Exploring the remission concept in rheumatoid arthritis with patients and rheumatologists: time for a new approach?

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Abstract

Objective

To explore the remission concept in rheumatoid arthritis (RA) and to compare remission definitions and related concepts between rheumatologists and patients with the purpose of identifying similarities and disparities to comprehend the different perspectives of the disease.

Methods

This was a qualitative study of discourse and content analysis through focus groups, conducted from February to March 2016. Four focus groups were set up, each one with different interests: rheumatologists involved in basic research (BR), rheumatologists with high specialisation in imaging techniques (IR), clinical rheumatologists (CR), and patients (PA).

Results

There is no consensus in a remission definition in RA; differences exist between-groups, rheumatologists and patients value remission differently, and there are discrepancies within the group of rheumatologists. Rheumatologists highlight quantifiable objective parameters, in contrast, patients did not consider objective measures as the best instruments, and they prefer subjective measures of remission. The data confirmed the existence of two sources of knowledge of the disease, technical (physicians) and experiential (patients). These sources of knowledge should concur in order to establish new remission criteria well-adjusted to reality.

Conclusion

The lack of consensus between key groups implicated in defining remission and remission criteria suggests a new strategy for its operational definition. Our group proposes that subjects with a balance between experiential and technical knowledge, should be the ones in charge of this assignment.

Key words

rheumatoid arthritis, remission, qualitative studies, knowledge, definition

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Introduction

Remission is a state that represents the absence of disease. In rheumatoid arthritis (RA) talking about a complete absence of the disease is a criteria that only few patients can achieve (1, 2). Defining remission and remission criteria has been difficult across time. The greatest limitation has been the lack of consensus in the acceptance of a unique definition by the rheumatologists and its generalisation to clinical practice (3, 4). In the last decade this concept has been revised and redefined by the international community. This effort has led to the development of new remission criteria by the American College of Rheumatology/European League against Rheumatism (ACR/EULAR) (2, 5-8). The current definition includes two different criteria: one applicable to the research context and another for clinical practice. However, this new definition of remission encountered the same limitations of its counterparts.

Given the advances in RA treatments, a state of remission is the target when treating patients. In spite of this, the absence of a unique definition makes reaching the target a chimera (3, 9-11).

The objective of our study was to explore the remission concept in RA with rheumatologists and patients to identify if there is a consensus in its definition. We also sought to compare remission definitions and related concepts between rheumatologists and patients with the purpose of identifying similarities and disparities that could let us comprehend the diversity of disease perspectives.

Methods

Study design

Qualitative study of discourse and content analysis through focus groups. The study was conducted from February to March, 2016. Four focus groups were set up, each one with different interest groups: rheumatologists involved in basic research (BR), rheumatologist with high specialisation in imaging techniques (IR), clinical rheumatologists (CR) and patients (PA).

The focus groups were moderated by doctors Estíbaliz Loza (IR and CR groups) and Loreto Carmona (BR and PA). The participants of the rheumatologists' focus groups knew the moderators previously, but at the date of the study Dr Loza and Dr Carmona did not keep any work relationship with the participants.

The participants of the focus groups were notified about the research purpose by the principal investigator (M.M.) prior to the start of the study. Their participation was formalised by the signing of an informed consent.

Participants

Participants were selected through purposive sampling; this type of sampling allows careful examination of the data to carry out a systematic comparison (12). The purpose of qualitative sampling is to reflect the diversity within the group or population being studied, rather than aspiring to select a representative sample. This sampling takes the most out of any identified atypical person and try to incorporate these individuals or groups, instead of discarding them as it would be done if the sampling were quantitative (13, 14).

Our interest was to contact with nuclear subjects with a real concern and experience with the problem under study – remission in RA (12-14).

The participants were contacted and invited to be part of the study via phone call by the principal investigator. Table I shows the characteristics of the sample. Patients had varying levels of disease activity, and they had all experienced remission or near remission at some point.

Materials and procedure

The focus groups were conducted in different dates. The rheumatologists groups were conducted in the facilities of Pfizer Madrid and the patients group in the *Asociación de la Coordinadora Nacional de Artritis en Madrid* (*Conartritis*).

In the focus groups, in addition to the moderators, the coder (J.B.) and the principal investigator were present as observer and as participant observer, respectively.

