



Published in final edited form as:

*Arthritis Care Res (Hoboken)*. 2014 November ; 66(11): 1662–1672. doi:10.1002/acr.22374.

## “Stiffness has different meanings, I think, to everyone”. Examining Stiffness from the Perspective of People Living with Rheumatoid Arthritis

Ana-Maria Orbai<sup>1</sup>, Katherine C. Smith<sup>2</sup>, Susan J. Bartlett<sup>1,3</sup>, Elaine De Leon<sup>2</sup>, and Clifton O. Bingham III<sup>1</sup>

<sup>1</sup>Johns Hopkins University School of Medicine, Baltimore MD USA

<sup>2</sup>Johns Hopkins Bloomberg School of Public Health, Baltimore USA

<sup>3</sup>McGill University, Montreal PQ, Canada

### Abstract

**Objective**—Stiffness is a well-recognized symptom of Rheumatoid Arthritis (RA). It is frequently queried during clinic visits as an indicator of disease activity, and was included in the 1961 and 1987 RA classification criteria. Little is known about how people with RA experience stiffness and its impact on their lives.

**Methods**—We conducted 4 focus groups with 20 people with RA (4-6 participants per group), from one academic clinical practice and one private practice, to generate accounts of stiffness experiences. Qualitative inductive thematic data analysis was conducted.

**Results**—Five overarching themes were identified: 1. Relationship of stiffness with other symptoms; 2. Exacerbating or alleviating factors and self-management; 3. Stiffness timing and location; 4. Individual meanings of stiffness experiences; 5. Impact of stiffness on daily life.

**Conclusion**—Focus group discussions revealed individual stiffness experiences as diverse and complex. Several stiffness features were endorsed by a majority of participants, but few, if any, were universally experienced, thus the significance of stiffness as an expression of the disease varied widely. Discussions yielded descriptions of how individual limits imposed by RA in general and stiffness in particular, may change over time and were intertwined with adaptations to preserve participation in valued life activities. These results concerning the diversity of the stiffness experience, consequential adaptations, and its impact suggest a more individualized approach to stiffness measurement may be needed in order to improve stiffness assessments.

### Keywords

Rheumatoid arthritis; Stiffness; Qualitative Research; Health related quality of life

## Introduction

Stiffness is a symptom widely experienced by patients with rheumatoid arthritis (RA) (1, 2) and is generally considered to have clinical significance (3-5) that often serves as indicator of disease worsening or flare (5, 6). Stiffness incidence and severity are problematic to quantify because stiffness cannot be measured directly. While scientists have tried to measure stiffness directly using the arthrograph, a device that quantified stiffness through measuring resistance of a small hand joint to passive motion (7-10), the measure did not correlate with patient-reported stiffness or active RA(11-14).

Various approaches to elicit stiffness estimates from RA patients are currently being used. Morning stiffness duration is the most common, yet there are no standardized duration measures (15). Indeed, “morning stiffness” has been included in screening tools for inflammatory arthritis (16), and therapeutic agents that reduced early morning stiffness duration were approved for RA (17). Other approaches include: querying how long stiffness lasts until completely disappearing; or how long until being able to function and embark on daily activities; or intensity of stiffness. The choice of stiffness measure matters: stiffness intensity predicted progression of early undifferentiated arthritis to RA in a composite score (18); whereas, duration dichotomized at 1 hour was not reliably associated with initiation of RA treatment (19). Others reported that stiffness intensity was more highly correlated with RA disease activity than duration (20). A recent study demonstrated stiffness significantly contributes to discordance between patient and physician assessments of RA disease activity (21).

There is an increasing emphasis on the development, validation and use of patient reported outcome (PRO) measures that reflect symptoms of importance to patients (22) to help guide clinical care. Worldwide organizations have updated guidelines for patient participation in PRO development. The US Food and Drug Administration PRO guidance document emphasizes the importance of developing measures based on a conceptual framework that integrates patient input (23-26). Moreover, the Prescription Drug User Fee Act of 2012 includes recommendations for advancing and qualifying PROs, and began an initiative for Patient-Focused Drug Development (27). The European League against Rheumatism, advocates involving patients throughout the research process, (28) and the international Outcome Measures in Rheumatology group recommends patient input into core set development and domain identification (29). The Patient Centered Outcomes Research Institute issued methodological guidelines stating that the outcomes in medical research should include input solicited directly from patients (22). With increasing emphasis on PRO development and validation, and deficiencies in existing RA stiffness measures, it is important to reconsider stiffness from the patients' perspective and to integrate it into a conceptual framework to guide measure development.

In this study, we conducted focus groups (FG) to explore meanings, perceptions and subjective experiences concerning stiffness in individuals with RA, as an initial step toward developing tools for more accurate stiffness measurement.

## Participants and Methods

### Participants

English-speaking adults with rheumatologist-diagnosed RA, were recruited from two rheumatology clinics, one affiliated with a university hospital (3 FGs) and one private rheumatology practice affiliated with a community hospital (1 FG). Participants completed a questionnaire including socio-demographic data, RA duration, visual analogue scale (VAS) assessments of pain, fatigue, stiffness, global disease activity, and disability using the modified Health Assessment Questionnaire (mHAQ).

### Methods

Each FG was moderated by two or more members of the research team (First Author: FG 1, 2, 4; Second Author: FG 1, 2, 3; Third Author: FG 1, 2, 3; Fourth Author: FG 3, 4). FGs prioritized experiences of stiffness and the elucidation of stiffness meanings in context of RA. FGs covered the following major areas in all groups: participants' descriptions of the phenomenon of stiffness in RA; significance of stiffness; variability in stiffness; impact on daily life; and modifications or adaptations as a result of stiffness. Three FGs were recorded and transcribed; recording failed in one FG (FG3 at the academic center). Data from FG3 are from a detailed written account taken at the time of this FG, and immediate post-group discussion of recalled details with the moderator. We followed the 'framework analysis' process described by Pope and Mays to qualitative data analysis (30). An initial thematic coding structure was developed through inductive thematic analysis after reviewing the first 2 transcripts. Once the final 2 focus groups were conducted the thematic framework was refined using inductive thematic analysis of new data and constant comparison with the framework from the initial 2 groups by two members of the research team independently. At this stage, no new themes emerged, but results greatly expanded in depth through identification of multiple sub-themes. At each stage, data were coded line-by-line. For data management we used the scientific software ATLAS.ti. version 7.0.91 (GmbH Berlin, Germany; 2012) (31).

