

## Original article

**‘I’m hurting, I want to kill myself’: rheumatoid arthritis flare is more than a high joint count—an international patient perspective on flare where medical help is sought**Sarah Hewlett<sup>1</sup>, Tessa Sanderson<sup>1</sup>, James May<sup>2</sup>, Rieke Alten<sup>3</sup>, Clifton O. Bingham III<sup>4</sup>, Marita Cross<sup>5</sup>, Lyn March<sup>5</sup>, Christof Pohl<sup>3</sup>, Thasia Woodworth<sup>6</sup> and Susan J. Bartlett<sup>7</sup>**Abstract**

**Objective.** People with RA have episodes of worsening disease activity (flares) that prompt them to seek clinical review or medication change. This study explored patients’ perspectives of flare that prompts them to seek medication review.

**Methods.** Fourteen focus groups across five countries comprised 67 RA patients. Transcripts were analysed by several researchers and a patient, using inductive thematic analysis.

**Results.** Patients use flare for five different scenarios, including flare that prompts medical help-seeking, where six themes were identified. In ‘Symptoms and early warnings’, pain is intense (wanting to die), constant and persistent and considered a key feature. Systemic features predominate, including fatigue, feeling generally ill (flu-like), physical and cognitive shut-down and social withdrawal. Warning signs (prodrome) comprise fatigue and flu-like symptoms. ‘Self-management of intensifying symptoms’ includes pacing, heat/cold, rest and increasing medication, often without medical advice. Patients ‘Define this as uncontrollable flare’ when clusters of unprovoked, persistent symptoms halt their ability to run daily life, until prompted into ‘Seeking help when symptoms can’t be contained’. Underpinning themes are ‘Individual context’ (e.g. different symptom clusters) and ‘Uncertainty’ (e.g. when to seek help). Patients report that the current patient global visual analogue scale (VAS) does not capture flare.

**Conclusion.** Patients use flare for multiple events and seek help for complex clusterings of intense, unprovoked symptoms that defy self-management, not necessarily captured in joint counts or global VAS. Flare terminology and definition have implications for clinical practice and trials, therefore further research should establish a professional/patient consensus.

**Key words:** flare, rheumatoid arthritis, qualitative, patient perspective, symptoms

<sup>1</sup>Department of Nursing and Midwifery, University of the West of England, Bristol, UK, <sup>2</sup>Patient Research Partner, Seattle, WA, USA, <sup>3</sup>Department of Internal Medicine II, University of Berlin, Berlin, Germany, <sup>4</sup>Department of Medicine, Johns Hopkins University, Baltimore, MD, USA, <sup>5</sup>Institute of Bone and Joint Research, University of Sydney, Sydney, NSW, Australia, <sup>6</sup>Roche Products, Welwyn Garden City, Hertfordshire, UK and <sup>7</sup>Department of Medicine, McGill University, Montreal, Canada.

Submitted 30 August 2010; revised version accepted 15 December 2010.

Correspondence to: Sarah Hewlett, Academic Rheumatology, Bristol Royal Infirmary, Bristol BS2 8HW, UK.  
E-mail: sarah.hewlett@uwe.ac.uk

**Introduction**

RA causes synovitis in multiple joints, pain, disability, emotional and social burden, and pharmacological interventions aim to reduce inflammation [1, 2]. Even with good inflammatory control, there are episodes of increased inflammation (flares), some of which lead to changes in medication, yet there is no standardized definition of RA flare. In clinical practice, medication change is instigated after assessment of various clinical variables of flare, such as the DAS, a weighted composite of

swollen joints, tender joints, inflammatory marker and patient opinion [3]. In clinical trials, different combinations and severity levels of variables are set for each trial, defining flare for entry criteria and disease worsening during the trial (e.g. a specific increase in painful/swollen joints) [4, 5]. This lack of a standardized flare definition makes comparisons between clinical trials difficult and complicates adoption into clinical practice.

