Editorial

Patient experiences of physical activity and exercise in rheumatoid arthritis

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 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 $3 \times 10$–15 min to $7 \times 10$–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.

Data availability statement
No new data were generated or analysed in support of this research.

Funding
No specific funding was received from any bodies in the public, commercial or not-for-profit sectors to carry out the work described in this article.

Disclosure statement: The authors have declared no conflicts of interest.

References
Indicated for the treatment of moderate to severe active rheumatoid arthritis in adult patients who have responded inadequately to, or who are intolerant to one or more disease modifying anti-rheumatic drugs. May be used as monotherapy or in combination with methotrexate.

*From biochemical assay, the clinical relevance of which is uncertain.

JAK, Janus kinase; RA, rheumatoid arthritis; TK, tyrosine kinase.

Refer to Summary of Product Characteristics (SmPC) before prescribing, and for full prescribing information.

**JYSELECA**® filgotinib 100 mg or 200 mg film-coated tablets.

**Dosage:**

- **Jyseleca** may be used as monotherapy or in combination with methotrexate (MTX). Dose: Adult: 200 mg once daily. Taken orally with/without food. It is recommended that tablets are swallowed whole. **Pharmacokinetics:** Refer to the SmPC for information regarding urinary monitoring and dose initiation or interruption. Elderly: A starting dose of 100 mg once daily is recommended for patients aged 75 years and older as clinical experience is limited. Renal impairment: No dose adjustment required. In patients with estimated creatinine clearance (CrCl) ≤ 60 mL/min. A dose of 100 mg of filgotinib once daily is recommended for patients with moderate or severe renal impairment (CrCl 15 to < 60 mL/ min). Not recommended in patients with CrCl < 15 mL/min. Hepatic impairment: Mild/moderate hepatic impairment: no dose adjustment required. Severe hepatic impairment: not recommended. **Children (< 18 years):** Safety and efficacy not yet established. **Contraindications:** Hypersensitivity to the active substance or to any of the excipients. **Active tuberculosis (TB), or active serious infections. Pregnancy, Nursing:** Precautions: See SmPC for full information. Immunosuppression: Combination use, with immunosuppressants e.g. ciclosporin, tacrolimus, biologics or other Janus kinase (JAK) inhibitors is not recommended. It is a risk of additive immunosuppression cannot be excluded. Infections: Infections, including serious infections such as pneumococcal and opportunistic infections e.g. tuberculosis (TB), herpes zoster, candidiasis, and cryptococcosis have been reported. Risk benefit should be assessed prior to initiating in patients with risk factors for infections (see SmPC). Patients should be closely monitored for the development of signs and symptoms of infections during and after filgotinib treatment. Treatment should be interrupted if the patient is not responding to antimicrobial therapy, until infection is controlled. There is a higher incidence of serious infections in the elderly aged 75 years and older, caution should be used when treating this population. **Tuberculosis:** Patients should be screened for TB before initiating filgotinib, and filgotinib should not be administered to patients with active TB. **Viral reactivation:** Cases of herpes zoster reactivation (e.g. herpes zoster), were reported in clinical studies (see SmPC). If a patient develops herpes zoster, filgotinib treatment should be temporarily interrupted until the episode resolves. Screening for viral hepatitis and monitoring for reactivation should be performed. **Malformations:** Immunomodulatory medicinal products may increase the risk of malformations. Malformations were observed in clinical studies (see SmPC). **Filgotinib:** Fertility, in animal studies, decreased fertility, impaired sperm morphology, and histopathological effects on male reproductive organs were observed (see SmPC). The potential effect of filgotinib on sperm production and male fertility in humans is currently unknown. **Haematological abnormalities:** Do not start therapy, or temporarily stop if an absolute neutrophil count (ANC) <1 × 10⁹ cells/L, ALC <0.5 × 10⁹ cells/L or haemoglobin <8 g/dL. Temporarily stop therapy if these values are observed during routine patient management. Vaccinations: Use of live vaccines during, or immediately prior to, filgotinib treatment is not recommended. **Use in pregnancy:** Filgotinib was associated with dose-dependent increases in lipid parameters, including total cholesterol, and high-density lipoprotein (HDL) levels, while low density lipoprotein (LDL) levels were slightly increased (see SmPC). **Cardiovascular risk:** Rheumatoid arthritis patients have an increased risk of cardiovascular disorders. Patients should have risk factors (e.g., hypertension, hyperlipidaemia) managed as part of usual standard of care. **Venous thromboembolism:** Events of deep venous thrombosis (DVT) and pulmonary embolism (PE) have been reported in patients receiving JAK inhibitors including filgotinib. Caution should be used in patients with risk factors for DVT/PE, such as older age, obesity, a medical history of DVT/PE, or patients undergoing surgery, and prolonged immobilisation. **Lactase content:** Contains lactose patients with rare hereditary problems of galactose intolerance, total lactase deficiency or glucose-galactose malabsorption should not take filgotinib. **Pregnancy/Lactation:** Filgotinib is contraindicated in pregnancy. Filgotinib should not be used during breast-feeding. Women of childbearing potential must use effective contraception during and for at least 1 week after cessation of treatment. **Driving/Using machinery:** No or negligible influence, however diziness has been reported. **Side effects:** See SmPC for full information. **Concomitant use:** To manage infection and disease: Uncommon (≤1/1000 to ≤1/100) herpes zoster, pneumonias, mycobacterial, mycoses and other infections, such as tuberculosis (TB), oesophageal candidiasis, and cryptococcosis (see Section 4.8) and blood creatine phosphokinase increase. Serious side effects: See SmPC for full information. **Legal category:** POM. **Pack:** 30 film-coated tablets/bottle Price: UK Basic NHS cost: £863.10. **Marketing authorisation number(s):** Great Britain Jyseleca 100mg film-coated tablets PLGB 42147/0001 Jyseleca 200mg film-coated tablets PLGB 42147/0002 Jyseleca 200mg film-coated tablets EU/1/20/1480/001 Jyseleca 200mg film-coated tablets EU/1/20/1480/002 Jyseleca 200mg film-coated tablets PLGB 42147/0001 Jyseleca 200mg film-coated tablets PLGB 42147/0002 Jyseleca 200mg film-coated tablets EU/1/20/1480/001 EU/1/20/1480/002 Further information: Galapagos UK, Belmont House, 1 Belmont Road, Uxbridge UB8 1QS, United Kingdom 0800 7878 1345 medicalinfo@glpg. com Jyseleca® is a trademark.

**References:**

1. **JYSELECA**® SPC. Available at: www.medicines.org.uk. Last accessed: June 2022.