This research was approved by Institutional Review Boards at both institutions.

### Results

FGs included 4 to 6 participants and were heterogeneous by age, sex (except FG4 was entirely women), race, disease duration, pain, fatigue, stiffness, and physical function. FG1 had the highest scores for disability, pain, fatigue, stiffness, and global disease activity (Table 1). Disease duration across all groups averaged 16 years (range 29-75).

### Thematic Analysis

Thematic analysis revealed five major elements within participants' descriptions of their stiffness experiences. Themes and illustrative extracts are presented in tabular format (Table 2).

**Theme 1: Relationship to Other Symptoms**—One of the most common aspects of the discussions of stiffness was the way in which this symptom was experienced and understood in relation to other symptoms.

**Comparison with pain:** Discussions of stiffness were frequently constructed around comparisons with pain and swelling, with many (but not all) participants diminishing the presence of stiffness in comparison to other symptoms. Participants' presentation of a hierarchical ordering of symptoms was apparent in several instances. One participant expressed that “*the pain's worse than the stiffness*” (Male, FG1), while another shared the opposite, “*stiffness is more debilitating for me as compared to pain*” (Female, FG1).

**Distinguishing among multiple symptoms:** Participants provided contrasting opinions, with some discussing an ability and desire to differentiate between pain, stiffness, and swelling, but others negating such distinctions. One participant shared answering stiffness questions asked at clinic visits in relation to what body part was difficult to move because of pain, swelling, or both: “*I'm translating that into: that means I'm not very flexible there*” (Female, FG4). Some envisioned stiffness as a satellite effect of pain or swelling rather than as a standalone symptom.

**Differentiating RA from non-RA stiffness:** Another facet of the discussion was the differentiation between stiffness attributable to RA and stiffness due to sore muscles or osteoarthritis. Distinctions were anchored around personal experiences and clinical explanations, with some participants giving accounts of being told that a sensation was linked with a condition: “*because what's in my neck is osteo [arthritis], the doctor well, he told me*” (Female, FG1).

**Others' understanding of symptoms:** Participants shared a common experience in which people without RA (family, friends and co-workers) offered more empathy and compassion for pain rather than stiffness. Other peoples' reactions and expectations regarding stiffness were often unhelpful and potentially alienating: “*I'm a little stiff and [...] my husband's always oh shake it off, get up, stretch, come on, pull, let's go and I'm like, don't pull that joint, don't pull on me like that*” (Female, FG1).

**Theme 2: Exacerbating or Alleviating Factors and Self-Management**—The concept of change permeated discussions of RA symptoms: “*you only see your doctor every two to three months and your disease changes daily*” (Female, FG2). There was lively discussion of potential triggers and significance of symptom change. Considerations of factors that exacerbate stiffness and other symptoms were interwoven with descriptions of alleviation and self-management strategies.

**Exacerbating Factors:** No single factor was espoused by all participants, but weather, periods of immobility, physical activity and stress elicited considerable engagement in more than one group.

**Weather and changing seasons:** Cold and rain were discussed as potentially provoking new symptoms or worsening disease. Some interpreted RA symptoms as clues to

approaching weather and described being able to forecast weather. While cold and rain were related to increased stiffness in particular (exchange in FG1), change of seasons was connected to swelling and aching (Female, FG2). The opposite experience, weather not affecting RA, was also described (Female, FG2; Female, FG3).

**Immobility:** Participants related periods of immobility such as driving and flying on airplanes to stiffness. The duration of time spent immobilized was identified as the main determinant of subsequent stiffness, with one participant stating that the cutoff for driving was “*over 45 minutes*” (Male, FG1).

**Physical activity:** Activity was a commonly described trigger for RA worsening. One participant described how repetitive movements she had to perform at work caused pain: “physically doing things can bring on pain” (Female, FG1). When participants described exercise, many also described having to endure pain or stiffness afterwards.

**Other exacerbating factors:** Stress was identified as aggravating RA stiffness (Female, FG1). Such accounts, were not, however, ascribed by all participants, as some expressed that their RA symptoms were impervious to changes in life situations or circumstances (Female, FG2). Lack of sleep was also described to cause worsening stiffness by one participant (Female, FG3).

**Alleviating Factors:** Participants' descriptions of alleviating strategies were central to each group and occurred more in terms of overall disease state than just one symptom. Alleviation strategies served to reduce and delay the burden of symptoms independently or to serve as a bridge to seeking medical help.

**Warmth:** The most frequently discussed stiffness alleviation strategy (in all groups) was applying or being exposed to heat through taking a shower, using a heating pad, warm tub, sauna, or raising the temperature in the house: “*I think that it was that warm feeling [...] I have no stiffness then. But I needed that shower really bad*” (Female, FG1).

**Physical activity:** Discussions of activity had contrasting aspects: exercise was not only a potential trigger for symptom worsening, but also a strategy to overcome RA symptoms or limitations. One participant in remission shared that she performed yoga backbends to alleviate her stiffness (Female, FG1). Another example was swimming with its effect described as taking gravity off the joints (Male, FG3). One participant described fast walking as an activity to “*get the blood moving*” (Female, FG4). Stretching while in a warm sauna combined strategies to maximize benefit (Female, FG4). The ability and desire to employ such strategies was, however, far from universal. One individual related that he was unable to engage in alleviating strategies that worked for others because of physical limitations including an inability to independently get out of the pool (Male, FG3).

**Moving, adjusting position and getting comfortable:** Participants talked about using pillows and constantly adjusting position, choosing seats to allow stretching, and setting reminders to get up and move around to prevent stiffness (FG1).

**Other alleviation strategies:** Diet modification was endorsed as a strategy to improve RA symptoms. Eating a raw vegetable diet was specifically connected to preventing/reversing stiffness (Female, FG1), while prioritizing eating healthfully, avoiding fast food, and eating more soy-based proteins was tied to improving RA in general (Female, FG3).

**Self-Management and Adaptation:** Descriptions of managing stiffness, beyond exhausting the use of alleviation strategies, focused on dealing with symptoms and reducing participation, sometimes to the extreme of staying in bed. Motivations presented for limiting engagement in physical activities were to preserve well-being without having to trade off later for pain, stiffness, or flare; or to reduce psychologically damaging reminders of the physical limitations associated with RA (Female, FG4).

