are well informed about the disease, but these numbers decrease if we consider information about treatment options (46.2%), the concept of remission (20.6%) or the recognition of the DAS 28 scale (17%). As preferred sources of information about the disease, 67.7% of individuals indicate their rheumatologist, 31.4% their general practitioner, 17% the Internet and 9% the attending nurse. The same order is obtained when asked about treatment information. As to the need for additional information, the patients refer «more information about therapies/treatments» (26.9%), «new scientific developments and social support» (17.5% each), «how to improve symptoms and live better in everyday life» (16.6%). «What is the disease» (6.7%) is referred last, being that only 8.1% of patients consider they are well informed. In what concerns discussion and participation in the process of clinical decision about medication, 56.1% of patients say that they share it with their doctors during their consultation.

Conclusion: These results, which somewhat differ from the existing literature, demonstrate that there are important issues that should be considered in clinical practice, both relating to clinical issues and the unmet needs of our patients.

We are unaware of the results coming from a treatment strategy designed to increase the RA patient's perception of their general state of health or of their perception of function. We should, however, keep in mind that pain, wellbeing and disease activity (as well as remission) should be important

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goals in therapeutic strategies that are to be increasingly shared with our patients.

Keywords: Patient Perception; Needs; Expectation; Rheumatoid Arthritis.

Introduction

Rheumatoid arthritis is a chronic systemic inflammatory rheumatic disease which, due to its characteristics, has a clear impact in the life of the patient and his/ her family.

Doctor-patient relationship is increasingly based on communication and information transfer. In the case of chronic diseases and especially in RA, that information is fundamental for a better compliance, but also for the prevention of problems and a better and adequate management by the patient on a daily basis.

Nowadays, the making of clinical decisions by doctor and patient together is reflected in many health policies of various countries¹.

Patients are eager to know more about their disease and, according to some studies, only half actually acquire that knowledge in a clinical environment (Kay 1988).

Current clinical practice is increasingly less about a decision taken within the scope of a more or less informed consent by the patient. It is a dynamic process and the patient is involved in making the clinical and therapeutic decision. The different value given by the patient and by the doctor to different aspects of health often lead to difficulties in the relationship and in achieving the goals that should in principle be common ones².

In the patient's point of view, the medical appointment is a partnership in which his/ her perspective is considered and which influences the final treatment decision.

Other functions the consultation has are sharing symptom and care information, being a place of *feedback* about progress, having access to a specialist, being a source of supporting information, a way of reassuring the patient about his/ her doubts and incorporating the dimension of feeling in the relationship between doctor and patient – empathy³.

But which is the main source of information about the disease and treatment options?

In an American study, doctors and nurses were considered the biggest source of information, and

occupational therapists and physiotherapists were given less prominence. The internet was referred by only 14% of patients, which is inferior to what another study states (25%)⁴. We also know that women and younger patients have a higher need for information than older patients⁵.

Other sources of information, such as leaflets, may also have a continuing impact of a few months in terms of information quality, even more if they are given out at the consultation by the specialist⁶.

Thus, several studies demonstrate that patients with RA want to understand their disease and its available treatments better, but also want to know how to manage the variable symptoms of the disease and pain deriving from it.

There is evidence that patient education improves understanding of disease progression, treatment types and prognosis. Such understanding appears to be even more relevant in early arthritis.

For all these reasons, the rheumatology consultation and the relationship with patients with RA have a significant impact, for they contribute decisively towards a perception of disease control on part of patients. There seem to be three points to consider: 1 – the involvement in consultation 2- the way of expressing the type of medical care to patients 3 – specialized knowledge.

Diminishing physical symptoms as pain or stiffness must be attained for the patient to consider that the disease is under control.

When talking about expectations in the case of a potentially debilitating and incapacitating disease, there's the need to define two types of expectations – those of the doctor and those of the patient.

The expectations the patients hold have to do with their projects and personal concerns, as well as with trying to lead as normal a life as possible.

