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REHABILITATION SCIENCES AND THE RHEUMATIC DISEASES

The Future of Axial Spondyloarthritis Rehabilitation: Lessons Learned From COVID-19

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Supervised physical therapy and rehabilitation are vital for effective long-term management of axial spondyloarthritis (SpA). However, the unprecedented year of 2020 and the COVID-19 pandemic has prompted a drastic change in health care provision across all disease areas. In this review, we summarize changes that have been introduced to support rehabilitation in axial SpA during the pandemic and considerations for the future of axial SpA rehabilitation in the wake of COVID-19. We have witnessed the launch of online virtual physical therapy and education, in addition to an emphasis on remote monitoring. We have been propelled into a new era of digital service provision; not only providing a temporary stop-gap in treatment for some patients, but in the future, potentially allowing for a wider reach and provision of care and resilience of vital services. Unique collaboration between patients, health care professionals, and researchers will be key to fostering relationships and trust and facilitating wider evaluation and implementation of digital services at each stage in a patient's journey, which is imperative for relieving pressure from health care providers. Despite the potential of such digital interventions, it is important to highlight the maintained critical need for face-to-face services, particularly for vulnerable patients or during diagnosis or a flare of symptoms. It is also vital that we remain vigilant regarding digital exclusion to avoid further widening of existing health inequalities. Optimization of digital infrastructure, staff skills, and digital education alongside promoting accessibility and engagement and building trust among communities will be vital as we enter this new age of blended in-person and digital service provision.

Introduction

Physical therapy and rehabilitation are cornerstones of nonpharmacologic treatment for axial spondyloarthritis (SpA) and are critical for adequate long-term disease management (1,2). There is extensive evidence to suggest that physical activity is effective at reducing symptoms and disease activity in axial SpA, with a corresponding increase in spinal mobility, physical function, and cardiorespiratory fitness (1,3–8). As such, European treatment guidelines highlight the importance of a combination of nonpharmacologic and pharmacologic treatment modalities, including an emphasis on physical therapy, to optimize management of the condition (9). However, the most effective protocol for physical activity in axial SpA remains unclear (1,10).

Recent evidence suggests that physical therapy for axial SpA should be prescribed based on the individual, while covering aerobic, flexibility, resistance, and neuromotor training (1). While unsupervised home-based exercises have been found to be efficacious for patients, supervised physical therapy has been suggested to be more effective (2,11–14). Furthermore, recent research has highlighted the potential paradoxical role of biomechanical stress and entheseal microdamage in the radiologic progression of axial SpA through potential development of tissue-specific inflammation and complex interactions between proinflammatory pathways, including the likely role of cytokines, growth factors, and

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tissue-resident cells (10). Therefore, evidence-based exercises provided in a one-to-one or group setting guided by a highly experienced, specialized physical therapist may be preferable initially, whereby the specialist can gauge the capabilities of the patient and recommend appropriate stretches and exercise accordingly on a case-by-case basis. This supervised mode of delivery by a specialist has also been identified as important to patients (13).

The unprecedented year of 2020, however, and the COVID-19 pandemic have prompted a drastic change in health care provision across all disease areas. Patients have been unable to attend face-to-face appointments or supervised physical therapy, and a widening of existing gaps in health care have been highlighted (15). In the international REUMAVID study, of 1,707 patients with rheumatic musculoskeletal diseases (RMDs) surveyed from 15 European countries (47.5% of patients with an axial SpA diagnosis), 45.0% reported worsening health during the pandemic (16). In REUMAVID, patients also reported increased alcohol consumption, smoking, weight gain, and reduced physical activity, including an inability to continue rehabilitation exercises or physical therapy programs (17). Individuals participating in REUMAVID received poor access to care, 60.6% being unable to keep their rheumatologist appointment, 92.5% of which were canceled by their health care provider. More than one-half of participants perceived their health status to be "fair to very bad" and reported poor well-being as indicated by the World Health Organization Five Well-Being Index. Similar results have been reported in the UK specifically, where in a survey of health care professionals and patients conducted by the National Axial Spondyloarthritis Society (NASS), almost one-half of the patients reported a worsening of symptoms and deterioration of both general and mental health during lockdown (15). In the US, a study of 1,692 rheumatology patients from New York demonstrated that difficulties with medication access and flares were common during the peak of the pandemic (18). Furthermore, difficulty with medication access and COVID-related distress were both strongly associated with patient-reported flare and disease activity in this patient group.

