Research Article

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# Perceptions of physical activity engagement among adults with rheumatoid arthritis and rheumatologists

**Aim:** Physical activity (PA) among adults with rheumatoid arthritis (RA) is suboptimal. This study assessed PA motivations and perceptions in adults with RA and rheumatologists. **Methods:** Patients and rheumatologists participated in structured interviews led by a behavioral scientist. Sessions were audiotaped, transcribed and coded. **Results:** Twenty-three patients (mean age = 63 [standard deviation = 10], 96% female) and seven rheumatologists (57% male, 29% fellows) participated. Nine themes emerged: communication with the rheumatologist, environment/access, symptom management, social support, mental health, breaking inactivity cycles, integrating PA into routines, staying in control and challenge/intimidation. Highly active patients viewed PA differently than **low active** patients. The need to compete with RA-free individuals may impede PA. **Conclusion:** Understanding how patients conceptualize PA will enable clinicians to formulate PA strategies to motivate patients.

**Keywords:** motivators • perceptions • physical activity • rheumatoid arthritis

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Rheumatoid arthritis (RA) is a chronic inflammatory autoimmune disease that generally results in joint damage, functional loss, pain, disability [1] and reduced life expectancy [2,3]. Excess cardiovascular risk, reduced aerobic capacity and physical deconditioning are common secondary effects, and may result from inactivity, pain or be a direct effect of RA (e.g., dyslipidemia, endothelial dysfunction) [4]. Research strongly supports use of exercise, planned activity designed to improve health outcomes, to reduce functional limitations and disability in RA without comprising joint integrity [5]. Studies demonstrate that exercise at any intensity, low to high, can improve health outcomes [5,6]. Based on these data, exercise is recommended as a primary component of the management of RA [7,8].

In recent years, there has been a greater emphasis on maintaining and promoting a physically active lifestyle to reduce the cardiovascular effects of RA and improve health [9,10]. Data indicate that physical activity (PA) levels in adults with RA are suboptimal [10] and are lower than PA levels in healthy individuals [10,11]. Factors associated with low PA in adults with RA include deconditioning, pain, fatigue or negative beliefs concerning the safety and efficacy of PA to manage symptoms [12–15].

Self-management is an important tool for managing RA symptoms, but is challenging for patients experiencing an unpredictable disease course. Therefore, strategies have been developed to help patients adapt their behaviors in response to changes in symptoms and severity [15,16]. Patients' knowledge, attitudes and beliefs about RA can be identified and targeted to develop individualized self-management strategies to promote positive health behavior changes [14–18]. Research indicates that increased self-efficacy, mental health, general function and reduced healthcare costs often result from these changes [18]. However, changing patient behaviors presents significant challenges to healthcare providers [17–19].

Studies have examined psychosocial factors influencing exercise prescriptions and

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engagement in exercise among adults with RA [18–20]. Iversen *et al.* [18] reported patients with RA are less likely to engage in exercise if their rheumatologists do not discuss exercise regularly during the clinical visit and these individuals were less likely to receive an exercise prescription [18]. Law *et al.* [19] in a cross-sectional study survey of 247 adults with RA found health professionals' knowledge of exercise, fear of exacerbating joint disease or causing pain with exercise, knowing what exercises can or should be performed and recognizing exercise is good for RA were important factors influencing patient participation in exercise [19]. Munneke *et al.* [20] examined expectations of exercise among adults with RA, rheumatologists and physical therapists in the United Kingdom and discovered expectations of exercise were less positive toward high-intensity exercise. Interestingly, physical therapists reported less positive feelings toward high-intensity exercise than rheumatologists. If physicians appear ambivalent about which exercises are beneficial to manage RA symptoms or feel uncomfortable or uncertain about suggesting exercises for their patients, they will be less effective in motivating patients to exercise [18,20].

