

The patient perspective on remission in rheumatoid arthritis: “You’ve got limits, but you’re back to being you again”

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Objectives: The aim of rheumatoid arthritis (RA) treatment is remission. It is important to understand how patients perceive remission, and to assess whether the current remission definition adequately reflects these perceptions. The objective of this study is to explore the patient perspective on remission in RA.

Methods: Nine focus group discussions in Austria, Netherlands and UK were conducted, including patients in ACR/EULAR remission, self-declared remission and in moderate/high disease activity. A prespecified interview guide helped to engage patients in a discussion on their experience with remission. Inductive thematic analysis was performed within each country, and identified themes were discussed across countries.

Results: 47 RA patients (66% female, disease duration 9 years) participated. Three major themes of patient-perceived remission emerged: 1) symptoms would either be absent or strongly reduced, 2) impact of the disease on daily life would diminish by increased independence, ability to do valued activities, improved mood and ability to cope; 3) leading to a return to normality, including work, family role and perception of others. Patients felt the concept of remission was influenced by ageing, side effects of medication, co-morbidities, accrued damage to joints and disease duration. Opinions on duration of state, the role of medication and measurement instruments varied widely.

Conclusion: Patients characterize remission by the absence or reduction of symptoms, but more directly by decreased daily impact of their condition and the feeling of a return to normality. The next step is to study whether an additional patient-perceived measure of remission may add value to the ACR/EULAR definition of remission.

The degree of disease activity and response to treatment in rheumatoid arthritis (RA) are traditionally evaluated by outcome measures gathered in the RA core set or indices derived thereof.[1-5] The core set contains three outcomes directly reported by patients, so called patient reported outcomes (PROs): physical function, pain and global assessment. These subjective patient reported outcomes are at least as informative as other physical and biochemical (more 'objective') measures in assessing baseline disease status, improvement during interventions or prediction of long-term outcome.[6-10] However, several areas have only recently been identified as important to patients and thus as potential core areas for measurement. For example, data have shown that measurement of fatigue, one of the most important problems identified by RA patients, is highly reliable, sensitive to change and an independent determinant of disease activity.[11-13] Therefore, OMERACT (an international scientific organization studying outcome measures in rheumatology) now recommends fatigue should be assessed in all RA clinical trials.[14] This reinforced the notion that patients should be regarded as crucial partners in obtaining relevant information and prioritizing areas of research, as patients and professionals bring different skills, values and experiences to research.[15;16]

Treatment of RA is increasingly aimed at remission. In 2011, the ACR/EULAR remission criteria were developed. According to these criteria, remission is reached when the tender joint count, swollen joint count, patient global assessment of disease activity and C-reactive protein are all smaller than or equal to 1, or when the simplified disease activity index is smaller than or equal to 3.3.[6] The committee used prognostic factors and outcome measures available in clinical trial data, including the three core set PROs. PROs on other potential important aspects of remission were not available, highlighting the lack of knowledge on the patients' perspective on remission. At OMERACT-10 patients and professionals agreed that there is an urgent need to study the concept of remission, including the identification and measurement of domains that are important to patients.[17] This is in line with international recommendations for treating to target, with the target being remission and the treatment described as a shared decision between the patient and the rheumatologist.[18]

The aim of this study is to capture the patient experience of remission in RA-

METHODS

Focus group discussions were conducted to investigate the domains of remission according to patients with RA in three European countries. Focus groups rather than individual interviews were used as they promote discussion and debate amongst participants.[19]

Patients

Patients over the age of 18 years with a confirmed diagnosis of RA receiving usual care in one of the 3 centers (Reade Research Institute in Amsterdam The Netherlands, Medical University of Vienna Austria and the Bristol Royal Infirmary in Bristol UK) were asked to cooperate in a qualitative study.[20] To get a broad range of patient characteristics, eligible consecutive patients attending outpatient clinics were invited to join a focus group discussion on 'when your disease activity is as good as gone' (rather than 'remission', which is not used with patients in the Netherlands and Austria, while UK patients are familiar with the word; this phrase was formulated with the help of patient research partners, who specifically advised us to refer to 'disease *activity* as good as gone', rather than 'disease as good as gone', as the disease can not be removed, but the activity can.).