The doctor's expectations will take into account the way how he thinks clinical control of disease activity will allow him to help his patient regain the physical and mental capacities that will let him live life as fully as possible. How can the doctor assess and structure a strategy to obtain this goal? Will the doctor talk about remission or low disease activity as objectives or should he follow the opposite road and, as a form of avoiding failures and of protecting the patient from disappointments, speak only of improvement or diminishing disease activity?

As such, the doctor will have to correctly assess the disease and its evolution. It is common

knowledge that the way a patient responds to treatment can be assessed through the response criteria of the American College of Rheumatology (ACR)⁷ or the criteria of the European League Against Rheumatism (EULAR)⁸.

However, in opposition to what happens in diseases like diabetes or hypertension, there is no gold standard evaluation for rheumatic diseases for assessment and follow-up of patients.

Resorting to composite indexes is one of the possibilities and some have been developed to evaluate patients with rheumatoid arthritis. Some are used more than others, as is the case of DAS 28 (disease activity score)^{9,10}, SDAI (simplified disease activity index)¹¹ or CDAI (clinical disease activity index)¹².

Most of these complex indexes include joint count of painful and/or swollen joints, which are the most specific and valued factor for rheumatologists in their assessment of patients^{13,14}.

The time needed to perform joint count limits the interaction between doctor and patient, since while the patient has the expectation of discussing other matters of relevance to himself/ herself, the doctor has to interrupt this interaction in order to register the resulting data.

As some authors advise, the main role of a rheumatologist should be making clinical decisions, not simply recording data¹³.

Among rheumatologists there are different perspectives about the core set and its value in disease activity. When asked about which values confer low disease activity or remission in RA, there is a variation between the answers given by specialists. The ESR value and the global assessment by the patient (the patient's VAS) are more consistent, whereas swollen and painful joints and PCR are harder to consider in a homogeneous way. Doctors accept a patient's VAS higher than their own, but tend to give more value to the latter¹⁵.

We are aware that increasing care quality for rheumatic patients is obtainable through the application of quantitative assessments, but not all rheumatologists perform joint counts, nor do they apply questionnaires. In a study done with 550 rheumatologists (16 of which were Portuguese) only 44% of rheumatologists performed joint counts on 50% of consultations or more, and 45% of surveyed rheumatologists on less than one in every four consultations¹⁶.

Clinical practice in rheumatology everywhere is broadly based on qualitative impressions ("ges-

talt"). Instead of being based upon evidence, it is based upon prominence, eloquence and elegance^{14,16-18}.

The use of other complementary forms of assessment, such as the application of questionnaires to be easily filled in by the patient, may provide the quantitative data about the disease that are so necessary to the highest standards of care^{13,14,19,20}.

This connection between better patient information for a better assessment and follow-up alone will conscientiously lead to sharing the management of disease with the patient. Both patient and specialist must boost the dynamics in the consultation so that more clinical data are obtained (in order for the doctor to be more capable to make choices) or information about the disease to be given (in order that the patient gets to know his/ her disease better).

As a specialist, the rheumatologist should keep in mind these two fundamental items when interacting with the patient. Information provides the power of decision-making. If such information is not correctly obtained by both parties, a winning strategy will not be achieved.

Methods

This was a cross-sectional study based upon the application of a questionnaire which was presented to patients being followed at a rheumatology consultation. Patients with a diagnosis of rheumatoid arthritis which fulfilled the criteria of the American College of Rheumatology²¹ were given the questionnaire in person and by telephone.

233 questionnaires were completed, of which 140 were applied randomly at the outpatient clinic of several Rheumatology units or departments - Hospital Conde Bertiandos (Ponte de Lima), Hospital de São João, Hospital Militar Regional nº 1 (Porto), Hospital de São Marcos, Hospitais da Universidade de Coimbra, Hospital de Santa Maria, Hospital Garcia da Orta and Hospital de Faro. The other 83 questionnaires were done by telephone, via contacts provided by consultants after informed consent was obtained in writing and provided by their patients.