### Theme 3: Stiffness Timing and Location

**Timing:** Stiffness was tied to time of day or daily activities using general terms such as “all day”, “a few minutes” or “until I get dressed”. There was no apparent consensus for timing of stiffness, although participants discussed patterns defining their individual experiences. Stiffness upon awakening was mentioned in 3 FGs and described as transitory, without major impact on routine activities. Several participants who experienced stiffness upon awakening described that movement or a warm shower, already part of their morning routine, helped to counter the symptom. In contrast, one participant shared he experienced stiffness persistently throughout the day (Male, FG1). Another aspect was unpredictable stiffness, which was tied to disease worsening or flares in group discussions (Female, FG1; Female FG2). There was also discussion of the experience of joints getting “tired and achy” at the end of the day “from overuse” (Female, FG2).

**Location:** Many accounts of stiffness focused on localization in the joints. One participant described the involvement of multiple joints that were hard to predict (Male, FG1). Another participant described multiple joints affected but could state exact location. There was recognition of heterogeneous joint-symptom combinations that were related to RA activity and impact. One perspective was that stiffness in the hands was extremely difficult to deal with (Female, FG2), but another was that stiffness affecting either feet or hands was easily reversed with movement (Female, FG2).

**Theme 4: Individual Context and Meaning**—Individual context was connected to diverse meanings participants gave to stiffness and other symptoms, as related to the overall RA experience.

**Descriptors for RA stiffness:** In two groups (FG1, 2), the experience of stiffness was described using imagery of the ‘Tin Man’ from L. Frank Baum's *The Wonderful Wizard of Oz*. This description was spontaneously produced in each group and elicited considerable acknowledgement from other group members. In a third group a participant similarly described the effect of warm water on the joints, as “*greasing the joints [...] oiling what needs to be oiled*” (Male, FG3).

**Normal/constant part of RA:** Participants introduced the concept of “RA normal”, a state that even though not symptom-free, was acceptable. The extent to which stiffness was part of “RA normal” or experienced in relation to disease change was variable among participants. There was discussion of acceptance of “RA normal”, understanding and adapting to reduced ability, and potentially changing boundaries around physical capacities. Participants discussed their acceptance of RA through repetitive exposure to symptoms, which over time increased the thresholds for acknowledging discomfort or limitations.

**Connected with RA flare:** Participants often described changes in stiffness timing and location as being informative whether RA was under control or worsening. Unexpected/unpredictable stiffness was connected to RA flare in 2 groups (FG1, 2). In context of flare, stiffness was described by one participant as the initial manifestation, preceding pain (Male, FG1). Another participant described stiffness in her hands as present only during RA flare (Female, FG2). However, there was no agreement on a first warning sign for flare.

**Theme 5: Impact on Daily Life—**Discussions yielded rich accounts of how people with RA experienced difficulties with certain daily activities, whether they understood these difficulties to be associated with stiffness, and how, in consequence, they persevered, adapted, or planned their life. Each group offered detailed accounts of the limitations associated with RA. In a few instances, descriptions highlighted feelings of frustration, loss of control, and fear. Discussions of isolation were related to worsening or unpredictable symptoms.

**Perseverance:** Participants described pushing through stiffness and other symptoms. This was most often described in relation to physical activity (FG1, 2, 4). One participant's example was continuing to work at a camp for children with cancer, even though she knew she would have to “*pay for it*” afterwards (Female, FG3).

**Mobility and adaptation:** The extent to which strategies and adaptations pertained entirely or primarily to stiffness was not always clear – partially because for many participants such distinctions of symptoms were not meaningful. Participants described successful adaptations or modifications, whereby they could continue to participate and live as normal a life as possible – even though the impact of RA was tangible and potentially debilitating. People described strategies used to ease daily routines, cope, and remain independent. In such discussions, one person's examples tended to spur animated discussions involving many/all in the group. Strategies discussed included purposefully choosing clothes without buttons, using pens that were comfortable, avoiding safety caps on medication, keeping a bar stool in the kitchen, and using grocery carts even for light shopping.

**Dependence on others:** Participants described having to depend on other family members for assistance with self-care activities and other daily activities because of stiffness and other RA symptoms. One participant described feeling like a burden when asking others to open jars or carry things for him (Male, FG1) and another, depending on her husband during RA flares (Female, FG2).

**Vulnerability, fear and isolation:** Participants described feeling vulnerable because they could not rely on their body to carry out certain activities fast enough or at all. Conversations about RA impact (and stiffness in particular), on life activities elicited vivid examples of feared situations because of the potential need to react and mobilize themselves quickly. Examples offered were crowded places (grocery store, sports stadium), stairs, or escalators. Other examples were fear of falling on ice or of fire, situations where participants said they would be helpless. Participants described various strategies routinely undertaken to protect themselves based on their limitations: avoiding crowded places, always being last on escalators, and making room for rushed people to pass. These modifications included abandoning previously enjoyed activities (like going to a football game or a concert) due to fear of being pushed or bumped into, and associated pain or other physical or psychological consequences.

***Conceptual Model for Stiffness in RA:*** Stiffness was described as spanning the spectrum of experience bounded by RA “normal” and “RA flare”. Across this spectrum, stiffness had specific meanings, either as a perpetual manifestation of controlled RA, a signal to increase alleviation strategies, or as a warning sign to expect/prepare for disease worsening. Stiffness changed in relationship to other cardinal RA manifestations (pain, swelling, fatigue) and around time of day, seasons, and joints affected. Significant stiffness was associated with major impacts on mental and social health by increasing feelings of vulnerability or fear, decreasing participation and potentially causing isolation. Figure 1 represents a conceptual model of stiffness in RA reflecting the emergent themes that can serve as an initial framework for further study.