Initially, three focus group discussions were organized in every country: one with patients in ACR/EULAR remission, one with patients in self-declared remission and one with patients in a moderate to high disease activity state, defined by a DAS28>3.2. Two-thirds of the patients in moderate to high disease activity must previously have experienced self-perceived remission or very low disease activity. Patients not fluent in the local language were excluded. Data collection was continued until saturation was reached. Three patient research partners were involved (WH, BD, MS-V).

Data collection

In the two week period before the focus group meeting, remission was assessed in all patients by the clinicians according to the new ACR/EULAR Boolean remission definition.[6] Clinical data collection was limited to a 28 swollen and tender joint count, the laboratory measurements ESR and CRP and a physician global assessment of disease activity. At this same visit age, disease duration, experience with remission in the past, current self-perceived remission status, and the patient's global assessment of disease activity were recorded. Specifically, the following three questions were formulated: '*Have you ever experienced a period of very low disease activity, in which you had the idea that your disease activity was as good as gone?*'(yes/no) '*Would you say that, at this moment, your disease activity is as good as gone?*' (yes/no), '*Considering all of the ways your arthritis has affected you, how do you feel your arthritis is today?*' (10 cm visual analogue scale, anchors very well to very poor).

A common focus group interview guide was developed (supplemental file 1) and translated in the local language by a researcher from Vienna and the Netherlands. All focus group discussions were conducted by experienced qualitative researchers (MS in Vienna, SH+CF+TSa in Bristol and LvT in Amsterdam) who were not involved in the clinical care

management of any of the patients. Discussions, lasting approximately 1 hour, were taped and anonymized at transcription, with patient names being replaced by codes.

Analysis

Inductive thematic analysis was used to ensure that findings were grounded in patients' data rather than imposed from professional literature. Initially, transcripts were read and re-read to gain an understanding of and familiarization with the issues. Then, small units of meaning were identified and given descriptive labels (codes). Next, the findings were explored to see how codes could be grouped to form sub-themes, and finally sub-themes were grouped to form overarching themes. [21]

This was carried out independently in each country by experienced qualitative researchers with their patient partners (TSt+MS in Vienna, SH+CF+TSa in Bristol and LvT+WH in Amsterdam). Next, the reports and supporting evidence from Vienna and Amsterdam were translated by two of the researchers in each center, and all sets were shared. A teleconference between the qualitative analyzers from each country was organized, followed by a one day meeting of all researchers and patients from all three countries at which emerging codes and themes were compared and agreed.

All necessary documents were reviewed by an Independent Ethics Committee under the responsibility of the chief investigator in each country. Patients were informed about the nature of the study and provided written informed consent.

RESULTS

In each country, data saturation was reached after 3 focus group discussions, which resulted in a total of 9 focus group discussions in total.

A total of 152 patients were approached to participate. As 105 declined the invitation, a total of 47 patients participated, including 66% females; overall mean disease duration was 9 years (Table 1).

Table 1: Patient characteristics

	overall	Amsterdam	Bristol	Vienna
Participants, n (n per group#)	47(18,14,15)	22 (8,7,7)	12 (5,4,3)	13 (5,4,3)
Disease duration in years, mean (min-max)	8 (1-40)	6 (1-14)	11 (1-40)	10 (1-27)
Age in years, mean (min-max)	56 (29-76)	58 (30-76)	52 (29-65)	57 (35-71)
Gender (% female)	66	64	75	62
Self perceived remission, n (%)	24 (51)	13(59)	4(33)	7(54)
Past experience with self perceived remission, n (%)	37 (79)	18(82)	7(58)	12(92)
ACR/EULAR remission, n (%)	13 (32)	7(32)	1(20)*	5(39)
PtGA (mean, min-max)	2,9 (0-9)	2,5 (0-8)	4,5 (0,5-9)	2,0 (0-5)
Disease activity score based on a 28 joint count, mean (SD)	2,3 (1,6)	1,8 (1,2)	3,8 (1,8)*	2,6 (1,6)