As described by the NASS in the UK, although the COVID-19 pandemic has highlighted existing gaps in service provision for patients with axial SpA, it has also accelerated change, with the introduction of virtual and remote consultations, including care for flares, and an increased interest in digital service provision and the importance of remote monitoring (15). Indeed, it has required a rapid adaptation of both patients and clinicians' practices to embrace new ways of working. The pandemic has also highlighted the need for imminent changes and prioritization of initiatives to revolutionize both the resilience and efficiency of our current health care systems to ultimately provide optimal support and the best possible care for patients with axial SpA (15). In the present article, we discuss changes that have been introduced to support rehabilitation in axial SpA during the pandemic and considerations for the future of axial SpA rehabilitation in the wake of COVID-19.

Change in axial SpA rehabilitation services during COVID-19

At the Royal National Hospital for Rheumatic Diseases (RNHRD) in Bath, the unique 2-week inpatient physical therapy rehabilitation program has been integral to axial SpA care since the 1970s. The course provides individuals with the tools that they need to confidently self-manage their condition, placing an emphasis on education, self-management, physical therapy, and hydrotherapy, with input from a multidisciplinary team of physical therapists, a consultant rheumatologist, occupational therapist, counsellors, pharmacist, dietician, and health care assistants. There are no strict entry criteria for program referral. However, it is thought to be particularly beneficial for newly diagnosed patients, those in flare and who are struggling to manage their condition, postsurgery (e.g., following hip replacement), or to maximize outcomes of biologic therapy. To cater to differing levels of disease activity, function, and mobility, the program is delivered at 3 levels of intensity depending on spinal mobility (according to the Bath Ankylosing Spondylitis Metrology Index [BASMI]): fast (BASMI score 0–3), fast/moderate (BASMI score 3–5), and moderate (BASMI score ≥5). Patients may attend the course more than once on an as- and when-appropriate basis.

Significant short- and long-term improvements in disease activity, spinal mobility, and function have been observed following course attendance (19,20). The social element of the course, including meeting others with the condition, is also a critical element of the program's success. Participants have been known to forge long-lasting relationships following the course and to form critical support networks of mutual understanding. Although yet to be explored in detail in the context of the course, relatedness indeed forms 1 of the 3 basic psychological needs as detailed in self-determination theory. Self-determination theory proposes that when 3 innate basic psychological needs for autonomy, competence, and relatedness are fulfilled, positive outcomes are achieved, with these 3 factors suggested to be the most predictive and reliable mediators of motivation, engagement, and well-being (21). The impact of the course on such outcomes is currently being explored in ongoing analysis.

During the pandemic, the importance of maintaining some form of supervised axial SpA rehabilitation delivery was recognized very early on at the RNHRD. As such, a group of highly skilled specialist physical therapists and rheumatologists, with input from a team of academics and behavioral scientists, was able to develop an online course to be delivered remotely via Zoom. While some services were obviously not available virtually (e.g., hydrotherapy), the core components of the course (education, self-management, and physical therapy) remained or could be reproduced, to an extent, online.

Similarly, we have seen organizations such as the NASS migrate from in-person to online educational events, enabling

a much wider reach for axial SpA education (22). The NASS has been hosting regular live online self-management sessions, with a wealth of legacy resources now available across its platforms, including recorded physical therapy sessions delivered live by specialist physical therapists.

Introduction of remote data collection for axial SpA services

At the RNHRD, not only are participants now able to attend the Bath axial SpA rehabilitation course from their own home, but standard patient-reported outcome measures collected pre- and post-course (and at each clinic appointment) have been migrated to an online system called Meridian. This includes measures such as disease activity (Bath Ankylosing Spondylitis Disease Activity Index [BASDAI]), function (Bath Ankylosing Spondylitis Functional Index [BASFI] patient global assessment), quality of life, fatigue (Functional Assessment of Chronic Illness Therapy), anxiety and depression (EuroQol 5-domain instrument), work productivity (Work Productivity and Activity Impairment questionnaire), and sleep (Jenkins sleep scale). Patients enter data via a unique online Meridian portal, and these data are then automatically integrated into the hospital system. This has facilitated the previously unforeseen efficiency of data collection both for research and for clinical use in axial SpA. Clinicians can now access individual patient-level graphical representations of, for example, disease activity (BASDAI) over time via Meridian during a clinic appointment, while approved researchers can access anonymized, aggregated data for patients who consented to the Bath Spondyloarthritis Research Biobank. More than 30 years' worth of paper records have also been digitized and integrated into Meridian. This includes additional measures such as spinal mobility (BASMI) and laboratory results such as C-reactive protein level. Furthermore, additional digitized information for research, such as coded Margolis Pain Diagrams (specifying regional or chronic widespread pain) and occurrence of significant life events, is available for a subset of ~200 patients.