Less data exist regarding psychosocial factors influencing PA participation and maintenance in adults with RA [13,15,16,21]. Leoppenthin *et al.* [21] conducted a qualitative study to examine factoring impacting PA maintenance in adults with RA and identified three themes: a sense of autonomy and social belonging, accepting responsibility and enjoying challenges, and enjoying the body. In this study, a patient who regularly performs PA states her physical therapist motivates her by providing the right types of exercise to suit her needs. Nessen *et al.* [22] examined the experiences of 12 Swedish physical therapy coaches participating in a clinical trial to promote PA in adults with RA and reported challenges in the coaching role, growing into the coaching role, and coach education and support to support the use of behavioral change techniques were major factors impacting the success of the coaches.

The biopsychosocial model of health considers all aspects of an individual's life experiences including biological, behavioral, psychological and environmental. However, this totality of influences is not fully appreciated by all medical professionals seeking to change patients' health-related behaviors [22]. A greater understanding of these unique patient factors may guide future behavior change interventions.

In this study we explored perceptions of PA engagement and maintenance among adults with RA and their rheumatologists. A unique aspect of this study involved exploring behavior patterns and characteristics of patients who successfully engage in PA, and those who do not, by conducting in-depth interviews stratified by level of PA engagement. Additional interviews were conducted with rheumatologists to ascertain attitudes, beliefs and information communicated regarding PA counseling.

## Patients & methods

### Design & recruitment

Focused in-depth interviews were conducted by an experienced behavioral scientist. Rheumatologists were recruited from a large tertiary care urban medical center arthritis clinic (MA, USA) and patients were purposefully sampled from the center's RA registry. The RA registry consists of over 1300 patients with rheumatologist confirmed RA or seronegative inflammatory arthritis (714.0 or 714.9 ICD-9 billing codes). All patients are ≥18 years of age. Patients enrolled in the registry complete a battery of questionnaires, receive a standardized physical examination and provide a blood sample to assess C-reactive proteins (CRP) and other biomarkers for RA. Questionnaires completed include demographic and medical history, PA participation, attitudes, beliefs and social norms about PA.

Patients were purposefully sampled based on their responses to a PA self-reported questionnaire. To be eligible, patients had to be either in the top tenth decile or bottom tenth decile of self-reported PA participation levels. All eligible patients were contacted by mail. Rheumatologists were recruited via mailed invitations. Rheumatologists who expressed interest were scheduled for the structured group interview. Both patients and rheumatologists signed an informed consent approved by the institutional review board following procedures in accordance with the ethical standards of the Human Subjects Research Committee and with the Helsinki Declaration of 1975, as revised in 1983, prior to participation.

## Measures

Registry patients complete surveys and receive a physical examination. Demographic data include age, gender, ethnicity, race, smoking history, psychosocial support, income, marital status, employment status and education. Comorbidities are assessed using the Charlson comorbidity index [23,24]. Information pertaining to medication usage is extracted via self-report and medical records and classified by drug category as follows: NSAIDs; corticosteroids; disease modifying anti rheumatic agents (DMARDs); biologic disease modifying antirheumatic agents; and polytherapy.

Disease activity was measured using the Disease Activity Score 28-CRP3 (DAS28-CRP3) [24]. This score was calculated based on the number of swollen and tender joints, and CRP. The summary score ranges from 0 to 10 and is a valid (construct validity with health assessment questionnaire r = 0.49) and reli-

able measure of disease activity [24]. Scores are generally classified as minimally active (<3.2), moderately active (3.2–5.1) and highly active (>5.1). Disease severity was measured using the physician's global assessment scale [25]. This physician-based measure uses visual analog scale creating a score ranging from 0 to 10 that is used to classify disease severity into three categories: mild (0–3); moderate (4–6) and severe (7–10). Disability and function were assessed using the multidimensional health assessment questionnaire, a valid and reliable measure of disability and function in RA [26].

Exercise attitudes, beliefs and social norms were assessed using the exercise attitude questionnaire [27]. The exercise attitude questionnaire contains 18 items, using a 10 cm visual analog scale response, to evaluate patient attitudes, beliefs and social support for exercise and PA. Scores are summed across the 18 items (range 0–180) with a higher score indicating more positive attitudes, beliefs and social norms for exercise and PA. The scale has high internal consistency (Cronbach's $\alpha$ = 0.80) and has been used to assess attitudes, beliefs and social norms in patients with RA [27]. PA participation was assessed using the Nurses Health Study II (NHSPAQ) PA self-report questionnaire [28]. Six items are used to assess modes of exercise and frequency of exercise per mode over the subsequent week. From these items, metabolic equivalents are calculated using a standardized formula [28,29].