Scripts with guide questions were created in order to be used by the moderators in each focus group. The scripts were not used in a strict way. The emergence of topics and issues out of the script

Table I. Characteristics of the sample (n=23).

	n	Women	Mean age	Mean experience in years*
Basic research rheumatologists (BR)	6	3	51	22
Rheumatologists specialised in imaging techniques (IR)	6	3	52	22
Clinical rheumatologists (CR)	6	2	55	25
Patients (PA)	5	4	45	12

*In rheumatologists figures represent years of experience in RA and in patients it means years of experience with the disease.

were allowed in order to create a safe environment for free discussion.

Data collection and analysis

The duration of each focus group was 90 minutes. Audio recorder equipment was used by the coder for data collection; in addition, field notes were taken by the moderators, and were handed over to the coder after each group.

The coder was in charge of the transcription of the audio files. For the transcription and data analysis ATLAS.ti (GmbH, Berlin, v. 7) software was used, for which the coder is a certified trainer.

Data codification was divided in two stages: 1. inductive codification – audio files transcriptions were coded directly without reading the field notes nor reviewing the literature; a total of 10 codes were developed; 2. deductive codification – the codification was debugged after reviewing the literature and reading the field notes; 59 new codes were created, and will be referred to as the coding tree hereafter (A list with all codes is available in the Supplementary file).

Data were classified into one of two groups: rheumatologists or patients. This classification allows us to make comparisons of the concept of remission in RA between groups.

To diminish the possible bias of having only one coder, the results and analyses were sent to two of the researchers (E.L. y L.C.). They reviewed it separately and gave feedback to the coder which was applied in the final version.

Codes co-occurrence tables

Analysis of codes co-occurrence tables were done through a codes matrix in where the importance of the results lies, not in the frequencies of the topics, but in the amount of times a topic or subtopic co-appear with another (co-occurrence). This association of co-occurrence allows us to identify important concepts that might be associated with each other and could be playing a key role in remission. Quotations are presented as examples of the relationship between topics and concepts.

Results

The coding tree derived from the content analysis was divided into five main topics:

1. Remission: encompasses any comment referring to remission;
2. Instrument/measure: any instrument or measure used to evaluate remission;
3. Quantify: encompasses everything that makes reference to objective measures and its contrast with subjective measures;
4. Symptoms: relevant symptoms in RA;
5. Future research: possible future research needed to find a new definition of remission.

These main topics were present in both groups with the exception of future research, which was only mentioned by the rheumatologists group.

More specific subtopics emerged from the main topics. The subtopics could be nested in any of the main topics.

The most highlighted subtopics were:

a: remission_n_definition – concepts that should be included in a new definition of remission,

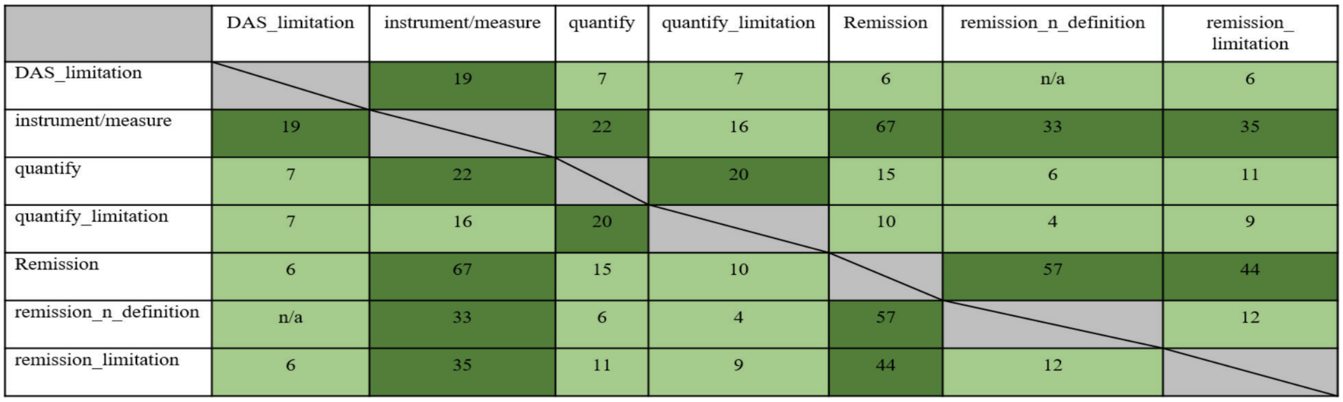
b: remission_limitation: current limitations of the remission concept,

c: quantify_limitation: limitations of objective measures, and (d) DAS_limitation: encompasses the DAS limitations.

The results of co-occurrences for each group are presented below.