## Discussion

Participants identified stiffness as integral to the RA experience. As described by people living with RA, the stiffness experience can be structured under five major themes: Relationship of stiffness with other symptoms; Exacerbating or alleviating factors and self-management; Stiffness timing and location; Individual meanings of stiffness experiences; and Impact of stiffness on daily life. Stiffness relationship to other RA symptoms may be of crucial importance for eliciting and interpreting symptom reports. Some participants explicitly challenged the value in separating out experiences of pain from experiences of stiffness, a phenomenon previously observed (20). Examples of differentiating RA from non-RA stiffness provided more insight into how participants' concepts of their disease experiences do not develop in a vacuum. Rather, they are shaped by health care providers' assessment of symptoms and by how other people accept and react to one's experiences with RA. Our data point to several potential reasons for the stiffness-pain interdependence: the experience of pain is overwhelming, with stiffness considerably shadowed; stiffness and pain experiences are tightly connected whereby separation is meaningless; and stiffness is poorly understood by other people in comparison to pain, such that reports of pain have more usefulness for people living with RA.

Discussions of stiffness management strategies also addressed other accompanying symptoms and consisted mainly of applying heat and increasing movement. Physical activity had a dual role: sometimes alleviating but also potentially exacerbating stiffness,



this being highly dependent on individual factors. Exacerbating factors pertained mostly to weather, confirming a previously observed association (32) and to immobility. While people with RA often described stiffness in relation to time, they did not conceptualize changes on a linear time axis. Patterns of stiffness in relation to time of day, sequence, and duration of routine life activities were learned from repeated experiences. Participants described a phenomenon of expected stiffness in stable RA, and another phenomenon of unexpected or worsening stiffness in flare. People related stiffness to their joints. Some joints were stiff in controlled RA, while other joints were only stiff during flare. Therefore stiffness timing and location helped discern change in RA.

Our data challenge the current assessments of stiffness used in clinical trials and clinical practice, which are based on a stiffness model that emphasizes duration of morning stiffness. Our participants did not project their experience of stiffness linearly in minutes or hours, or necessarily in the morning. Rather, changes in individual patterns of stiffness, its location, intensity, and impact on life activities were all meaningful. Participants introduced the concept of “RA normal” as their baseline state, yet very different than health prior to RA diagnosis. “RA normal” is important because it may become the new reference point for change within RA spectrum. Hewlett S. et al. had similar findings in their qualitative study of flare in RA (2). This has implications in terms of management; for instance, on a questionnaire concerning stiffness severity a patient may interpret an anchor of “no stiffness” as “normal stiffness”, resulting in a response that underestimated the presence or magnitude of the symptom. As people learn to live within limits set by RA, they adapt through different choices and management strategies, and ultimately acclimate to a certain degree of pervasive but tolerable symptoms. Stiffness affects daily life in the physical, psychological, and social spheres, and people with RA creatively adopt strategies and behaviors to minimize symptom impact. These include being resilient, planning, and tailoring social involvement and participation. Remaining functional encompassed some sacrifices: living with “discomfort days” at times, “pushing through” to accomplish routine activities, planning daily activities according to the RA state, and learning to pay extra attention to bodily clues that could be used to help prevent functional impact. Most participants viewed themselves as managing their life. Successful modifications that allowed continued participation in social roles and valued life activities were necessary for stiffness, but its overall impact was deeper in terms of choices and activities. Feelings of vulnerability and fear were described with unexpected or overwhelming symptoms. Reactions of family and friends to the implications of stiffness also potentially contributed to the damaging effects of the disease.

Strengths of the study include rigorous qualitative methods. The choice of inductive thematic analysis, which implies discovery of codes and themes without a priori assumptions, is suitable to the purpose of exploring stiffness from a new perspective, the experience of people with RA. Limitations of the study are limited generalizability of results to other populations than the sample studied, which was mainly women with longstanding RA seen in an academic clinic, although spanning across a range of ages, disability and symptoms, and including participants from a community-based rheumatology practice. In addition, there was a broad range of descriptions for stiffness experiences starting with the first group, and after the second group no new codes were identified. Another limitation is

failing of the recording in the third focus group at the academic center. Detailed research notes taken at the time of the focus group and additional post group discussion with the moderator formed the basis for analysis of this group. The first author was not present during the third focus group, however the second and third authors were present (*see Methods section*).

In summary, our results contribute information about the lived experience of stiffness and confirm its importance in RA. Heterogeneity of the stiffness experiences, interaction with other symptoms and disease activity, and dependence on individual context and self-management create a challenge for measurement. However, regardless of the individual experiences, there was a common language participants used to describe stiffness impact. This allowed us to develop a conceptual framework for stiffness in RA grounded in the patient's perspective, and upon which measures for stiffness in RA can be chosen or constructed. Prioritizing the patients' experience of RA, which includes stiffness, is central to efforts for improving treatment and long term outcomes ensuring that patient relevant symptoms and their impact on health can be accurately measured and incorporated into decision-making. Similar exploratory analyses of stiffness as experienced in other conditions may be valuable in broadening our understanding of this phenomenon across diseases.

## Acknowledgments

We are grateful to the people living with rheumatoid arthritis who have provided their insights into their symptoms and their impact. We thank Mrs. Michelle K. Jones, Johns Hopkins Arthritis Center, for her assistance in coordinating patient recruitment and arrangements for focus groups. We thank the rheumatologists associated with the Johns Hopkins Arthritis Center and Sibley Memorial Hospital for referring their patients, and Sibley Hospital for the use of space to conduct one of the focus groups.

**The sources of support in the form of grants:** Supported by the Ira Fine Discovery Fund, Donald and Dorothy Stabler Foundation, Sibley Memorial Hospital Foundation, Johns Hopkins Arthritis Center Research Fund, National Institutes of Health P30-AR053503

## References

1. Deandrade JR, Casagrande PA. A Seven-Day Variability Study of 499 Patients with Peripheral Rheumatoid Arthritis. *Arthritis and rheumatism*. 1965; 8:302–34. [PubMed: 14280261]
2. Hewlett S, Sanderson T, May J, Alten R, Bingham CO 3rd, Cross M, et al. '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. *Rheumatology (Oxford, England)*. 2012; 51(1): 69–76.
3. Mallya RK, Mace BE. The assessment of disease activity in rheumatoid arthritis using a multivariate analysis. *Rheumatology and rehabilitation*. 1981; 20(1):14–7. [PubMed: 7221396]
4. Jacobsson LT, Knowler WC, Pillemer S, Hanson RL, Pettitt DJ, McCance DR, et al. A cross-sectional and longitudinal comparison of the Rome criteria for active rheumatoid arthritis (equivalent to the American College of Rheumatology 1958 criteria) and the American College of Rheumatology 1987 criteria for rheumatoid arthritis. *Arthritis and rheumatism*. 1994; 37(10):1479–86. [PubMed: 7945473]
5. Bingham Iii CO, Alten R, Bartlett SJ, Bykerk VP, Brooks PM, Choy E, et al. Identifying preliminary domains to detect and measure rheumatoid arthritis flares: Report of the OMERACT 10 RA Flare Workshop. *Journal of Rheumatology*. 2011; 38(8):1751–8. [PubMed: 21807797]
6. Bartlett SJ, Hewlett S, Bingham CO 3rd, Woodworth TG, Alten R, Pohl C, et al. Identifying core domains to assess flare in rheumatoid arthritis: an OMERACT international patient and provider

combined Delphi consensus. *Annals of the rheumatic diseases*. 2012; 71(11):1855–60. [PubMed: 22772326]