*7 out of 12 missing data, as not all patients in Bristol had recent joint assessments to enable calculation of their remission status

groups included: ACR/EULAR remission group, self-perceived remission group, moderate to high disease activity group

PtGA: patient global assessment of disease activity

Three main themes emerged (symptoms, impact and normality), underpinned by a theme of influential factors and a related theme of 'assessment issues'. Together they form the concept of remission according to the patients' perspective (Figure 1). The five themes are discussed below, including supporting quotes; subthemes and additional quotes are presented in Tables 2 to 6.

Figure 1: Main themes of RA remission

1) Symptoms

It was important to patients that specific symptoms would either be completely absent or be reduced in intensity. Reduction of pain (Q1 and 2), stiffness (Q3 and 4), fatigue (Q5 and 6) and swelling (Q7) were mentioned frequently, but also recovery of strength (Q8) and improved sleep (Q9 and 10) were important to several participants (Table 2).

Stability of disease was seen as a sign of remission, manifested as fewer flares, and decreased unpredictability and variation in signs and symptoms:

UK2 G: For 5 full weeks, I've got out of bed and I've got on with the day, brilliant! I think that partly what I'm hoping is that being controlled means that there's a predictable component to my disease activity... that would be great because then if someone said to you they were wanting to have a party, you'd know you would be able to go. I've had to cancel so many social events.

UK2 H: 'I don't know how I'll be, If I'm okay I'll come.'

UK2 G: Yeah, but if your disease was controlled you'd be like, 'Yeah, I'll come along, I'll leave by ten and I'll probably drink too much before then!' That would be good. That's a major event.

There was no agreement on the importance of severity of symptoms. For some patients, remission meant the complete absence of the symptom (Q1), while for others a certain basic (low) level would suffice:

NL2 3: well, the pain, purely the pain. That's the whole story. The other day someone said to me 'girl, you don't know how it feels to live with pain everyday'. Then I said, 'in fact I do'. When you have arthritis, you always have pain. Even in good periods. There is always something, when you get up you think, 'oh yes'. But you accept it..

MOD: even in good periods?

NL2 1: yes

NL2 3: You accept it, because you got the disease.