Remission from the rheumatologists perspective

Figure 1 shows a fragment of the co-occurrence table for the rheumatologists group. From the coding tree, 49 codes were present and the eight pairs of topics /subtopics with higher co-occurrence were: Remission - instrument/measure,



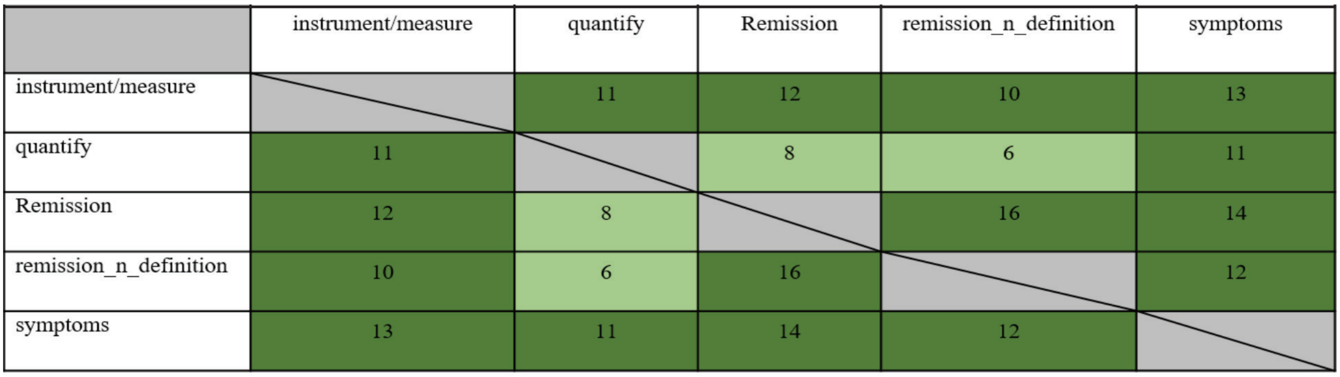
	DAS_limitation	instrument/measure	quantify	quantify_limitation	Remission	remission_n_definition	remission_limitation
DAS_limitation		19	7	7	6	n/a	6
instrument/measure	19		22	16	67	33	35
quantify	7	22		20	15	6	11
quantify_limitation	7	16	20		10	4	9
Remission	6	67	15	10		57	44
remission_n_definition	n/a	33	6	4	57		12
remission_limitation	6	35	11	9	44	12	

Fig. 1. Fragment of the co-occurrence table from the rheumatologists discourse: Eight topics with higher co-occurrence.
For the interpretation of the table, it must be borne in mind that the diagonal line separates the matrix in symmetrical parts. The numbers in the cells identify the frequency that a segment of speech was coded with two coexisting topics (column and row).

Table II. Direct quotations from the eight pairs of topics with higher co-occurrence in the physicians' discourse.