OMERACT is an international group that uses data-driven consensus to standardize definitions and core variables for trials [6, 7]. At OMERACT 9 (2008), some professionals suggested synovitis as the single component to define flare [8]. However, it is the person with RA who experiences flare and decides to seek clinical review and at OMERACT 9 an informal discussion with 11 patient delegates, suggested that not all patients experience synovitis in a flare, but many experience systemic and other symptoms [8]. People with AS report pain, fatigue, immobility and altered mood in flare [9], but no qualitative research has explored flare in people with RA.

In back pain, an exploration of commonly used terminology with lay participants and health professionals suggested that patients had significantly different understanding of many terms from those intended by professionals [10]. As flare is a precursor to major medication change, mismatch between clinician and patient perspectives might influence flare assessment and subsequent treatment decisions. The aim of this study was therefore to explore the patient perspective of RA flares that prompt them to seek medical review.

## Patients and methods

Adults with RA [11] and experience of flare were invited to participate. Participants were purposively selected from secondary care clinics of multiple clinicians, for a range of characteristics that might reflect different flare experiences: age, disease duration, disability (HAQ [12]), medication and patient global VAS (considering all the ways your arthritis affects you, how well are you doing, very well/very badly) [3].

### Data collection

Qualitative research is the most appropriate method to explore the breadth and depth of patient experiences, and focus groups promote discussion among participants, allowing common experiences to be clarified and diversity explored [13, 14]. Fourteen focus groups were

held (UK, Germany, USA, three each in Australia, two in Canada), facilitated by local OMERACT flare researchers, using a common interview schedule of neutral questions developed by the steering group including user involvement (J.M.) [15] (Table 1). As flare may not be a universal term, it was initially described to groups as 'the point at which you want your medication reviewed'. Discussions were recorded, transcribed and anonymized. German transcripts were translated into English and then reviewed by a second translator, enabling analysis across all countries, reflecting the international nature of clinical trials.

### Analysis

Inductive thematic analysis ensures that findings are grounded in the patient data by using a bottom-up approach to search for common themes [16]. Transcripts were read and re-read to gain overall understanding; systematically examined for small units of meaning, which were given descriptive labels (codes); codes were explored for links and grouped to form larger concepts; and then overarching themes. Analysis was iterative, moving back and forth between transcripts, analysis and subsequent focus groups to refine developing concepts [16]. The first transcript was analysed independently by S.H., T.S., S.J.B. and J.M., who then agreed the developing codes. Subsequent transcripts were analysed by S.H., with T.S. and J.M. providing additional analysis, and then by team review. No new concepts emerged after 11 transcripts (data saturation). As only the facilitator's contemporaneous notes were available from Group G due to equipment failure, those data were verified against the final findings. Approval for study was obtained (Barking and Havering Research Ethics Committee, UK, 08/H0702/67) and then each country obtained approval from their respective Ethics/Investigational Review Boards [Research Ethics Board, McGill University Health Center (REB 09-017-PSY); Johns Hopkins Institutional Review Board (NA-00027263); Schlosspark-Klinik Institutional Review Board, Teaching Hospital of the Charité, University Medicine Berlin; Northern Sydney Central Coast Health Human Research Ethics Committee (08/HARBR/174/175)]. All patients gave informed consent.

## Results

Fourteen focus groups comprised 67 participants with a range of characteristics (Table 2). Analysis identified 295

**TABLE 1** Focus group interview guide

- 
- (i) What happens to you when your disease is active?
  - (ii) How do you decide when it is so active that you might need your drugs changed?
  - (iii) Do you have different words for daily variation in your symptoms, bad patches and the point where you want your medication changed?
  - (iv) How would you define this very active disease or flare situation?
  - (v) Do you get early warning signs that a flare is coming?
  - (vi) How do you manage a flare?
  - (vii) If we could measure this flare on a scale, what would the points on the scale say?
-