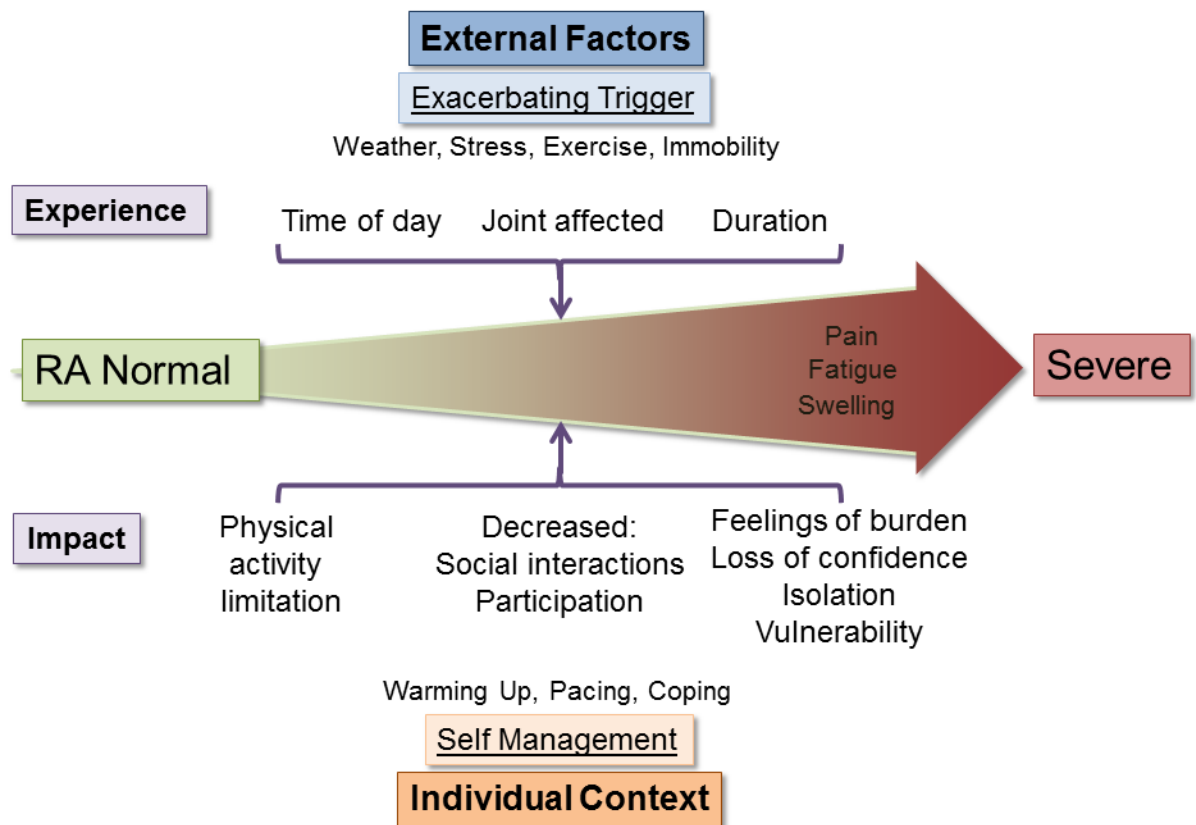
7. Wright V, Plunkett TG. Scientific assessment of the results of physical treatment--measurement of stiffness. *Annals of physical medicine*. 1966; 8(8):280–91. [PubMed: 5954461]
8. Bäcklund L, Tiselius P. Objective measurement of joint stiffness in rheumatoid arthritis. *Acta rheumatologica Scandinavica*. 1967; 13(4):275–88. [PubMed: 5590759]
9. Hicklin JA, Wighton RJ, Robinson FJ. Measurement of finger stiffness. *Annals of physical medicine*. 1968; 9(6):234–42. [PubMed: 5655417]
10. Tiselius P. Studies on joint temperature, joint stiffness and muscle weakness in rheumatoid arthritis. An experimental and clinical investigation. *Acta rheumatologica Scandinavica*. 1969; 14(Suppl 14) 1+
11. Helliwell PS, Howe A, Wright V. The measurement of stiffness in the rheumatoid hand. *Engineering in medicine*. 1987; 16(4):203–7. [PubMed: 3691933]
12. Helliwell PS, Howe A, Wright V. Lack of objective evidence of stiffness in rheumatoid arthritis. *Annals of the rheumatic diseases*. 1988; 47(9):754–8. [PubMed: 3178316]
13. Rhind, VM. Durham theses. Durham University; 1988. The validity and inter-relationship of subjective and objective measurements of stiffness in human joints [Master of Science].
14. Wright V. Measurement of outcome in rheumatic diseases. *Journal of the Royal Society of Medicine*. 1985; 78(12):985–94. [PubMed: 3877808]
15. Hazes JM, Hayton R, Burt J, Silman AJ. Consistency of morning stiffness: an analysis of diary data. *British journal of rheumatology*. 1994; 33(6):562–5. [PubMed: 8205405]
16. Tavares R, Wells GA, Bykerk VP, Guillemin F, Tugwell P, Bell MJ. Validation of a self-administered inflammatory arthritis detection tool for rheumatology triage. *The Journal of rheumatology*. 2013; 40(4):417–24. [PubMed: 23378469]
17. Buttgerit F, Mehta D, Kirwan J, Szechinski J, Boers M, Alten RE, et al. Low-dose prednisone chronotherapy for rheumatoid arthritis: a randomised clinical trial (CAPRA-2). *Annals of the rheumatic diseases*. 2013; 72(2):204–10. [PubMed: 22562974]
18. van der Helm-van Mil AH, Detert J, le Cessie S, Filer A, Bastian H, Burmester GR, et al. Validation of a prediction rule for disease outcome in patients with recent-onset undifferentiated arthritis: moving toward individualized treatment decision-making. *Arthritis and rheumatism*. 2008; 58(8):2241–7. [PubMed: 18668546]
19. Funovits J, Aletaha D, Bykerk V, Combe B, Dougados M, Emery P, et al. The 2010 American College of Rheumatology/European League Against Rheumatism classification criteria for rheumatoid arthritis: methodological report phase I. *Annals of the rheumatic diseases*. 2010; 69(9):1589–95. [PubMed: 20699242]
20. Rhind VM, Unsworth A, Haslock I. Assessment of stiffness in rheumatology: The use of rating scales. *British journal of rheumatology*. 1987; 26(2):126–30. [PubMed: 3828664]
21. Khan NA, Spencer HJ, Abda E, Aggarwal A, Alten R, Ancuta C, et al. Determinants of discordance in patients' and physicians' rating of rheumatoid arthritis disease activity. *Arthritis Care and Research*. 2012; 64(2):206–14. [PubMed: 22052672]
22. Methodology Committee of the Patient-Centered Outcomes Research I. Methodological standards and patient-centeredness in comparative effectiveness research: the PCORI perspective. *JAMA : the journal of the American Medical Association*. 2012; 307(15):1636–40.
23. US Food Drug Administration. Guidance for Industry Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims (2009). 2009. [cited 1/23/2014]; Available from: [www.fda.gov/downloads/Drugs/Guidances/UCM193282.pdf](http://www.fda.gov/downloads/Drugs/Guidances/UCM193282.pdf)
24. Patrick DL, Burke LB, Powers JH, Scott JA, Rock EP, Dawisha S, et al. Patient-reported outcomes to support medical product labeling claims: FDA perspective. *Value in health : the journal of the International Society for Pharmacoeconomics and Outcomes Research*. 2007; 10(Suppl 2):S125–37. [PubMed: 17995471]
25. Patrick DL, Burke LB, Gwaltney CJ, Leidy NK, Martin ML, Molsen E, et al. Content validity--establishing and reporting the evidence in newly developed patient-reported outcomes (PRO) instruments for medical product evaluation: ISPOR PRO good research practices task force report: part 1--eliciting concepts for a new PRO instrument. *Value in health : the journal of the*