Co-occurrent topics	Direct quotations
Remission - instrument/measure	*BR2: …MMP3 and calprotectin are fantastic, because they are present whenever there is inflammation…* *BR4: I do not know what remission by Doppler is, I only know that they are correlated.* *IR1: One thing is research and another is the day-to-day clinic.* *IR5: There are good and bad sonographers. The ultrasound is determined by the sonographer; a poor captured ultrasound is useless.* *CR5: Remission is not only quality of life at the present moment, instead, it is quality of life maintained in time (long term quality of life).*
Remission - remission_n_definition	*BR5: Changing the definition of remission must come along with something more than a simple correlation.* *BR6: …the best measure should be inflammation; the problem is that everything is inflammation. Comorbidities make it very difficult, we should adjust remission by patient's age.* *IR1: …there should be an agreement between experts (physicians) and sick persons (patients).* *IR2: (the new definition should be)…according to patient's age and severity of disease.* *CR1: Every patient has his own remission point.*
Remission - remission_limitation	*BR1: I don't know what instrument or biomarker is better, I use what I learnt to use. Using any other method implies that I have to learn again.* *BR4: We are not equals to the cardiologists (about the lack of a 100% objective instrument).* *CR6: Patients tell lies to gain sympathy from the physician. They say they're doing OK, when they are not.* *CR5: There are patients that say "I want to keep feeling the way I feel right now". Sometimes with severe rheumatoid arthritis patients we have to reach an agreement on how far we can get, because achieving a total remission is very difficult.* *CR2: Another problem emerges when there is discordance, because the patient says he's OK and the physician says he is not or vice versa.*
Instrument/measure - remission_limitation	*BR4: Inflamed joints should score more than painful ones.* *BR5: Biomarkers actually does not give us anything new but they are used in research.* *IR6: Imaging techniques are as good as other instruments, but they depend on the scenario.* *CR4: We have to seek what to measure, but it is very artificial.* *CR1: There is no problem with ultrasound imaging, but there are also subjective things to look.*
Instrument/measure - remission_n_definition	*BR3: I will include calprotectin in a new definition of remission.* *IR2: Patient Report Outcomes must be included because the context is very important. The psychosocial variables have a great weight…Mobility must be taken into account. It is not just pain. Rheumatologists forget to assess mobility.* *CR1: …there is a tendency of overvaluing the imaging techniques, but I agree with my colleague that image has not proven to be better than the clinical targets.* *CR2: It should be defined more by the patient than the physician. Expressions of feeling good are a good sign. It is important to differentiate between advanced and recent patients.* *CR4: a variable that never has been studied: number of prescriptions.*
Instrument/measure - quantify	*BR5: The visual analogue scale forces you to register data. It has been internalised that we need to know the number of joints (about the DAS).* *CR1: There is a new tendency of comparing with objective imaging techniques.* *CR2: It is useful for comparing a patient with himself across time.* *CR3: In subjective evaluation I get lost, because the patients do not explain well. I try to use objective parameters… Imaging techniques are the best measure; the other measures are too subjective.* *BR4: … it is not as sensitive as we believe and not as specific as we want (about laboratory parameters and DAS in remission).*
Quantify - quantify_limitation	*CR1: This is the objective data generation… What is important is the interpretation of the data. Only reading what the radiologist or sonographer gave you is not enough… The exploration and communication with the patient are very important. We are not teaching well to the next generation of physicians; they give more importance to the objective scores of the tests or measures.* *CR4: The communication is very important. The young physicians do not talk; they go directly to the numeric result …The problem is not the number, is the circumstance.* *CR5: We cannot be objective with subjective individual things… We cannot have the illusion that this is an exact science, because it is not.* *IR: What is important is the artist behind. The attitude.* *CR6: This is not mathematics is medicine.*
Instrument/measure - DAS_limitation	*BR2: It's a problem because there are patients that cannot move the hip but in the DAS this information is not collected.* *BR4: The problem of the DAS is how and where it is done. It was created in an historical context, but this context has changed and the DAS has lagged behind. The DAS is absurd. The inflamed joints should receive a higher punctuation than the painful ones.* *BR6: The DAS doesn't go farther than: How are you? But if you want to publish you need to have an objective measure.* *CR5: One should not give attention to the DAS, you register the result and that´s it.* *IR4: The DAS has a lot of limitations. It's very subjective. Sometimes the VAS is misunderstood by the patients. The DAS leaves you desiring more.*

BR: basic research rheumatologist; IR: rheumatologist specialised in imaging techniques; CR: clinical rheumatologist.



	instrument/measure	quantify	Remission	remission_n_definition	symptoms
instrument/measure		11	12	10	13
quantify	11		8	6	11
Remission	12	8		16	14
remission_n_definition	10	6	16		12
symptoms	13	11	14	12	

Fig. 2. Fragment of the co-occurrence table from the patients' discourse: Eight topics with higher co-occurrence.
For the interpretation of the table, it must be borne in mind that the diagonal line separates the matrix in symmetrical parts. The numbers in the cells identify the frequency that a segment of speech was coded with two coexisting topics (column and row).

Table III. Direct quotations from the eight pairs of topics with higher co-occurrence in the patients' discourse.