TABLE 2 Demographic data for focus group participants

Variable	Overall (n = 67)	UK (n = 18)	USA (n = 10)	Germany (n = 21)	Australia (n = 13)	Canada (n = 5)
Group label		A, B, E	F, H, K	L, M, N	C, D, G	J, O
Female/male, n	57/10	14/4	9/1	16/5	13/0	5/0
Caucasian, n (%)	62 (92)	18 (100)	6 (60)	21 (100)	12 (92)	5 (100)
Age, years	57.0 (27–78)	58.1 (35–78)	56.7 (46–71)	55.8 (31–75)	61 (43–72)	48.8 (27–68)
Disease duration, years	14.5 (1–50)	15.6 (1–49)	11.1 (1–19)	8.9 (1–33)	23.4 (9–50)	17.8 (2–45)
Patient global VAS <sup>a</sup>	3.94 (0–9)	4.28 (0.4–9)	1.3 (0–4)	5.05 (2–8)	3.52 (0.4–8.3)	3.8 (0.3–8.7)
Disability, HAQ <sup>b</sup>	1.21 (0–3)	1.48 (0–2.5)	0.625 (0–1.5)	1.09 (0–2.375)	1.47 (0–3)	1.3 (0.125–2.5)
DMARD therapy, %	83.6	100.0	80.0	76.2	76.9	80
Anti-TNF/biologic therapy, %	44.8	22.2	80.0	33.3	61.5	60

Values are represented as mean (range), unless otherwise mentioned. <sup>a</sup>0–10, high bad. <sup>b</sup>0–3, high bad.

flare codes, which could be grouped into 21 concepts and 6 overarching themes. There were no major differences between the countries. Patients used the word flare to convey multiple situations. Flare as a single symptomatic joint, increased symptoms within normal variation, increased symptoms from external causes (e.g. stress) or flare from over-exertion (i.e. self-induced) are perceived as having a cause and being manageable. The fifth use of flare is characterized by unprovoked, increased symptoms that are unmanageable, persistent and lead to seeking help. This article explores that latter definition, and six overarching themes comprised ‘Symptoms and early warnings’, which lead to increased ‘Self-management of intensifying symptoms’, and if this fails, patients ‘Define this as uncontrollable flare’, which leads to ‘Seeking help when symptoms can’t be contained’, all underpinned by ‘Individual context’ and ‘Uncertainty’ (Fig. 1).

### Symptoms and early warnings

Patients describe a depth and breadth of symptom intensity and consequences that extend beyond a count of painful, swollen joints. The concept of pain in multiple joints was raised in every group, differentiated from normal RA pain by its intensity, quality and constancy:

Ear piercing. Ear-shattering pain. It goes from just aching, a dull background ache to an ear-shattering pain (Group D, Patient 21)

Maybe that’s the difference for me that it [pain] doesn’t let up. [...] it just is unrelenting (H37)

When it’s bad [pain], a lot of joints. I just feel that all my body, my feet, my knees, my hands, even sometimes my hips and my shoulders, in my neck, you know, like everything (O44).

Although patients experience joint symptoms of swelling and heat, not all patients have, or do not perceive they have, swelling:

I get sometimes in my ankles, in my toes, my feet feel like they’re on fire you know? Whatever pair of shoes

I’ve got on they just don’t seem to go on my feet because they’re all swollen (B11)

The joints, they were not warm, they were not swollen either, but I had the pain (N64).

Stiffness, both in joints and overall morning stiffness is dramatic:

I feel I am stuck together with superglue, everything is so stiff and won’t move (G30). I say I’m locked in a box (G31)

I needed 2 hours in the early mornings to get going. [...] But the increase in pain and morning stiffness were extreme. [...] The simplest things like washing or cleaning, combing my hair, all very tiring and stressful (L48).