Results

233 patients participated in the study, most of

Table I. Distribution by age group

Age	no	(%)
40 years or less	41	18.4
41-55 years	74	33.2
56-70 years	69	30.9
71 years or more	39	17.5
Total	223	100.0

Table II. Distribution by time of diagnosis

Time of diagnosis	no	(%)
Less than 2 years	26	11.7
Between 2 and 5 years	39	17.5
Over 5 years	155	69.5
DNK/DNA	3	1.3

Table III. Impact of Rheumatoid Arthritis in various aspects of everyday life (percentage)

	% of enquired that fully agrees with the statement (1)	% of enquired that tends to agree with the statement (2)
Above all, RA has an impact on my quality of life	17.5	32.3
RA has affected my ability to enjoy life	15.7	26.4
I experience difficulties in performing some daily tasks due to RA	14.3	31.8
My family does not understand how RA affects my life	11.4	18.2
RA forces me to depend too much on other people	9.0	21.1
RA symptoms control my life	8.5	25.1
I feel constantly tired due to RA	8.1	25.1
I sometimes feel tired due to RA	7.8	20.3
RA affects my work capacity	6.8	24.7
I feel alone in my fight against the disease	6.7	22.4
RA affects my sexual life.	6.5	17.2
I cannot take responsibility for myself or other people due to my RA symptoms.	4.5	13.9
RA affects my relationship with my family.	4.0	19.6
RA affects my relationship with my friends.	3.2	11.4

(1) % of individuals who answered 10, in a 1 to 10 agreement scale, in which 10 means full agreement

(2) % of individuals who answered 8, 9 or 10, in a 1 to 10 agreement scale, in which 10 means full agreement

which were female (184, 82.5%; 39 of males, 17.5%), mean age 55.13 +/- 14.49 years. Most of the patients had a disease evolution of more than 5 years.

For a relative majority of the 223 patients that were surveyed (32.3%), rheumatoid arthritis was a disease that has an impact in quality of life. 31.8% of patients expressed high difficulty in performing activities of daily living, 25.1% said they felt constantly tired, 26.4% recognized that rheumatoid arthritis made them less able to enjoy life and 24.7% said it affected their ability to work (Table III).

About a quarter of the individuals (25.1%) stated that the symptoms of arthritis controlled their daily lives. 22.4% of patients confessed they felt alone in fighting the disease or that they did not receive much support from outside to do it.

Among the activities of daily living that patients

find harder to perform due to the disease are tasks like gardening, practicing sports, performing household chores and simply being able to sleep, having all a mean score above 5 in a scale of difficulty with 10 as maximum score, which means extreme difficulty in perform the task (Figure 1).

The consequences of rheumatoid arthritis are also visible at work, through the patient's absenteeism over the previous three months. In fact, of the 102 patients with professional activity at the time, 21.6% admitted having been absent from work due to illness. These absences had a mean duration of 16-17 days.

The value given to some symptoms was one of the focuses of the questionnaire. 87.9% of patients said that they had pain caused by arthritis more or less frequently, and a significant percentage of in-

