



Editorial

Patient experiences of physical activity and exercise in rheumatoid arthritis

Lay Summary

What does this mean for patients?

Physical activity and exercise have been shown to have many benefits for people living with RA. These include improvements in symptoms associated with RA, such as pain, stiffness and fatigue. Participating in physical activity and exercise has also been shown to improve cardiovascular health and overall quality of life and is therefore an important part of disease management. Despite this, physical activity levels in people with RA are notably lower than those seen in people without RA, meaning that many RA patients do not experience the associated health benefits. By listening to the experiences of those with RA, researchers have been able to identify many of the reasons or barriers that make it harder for people with RA to exercise regularly. These include lack of professional support, feeling embarrassed or worrying about making symptoms worse. These important patient insights have also allowed researchers to understand other factors that support physical activity and exercise among people with RA, such as encouragement from family and friends and enjoying the feeling of achieving exercise-related goals. This paper includes the personal accounts of three patients with RA and their experiences with physical activity and exercise at different times: during childhood, during a flare and during a pandemic. Exploring the experiences of a wide range of patients is crucial in guiding the development of appropriate exercise-related advice and programmes that will support physically active lifestyles in this group of patients.

Introduction

Patient and public involvement (PPI) is crucial in the planning, development and evaluation of health services and policies [1], with people with lived experience providing unique knowledge and insight to support the design and improvement of patient-centred approaches to care [2]. Recognition of the importance of physical activity and exercise in people with RA has highlighted the need for interventions and programmes to be co-designed by those with RA [3]. Studies exploring the experiences and perceptions of physical activity and exercise in RA patients have revealed the existence of complex disease-specific barriers that impede patients with RA from engaging in regular physical activity and exercise. Such barriers include physical limitations (e.g. pain, stiffness, reduced mobility and fatigue), lack of confidence, fear of embarrassment, injury or exacerbating symptoms, lack of professional input/advice and programmes, inaccessible facilities and financial costs [4–6]. Further studies exploring the successful maintenance of physical activity and exercise among people with RA also identified numerous facilitators, including professional knowledge/guidance, peer/social support, improvement in symptoms and overall enjoyment [3, 4, 7].

Importantly, the constant presence of RA impacts physical activity as an agile lifelong behaviour, thus emphasizing the need for long-term individual support [8]. Tailored exercise programmes can alleviate uncertainty and negative exercise-related beliefs in those with RA, while also supporting the development of coping strategies to overcome RA-associated barriers, in turn promoting individual physical activity and exercise [9]. Some studies have shown that patients prefer RA-specific, group-based exercise programmes with ongoing expert guidance to support patient education and self-management strategies [9–11]. The

development of suitable and effective physical activity interventions should therefore be guided by the experiences of patients in order to recognize and understand potential barriers, along with any other factors that might positively or negatively influence exercise-related behaviours in RA populations [4]. This paper includes personal accounts of our experiences (as RA patients) with exercise at different times, followed by a discussion of the perceived barriers and facilitators to physical activity and exercise in people with RA and the importance of patient experiences in the development of interventions.

Exercise in childhood—Ruth's story

My family were all sports crazy, and my first major sporting event was listening to England win the World Cup in 1966, when just a few months old. I was diagnosed with Still's disease as a toddler and count myself lucky not to have experienced the sudden loss of ability that other patients do. My parents were well advised 'not to wrap me in cotton wool'. I had two boisterous brothers who did all the usual things: football, cricket, running, climbing and, of course, fighting! I joined in everything, although my rheumatologist was clear that I shouldn't play rugby! Early on, I learnt to catch and throw a ball, went for long walks and learnt to swim.

I started school prematurely on the assumption I would need frequent time off for hospital visits; my only medication at this time was aspirin. On one occasion, I was told that I could not play football because the metal on my callipers was 'too dangerous for others'. Bored, I spent the lesson inside entertaining myself by filling my teacher's shoes with sand! In

contrast, I was allowed to climb the high metal climbing frame, play netball, rounders and dance with everyone else.

I attended physiotherapy three times a week, on Mondays, Wednesdays and Fridays, causing chaos for both my Mum, who escorted me, and my teachers, who had to adapt to my schedule. Physiotherapy was made fun by doing a wide variety of activities to keep joints mobile and muscle groups strong. I remember being dipped in wonderful hot wax before doing hand and foot exercises, walking around on my heels while gripping marbles in my toes, climbing up and down the monkey bars and lifting ankle weights to keep my quads strong. The boring bit was measuring every joint for improvement and the disappointment as my grip strength waned.