Table 2: Quotes supporting the 'symptom' theme of patient perceived remission

Symptoms			
Less or no pain	1	MOD: NL1 3: NL1 6: NL1 3:	So you all indicate that you should be free of pain or close to free of pain when in remission well, I would not say 'close to', but NO pain. I agree, NO pain is remission. but not close to or almost
	2	AT2 1:	When the disease was as good as gone, I had absolutely no symptoms; I was strong, had absolutely no pain, no stiffness, nothing. But when it started again, it was quite bad, everything hurt, I couldn't walk, couldn't carry anything.
Less stiffness	3	NL2 2:	...it is more a stiffness during the whole day. It's in all your movements. That's why I call myself, I'm not there yet, but I sometimes feel like a stiff elderly person. In moving, and stiffness and fine motor skills. So when you squat, and you have to grab all kind of things to get back up again. Well, that is... if you are still rather young, that's really not amusing.
	4	UK2 D:	I was so much looser in my body [when the disease activity was gone]. There wasn't this sort of tightness or ... I mean sometimes it feels to me like I've got a mild form of cramp all the time
Less fatigue / more energy	5	NL2 2:	For me the stiffness and fatigue. That I would just have the energy, and I would even be prepared to put up with the pain... That is, except the real heavy pain attacks, but I rather have my energy back and that overall feeling of stiffness... I would be happy then.
	6	UK2 D:	I mean I have this heavy aching all over despite the medication and being very tired a lot of the time and I can't imagine ... I mean that would be perfect for me if all that disappeared completely, but I don't think that will ever happen.
Less swelling	7	UK1 C: MOD: UK1 C: UK1 A:	[...] I haven't had any swelling to talk of, what I would call swelling, for the last two years. I get flare ups, like the other day, my elbow was absolutely killing me, but that's what you get, you get that ... or your wrist is absolutely a pain like, all day long, and then the next day it's gone, it comes and goes, it does that all the time. So is swelling an important part of ... ? Massive. God, yes, definitely.
More strength	8	NL3 1: MOD: NL3 1:	not so much the fatigue, for me it was the strength. When the disease was at its heaviest, that was only in the beginning. I had no strength in my hands. Couldn't do a thing. I had two young daughters back then. Had to do their hair. I just couldn't. because of the pain? or not pain but, ...? pain, and strength.
Better sleep	9	NL2:	The pain and with that the fatigue and the not sleeping at night. I have had functioning problems at work, just because I didn't sleep properly at night. So he [rheumatologist] gave me something to suppress the inflammation and sleep better. And then you become so much more fit. Many symptoms disappear. Everything is easier.
	10	AT3 2:	And as the lady said it is the mind, and that includes everything. Because when I have extreme pain, then I cannot sleep, then I am not well rested, then I am tired and listless ... so that I doze off constantly and anyhow I cannot sleep. And that is really unpleasant.

2) Impact

Reduction in the impact these symptoms led to was deemed as important as the symptom reduction itself. These impacts included physical functioning (Q11), activity of daily living (Q12 and 13), and being independent (Q14 and 15) (Table 3). Patients saw remission as being able to do valued activities, have an improved mood and feel able to cope.

UK3 L: I can just get on and do whatever I like

AT3 5: I realize, when I am absolutely without pain and there is no severe swelling, one feels somehow more positive, ... well I realize that I am active, I make a lot of plans and I am somehow nicer to my colleagues and co-workers and just agreeable. And my husband is happy as well.

Table 3: Quotes supporting the 'impact' theme of patient perceived remission

Impact			
Physical functioning	1 1	NL3 3:	I am physically limited by this disease. When it would really be gone, I would be able to behave differently. The whole day, really. I could do so much more, I would be so much more mobile so to speak. Because I limit my activities to reduce the disease activity.
Activities of daily living	1 2	MOD NL2 3: NL2 4: NL2 2:	What are the features of a good period for you personally? much more active, you are in the mood to go to the market when you feel good, you go out, do this, do that, you know... That you can do your normal daily activities. That you're not depending on anyone else.
	1 3	AT2 2:	The main difference I can feel is in performing everyday activities. For example putting on your socks can turn into a torture. Then you already know that the disease is active again.
Independence	1 4	UK2 G:	... independence of personal care and independence of the jobs in the house that I think of as being my jobs and being able to do some of the fun things as well. Before, if I cooked dinner that would be me done for the entire weekend. I love cooking, the kids really love my cooking and ... but for me to do them a Sunday roast that would be me absolutely done, and there was be no frills on it. Whereas now I can go to the park as well and, so you kind of get like I like to be independent.
	1 5	AT1 1:	I'm happy that I can open a jar with cucumbers without going to somebody else and asking for help – this is what always reminds me of it [active disease]...

3) Normality

The reduction in symptoms and impact of the disease on daily life would eventually mean a return to normality.

UK2 H: So, um, but for me remission is, like you say, feeling normal really.

NL1 C: When I am doing well, I am my normal, cheerful self.

Return to normality could either be a return to the 'old' normal life, or a 'new normality' including the ability to (regain) work (Q16), enjoy one's family role (Q17 and 18) and be seen as normal by other people (Q19 and 20) (Table 4).