Function, such as mobility and ability to do daily chores is profoundly compromised:

All I do when I have a flare-up is lie down, and get up to go to the toilet, and it takes me half an hour to get to the toilet (A5)

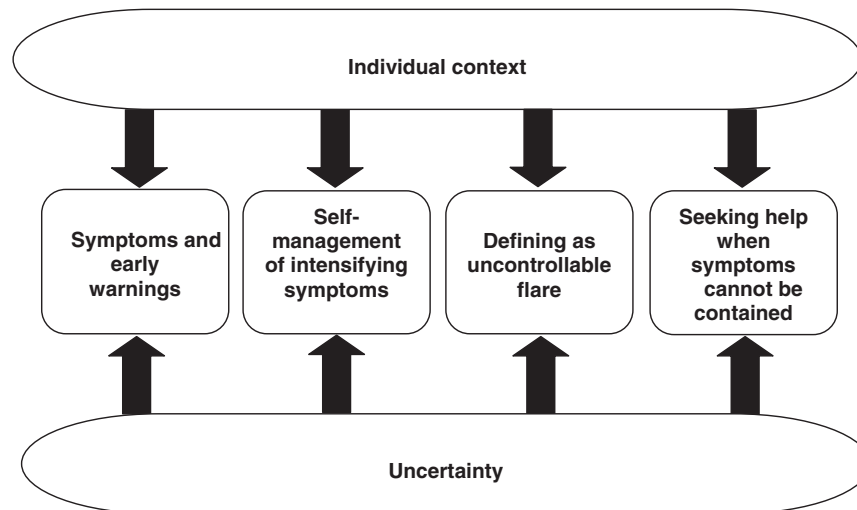
The simple little things, just trying to pick up something, I tend to drop things a lot more. It takes me a lot longer to get ready in the morning, to shower, to get ready, because I work full-time, and it is just the amount of time that everything takes. So it really affects you and your day (J38).

Fatigue is a key symptom, discussed in every group. Flare fatigue differs from normal RA fatigue by its intensity:

You get very tired (D20). It’s killer fatigue to the point where breathing is a real... it’s using energy just to breathe (D21). You can sleep all day and night and never feel refreshed (D19). Yes (D20). Never feel refreshed (D21)

I have this wipe-out feeling where even down to the tips of my fingers I have got no strength or energy at all [...] I mean I’ve been to bed and slept for three hours in the middle of an afternoon, which isn’t me at all (A1).

Fig. 1 Main themes and underpinning themes of RA flare.



Systemic features of flare are a major issue, primarily flu-like symptoms and feeling bodily ill:

The shivering, feverish feeling. The evidence points to 'flu and you think it is, but it isn't (L47)

I just felt ill. I just felt as if all my glands throughout my body were up, plus the pain [...] I just talk about it as making me feel bodily ill (C15)

A really terrible day is when I get up early and feel like a tractor has run over me (L54).

Participation in normal life is unthinkable during flare, with social withdrawal a feature for many people:

I'm just like an animal, go get in a cage somewhere until it goes away and then come back out (H34).

Cognition is reduced and many groups discussed feeling cognitively shut-down:

There are times when my thoughts seem like they're scattered, like I can't rein them in (K41). Trouble with concentrating! (K42). Right, less focus when you're in pain (K41).

Sleep is disturbed at night by pain:

I wake up in the night and have infernal pain and then take an Ibuprofen and then put a cooling-bag on it (N62).

Emotional distress is experienced by many, perhaps as a consequence of the combination of physical symptoms, feeling ill in oneself and inability to function. Such distress includes tearfulness, irritability and frustration, and the depth of desperation is evidenced by patients voicing a desire to cut off joints, kill themselves or die:

I was crying, I was just crying and praying, and my son came in and goes, 'Dad! Mom's crying!' So they

took me to the emergency room, and they just gave me some prednisone (K41)

I also find that I can't be around people when it gets really bad, because then I get into that sort of 'shut up whingers' mode (D21)

And it's a frustration that I feel within myself. [...] I get angry at myself for being this way, because I should be [...] I want to be normal (J38)

I'm hurting. Help me, I don't want to feel like this. When I go into my doctor and he says 'Why are you in here today?' I say 'Because I can't function like this. I'm hurting, I want to kill myself' (H36)

It's a pain that all I want to do (and I don't care who does it, or anybody that's willing to do it I will never say I'll sue you or anything), just get a knife, a saw, an axe, anything, just get rid of it (D22).