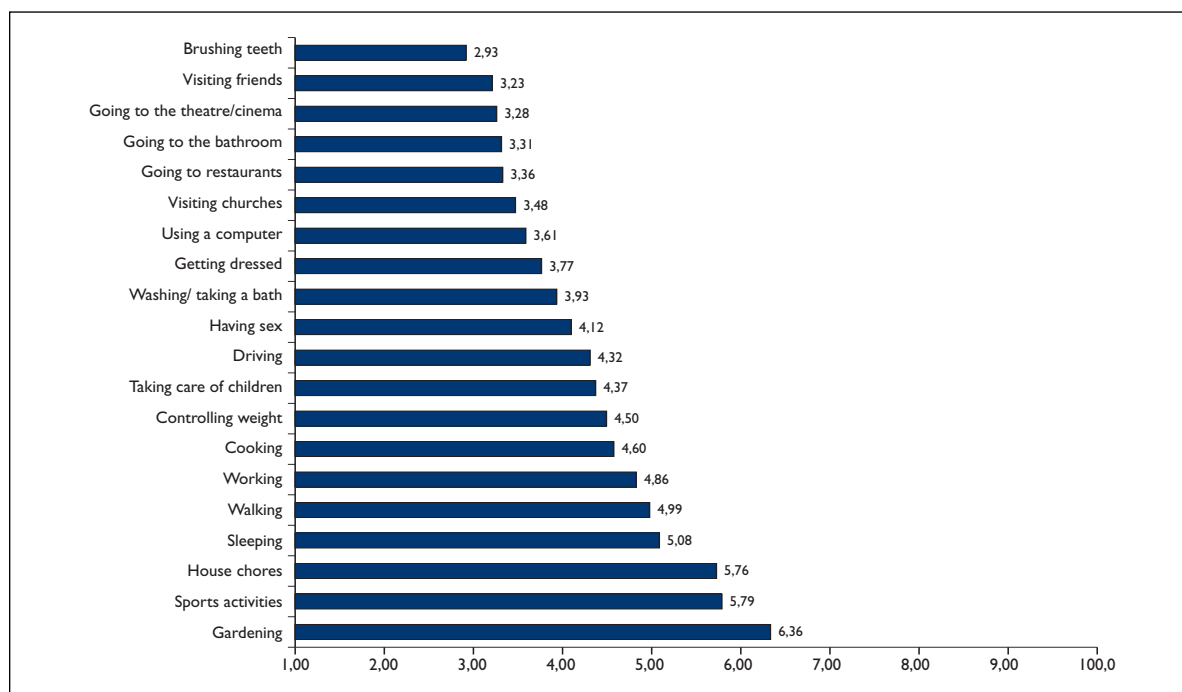


Figure 1. Level of difficulty associated to each activity of daily living (average values) (I)
1-10 scale, where 10 means extreme difficulty in performing the task

Table IV. Most frequent symptoms related to Rheumatoid Arthritis (percentage)

	Most frequent symptoms related to rheumatoid arthritis (I)
Pain	87.9
Joint swelling	78.0
Pain when moving	65.5
Morning stiffness	64.1
Fatigue/tiredness	60.1
Joint deformities	58.3
Lack of joint flexibility	52.9
Body pain (not only in the joints)	47.1
Problems affecting other organs (eyes/lungs)	29.6
Flu symptoms	10.8
Other symptoms	1.3

(I) Multiple answer: n = 223

dividuals (78.0%) referred to joint swelling as a common symptom.

Among other symptoms mentioned by the in-

dividuals are pain when moving (65.5%), morning stiffness in the limbs (64.1%) and fatigue/tiredness (60.1%). We could still add that approximately 50% of interviewees referred to joint deformities (58.3%), lack of flexibility in the joints (52.9%) and to general body pain (47.1%) (Table IV).

In practice, this sample of patients live almost daily with the consequences of the disease, among which pain occupies a central position, contributing to a physical discomfort with implications in social and professional activities. Furthermore, this situation is clearly visible in the way patients express their wants as to the management and treatment of rheumatoid arthritis: 81.2% of individuals said that they would like to have less joint pain, 73.1% would like to feel a general improvement of arthritis, 59.2% wanted to have less joint swelling and 57.4% would aim to achieve lasting relief of rheumatoid arthritis symptoms (Table V).

Regarding involvement in the course of treatment, 68.2% of patients considered they were well informed about rheumatoid arthritis, although the knowledge they declared having on the disease is less significant when they are questioned about specific issues related to treating and monitoring the disease: 46.2% said they knew of available treat-

Table V. Aspirations of Rheumatoid Arthritis Patients (percentage)

	Aspirations of Rheumatoid Arthritis patients (I)
Less joint pain	81.2
General improvement of arthritis	73.1
Less joint swelling	59.2
Lasting relief of RA symptoms	57.4
More joint flexibility	52.5
Improvement in morning stiffness in the limbs	43.9
Less tiredness/Less fatigue	41.7

n=223

(I) Multiple answer.

ment options; 20.6% recognized the concept of remission; 17.0% identified the DAS scale (Table VI).

Faced with this reality, 77.6% of individuals considered that their consultant had paid him/her due attention and care, and 56.1% also admitted talking to their doctor about treatment options in a context where 32.3% of patients said they have some weight in decision-making about treatment.

Access to medication was referred as difficult by 18.4% of enquired patients, insofar as these barriers are more intense among patients who are followed outside a hospital environment: 26.5% of patients that are not treated in a hospital referred difficulties, whereas the same applies to 13.6% of patients treated in a hospital.