## Interview methodology

Formal moderator guides were prepared *a priori* for patients and rheumatologists (Table 1). Initially, patients of high and low activity were mixed, but this environment proved less conducive for positive dialog. After the first session, based on patient feedback, patients were separated into two groups, highly active and those with low activity levels, based on self-reported activity level. Interviews varied in size from one to six participants. Length of discussion varied on the number of participants with larger groups yielding longer discussions. On average, sessions lasted 1.5 h. Focus groups were conducted until thematic saturation was reached. [30] Transcripts were audiotaped, coded and transcribed. Three coders independently examined transcripts for themes using open coding techniques then met to discuss and refine themes using a normative process [30]. Quotes were selected to illustrate themes by PA participation levels.

## Results

23 patients and seven rheumatologists participated. Patients' mean age was 63 years [standard deviation (SD) = 10], 96% were female and 83% were Caucasian. Mean disease duration and median disease activity (DAS28-CRP3) were 24 years and 2.6, respectively. Patients reporting low *PA* levels had longer RA disease duration and reported less favorable attitudes toward PA (124 vs 161; p = 0.003). There were no significant differences in disease severity or disease activity between the two groups. Table 2 provides details on subjects, stratified by self-reported level of PA. Four rheumatologists were male (57%), two (29%) were fellows and most were Caucasian (71%).

Independent review of the transcripts by three researchers revealed several universal themes. Themes were refined and negotiated in the subsequent normative process. Quotations that exemplified themes were derived from raw transcript data. Nine distinct factors emerged in the transcripts: symptom management, social support, 'breaking the cycle' (of inactivity), communication with their rheumatologist, mental health, exercise as part of a personal routine, fear/staying in control, challenge/intimidation and environment/access. Most surprisingly, both patients and rheumatologists brought up competition/challenge as a factor in their exercise decisions and discussions (Table 3).

## Communication with rheumatologist

Some subjects reported wishing their doctors had discussed exercise with them early in their diagnosis. Patients wanted to know what exercises or PAs were safe for them to perform. Subjects indicated initial fear about worsening their disease or wanting specific guidelines for activities tailored to their needs. Rheumatologists revealed they are largely uncomfortable prescribing exercises and suggesting PAs for their patients. Many felt they would like to spend more time on these discussions but medication was first priority in clinical visits. Additionally, some rheumatologists reported they felt unclear regarding available physical therapy services and others were less convinced of the efficacy of physical therapy at some community clinics. Rheumatologists reported exercises and PA were important for patient health, but reported low perceived self-efficacy regarding their ability to motivate patients. As one rheumatologist said, "I feel like I'm talking to them a lot [about PA] but I'm not necessarily sure I am being effective." This perceived lack of confidence discussing PA seemed to deter doctors from bringing up PA with patients or precipitated what amounted to a 'one size fits all' PA lecture given universally with limited expectation of results. Table 4 provides examples of statements made by patients and rheumatologists regarding PA and exercise.

## Environment & access

Generally, participants in the highly active group cited few barriers to access for PA. Participants in the

Table 1. Moderator guides for session with adults with rheumatoid arthritis and rheumatologists.

| Sessions with adults with RA | Rheumatologist sessions |
|---|---|
| Do you believe patients with RA should be physically active? | Do you believe patients with RA should be physically active? |
| Do you discuss exercise/PA with your doctor? If so, how? | Do you discuss exercise/PA with your patients? If so, how? |
| Are there factors that prevent you from exercising/engaging in regular PA? | Are there factors you think prevent your patients from exercising/engaging in regular PA? |
| Are there factors that help you engage in regular PA? If so, describe. | Are there factors that help your patients exercise/engage in regular PA? If so, describe. |
| What contributions does PA make to the management of RA symptoms? | What contributions do exercise and PA make to the management of RA symptoms? |
| How do you feel about exercise/PA as a means to manage your symptoms? If so, explain. | How do you feel about exercise/PA as a means to manage your patient's symptoms? If so, explain. |
| Are you concerned about being physically active? | Are your patients concerned about being physically active? |

PA: Physical activity; RA: Rheumatoid arthritis.

low active group made 30 statements regarding barriers including weather, cost, access to equipment or type of equipment available. Rheumatologists tended to perceive environmental barriers dichotomously, as either legitimate/financial barriers, or excuses to avoid exercises. This perspective may present another barrier to provider–patient communication about PA. See Table 4 for more examples of barriers.