Early warning of an impending flare is noticed by some patients, particularly flu-like symptoms, fatigue or symptoms in particular joints:

You can usually feel then that you're going to have a flare-up just about to start because personally I always feel kind of feverish you know, and I shiver a lot and then I think I'm coming down with a cold and think 'I haven't got a cold'. So having had a few in my time I think 'Yeah, that's it' and I say 'I've got a flare-up on its way' and then invariably, unfortunately I'm right (B7)

Most of the time it starts in my elbows and goes through the body. So when I feel that both of my elbows are hurting, this ripping pain, that is an indicator to me to say 'Damn, that is going to be a flare' (M58).

### Self-management of intensifying symptoms

Patients increase their usual level of self-management by resting, pacing, applying heat or cold and escalating medications such as gluco-corticoids, often without seeking medical advice:

Listen to some music or think 'Right that's it, I am going to put my feet up and get my DVDs on this afternoon. I am not going to do anything else and that's it!' (E27). I call it my duvet and chocolate day (E23)

Where I used to say that I would stay a little longer in the shop for half an hour, that doesn't work anymore because I couldn't get home. [...] That's the way it is, it demands planning, especially when the rheumatism is acute, a clear structure and an unholy amount of self discipline (L54)

My wife asked yesterday 'Do you want cool or warm?' We have to get a cool box or warm packs. She gives them to me and then leaves me in peace (L46)

I increase the prednisone, and take Panadol for the pain. Once I feel better I then decrease the prednisone slowly, every two days. If I go to the GP [...] he can't do anything else (D18).

Self-management of early warnings or minor flares that are perceived as having a cause may be successful, with patients returning to normal RA life (Fig. 2).

### Defining this as uncontrollable flare

This occurs with clusters of unprovoked, persistent symptoms that are not normal for their RA (Fig. 2):

Well, definitely, my joints are swelling a lot more, but it's lasting a lot longer, I get more pain, more fatigue, like I'm having to make myself move (O44)

I would describe it as an attack [flare], the sudden, unexpected occurrence. BANG! there it is. Without having exerted myself, for no reason (N64)

It doesn't go away as easily or readily, or the things that you normally do to make it go away don't seem to ease it (H37)

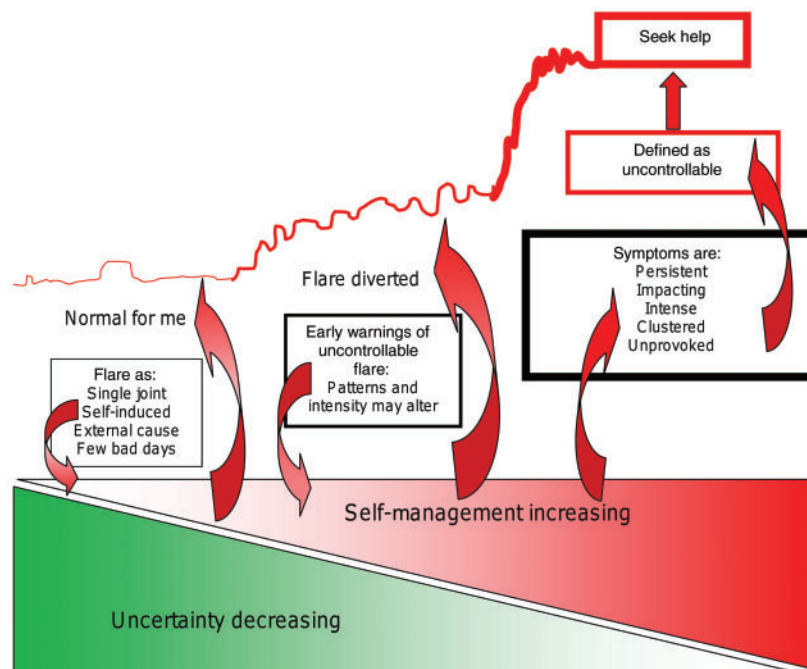
I knew it wasn't normal. [...] It was now impacting my life. It was impacting what I could do, I didn't want to do anything. I was exhausted, I didn't want to go anywhere. It hurt. Everything just ached (F29).