Methodologies altered over time: hot wax became cold mudpacks, strengthening weights became resistance exercises, and long stretches became US therapy. My horrid heavy leather callipers were replaced by lightweight night splints, and my bike was adapted to put my rear brake on my stronger right hand. I still failed my cycling proficiency because the examiner felt I hadn't looked over my shoulder; I did, but my neck was stiff! On sports day, my brothers always seemed to win; I never did, but I was always encouraged to join in. I felt special, not different.

Secondary school was tougher despite the arrival of DMARDs. My callipers had gone so as not to stand out in the crowd. Physiotherapy was much reduced to help maximize my studies. I loved team games and made new friends through sport. Gymnastics was tough because I couldn't do a handstand, having no extension at my wrists, and everyone 'worried' about my neck. I loved playing hockey and tennis, adapting the grip size to make it easier. My passion, once netball, became volleyball because we played that with the boys. I wasn't very good, but I needed to join in. During adolescence, I found that competition killed the joy of exercise for a me; it made me feel different, weaker and sad. I wish I had sometimes had the opportunity to play with other kids more like me.

Exercise during a flare—Jordan's story

I was a highly active, sports-loving teenager when I received my RA diagnosis. Needless to say, I was shocked! While searching for the right medication in the years that followed, my symptoms continued to worsen, and I had all but given up on exercising completely. The thing I once loved was now a rather intimidating concept.

Knowing its importance, however, I desperately wanted to increase my physical activity levels and build muscle to support my joints. I just didn't know how to do this safely. I didn't know where to start with this new body and the new limitations it imposed. All I knew was that if I wanted to exercise then I would have to find ways that worked for me, while also facing my new-found fear of exercise.

At the time, I turned mainly to the internet for guidance. Frustratingly, I found that much of the physical activity information and advice (during the 2000s) pertained to other forms of arthritis, mainly OA, and it wasn't clear to me how translatable this was to RA given the inflammatory aspect of the condition. Many of the suggested activities, such as chair yoga (although I understood and appreciated the benefits), simply didn't excite me.

I therefore set about creating my own workout routines using a trial-and-error approach. I picked exercises I could do from a variety of follow-along workouts and researched safe alternatives for those I couldn't manage. I planned routines that targeted different areas of the body with varying intensities, which meant that there was always something that I could do, even when certain joints flared.

Learning about anatomy, heart rate zones, stretching, resistance training and low-impact cardio allowed me to set myself meaningful and achievable targets, the benefits of which started to (slowly but surely) improve my day-to-day life.

I have found that having varying workouts allows me to adapt to the ups and downs of RA, meaning that I don't always have to put my life on hold every time my RA flares. Being able to perform these workouts at home also means that I can exercise at my own pace and take regular breaks when needed. These factors all contribute to my ability to exercise safely, even during a flare, which ultimately makes me feel like I am in control of my body again.

Exercise during a pandemic—Savia's story

My first thought when lockdown happened was that I needed to do more exercise because I wasn't going to be doing my usual weekly level of physical activity of climbing up and down stairs at train stations to get to hospital appointments. As I was 'shielding' and even going out for a walk would involve having to go through several communal areas of my block of flats, I was largely restricted to home exercise.

I increased the short 10–15 min workouts (aerobic or dance-based) I was doing from YouTube from three times a week to every day. I was pleased that now my Achilles tendonitis was better (thanks to my physiotherapist), I could do this. The real revelation was discovering that the university I'm affiliated with had started offering staff free online fitness classes to support our mental wellbeing. I didn't really think there'd be something I liked or that I could cope with 1 h of doing any type of exercise, but given that it was free, I had nothing to lose.

I signed up for yoga, Pilates, swing dance, boxing, tai chi, ballet barre and Zumba. Some classes I didn't enjoy, and others were plainly not appropriate for me and were increasing my joint pain (e.g. boxing). The thing I liked most about online classes was that I felt no pressure; I could keep my camera off and do whatever I could, while sitting out moves which caused too much pain. This was unlike group in-person classes I have previously tried where, after disclosing my RA, the instructor tells me to sit out the moves I can't do, resulting in me not doing half the class while others stare at me in the mirror as if I'm being lazy. I have an invisible illness, and people are quick to judge.