## RA symptom management

Highly active patients consistently reported using exercise as a means of RA symptom management. Almost 60 statements were made regarding exercise and symptom alleviation. Highly active patients made statements about 'the 1–2 punch of exercise and medicine' and tended to make comments with the following sentiment, "it just makes everything in your body work better." Low active patients acknowledged the role of PA and exercise in symptom management but many purported to be at a loss regarding where and how to start. Others commented that past experience with PA helped them feel better. In both groups, patients cited weight gain caused by medications as a motivational factor for increased PA. Rheumatologists also commented on this topic, and noted weight loss was a motivator for their patients, especially female patients. Interestingly, rheumatologists reported exercise and PA were crucial for symptom management, but felt they could not effectively influence their patients' PA levels.

## 'Breaking the cycle' of inactivity

All three groups brought up the idea of 'breaking the cycle of inactivity' or 'falling off the wagon.' Low active participants were more likely to report a current exercise 'rut.' A characteristic statement made by patients who engage in low levels of PA was, "I've been in this pit that I'm trying to climb my way out of." Whereas, highly active patients reported more frequent success with engagement in PA and reported greater perceived ability to return to full activity after setbacks. These patients tended to view a setback as a minor event and move forward again easily with their regular routine. Further exploration of active participants' resilience and coping strategies may provide insights on successful rebound after setbacks or even flares.

## Social support for PA

Patients in the highly active group made 20 more statements about social support than the low active group. Many participants in the highly active group expressed the sentiment that social support was not necessary to maintain PA; however, these same individuals reported people in their life viewed exercise positively. They also mentioned they enjoyed participating in group activities. Patients in the low active group emphasized the need to find the right level of social support or right type of group in order to remain adherent to an exercise routine. When discussing past experiences with exercise, some low active members cited losing an exercise partner as a key reason for 'falling off the wagon.' Low active patients were much more likely to react positively to the creation of support groups.

## Mental health

Patients in the highly active group cited mental health as a positive outcome of exercise/PA more often than their low active counterparts. Rheumatologists also discussed the positive mental health benefits of exer-

Table 2. Demographic and clinical characteristics of adults with rheumatoid arthritis.

| Variable | Low physical activity (n = 13) | | High physical activity (n = 10) | | p-value |
|---|---|---|---|---|---|
| | Mean [SD] or median (range) | # (%) | Mean [SD] or median (range) | # (%) | |
| Female | | 13 (100) | | 9 (90) | NS |
| Age (years) | 66 [11] | | 61 [8] | | NS |
| • Graduated College or attended/ completed graduate school † | | 6 (50)† | | 6(60) | NS |
| • Caucasian | | 10 (77) | | 9 (90) | NS |
| • Married | | 7 (54) | | 5 (50) | NS |
| • Employed | | 3 (30)‡ | | 5 (50) | NS |
| • Attitude toward exercise and PA | 124 [30]† | | 161 [12]† | | **<0.003** |
| **Clinical features** | | | | | |
| • Medications | | | | | |
| - Taking NSAIDs | | 3 (23) | | 3 (30) | NS |
| - Taking steroid | | 2 (15) | | 3 (30) | NS |
| - Taking nonbiologic DMARDs | | 9 (69) | | 5 (50) | NS |
| - Taking biologic DMARD | | 10 (77) | | 8 (80) | NS |
| - Polytherapy | | 8 (62) | | 3 (30) | NS |
| • Disease duration | 29 [8.3] | | 18 [9.5] | | **0.005** |
| • Seropositive | | 9 (69) | | 6 (60) | NS |
| • Disease activity (DAS28-CRP3) | 2.2 (2–4)† | | 1.8 (1.2–3.2] | | NS |
| • Comorbidities | 0.7 [1.1] | | 0.6 [0.9] | | NS |
| • Function (MDHAQ) | 3.2 [3.1]‡ | | 2.5 [2.1] | | NS |
| • Physical activity (METs) | 8.3 (1–15) | | 36 (25–53) | | **0.003** |
| • Physician global score | 19 [13] | | 16 [13] | | NS |