Table 4: Quotes supporting the 'normality' theme of patient perceived remission

Normality			
Being able to work	16	NL1 C:	I'm working fulltime again, so to me that means I'm doing really well.
Family role	17	UK1 B:	Erm, playing with the kids, going on long walks with the kids, whereas before we could never do that. It was like being normal.
	18	UK2 G:	So I think there's this new person that I'm now - a mum, but I'm an independent mum and it's the first time and he's two and a half
Perception of others	19	UK2 D:	I feel pretty good again and it's good that no one else can tell that I've got it, I think that makes me feel that there's nothing wrong.
	20	UK2 E:	Just normal, back to being normal, yeah. People's perception of you, if you get out of a chair like that, especially at my age... When I'm struggling to get out of a chair, people look at me quite funny and think what's wrong with him, but for me to just get out of a chair and just do stuff without thinking about it, I class that as just being back to normal.

4) Assessment issues

There was no consensus on the minimal duration of this state that was needed in order to define it as remission, which varied from 24 hours to forever (Q21 to 24). Likewise, the opinion on role of medication in the concept of remission varied between patients (Q25 to 27). There was confusion over the patient global measure, which was felt to be inappropriately worded to capture remission as it did not ask about disease activity (Q28); moreover, patients felt that the score was heavily influenced by their mood that day (Q29 and 30). Others were disappointed with the symptoms they still experienced while in clinical remission (Q31 and 32) (Table 5). Ideas on measurement of remission focused on measuring what one could do, rather than how one felt.

AT2 2: When both of us try to open a bottle of mineral water - the same bottle - then we have the same starting point. We cannot open the bottle because the disease is active, we are not strong enough to open it. And actually this is the criterion, isn't it? This is better than a line with a mark[VAS], because that is only a subjective opinion.

There was a belief that the patient and physician definitions of remission might differ:

NL1 F: *So when you ask me if my disease is as good as gone... Well, my physician says it is. But if you ask me, do I feel better? Well no, I am not cured. My life, my days, my weekends are focused towards: 'maybe I need to sleep'; or 'if we do this on Saturday, I will need to rest on Sunday'; my grandmother of 80 years old can do more than me sometimes...*

Table 5: Quotes supporting the theme 'assessment issues' of patient perceived remission

Assessment issues			
Duration	21	UK2 G:	Twenty four hours for me!
	22	AT3 5:	In order to feel it [that the disease is as good as gone] substantially and realize it, it must be ongoing for more than half a year.
	23	UK3 L: UK3 I: UK3 J:	I would say eighteen months, two years and then the champagne is opened! A year. Around about two years.
	24	AT1 3:	Until one forgets to think about it [the disease].
Use of medication	25	NL1 2:	Yes, I would like to step down and stop, because you are wondering about the side effects of those drugs. Like mood changes... Is that me or is that menopause or what?
	26	NL1 2:	Last summer, my rheumatologist advised to step down. And within a month I had trouble with walking again. So no thank you. I hate it, MTX and prednisone. Hate it, but can't do without it apparently.
	27	AT3 1:	Remission means for me freedom of symptoms and reduction of the medication.
Measurement	28	UK3 I: UK3 L: UK3 K: UK3 L: UK3 I:	That's right. It's [patient global assessment] also how you're feeling. Isn't it more to do with what you're capable of doing rather than how you're feeling. A combination maybe. I usually think what I can and can't do physically. I think you're right, that your actual mental state is critical. We're actually answering this in a ... answering a different question really aren't we? You're saying how you feel mentally and I'm saying what it's stopping me doing, how far I can walk or whether I can ...
	29	NL1 2:	Yes, those measurements... It depends on when you see me. If I am cranky or short tempered... while my disease is on the same level, you will get different answers out of me.
	30	NL1 6:	What you say, if you get up with the sun shining and all, you feel different then when it is raining...
Discordance between patients and physicians	31	AT3 1:	Well, according to the physicians it [the disease] shouldn't be active, but I still have complaints. I don't feel that bad, but ... the strength in my hands is deteriorating"
	32	UK2 G:	I suppose in part though also if there was a medical measure for your disease being controlled or not. If they said "Oh well, you know, from a medical point of view, your RA is well controlled or in remission", or whatever, then you still felt like complete rubbish, then wouldn't that then make them look at the other components to it?