- International Society for Pharmacoeconomics and Outcomes Research. 2011; 14(8):967–77. [PubMed: 22152165]
26. Patrick DL, Burke LB, Gwaltney CJ, Leidy NK, Martin ML, Molsen E, et al. Content validity--establishing and reporting the evidence in newly developed patient-reported outcomes (PRO) instruments for medical product evaluation: ISPOR PRO Good Research Practices Task Force report: part 2--assessing respondent understanding. *Value in health : the journal of the International Society for Pharmacoeconomics and Outcomes Research*. 2011; 14(8):978–88. [PubMed: 22152166]
27. US Food Drug Administration. Prescription Drug User Fee Act of 2012 (PDUFA-V) Reauthorization Performance Goals and Procedures Fiscal Years 2013 through 2017. 2012. [cited 2/7/2014]; Available from: <http://www.fda.gov/downloads/forindustry/userfees/prescriptiondruguserfee/ucm270412.pdf>
28. de Wit MP, Berlo SE, Aanerud GJ, Aletaha D, Bijlsma JW, Croucher L, et al. European League Against Rheumatism recommendations for the inclusion of patient representatives in scientific projects. *Annals of the rheumatic diseases*. 2011; 70(5):722–6. [PubMed: 21257615]
29. Boers M, Kirwan JR, Wels G, Beaton D, Gossec L, d'Agostino MA, et al. Developing Core Outcome Measurement Sets for Clinical Trials: OMERACT Filter 2.0. *Journal of clinical epidemiology*. 2014 in press.
30. Pope C, Ziebland S, Mays N. Qualitative research in health care. *Analysing qualitative data*. BMJ (Clinical research ed). 2000; 320(7227):114–6.
31. ATLAS.ti 7.0.91 ed. Scientific Software Development GmbH; Berlin, Germany: 2012.
32. Drane D, Berry G, Bieri D, McFarlane AC, Brooks P. The association between external weather conditions and pain and stiffness in women with rheumatoid arthritis. *Journal of Rheumatology*. 1997; 24(7):1309–16. [PubMed: 9228130]

### Significance and Innovations

- Stiffness is an important symptom for people with RA that is insufficiently understood and inadequately measured
- Individual experiences of stiffness are extremely diverse, but participants used a common language to describe stiffness impact
- A conceptual framework for stiffness is proposed and can be considered in developing new measures for stiffness

## Conceptual Framework for Stiffness in RA



**Figure 1.**

Stiffness is a defining part of the RA experience and while important, it is difficult to separate from other RA symptoms, particularly in states of RA worsening. Stiffness impact is a function of the mix of symptoms and their intensity, and individual context.

**Table 1**  
**Participant Demographics and RA Characteristics by Focus Group (FG)**

	FG 1	FG 2	FG 3	FG 4	Total
Participants	6	4	5	5	20
Age in years, mean (SD)	51(12)	51 (12)	57 (14)	69 (7)	57 (13)
Sex					
Female	3	3	4	5	15
Male	3	1	1	0	5
Race					
African-American	1	1	1	0	3
Caucasian	5	3	4	5	17
Disease duration in years, mean (SD)	14 (3)	11 (8)	18 (9)	20 (10)	16 (8)
Patient Global VAS <sup>***</sup> , mean(SD)	67 (22)	31 (29)	45 (26)	27 (19)	44 (27)
Pain VAS, past week, mean (SD)	63 (22)	44 (37)	48 (35)	29 (25)	47 (30)
Fatigue VAS, past week, mean (SD)	61 (30)	33 (25)	55 (33)	34 (33)	47 (31)
Stiffness VAS, past week, mean (SD)	53 (31)	29 (23)	44 (32)	27 (20)	40 (27)
Modified HAQ <sup>***</sup> score, mean (SD)	0.94 (0.70)	0.13 (0.25)	0.35 (0.45)	0.35 (0.32)	0.48 (0.55)

\* Rounded to closest whole number, except for HAQ.