Then in summer 2021, I saw that the National Rheumatoid Arthritis Society (NRAS) was offering a 6-week course on resistance training for people with RA, run by a personal trainer with RA. With some new-found confidence in my ability to exercise sustainably without being in a boom-and-bust cycle (largely owing to work my physiotherapist had done with me before lockdown) and my preference for online classes, I immediately signed up. I had been wanting to get stronger for a long time, primarily because it will make my day-to-day activities much easier (e.g. carrying shopping).

Now, 1.5 years into the pandemic, I have gone from doing 3 × 10–15 min to 7 × 10–15 min aerobic/dance workouts a

week, plus 2 × 1 h resistance training, 2 × 1 h Pilates, 1 h Zumba and 1 h restorative yoga per week. I have lost 8 kg through a combination of intermittent fasting and exercise, resulting in my BMI returning to a normal range and significant improvements in my blood work. At a recent visit, my physiotherapist said I'm her 'success story', which made me smile. It only took a pandemic for me finally to get fit!

Conclusion

This paper has highlighted numerous barriers that exist for people living with RA in relation to physical activity and exercise. For example, a lack of tailored advice and easily accessible resources to support RA patients during a flare can discourage physical activity and exercise through fear of injury or aggravating pain or fatigue. The format of exercise is also important, because generic in-person programmes might not be suitable for people with RA, potentially impacting participation and causing feelings of embarrassment or inadequacy. Here, digital formats can be preferable. Our personal stories are consistent with findings from several studies that identified similar barriers, while also highlighting numerous facilitators, such as the role of enjoyment and others' encouragement, the value of self-selected goals, ability to adapt and the desire to exercise to experience the associated physical, emotional and social benefits. Overall, our accounts illustrate that a standardized approach to physical activity and exercise for people with RA would be inadequate, instead indicating the need for a more personalized, patient-centred approach. Nevertheless, there remains a lack of physical activity and exercise programmes specific to the needs of RA patients. Healthcare services and professionals should better apply existing findings relating to barriers and facilitators of exercise into the development of suitable advice, interventions, equipment and programmes with options, in order to maximize recruitment and support RA patients to sustain physically active lifestyles.

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References

1. Staniszewska S. Patient and public involvement in health services and health research: a brief overview of evidence, policy and activity. *J Res Nurs* 2009;14:295–8.
2. Bate P, Robert G. Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *Qual Saf Health Care* 2006;15:307–10.
3. Swärdh E, Nordgren B, Opava CH, Demmelmaier I. "A necessary investment in future health": perceptions of physical activity maintenance among people with rheumatoid arthritis. *Phys Ther* 2020; 100:2144–53.
4. Veldhuijzen van Zanten JJ, Rouse PC, Hale ED *et al.* Perceived barriers, facilitators and benefits for regular physical activity and exercise in patients with rheumatoid arthritis: a review of the literature. *Sports Med* 2015;45:1401–12.
5. Riggs DM, Killingback C. What factors influence physical activity participation in people with rheumatoid arthritis. *Phys Ther Rev* 2019;24:298–307.
6. Qvarfordt M, Andersson MLE, Larsson I. Factors influencing physical activity in patients with early rheumatoid arthritis: a mixed-methods study. *SAGE Open Med* 2019;7:1–11.
7. Thomas R, Hewlett S, Swales C, Cramp F. Keeping physically active with rheumatoid arthritis: semi-structured interviews to explore patient perspectives, experiences and strategies. *Physiotherapy* 2019;105:378–84.
8. Swärdh E, Opava C, Brodin N. Physical activity in patients with rheumatoid arthritis - an agile lifelong behaviour: a qualitative meta-synthesis. *RMD Open* 2021;7:e001635.
9. Swärdh E, Biguet G, Opava CH. Views on exercise maintenance: variations among patients with rheumatoid arthritis. *Phys Ther* 2008;88:1049–60.
10. Withall J, Haase AM, Walsh NE, Young A, Cramp F. Physical activity engagement in early rheumatoid arthritis: a qualitative study to inform intervention development. *Physiotherapy* 2016;102: 264–71.
11. Bearne LM, Manning VL, Choy E, Scott DL, Hurley MV. Participants' experiences of an Education, self-management and upper extremity eExercise Training for people with Rheumatoid Arthritis programme (EXTRA). *Physiotherapy* 2017;103:430–8.