†Missing 1.
‡Missing 3.
DMARD: Disease modifying antirheumatic agent; MDHAQ: multidimensional health assessment questionnaire; MET: metabolic equivalent; NS: Not significant; PA: physical activity; SD: Standard deviation.

cise, but felt their low active patients required a 'mind shift' before they could access such benefits.

## Personal routine

Highly active patients incorporated planned exercise as part of their daily routine. Mode, frequency and duration varied from patient to patient, but highly active patients expounded 'aggressive defense' of their exercise routine. These participants commented that they responded very negatively to suggestions by family members or friends that they were 'over-doing it.' Low active patients tended to see 'movement' as a component of their personal routine. These individuals were predominantly sedentary, but considered incorporation of brief excursions to perform errands or cooking to be examples of PA that sufficed as intense enough to maintain fitness (Table 4).

## Fear of disease taking control of their lives/ staying in control

Both low active and highly active patients cited fear of the disease taking over their lives and a need to stay in control as significant factors related to PA engagement. Both groups felt staying active was crucial to sustaining control over their RA and their lives. Low active patients reported maintaining independence and the ability to perform household activities as a way of maintaining control over their disease. Highly active patients viewed physical fitness as a vector of control over their disease, noting each spin class accomplished or tennis match completed was a victory over their diagnosis. One participant reasoned, "you can control trying to be physically fit." Patients with a self-report-limited history of exercise described more fear about their condition and engagement in PA. They worried that they would dam-

Table 3. Themes extracted from focus groups and interviews with adults with rheumatoid arthriti and rheumatologists.

| Theme | Number of statements | | |
|---|---|---|---|
| | Physicians | Low active patients | Highly active patients |
| Communication with rheumatologist | 30 | 14 | 44 |
| Environment and access | 9 | 30 | 20 |
| Symptom management | 16 | 28 | 59 |
| Social support | 15 | 38 | 58 |
| Mental health | 4 | 4 | 23 |
| Breaking the cycle | 6 | 12 | 12 |
| Personal routine | 12 | 25 | 34 |
| Fear/staying in control | 14 | 32 | 34 |
| Challenge/Intimidation | 1 | 17 | 24 |

age their joints or injure themselves exercising the wrong way. For example, one patient stated she "had never exercised in the past (and) didn't know the right way to exercise." Highly active individuals viewed exercise and being physically active as a means to maintain task independence, whereas low active patients viewed the tasks as a means of maintaining general function.

## Challenge/intimidation

Low active and highly active patients consistently brought up feeling challenged or intimidated by others who did not have arthritis when they were engaging in PA in public forums (e.g., gyms). This factor seems to be a newly identified phenomenon, as there is limited literature on this topic as a barrier to exercise for patients with RA. Patients became quite animated and passionate when the topic arose. Both groups reported discomfort in being compared with individuals who are disease free. Statements such as, "I stopped [exercising] because you just see people bent over like pretzels." or "I get really frustrated because when I'm walking on the treadmill. I see someone next to me running." Similar statements made during the sessions revealed concern about feeling constantly compared with healthy counterparts and even with their peers who have RA but who appear to be less affected by their disease. These statements clearly expressed feelings of inadequacy regarding their ability to keep up with others. One low active patient noted she formerly was very physically active but felt she could no longer live up to her past and cited this feeling as a reason to stop trying to engage in PA. Rheumatologists rarely remarked about the possibility of feeling challenged or intimidated by others who are more active, as a barrier. One doctor was surprised when this issue was brought up and surmised that his own high level of PA likely intimidated his patients and prevented any meaningful discussion of this topic during clinical encounters.