\*\* 100 mm visual analogue scale.

\*\*\* Modified Health Assessment Questionnaire 8 item, score rounded to two decimals

**Table 2**  
**Themes and Illustrative Extracts**

Themes	Illustrative Extracts
<b>Theme 1: Stiffness Relationship to Other Symptoms</b>	
Comparison with pain	The stiffness, I mean it's constant, all day long from the time you get up until you go to sleep. Your fingers, it just feels like they're constantly swollen, you go to bend them, you can feel the pressure in your hands, in your fingers, your ankles, your shoulders. You feel it. The pain's worse than the stiffness. Ten times worse than the stiffness. (Male, FG1) So I don't really remember life prior to, without having RA, and I will tell you my stiffness is more debilitating for me as compared to pain. (Female, FG1) And as painful as it is you still have to push through the pain or stiffness or whatever you want to call it and I think that we both pretty much identified that it's more pain than stiffness that drives us. (Female, FG4)
Distinguishing among multiple symptoms	It's not literally well you're just stiff and you're not in pain. They all, they come hand in hand. (Male, FG1) I have a problem with fatigue and I have to battle that to get to the stiffness. (Male, FG1) It's very hard to describe because when I have trouble in the joints, it's more just pain. I mean you could call it stiff but the fact is that it's just hard to move because it hurts. (Female, FG4) It's not stiffness, it's actually how much swelling or how much pain do I experience. And I'm translating that into that means I'm not very flexible there. (Female, FG4)
Differentiating RA from non-RA stiffness	There is a different type of stiffness that you have from just doing a big race. And your muscles are tired and achy. There's a difference from RA stiffness and feelings. (Female, FG1) What's in my neck is you know, osteo, the doctor well, he told me. (Female, FG1)
Others' understanding of symptoms	F2: Pain, I think people have an understanding, where but with stiffness, I don't think they do. They don't understand when I take forever to get out of the chair or I sometimes have to roll out of the chair. F3: Right. M3: And roll out of bed. F2: I know people, like my husband for example, just looks at me. And I tell people, just leave me alone. Just let me just do what I have to do but, like to roll, like that's just that and that's pure stiffness. (FG1) I know when that flare is coming, if I've been stiff I'll say you know, I'm a little stiff and [...] my husband's always oh shake it off, get up, stretch, come on, pull, let's go and I'm like, don't pull that joint, don't pull on me like that. (Female, FG1) I was parking close and people would just kind of look at me like why do you have a handicap sticker? Or I would go to the mall, and I would feel bad parking there because on the outside it really doesn't look like there is anything wrong with [me] and [they] don't really realize that every step that [I] take is hurting. (Female, FG2)
<b>Theme 2: Exacerbating or Alleviating Factors and Self-Management</b>	
<b>Exacerbating Factors</b>	
Weather and changing Seasons	F2: And I find that the weather though, like when it's a cold and drizzly day, I'm more stiff, not that I'm going to be [...] F3: When it's damp, right. F2: That makes me more stiff, and where I just know it's going to be a horrible, like everything, just the fatigue, but it's the stiffness during those days, which I hate. So it's the weather for that, I know that's just a bad thing. [...] M3: I know it's going to rain that next day, just that, at that night, I'll feel it, I really believe F2: Yeah, and I know when it's going to be a bad day. F3: My body will forecast it. F1: Yeah.”(FG1) The changes in the season so going from winter to spring, usually you get kind of more swelling and like achy but then you get settled into the season and it kind of goes away and then when you go summer to winter, you get achy again. (Female, FG2) You know, people have asked me if the weather affects it. It doesn't affect mine. (Female, FG2)
Immobility	If I have to take a drive anywhere over 45 minutes, it takes me forever to get out of the vehicle. (Male, FG1)
Physical activity	I always think when I'm having the stiffness I just need to get the blood flowing and then I can even run, and then I always get stiffness right after I run. (Female, FG1) I was very active with my children and the last time I went horseback riding I went into total lock up. I couldn't even get off of the horse. (Female, FG4)
Other exacerbating factors	I was really stressed out from some family things and it immediately made me flare up. [...] And I think the stiffness is for me, is what makes me, that and the fatigue is what's so much more debilitating. (Female, FG1) Moderator: Do you find that stress can make it worse? Your stiffness? Participant: I never connected the two and that's one of the things I experience is that there wasn't really a rhyme or reason. It just happens.” (Female, FG2)
<b>Alleviating Factors</b>	