5) Influential factors

Patients struggled with the concept of remission itself, feeling it was confounded by normal ageing (Q33), side effects of medication (Q34 and 35), symptoms from co-morbidities (Q36), accrued damage to joints (Q37) and disease duration (Q38) (Table 6).

NL3 1: *It is sometimes difficult to say, the fatigue for example: age, medication or arthritis? But the symptoms are very specific, wrists and stuff. If you strain them, it really hurts. That is arthritis.*

Table 6: Quotes supporting the 'influential factors' theme of patient perceived remission

Influential factors			
Age	33	UK3 L:	If you've got somebody in their eighties or somebody in their forties, their idea of remission is going to be different as well.
Side effects	34	UK3 I:	It's quite hard because it's managing the disease level and activity, but it's also creating a whole range of other issues and problems as well though, ...sometimes I think well is this the arthritis or the medication, or is it something else really, you know. Sometimes it's kind of masking things so it's quite hard to work out really.
	35	NL3 2: NL3 4: NL3 2: NL3 4:	It sounds weird, but I think the medication is troubling me more than that the disease is. Well, it doesn't sound weird, I have exactly the same It's hard to say. Am I tired because the disease is active or is it the medication? I have a lot of side effects. I don't feel well on the day that I take [drug name]
Comorbidity	36	UK2 G:	I suppose there's certain things which I relate to my RA and there's certain things which I might relate to something else, I get back pain and I'm pretty sure it's because I fell over in a flume [red: theme park ride] as opposed to it being because of my RA.
Damage	37	UK1 C:	I've had improvements but it's taken operations to give me improvements. But it's not only that, it's the deformity as well, so you might be in remission but then when your hands and your fingers go like that ...
		UK1 A:	Yes.
		UK1 C:	How can that be ... what can you do, even with remission? You're stuck with ...
Disease duration	38	AT3 5:	Regarding the disease activity, I've already experienced much worse and really dramatic phases during the whole course [duration] of the disease, too. Now, I can work perfectly, I can walk, so I feel really, really good...

DISCUSSION

This is the first study that gives insight into the perception and experience of remission in patients with RA. Patients indicate that, for their disease to be as good as gone, the symptoms would need to be absent or reduced in intensity, but more in the foreground was the reduced impact of these symptoms on their life, eventually leading to a feeling of normality. This is consistent with the proposal that patients experience the impact of their condition, an interaction between severity of the disease, their personal circumstances and their ability to cope with the condition, and are less directly aware of specific pathological changes.[22]

Patients struggled with attribution of signs and symptoms to either the disease or influential factors such as aging or side effects of medication. Many PROs assume patients are able to differentiate between for example pain due to RA and pain due to flu, and there is some evidence that this may well be the case.[23] Conceptual aspects of remission that are of great interest to professionals, were hard to grasp for patients; opinions on importance of

duration for defining remission, as well as on the use of medication were very diverse; if anything, these aspects should be reviewed for each patient individually. In this respect, the omission of duration as well as medication from the ACR/EULAR remission definition seems sensible.

Not much is known about the patients perspective on remission. The only comparable work is a focus group study by Kristiansen et al, studying self-identity, social relationships and work relationships of early RA patients in remission.[24] As participants were chosen because of the success of the treatment regimen they were taking, they had experienced only limited changes on everyday life and were able to manage the varying limitations experienced. Interestingly, aging was identified as a means to normalize symptoms and disabilities, which was also seen in our study.