### Seeking help when symptoms cannot be contained

The tipping point for seeking professional help is reached when multiple symptoms cannot be controlled by even increased self-management strategies, and patients cannot run their normal lives (Fig. 2). They may be supported or prompted in this decision by family:

When it's all over, along with the other symptoms that I know I get with inflammation, that's my personal tipping point (E26)

Fig. 2 Cycles of self-managing flare symptoms on the patient journey to seeking help.





In such a place of despair I think 'I just can't go on with this anymore' and I'm trying this medication and I'm trying to pace my working, I'm trying to have so many hours sleep and I'm still waking up in pain. [...] and it's still not working (A5)

The reason that I end up running back to [Rheumatologist] crying is, I've got 3 young children and I teach and it's where it gets to the point where I can't function any more [...] it's got to the point where I'm not coping, the household chores just aren't being done and I just beat myself up because I can't be like all the other mums and do little things for the kids. [...] If it's not me it's my husband, he'll say 'You need to go and get some reinforcement' and usually I go to the GP (D21).

### Individual context

This underpinned the four themes; for example, individuals have different clusters or types of symptoms:

I go shivery cold, horrible cold (A6) That's interesting, the cold, because when I have a flare and there's a lot of pain I have a feeling that I'm burning up... my whole body is hot... my skin is hot as well as the actual painful bits... I feel as though I've got a very high temperature (A1)

This is what I find frustrating when I come and see the rheumatologist sometimes [...] I can't convey what I've felt [...] because I haven't fitted into that lovely, neat little box (B8).

### Uncertainty

This also underpinned the four themes; for example, uncertainty about whether this was a true flare:

But you never know when a flare starts whether it's going to be a mini thing that in a week will disappear or whether it's the 'Grrrrr', the killer (D21).

In terms of measuring flare, patients consider that the current patient global VAS (3) is inadequate to capture disease activity or flare, feeling that it asks about coping rather than about disease state:

It's about me as a person, how I think I am doing, not just the arthritis [...] Yes if I was in a flare I would probably still say well 'Yeah I am not doing too bad' (E27)

Do you think that reflects how active your arthritis is? (Moderator). No, not really because it's the way you cope with it, isn't it as well? I mean you can be awful can't you, but still plodding on with it because needs must (B8).

Patients favour a more direct global question, with anchors that allow them to judge flare against their normal RA symptoms vs uncontrolled symptoms:

'Are you having a flare-up?' Get straight to the point! (E23). Compared to how you normally are on average' (E26)

What would be the words be at the beginning and end of that scale? (Moderator). Controlled, uncontrolled (A6).

## Discussion

Patients use flare to describe five situations: four that are usually contained by self-management, and one that relates to uncontrollable flare that prompts a request for medical help. These multiple uses of the word flare highlights the need for clinicians and patients to clarify a common language concerning flare. Patients and professionals may be describing different entities or simply prioritizing different facets (e.g. fatigue vs synovitis) of a single concept (inflammation) but the resulting potential for confusion and misunderstanding may hinder shared treatment decisions. It would be informative to conduct similar research with professionals [10], to clarify their intended meaning(s) of the word flare.

Flare that prompts patients to request clinical review is experienced as a complex, multi-layered, whole body experience. The breadth and intensity of symptoms implies that clinicians need to explore the patient's flare experience in depth (feeling systemically unwell, emotional distress, wanting to die, inability to manage daily life) as flare may not be captured adequately by traditional joint counts, and not all patients prioritize, experience or notice synovitis. Some patients report an early warning prodrome (flu-like feelings, fatigue, pain). This might only be appreciated with hindsight; therefore, further research needs to capture symptoms prospectively, as a prodrome could imply that early medical intervention might divert a flare.