Among those who felt difficulties in this area, 46.3% pointed out financial issues as the main barrier, followed by treatment availability in pharmacies (22.0%).

There are sources of information that patients find they prefer. Doctors are the biggest source of information patients have on the disease and respective treatments. In fact, 67.7% of patients said they obtained information about the disease from their rheumatologist and 31.4% stated the same about their general practitioner. Concerning information on treatments, the same order is maintained, although the relative distance between rheumatology and general practitioners is larger: 85.2% referred their rheumatologist and 25.1% indicated their general practitioner (Table VI).

9.9% of patients resort to nurses to obtain infor-

Table VI. Declared knowledge of areas connected to Rheumatoid Arthritis treatment (percentage)

State to have knowledge on treatment options	46.2
Recognize the concept of remission	20.6
Recognize the DAS scale	17.0

n=223

mation on the disease and 6.3% also approach the nurse to acquire information about their treatment. The Internet is nowadays also somewhat important and is consulted by 17.0% and 10.3% of patients, respectively for obtaining information about the disease or about treatments (Table VII).

Although it was clear that most patients consider they are well informed about the disease, 78.0% expressed additional needs in information. Among these are to be highlighted their want in knowing more about therapies and treatments (26.9%), available social support (17.5%), news scientific developments (17.5%) and their will to learn new ways to improve their symptoms and live better in everyday life (16.6%) (Table VIII).

Discussion

The patient's clinical perception is a factor that should be increasingly more valued in the case of chronic diseases and especially in RA. Some results of this study should cause us to reflect about the strategies used in the follow-up of these patients.

If pain is a universal symptom in clinical terms and is greatly valued by the patients, other symptoms such as joint swelling, fatigue and stiffness are considered more relevant by the patients, while joint deformities are given less importance. In this group of patients, pain, a general improvement of symptoms and reducing signs and symptoms of arthritis come up as the three first concerns of patients with RA. Other studies are coincident in having pain as a major determinant of incapacity in RA^{22,23}.

Is the control of pain an urgent need that is not being valued? In the case of our patients, as equally happens in other studies, pain is an important symptom and it is not possible to value it^{9, 24}.

Pain influences the perception of disease con-

Table VII. Information sources considered for the disease and treatments (percentage)

	Information sources about the disease (I)	Information sources about the treatments (I)
Rheumatologist	67.7	85.2
General practitioner	31.4	25.1
Internet	17.0	10.3
Nurse	9.9	6.3
Other RA patients	7.2	1.3
I do not search for information about the disease/ treatments	2.7	6.7
Other information sources	2.7	4.0
Conferences or talks	2.7	2.7
Media	2.7	6.3
Documents from Patients Associations	1.3	0.0
Portuguese Rheumatology Institute	2.7	1.3
Pharmacist	1.3	1.3
Books	1.3	0.0

n=223

(I) Multiple answer

Table VIII. Additional information required on Rheumatoid Arthritis (percentage)

	Additional information required (I)
Therapies / treatments	26.9
Social support	17.5
New scientific developments	17.5
Learn how to improve symptoms and live better in everyday life	16.6
What is the disease	6.7
Causes / Origin of the disease	6.3
Disease progress	4.5
Would like to know more in general	4.0
Studies made	2.7
What I can and cannot do – conditionings	2.7
Concomitant diseases	2.7
Treatment consequences	1.3
Nothing; I consider myself well informed	8.1
DNK/DNA	22.0

n=223

(I) Multiple answer.

trol inversely. An increase in pain is felt as a reduction in disease control. Pain unbalances the per-

son's life concerning his/ her relationship with others, self-esteem, the capacity to fulfill tasks and his/ her daily life³.

There are activities recognizably harder for a patient with RA (gardening, practicing sports), but some basic tasks are equally considered hard by our patients, such as household chores, sleeping and walking.

The most referred sources of information are mainly medical (the rheumatologist and the general practitioner), but the Internet is clearly already the third most important source of information, coming before nurses and being much more relevant than the media. Such data reinforces the role of these new platforms, but also stresses the weak appeal of rheumatic diseases to the media in general.