## Discussion

PA is an important factor in RA self-management [7,8,17]. Exercise can reduce inflammation, decrease joint stiffness and discomfort and elevate mood, providing a sense of well-being [31]. Evidence-based research demonstrates even low to moderate intensity exercise (e.g., strengthening exercise) can be an effective modality to increase joint motion in individuals with early RA [5,6,32,33] and can also mitigate negative cardiovascular effects and prevent or reduce depression [5,6,9,33,34]. However, despite proven safety and efficacy of exercise and PA, adults with RA participate in PA at suboptimal levels [10,11]. Throughout this study, patients' statements confirmed earlier research on the positive perceived effects of exercise as effective symptom management [5,6]. The theme, fear of exacerbating RA symptoms through PA engagement, is consistent with other qualitative research findings [13,18–20]. Data from prior studies also identify communication with rheumatologists as an influential factor in patients' decision making regarding PA engagement [18–21]. However, patients in both low active and highly active groups reported wishing their doctor had offered advice or delineated specific exercises or options for PA engagement during clinical encounters.

Biological factors alone do not account for patient behaviors, disease management activities and outcomes. This study was unique in that it examined the knowledge, beliefs, attitudes, social norms and experiences of patients with RA separately for those who were highly active and those who self-reported being relatively sedentary or engaging in low levels of PA. Most importantly, patients who described themselves as highly active enjoyed the physical experience of exercise and

felt that being physically active added to their sense of well-being and their ability to control their disease. This finding is supported by a recent study [21] that reported patients with RA engage in PA to help create a new body image and this consequence of being active is an important component in decision making about exercise.

By exploring attitudes, beliefs and social norms about exercise separately for patients who are highly active and those who self-reported low to sedentary behavior, we were able to uncover differences in how PA is perceived between these individuals. As noted in the transcripts, highly active individuals viewed exercise as a means to maintain task independence, whereas low

Table 4. Supporting statements for themes responding physical activity in rheumatoid arthritis.

| Theme | Rheumatologists | Low active patients | Highly active patients |
|---|---|---|---|
| Communication | "We do these assessments for RA now, but how would we apply those to gear people to do the right types of activity and exercise?" | "She (rheumatologist) tells me to exercise." | "If your rheumatologist tells you what will be good for you, you will listen to him. If he tells you how important exercise is, most of us will do it." |
| | "I feel like I'm talking to them a lot but I'm not necessarily sure I am being effective." | | "Doctor's could give you a prescription for exercise." |
| Environment and access | "It's (physical therapy) expensive and patients get really annoyed because they could spend an afternoon in therapy." | "I would prefer to do swimming but there is nothing available I can afford." | "Finding the right shoe is an issue when you have arthritis." |
| | "I have a few patients who perceive going to the gym as the only way to get their exercise and gym memberships are expensive." | "It's difficult to be active when the weather is cold and snowy." | "In the long run it (covering the cost of physical activity) might prove cost–effective to the insurance companies." |
| Symptom management | "If you have a joint deformity or specific weak member that you want to build up, you do therapeutic exercises." | "I just started an exercise program which I've never done before. What prompted me to do it was weight. " | "It just makes everything in your body work better." |
| | "In an ideal world you'd want to spend equal time on that (exercise)." | | "Exercise and medicine are a 1–2 punch." |
| Social support | "... a peer supporter that can motivate you to exercise would be something to think about." | "Doctors should organize support group because I found I learned a lot from other people." | "You force yourself to just go out, you are with people. I am part of this world and I feel good about it." |
| Mental health | "I don't think they realize that it can really help them. It requires a mind shift on their part in some ways." | "It's (exercise) just best all around for mental health and you just feel more alive." | "You feel so much better mentally." |
| Breaking the cycle | "I don't think the pain is going to get better w/out physical activity." | "I've been in this pit that I'm trying to climb my way out of." | "My philosophy has always been you can work through it." |
| Personal routine | "I actually really focus on sedentary people. If it really looks like they haven't been doing anything other than physical therapy and walking." | "I know if I stop moving then I'm not going to be able to move." | "I will get aggressively defensive of it (exercise) if somebody says, 'Oh you know you don't have to go to the gym today.' Yeah, I do!" |
| | "I thinking a lot of them were motivated before they had their disease." | | |

RA: Rheumatoid arthritis.