Co-occurrent Topics	Direct Quotations
Remission - remission_n_definition	*PA2: … time without inflammation.* *PA4: For me remission is not having flares for a long time, 1 year without flares. Time is important in this concept.* *PA5: (about the physician) I said this and he puts other thing different from what I said (on the clinical record). In the moment you say you feel better it doesn't matter the context and they put it on the record. We must be careful with the information we give.*
Remission - symptoms	*PA2: For me being better is measuring the inflammation and what I do to measure it is being aware of the days I woke up well, with less stiffness and without help.* *PA4: …being in remission is not having stiffness… I understand remission as not having flares …* *PA5: If you do not have flares they (physicians) consider you in remission.*
Intrument/measure - symptoms	*PA3: I have to say what hurts me, but: what you (physician) want to hear?* *PA5: The fatigue is the heaviest duty, but nobody asks about fatigue. Something should be developed to measure it. For me fatigue is the worst symptom, even worse than pain.* *PA2: CRP (C-reactive protein) doesn't have nothing to do with pain.*
Remission - instrument/measure	*PA2: Test values and measures don't have any importance. A lot of times there is not only what the laboratory results say, there is a lot more at stake.* *PA1: My remission measure is that my feet fit without problem in shoes different from sport shoes.*
Symptoms - remission_n_definition	*PA4: …you will always have pain but that pain is different from the pain of the flare … getting up, taking a bath and absence of stiffness. I don't agree that time between physician's appointments is a measure of remission, because you may not have a flare but the physician needs to see me as a follow up of the medication and its adverse effects.*
Symptoms - quantify	*PA3: I don't take into account the levels. If I say a seven they (physicians) say that I am a liar. If I say that I am painless as consequence, they give me a lower dose of the biological medication that is the responsible of my wellbeing.* *PA5: There are two different things, one is the laboratory results and the numeric values and another is how you feel: stiffness, fatigue, and lack of energy.*
Instrument/measure - quantify	*PA5: …for me a good day is taking a bath without dropping the soap.* *PA2: When they (physicians) give me a numeric scale and ask me to circle the number that reflects my pain, I make a circle in the complete scale.*
Instrument/measure - remission_n_definition	*PA2: The physicians give you follow up appointments because of the medication but not because of the disease. It's like a control. It doesn't matter time between visits, what's really important is the time without inflammation.*

PA: patient.

Remission - remission_n_definition, Remission - remission_limitation, instrument/measure - remission_limitation, instrument/measure - remission_n_definition, instrument/measure - quantify, quantify - quantify_limitation, and instrument/measure - DAS_limitation.
Table II shows direct quotations from the eight pairs of topics with higher co-occurrence.

Remission from the patients' perspective

Figure 2 shows a fragment of the co-occurrence table for the patient group. From the coding tree, 29 codes were present and the eight pairs of topics/subtopics with higher co-occurrence were: Remission - remission_n_definition, Remission - symptoms, instrument/measure - symptoms, Remission - instrument/measure, symptoms - remission_n_definition, symptoms - quantify, instrument/measure - quantify, and instrument/measure - remission_n_definition. Compared with Figure 1, co-occurrence frequencies are lower; please, note that low numbers do not reflect lower importance but denote a smaller group size than in Figure 1.
Table III shows direct quotations from

the eight pairs of topics with higher co-occurrence.

Discussion

The data show that there is no consensus in a remission definition in RA. There are differences between-groups, as rheumatologists and patients value remission differently. There are also discrepancies within the group of rheumatologists.

If we compare the co-occurrence table of rheumatologists (Fig. 1) with the co-occurrence table of patients (Fig. 2) it can be seen that the predominant topics among rheumatologists have a tendency or point of view focused in what we call objective. Their discourse highlights the limitations of the current parameters, but at the same time they seek a new definition based on quantifiable parameters. This discussion reflects clearly the current remission criteria and their limitations described in the literature (2, 5, 8, 15, 16). However, among patients it can be seen that although the current limitations of the concept remission are mentioned, this topic did not dominate their speech. They highlighted the importance of finding a new definition of remission that reflects what they really feel, as well as of developing new instruments and measures that take into account the variety of symptoms. The patients, in contrast to the rheumatologists, did not consider objective measures as the best instruments. In their daily life, they use nontraditional measures or subjective measures different from the ones the rheumatologists use in the clinical environment (Table III). The international community recognises this discrepancy and they are making efforts to integrate the perspective of patients in developing new remission criteria (8, 17-21).

Of note, imaging techniques and their role in RA remission (6, 9) were a topic only present in the rheumatologists group, since no patient spoke about the benefits or limitations of the use of these techniques and the impact they can have in the course of their disease.

This difference in disease related concepts among rheumatologists and patients has been described in previous works (19, 22, 23). These studies suggested two sources of disease knowledge and, therefore, two different approaches: technical knowledge and experiential knowledge. The way RA is seen will vary depending on the type of knowledge. Technical knowledge is attributed to the physicians and will depend on the quantity and quality of the technical resources they learn over time. Technical resources can be: formative years, clinical experience, continuing education programs, etc. Instead, experiential knowledge is attributed to patients and will depend on the quantity and quality of experiential resources they acquired over time, such as: coping, social support network, learning by trial and error, etc. (24). This framework explains why rheumatologists and patients may value different things of the same concept.