Themes	Illustrative Extracts
Warmth	I would go in the shower right before going to school [...] my parents would yell at me because I would be there for so long. [...] I think that it was that warm feeling [...] I have no stiffness then. But I needed that shower really bad. [...] I have the temperature raised up really high in my house. (Female, FG1) I love going into the sauna [...] and I do my stretching exercises in the sauna when I'm all nice and warm. (Female, FG4)
Physical activity	In the morning time or when I have some stiffness in the evening time or even actually at work, I'll close the door and I'll just do a backbend. (Female, FG1) I try and go swimming three times a week and I think it really, really does help. (Female, FG4) I just make myself do something, physically [fast walking], every single day because if your blood is moving, you're going to move and I always feel better. I really do. (Female, FG4)
Moving, adjusting position and getting comfortable	[car trips] prop a little rolled pillow behind my head, put the seat as far back as I can, and sometimes I'll put my feet on the dash [...] I have to constantly be adjusting so that I don't get stiff. (Female, FG1) I would get out of bed and I would just slowly move my hands to get the stiffness out of them because they would be stiff and my feet, I would just sit on the side of the bed and move my feet around before I got out of bed. (Female, FG2)
Other alleviation strategies	When I was in my flare-up part of it last week, I made sure I was really strict on my diet, and even now maintaining a raw diet of eating all fresh vegetables [...] I do find that for me that really does make a difference. (Female, FG1)
<b>Self-Management and adaptation</b>	
	And then I start hurting like crazy, that's why I don't drive. If I drive from here to the ocean, I can't pick my arms up. (Male, FG1) It's difficult for me to kneel sometimes it's painful and it's a catch 22 to do exercise 'cause I know you should do exercise but then you get reminded how much of a cripple you can be so it, that to me is the psychology behind it, that I'm not, it reminds me when I do physical that I can't do as much as I used to. I've got an ego and don't want to be ill so that's been the hardest part of it. (Female, FG4)
<b>Theme 3: Stiffness Timing and Location</b>	
<b>Timing</b>	
Upon awakening	The stiffness with me, I would feel it first thing in the morning when I get out of bed. I would feel it in my feet but once I walked around, by the time I got ready to leave, it would be gone. (Female, FG1) I would have it in my hands only in the morning but I would move around and it would get better but then after I got into a nice warm shower by the time I got out of the shower, it was gone. (Female, FG2) It's funny when it was in my feet, I had stiffness, it would be about five minutes in the morning. I would wake up and you know walk around or as I was getting dressed. Then they just kind of naturally loosen up and they get tired by the end of the day. (Female, FG2) Well you know that initial stiffness where it takes a while to start moving around might only last five minutes. (Female, FG4)
All day	The stiffness, I mean it's constant, all day long from the time you get up until you go to sleep. (Male, FG1)
Unpredictable	Usually I'll get up and I'm okay in the morning, it just depends on if you get a flare or, you know, the fatigue. It kills me. (Female, FG1). In the mornings, the only thing I felt was my feet, the stiffness in my feet but when I would get the stiffness in my hands, it would just come at any time and I just couldn't use them. (Female, FG2)
End of day	Stiffness is something that would loosen, become un-stiff or maybe go away. When it was in my feet, which was like just on the balls of my feet or those joints, it would loosen up and go away as I walked around during the day and then you would get more tired at the end of the day and they would be like achy from overuse. (Female, FG2)
<b>Location</b>	
Many joints affected	M1: RA don't pick one joint. F2: Yeah. M1: It's in your jaws, it don't matter, your back. F1: No it's not all my joints. It truly isn't. Basically, this hand more than this, but this one's been getting into it more, and my ankles and my shoulder. Because what's in my neck is you know, osteo, the doctor well, he told me. (FG1)
Different joint symptom combinations	My knuckles are swollen right now and not stiff. My wrist is stiff but my knuckles aren't, my fingers aren't. (Male, FG1) It depends on where the pain is. If it's on the bottom of the feet, it can be a pain but it can be stiffness. (Female, FG2) The swelling would be there regardless of whether the stiffness was there or not. I couldn't wear my rings [...] but my stiffness in my hands, I think that was the worst stiffness that I experienced. (Female FG2)
<b>Theme 4: Individual Context and Meaning</b>	

Themes	Illustrative Extracts
Descriptors and explanations for stiffness	I feel like the Tin Man, you know, get me a bit of oil or something. (Female, FG1) I mean, the stiffness come from the pain in the joints because you're not going to move when you have the pain [...] So then, since you don't move the joint, when you do move it, it's going to be a little stiff. You're going to have a little of that Tin Man in you from the Wizard of Oz. (Male, FG2)
Normal/constant part of RA	I recognize though I have RA normal. So my RA normal is always going to have some pain. I tell that all the time to my family. Every day I have pain. It's never going to go away. Stiffness every day I'll have that. Fatigue though, I don't, that's different, fatigue I don't have every day. But stiffness and pain I do, and that's just part of RA. (Female, FG1) If you've had it a long time you just get used to things, you don't realize what's going on. You're just used to it. (Male, FG1)
Connected with RA flare	If it is only in the morning and just a short time [it's] more under control. But if you're getting it throughout the day [...] that's where I know for me [...] this is getting to be a flare-up. (Female, FG1) Mine is in the morning, I have some stiff, I know I'm always going to have some stiffness but it's nowhere near as when I'm in a flare-up. (Female, FG1) If I get a flare I know it's coming because it'll start real small, like it's going to be this wrist. The stiffness will start and then the pain will start, and then it'll just grow and grow into the big hairy monster it turns out to be. (Male, FG1) That's the only time I have stiffness in my hands, when I'm in a flare. (Female, FG2)
<b>Theme 5: Impact on Daily Life</b>	
Perseverance	I always get stiffness right after I run [...] every time I'm running I'm always thinking, I'm always saying to myself, you have RA and you're running, you're doing so good (Female FG1) If you stop moving you lose it. And so I have just forced myself. There are days I trudge down to my treadmill and the last think I want to do is that treadmill (Female FG4)
Mobility and adaptation	It always takes you longer. There are no shortcuts with RA. (Male, FG1) M2: Like a shirt like he's got on with the buttons, it would take me ten minutes to get that shirt buttoned up. M1: I haven't worn a shirt like that in years. F2: Yeah, and consciously about the medications that I got, like in terms of getting the arthritis caps or just even with a prescription M1: I keep a barstool in the kitchen so I can cook. [...] Because of my stiffness. F3: Yeah, to sit down. M1: Oh yeah. I'll drag the barstool over and do dishes. F2: Shopping, grocery shopping. I always have to use a cart. M1: Yeah, to hold on. F2: I purposely just buy really fat pens. M1: I have ice cream scoops that have a real fat handle. (FG1)
Dependence on others	I could, I can deal with the stiffness. I mean it does hinder me, I feel like a burden around home, got to get people to open jars for you, you know, carry things for you. (Male, FG1) I had the help of my husband of course, because I went through a time when I couldn't dress myself, couldn't open jars (Female, FG2)
Vulnerability, fear, isolation	You can't get up off a chair, and forget it, if I sat on the ground, I would need help [...] If this place caught on fire and I was on that ground, I'm dead, because I am not getting up. (Male, FG1) I think the stiffness is what makes you insecure. [...] it makes me self-conscious and insecure about that you're more likely to fall, that you kind of just, you feel unsteady. (Female, FG1) You know that any minute you might not hit the step just right or you know you might not lift your foot up exactly right so you'll go off the front of the edge of the step or something. (Female, FG1) When you do get in those flare-up times and those really, really stiff times, like when it's like cold, and damp and God forbid that it snows you know, and I dread going outside and perhaps falling. (Female, FG1) It's that fear of falling or when you said like someone bangs into you, like sometimes my dog bangs into me and it is excruciating. (Female, FG1) I can't go to a football game, I can't go to a concert [...] I don't feel secure going up them 20 steps to get in that seat and then sliding by people also scares the heck out of me. (Male, FG1)