Table 4. Supporting statements for themes responding physical activity in rheumatoid arthritis (cont.).

| Theme | Rheumatologists | Low active patients | Highly active patients |
|---|---|---|---|
| Fear /staying in control | "Patients are more comfortable talking about pain than they are about dysfunction. I think in the back of their minds they're worried about being crippled." | "You have RA, the RA doesn't have you." | "Well you can control trying to be physically fit because, rationally, logically it will make you feel better." |
| | | "I never exercised in the past, I didn't know what the right way to exercise was." | |
| Challenge/ intimidation | "Maybe that's (personal exercise routine) why I have so much trouble relating to patients." | "I stopped because. you just see people bent over like pretzels, I couldn't do that. I felt so uncomfortable in a regular class." | "I get really frustrated because when I'm walking on the treadmill and I see someone next to me running. It really bothered me." |

RA: Rheumatoid arthritis.

active patients saw these daily tasks as being sufficient for maintaining function. This is an interesting finding that may provide avenues for tailored PA counseling.

Rheumatologists discussed the positive mental health benefits of exercise, but felt their low active patients required a 'mind shift' before they could access such benefits. Significant research shows that PA should not be postponed until after a change in mental health status has occurred. A specific PA program that individually targets each patient's perceptions and addresses individual perceived barriers may increase feelings of safety and decrease fear of movement.

Rheumatologists also reported feeling less comfortable discussing exercise/PA with their patients despite the fact that they recognize their benefits. These feelings stemmed from a lack of knowledge regarding what to prescribe for exercise and whether high-intensity PA are appropriate for patients with RA. As a result, rheumatologists are less inclined to emphasize PA and exercise in their disease management plans. These comments resonated with data from an earlier study of clinical discussions regarding exercise to manage RA symptoms [18] in which 83% of rheumatologists reported they believed that physical therapy/exercise could effectively manage symptoms but none felt they were able counsel patients appropriately. Munneke *et al.*'s study [20] also supports a lack of understanding regarding the benefits of high-intensity PA for adults with RA among healthcare providers. Although rheumatologists described significant discomfort discussing, let alone prescribing specific exercises and activities, this is clearly an area where improvements appear to play a strong role in supporting patient motivation and confidence for PA. As Loeppenthin *et al.* [21] noted in their study of highly active patients with RA, lack of advice and support was an important barrier to PA for these patients. Individualized education by healthcare professionals, not just the rheumatologist, may be needed to develop safe and effective activities. Additionally, as past experience with exercise and an active lifestyle influence current behavior, the incorporation of a single item regarding past exercise and PA patterns during clinical visits may assist healthcare providers in tailoring clinical counseling to meet individual patient needs.

Competition/intimidation emerged as a barrier to PA in this study. Competition could be linked to the dichotomous internal and external expression of RA. While it may be difficult for patients to perform activities of daily living, outsiders may perceive patients with RA as not being affected by a chronic illness and discount the hidden symptoms of pain and fatigue. Patients in both groups reported instances when others around them did not recognize the severity of an RA flare or impact on their symptoms on daily living. Patients feared being labeled malingerers and perceived negative judgments by family and peers. These fears and perceptions appeared to be very distressing. Thus, patients reported avoiding situations in which they were compared with healthy individuals to avoid judgment or embarrassment. As illustrated in Rimmer *et al.*'s study [35], patients with physical disabilities reported feeling intimated when exercising next to healthy adults in public gyms. These same individuals, however, reported a need for others to help support them to become physically active and keep them 'on track.' The remarks from patients in this study who reported low PA levels indicated they respond more positively to the creation of support groups in which the members of the groups have similar levels of disease severity and perspectives on exercise. Further, trainers in a typical health center may lack knowledge of how to

instruct someone with RA to exercise safely or unknowingly cause further intimidation. Thus, PA programs for patients with RA need to consider both the physical aspects of the program (frequency intensity, duration and mode) as well as the psychological impact and motivators for PA and not treat all patients with RA the same way.