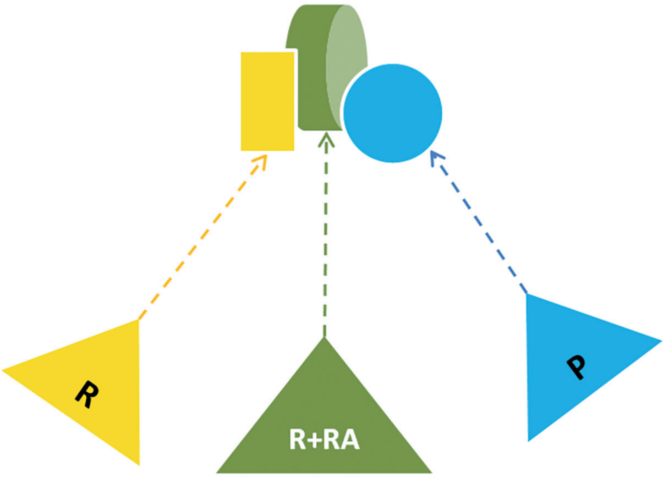


Fig. 3. Consensus proposal to establish remission criteria in RA.

In addition to these discrepancies between rheumatologists and patients, it has been revealed that there are discrepancies within the group of rheumatologists (Table II) with concepts related to remission. Rheumatologists value different parameters and attribute different levels of importance according to their training (education) and clinical experience (3, 4, 25). There are rheumatologists who think the DAS is useful, others that it is useless; some believe that certain biomarkers are useful and others think that those same biomarkers are useless. Some rheumatologists are in favour of seeking an objective definition of remission with the assistance of some type of instrument, but others safeguard a subjective point of view in which each patient has his own point of disease remission. This lack of consensus and disagreement between rheumatologists in clinical practice, instead of strengthening the current remission criteria (2, 5) and facilitating the emergence of a single definition, generates an unlimited number of different remission criteria that are constantly modified by individual preferences.

The results show that although there is disagreement on various topics between rheumatologists and patients, many rheumatologists agreed with patients that a new definition of remission should consider two concepts: (i) psychosocial variables and
(ii) the context. Although not all rheumatologists expressed explicitly their agreement with this idea, they did not express rejection to their inclusion in a new definition, whereas they expressed discomfort with the inclusion of some biomarkers.

One of the limitations of our study is that there was only one focus group of patients in contrast with three groups of rheumatologists. This single group did not let us reach data saturation, so there must be some important issues from the point of view of patients missing in our analysis. Another limitation is that there was only one man among four women in the patients' focus group. Although this man shared his experience living with RA, the ideal would have been to have more than one man to distinguish the experiences attributable to gender or other variables.

Remission and remission criteria have been studied and developed, including the RA perspective of rheumatologists and patients. Despite this, there is still a lack of consensus in a remission definition and a new problem arises: in order to have consensus for a definition of remission, to which knowledge we must attribute greater importance, technical or experiential?

This problem leads us to make a recommendation to the international community for the creation of a new consensus for the development of a new definition of remission in RA. Perhaps we have been trying to define remission incorrectly. If we agree that there are two sources of disease knowledge, the solution cannot come from basing the definition on the opinion of two groups of people who have different knowledge; instead, we should find people in whom both sources of knowledge coexist (Fig. 3). Each group, rheumatologists and patients, have a partial view and probably a blind spot in remission, in relation to the type of knowledge they possess. According to our proposal, remission criteria and its definition need to be established by a group of rheumatologists living with the disease, as they represent the balance between technical and experiential knowledge. This will let us enjoy a complete view of the RA.

Remission from the point of view of patients (P) and rheumatologists (R) is biased. Remission is a complex concept and for this reason is difficult to reach a consensus between patients and rheumatologists, both with different types of knowledge. Rheumatologists with rheumatoid arthritis (R+RA) with a balance between experiential and technical knowledge, should be the ones in charge in defining remission and remission criteria.

Our study reveals that there is a lack of consensus between rheumatologists and patients, and between rheumatologists with different specialisations on the concept of remission in RA. Moreover, the existence of two sources of disease knowledge is confirmed: technical and experiential. Probably the best strategy to achieve a comprehensive and valid definition of remission will be to concur in the same group of people experiences and technical expertise.

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Key messages

- Rheumatologists and patients did not see remission in rheumatoid arthritis (RA) from the same perspective.
- Symptomatology is the most relevant aspect of the disease for patients, in contrast for rheumatologists the most important aspect is the availability of objective instruments to quantify the disease.
- A group of rheumatologists with RA should be responsible for defining remission and remission criteria.

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