Within a background of daily self-management, patients increase their strategies to tackle escalating symptoms. As in other long-term conditions, patients increase medication (e.g. gluco-corticoids) without reference to their clinician, which is highly pertinent to clinical care and clinical trials [17]. People with RA interpret their increasing flare symptoms within the context of individual normal RA symptoms, and negotiate a journey from uncertainty to legitimacy in seeking help, clarified through family discussion and failure of usual expert self-management. This journey is seen in other long-term conditions, but identified largely in relation to help-seeking for the initial diagnosis [17–19]. As modern medication regimens provide better inflammatory control, symptom patterns may become more stable, and thus even small symptom changes might become important early markers for reviewing medication. In AS, patients could identify their personal flare pattern from sample graphs, and some patterns suggested better outcomes [20]. Further research is currently exploring these in individual RA interviews, and a longitudinal study.

The inverse of the DAS improvement criteria has been proposed as a measure of flare [21]. However, patients require only small symptom changes to consider that disease activity is worsening, but large changes to perceive that disease activity is improving [22]; therefore, DAS

inversion would be inappropriate. Patients perceive that the patient global VAS, used for a variety of purposes, does not ask about coping disease state or flare; therefore, a patient-reported outcome measure (PROM) that captures and defines flare needs to be developed [23]. Patients want a flare PROM to be anchored by their normal daily RA symptoms, but only one qualitative study has explored normal life with RA in the past 10 years (i.e. on current treatments) [24]. Those patients reported a roller-coaster life but flare patterns or clusterings were not explored, and other researchers are currently quantifying these prospectively. A combined patient/professional Delphi survey is now merging the patient data presented here with traditional professional variables, to seek consensus on uncontrollable flare definition and inform PROM development.

The limitations of this study are that the participants were mainly white, and other racial and ethnic groups may have different experiences. The German transcripts were carefully translated but would have benefited from back-translation [25] or analysis in German. The strengths of the study are its international breadth and robust analysis by several researchers, including a patient.

This novel insight into the patient perspective of uncontrollable RA flare reveals a multi-layered, complex experience with intense, wide-ranging symptoms and devastating consequences, such as a wish to die. The common global VAS does not adequately capture flare, which does not fit into that neat little box. This detailed understanding of the patient's flare experience and terminology should enhance communication between patients and professionals, to help recognize early warning signs, define thresholds for intervention, and improve outcomes and quality of life.

#### Rheumatology key messages

- Flare is currently assessed by inflammatory markers, painful/swollen joints and patient global VAS (doing well/badly).
- Patients experience uncontrollable symptom clusters (physical, systemic, emotional, cognitive) and consider the VAS inadequate.
- Assessment of flare should include patient experiences to improve communication and management.

## Acknowledgements

The authors would like to thank the patients for participating, and the translators.

**Funding:** Data transcription and translation in Germany were supported by an educational, non-restrictive grant from Wyeth.

**Disclosure statement:** L.M. has received research support from Roche, Wyeth/Pfizer, Abbott and Schering-Plough/Merck. C.O.B.III has served as a consultant to and/or received grant support from Roche/Genentech, UCB, Bristol-Myers-Squibb, Centocor Ortho Biotech, Abbott

and Amgen. He has been supported in part through grants from the Arthritis Foundation (Maryland Chapter), the ACR Research and Education Foundation Within Our Reach: Finding a Cure for Rheumatoid Arthritis Campaign, and the Stabler Family Foundation. All other authors have declared no conflicts of interest.