More research has been done on perceptions of patients in active disease, that shows a lot of resemblance with our work on remission. A recent cooperation between patients and professionals resulted in a new patient-derived score to capture impact of RA on daily life (RAID).[25] The domains captured by the RAID, ie pain, daily functioning, fatigue, sleep, physical and emotional wellbeing and coping, were all of importance to the perception of remission as well, although patient perceived remission may not necessarily be represented by a low score on the RAID: RAID specifically measures impact of RA, while remission is a larger concept, where low impact leads to a return to normality, which is a complex concept in patients with a chronic disease.[26]

The new definition of remission in RA has been hampered by the lack of adequate data on the patient perspective of remission. The PRO included in the new remission criteria, the patient global assessment of disease activity, is a well-known and widely used instrument that should give an overall rating of the patients' perception of disease activity. However, cut points for remission have never been validated and recent studies suggest that a remission PtGA of ≤ 1 might be too restrictive, excluding patients with comorbid conditions to achieve remission.[27;28] Although not specifically addressed in this study, our work suggests that the PtGA is interpreted differently by different patients and can be influenced by many aspects of the patients life. As such, the PtGA may reflect disease impact, not just the notion of pathological severity implied by 'disease activity'. Our study provides domains of patient perceived remission that may contain information currently not captured by the ACR/EULAR remission criteria, yet crucial for optimal targeted therapy, thus implying that both should be measured.

This study had a qualitative design, ensuring a wide, unbiased approach towards the identification of aspects of remission according to patients. The involvement of patients from three different countries and different languages, allows for transferability across Western Europe. Another important point is the involvement of 3 patient research partners who ensured a patient perspective during every phase of this work, through their input at the development stage of this project, by reviewing the patient information material and interview guide, by being an observer during the group discussions as well as taking part in the interpretation and analysis of the data and finally by their participation in the meeting of researchers in Amsterdam.

A limitation of this study is that the Dutch and Austrian transcripts were analyzed locally, i.e. not translated and reviewed by the other centers. However, the data were carefully combined during a meeting with researchers and patient partners. For example, it was discussed that not all aspects of the domains were mentioned in every country (improved mental power was only mentioned in Austria; swelling was hardly mentioned in Netherlands). During the meeting of researchers it was decided that these aspects would nevertheless be taken to the next phase of the study.

The intention to have three group discussions stratified for disease activity wasn't strictly effectuated. As patients were invited to join a specific group several days prior to the actual day of the discussion, disease status could have changed in the meantime; this was especially the case for the ACR/EULAR remission group, where the patient global assessment on the day of the discussion caused a shift in classification in two patients. This resulted in a total of 13 patients that were actually in ACR/EULAR remission. However, this was compensated by the number of patients who had experienced periods of remission and where able to share their experience. Moreover, it was never our intention to analyze the results of the three groups separately; the stratification was made to ensure a variety of conditions and experiences, yet grouping patients in a similar condition together to enhance group dynamics.

It can be debated whether the patients that participated in the group discussions are somehow different from the patients that declined the invitation. In each country, the group in ACR/EULAR remission was the most difficult to compile. Most likely due to the low prevalence of ACR/EULAR remission, but also due to this group of patients feeling well and working / not wanting to think of their disease.

There were clear signals that factors such as age, disease duration and comorbidity play an important role when evaluating remission perceptions of patients. However, this study was

not designed to specifically address these issues and the qualitative nature does not allow for stratification of results. Quantitative research would be needed to test this. Therefore, follow up research has been initiated, where all domains will be rated for importance by a second larger group of patients. This work will also include identified influential aspects of age, drug side-effects, damage and disease duration. The most important domain(s) of patient perceived remission, which will most likely relate to the overall impact of their condition, can then be taken forward in validation studies, to evaluate their psychometric properties and added value to defining remission in RA.

In summary, the patients perspective on remission in RA is characterized by the absence or reduction of symptoms, by decreased daily impact of their condition and the feeling of a return to normality. The next step is to quantitatively study the identified domains and their added value to the ACR/EULAR definition of remission.

Competing interests

The authors have no competing interests regarding this work

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