Highly active patients exhibited more resilience to setbacks and barriers to PA than low active patients. One possible explanation for this difference between groups may be due to how these individuals view the consequences of exercise and PA. Individuals who are less physically active reported more fear about exercise and PA damaging their joints than those who were physically active. Additionally, from the interviews it appeared rheumatologists are not entirely comfortable about helping their patients engage in exercise and PA. Better recommendations appear to be warranted to help rheumatologists and patients understand what forms of exercise and PA are beneficial for adults with RA and how healthcare professionals can counsel patients based on personal traits and perceptions.

## Strengths/limitations

This study has some limitations that should be acknowledged. While qualitative studies are not designed to be generalizable, we acknowledge that our patients were sampled from a single-center RA registry that is predominantly comprised of subjects with high socioeconomic status and the subjects who volunteered to participate in this study were predominantly women. Additionally, the limited number of rheumatologists available to participate may not be indicative of rheumatologists as a whole. Although the number of rheumatologists enrolled in the study represented nearly half of the rheumatologists actively seeing patients in the clinic and included a balanced sample of attending physicians versus rheumatology fellows. We used a mixed methods approach combining small groups and structured interviews that may have led to less disclosure of information in some sessions. However, this modification to the methods was conducted in response to patient requests and thus, we believe, did not affect the disclosure of information.

## Conclusion

This study demonstrates that patients with RA differ in their perceptions and motivators for PA. Specifically, patients who self-report high levels of PA do not require external motivators to engage in or maintain their current PA levels. They are also not dissuaded by others and are able to engage in PA at higher performance levels. However, patients with RA who considered themselves relatively inactive or sedentary view light activities are sufficient to manage RA symptoms. These individuals are also strongly influenced by their rheumatologist, friends, family and others. These individuals fear symptom exacerbation and are negatively influenced by a perception of competition when exercising in public venues. These individuals prefer support groups that aggregate patients who have similar RA profiles with respect to disease severity and levels of PA.

Rheumatologists recognize the benefits of PA but are unsure how to motivate and instruct patients with RA in such activities. These rheumatologists were not aware of certain patient-specific motivators such as 'challenge and intimidation' or how highly active patients with RA perceive social support differently than those who are inactive. These results can be used to inform the development of PA inventions for patients with RA and guidelines for PA counseling for rheumatologists and healthcare professionals.

## Future perspective

Given the differences in perceptions of PA among patients with RA who are highly active and those who self-report low PA levels, providing a brief screen regarding PA perceptions in the clinic may provide insights into how best to counsel patients with RA to become physically active or maintain PA levels. These tailored counseling programs should also recognize the differences in resiliency and coping strategies used by highly active and low active patients. A 'one size fits all' approach may not be effective in this patient group. The recent emphasis on the use of mobile applications to promote PA among adults (PA tracking devices, automated feedback) may be a mechanism for patients with RA who are highly active or low active as many mobile applications allow for social feedback/social networking or can be used alone to provide personalized feedback and motivational messaging.

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### Ethical conduct

The authors state that they have obtained appropriate institutional review board approval or have followed the principles

outlined in the Declaration of Helsinki for all human or animal experimental investigations. In addition, for investigations involving human subjects, informed consent has been obtained from the participants involved.

## Executive summary

- Highly active patients exhibited more resilience to setbacks and barriers to physical activity (PA) than *low active* patients.
- Patients with rheumatoid arthritis (RA) who maintain an active lifestyle view PA as a primary means of controlling symptoms and are not negatively impacted by feeling of competition or intimidation.
- Patients with RA who are inactive acknowledge the role of PA in symptom management but many purported to be at a loss regarding where and how to start. These individuals are negatively impacted by feelings of intimidation in public areas (e.g., gyms) by those who are more active than they are.
- Need for social support for PA varied depending on patients' self-reported PA levels. Those who were physically active despite their disease relied less on external motivators and set internal limits. Those who were inactive desired social support from individuals with similar disease activity and experiences.
- In this era characterized by a proliferation of medical therapies to manage RA, rheumatologists recognize the importance of PA but remain uncertain regarding how to motivate patients to become physically active or maintain an active lifestyle, what PA to recommend to patients and whether high-intensity activities are suitable for their patients with RA, how to prescribe exercises (e.g., frequency, intensity, duration, mode of exercise) and how to discuss PA in the clinical encounter.

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