## References

- 1 Young A, Dixey J, Cox N *et al*. How does functional disability in early rheumatoid arthritis affect patients and their lives? Results of 5 years of follow-up in 732 patients from the Early RA Study (ERAS). *Rheumatology* 2000;39: 603–11.
- 2 Kennedy T, McCabe C, Struthers G *et al*. BSR guidelines on standards of care for persons with rheumatoid arthritis. *Rheumatology* 2005;44:553–6.
- 3 van der Heijde DM, van't Hof M, van Riel PL, van de Putte LB. Development of a disease activity score based on judgement in clinical practice by rheumatologists. *J Rheumatol* 1993;20:579–81.
- 4 Fleischmann RM, Cohen SB, Moreland LW *et al*. Methotrexate dosage reduction in patients with rheumatoid arthritis beginning therapy with infliximab: the Infliximab Rheumatoid Arthritis Methotrexate Tapering (iRAMT) trial. *Curr Med Res Opin* 2005;21: 1181–90.
- 5 Rahman MU, Strusberg I, Geusens P *et al*. Double-blinded infliximab dose escalation in patients with rheumatoid arthritis. *Ann Rheum Dis* 2007;66:1233–8.
- 6 Tugwell P, Boers M, Brooks P, Simon L, Strand V, Idzerda L. OMERACT: an international initiative to improve outcome measurement in rheumatology. *Trials* 2007;8:38.
- 7 Felson DT, Anderson JJ, Boers M *et al*. The American College of Rheumatology preliminary core set of disease activity measures for rheumatoid arthritis clinical trials. *Arthritis Rheum* 1993;36:729–40.
- 8 Bingham C III, Pohl C, Woodworth T *et al*. Developing a standardized definition for disease "Flare" in Rheumatoid Arthritis: OMERACT 9 Special Interest Group. *J Rheumatol* 2009;36:2335–41.
- 9 Brophy S, Calin A. Definition of disease flare in AS: the patients' perspective. *J Rheumatol* 2002;29:954–8.
- 10 Barker KL, Reid M, Minns Lowe CJ. Divided by a lack of common language? A qualitative study exploring the use of language by health professionals treating back pain. *BMC Musculoskelet Disord* 2009;10:123.
- 11 Arnett FC, Edworthy SM, Bloch DA *et al*. The American Rheumatism Association 1987 revised criteria for the classification of rheumatoid arthritis. *Arthritis Rheum* 1988; 31:315–24.
- 12 Fries JF, Spitz P, Kraines RG, Holman HR. Measurement of patient outcome in arthritis. *Arthritis Rheum* 1980;23: 137–45.
- 13 Hayes N. *Doing qualitative analysis in psychology*. London: Sage, 1997.
- 14 Kreuger RA, Casey MA. *Focus groups: a practical guide for applied research*. Thousand Oaks, CA: Sage, 2000.

- 15 Hewlett S, De Witt M, Richards P *et al.* Patients and professionals as research partners: benefits, challenges and practicalities. *Arthritis Rheum* 2006;55:676–80.
- 16 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
- 17 Thorne S, Paterson B, Russell C. The structure of everyday self-care decision making in chronic illness. *Qual Health Res* 2003;13:1337–52.
- 18 Davison C, Davey-Smith G, Frankel S. Lay epidemiology and the prevention paradox: the implications of coronary candidacy for health education. *Sociol Health Illn* 1991;13:1–19.
- 19 Sheppard J, Kumar K, Buckley CD, Shaw KL, Raza K. ‘I just thought it was normal aches and pains’: a qualitative study of decision-making processes in patients with early rheumatoid arthritis. *Rheumatology* 2008;47:1577–82.
- 20 Stone MA, Pomeroy E, Keat A *et al.* Assessment of the impact of flares in AS disease activity using the Flare Illustration. *Rheumatology* 2008;47:12213–8.
- 21 Den Broeder AA, Creemers MC, van Gestel AM, van Riel PL. Dose titration using the disease activity score (DAS28) in rheumatoid arthritis patients treated with anti-TNF-alpha. *Rheumatology* 2002;41:638–42.
- 22 Leeb BF, Sautner J, Leeb BA, Fassl C, Rintelen B. Lack of agreement between patients’ and physicians’ perspectives of rheumatoid arthritis disease activity changes. *Scand J Rheumatol* 2006;35:441–6.
- 23 Bingham CO III, Pohl C, Alten R *et al.* “Flare” and disease worsening in rheumatoid arthritis: time for a definition. *Int J Adv Rheumatol* 2009;7:85–91.
- 24 Lütze U, Archenholtz B. The impact of arthritis on daily life with the patient perspective in focus. *Scand J Caring Sci* 2007;21:64–70.
- 25 Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *J Clin Epidemiol* 1993;46:1417–32.