In several previous studies, the rheumatologist was also considered the main source of information in several studies, followed by the nurse, which did not prove the same among this group of patients^{1,25,26}.

In the 2009 RAISE study, McInnes *et al*²⁴, in an assessment of 586 patients with RA coming from 9 different countries came to somewhat different conclusions than those of our study, insofar as the internet and the written media were the main sources, which may indicate a future pathway concerning sources of information, or merely be the mir-

ror of the different socio-cultural characteristics existing in those countries when comparing with Portugal and Spain.

Even so, about two thirds of patients (68,2%) say they were well informed about the disease, a figure which is reduced to less than half when they are asked about treatment options (46,2%), being that only 20,6% knew the concept of remission and a mere 17% knew what is a DAS 28 score.

In a study by Van Campen, the assessment patients made of their doctors demonstrated that the practitioner's efficiency and the sharing of information were the most valued factors, although sharing the decision as to follow-up, treatments and other solutions, as well as the fact of being taken seriously with their complaints, were equally highly valued by the patients²⁷.

Disease impact is important and 32.3% of individuals referred that RA had an impact on their quality of life, limiting their activities of daily living (31.8%). It should be highlighted that more than a quarter of patients said that RA stopped them from enjoying life (26.4%), that the disease controlled their life (25.1%) and that they were constantly fatigued (25.1%), which became visible in their ability to work (24.7%).

We know that when patients consult with rheumatologists their prognosis improves in the case of patients with RA²⁸⁻³¹.

Some of the data resulting from this work reflects the need for more time and a greater involvement of the rheumatologist in the follow-up of patients with RA. In order to share data and information, the specialist needs more time in each consultation so that care quality is achieved. Naturally, as in the rest of the world, in Portugal DAS 28 is calculated in a percentage that is supposed not to reach 50% of patients, however that percentage is much inferior to the 17% of patients who recognize the scale. This means that although it is calculated, such information is not shared nor is it valued^{14,16-18}.

Conclusion

A study which is based upon the expectations and assessments of patients holds an important set of limitations. It has two types of data collection - in person and by telephone. The inexistence of data about education, income, disease activity, incapacity, exact duration of RA, the existence of a rheu-

matoid factor or not and joint erosions, among other factors, limits some of the conclusions, since they can be cause for confusion.

However, the high number of patients, the fact that all were consulted in rheumatology units and the descriptive and personal character of the questions give this work some range and quality.

There is a clear difference between the aspirations of patients and those of doctors. Patients want a stronger control over their own lives and that the doctors ask them about their lives and not only about their disease. Doctors want to reduce inflammation, prevent structural damage and incapacity and aim at remission^{24, 32, 33, 34}.

We are unaware of the results coming from a treatment strategy aimed at increasing RA patients' perception of their general state of health or their perception of function. Nevertheless, we should keep in mind that pain, wellbeing and disease activity should be important objectives within the treatment strategy³⁵.

Being able to listen and to influence through providing correct information is something that is closely linked to medical practice, but over the latest years is coming against the set objectives of consultation numbers, quotas and exceedingly controlled activity.

If we continue to ignore the needs and expectations of patients, we may be irrevocably stepping away from an ideal solution for each patient as a person. A patient-centered vision should increasingly be our goal, regarding the patient's expectations about the disease, treatments, but also about his/ her consultant³⁴.

Thus arises the need for deciding what to do concerning our role as specialists. Should we maintain this attitude of being information collectors or should we opt for another strategy, resorting to automatic questionnaire systems and new technologies in a way that we concentrate on being an informed decision-maker while including the patient in the decision made? Will we be for much longer still the main source of information for our patients? Do we want to be that source? Do we acknowledge that the Internet and other platforms will overcome this function and use them as a way of improving the quality of information?

This study allows us to think about the distance which still exists between what we intend to achieve and what the patient wants. The concept of remission and low disease activity should represent what we can achieve nowadays, if not in all cases,

at least in a significant amount of patients, and we should decide on a common strategy to obtain such objectives together with our patients.

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XII Fórum de Apoio ao Doente Reumático

Portugal
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