Although traditional patient-reported outcome measures are critical for understanding overall changes in disease activity and quality of life over time, they are subject to recall bias and may fail to capture a significant proportion of day-to-day disease information. In chronic, inflammatory conditions such as axial SpA where there may be fluctuating periods of disease activity and flare, these subtle daily changes in symptoms could be of critical importance for gaining a better understanding of the condition and for optimizing and personalizing treatments such as physical therapy. In 2017, the European Alliance of Associations for Rheumatology produced a "research roadmap to transform the lives of people with RMDs," often referred to as Rheuma-Map, which highlighted the need to better explore the impact of physical activity and lifestyle on the progression of axial SpA. Implementation of remote monitoring and digital technologies such as wearable devices and smartphones for granular, daily remote monitoring of symptoms and activity could be critical to meet this outlined need. Monitoring of lifestyle and physical activity and symptom data may also allow patients to gain a better understanding of their condition, while allowing them to gauge the level of physical activity that feels good for them and implement lifestyle changes accordingly. Since the start of the pandemic, we have seen an increased interest in remote monitoring both for research and clinical purposes. At the RNHRD, >350 patients are now registered with the RNHRD Project Nightingale study (www.projectnightingale.org), whereby individuals can use a smartphone app to track daily self-reported data in between clinical appointments, as well as before, during, and after course attendance. This includes variables such as pain, mood, stress, sleep, fatigue, flare, use of antiinflammatory drugs, and recommended exercise in addition to less explored variables such as menstrual cycle, caffeine intake, and screen time. The app can also be linked with an individual's wearable device if they have one to collect data on steps, heart rate, and sleep. Since September 2020, all patients invited to attend the virtual rehabilitation program have been invited to participate in Project Nightingale when referred to the course. This will form a larger piece of validation work to determine the capabilities of smartphone technologies to support both assessment of rehabilitation outcomes and potentially self-management. Indeed, enthusiastic patients at the RNHRD have expressed how Project Nightingale has helped them better self-manage and understand their disease while providing them motivation to exercise independently following intensive, supervised rehabilitation (23). However, until the platform has been evaluated scientifically, we cannot make firm recommendations for its use in health care.

Considerations for future axial SpA rehabilitation delivery

In terms of rehabilitation specifically, as suggested in feedback from RNHRD patients' post-virtual course, the future will likely involve a blended combination of in-person and online physical therapy with complementary remote data collection pre- and post-course. Online therapy could be implemented either as a "top up" between in-person appointments or as an alternative for patients who may not have the time to commit to an intensive rehabilitation program, such as the 2-week inpatient course delivered at Bath. Indeed, axial SpA often develops in the second or third decade of a patient's life, which is a critical time for establishing relationships and careers. Therefore, some individuals may prefer a shorter online course, whereby they can fit their initial education and physical therapy around their daily routine. This could also potentially be beneficial in terms of incorporating patients' habits into their usual environment, which may be trickier to implement and adjust to if they are coming from an immersive program away from day-to-day life.

In Bath, while feedback on the axial SpA virtual rehabilitation program has been overwhelmingly positive, we need further

robust evidence to ensure the acceptability, accessibility, and efficacy of digital rehabilitation interventions, and in particular, their comparative effectiveness alongside in-person rehabilitation. While there is some published evidence to suggest telerehabilitation as a suitable substitution for face-to-face interventions in chronic nonmalignant musculoskeletal pain, including some forms of arthritis, we should be cautious about generalizing these results to axial SpA specifically, and methodologic limitations have been described (e.g., small sample size, short follow-up) (24). Research has been conducted assessing the effectiveness of telerehabilitation in RMDs more broadly. These studies have found that real-time telerehabilitation can improve physical function and pain and is comparable to face-to-face intervention in terms of this improvement (25). A recent systematic review in rheumatoid arthritis identified 5 randomized controlled trials reporting a positive impact of telehealth interventions on factors such as disease activity, medication adherence, physical activity, and self-efficacy (26), although there was high heterogeneity in the interventions described. Similarly, a recent rapid review identified 14 systematic reviews exploring the effectiveness of telerehabilitation in musculoskeletal conditions, whereby, despite contradictory results, telerehabilitation could be comparable with in-person rehabilitation or better than no rehabilitation for conditions such as osteoarthritis, low back pain, and hip and knee replacement (27). These findings suggest that telerehabilitation may be effective in improving symptoms in RMDs. However, evidence is still limited, and there is an imperative need for better quality clinical trials and systematic reviews to provide sufficient evidence on efficacy and effectiveness (27). Analyses of the virtual rehabilitation program for axial SpA are currently ongoing in Bath, while similar web-based physical therapy interventions are also being tested for axial SpA in Glasgow (28).

Input and considerations from physical therapists will also be critical when considering implementation of telerehabilitation for axial SpA. Key challenges currently identified are difficulties assessing patient mobility via Zoom or when observing and instructing patients, particularly while monitoring their performance of instructed exercises or if needing to provide discrete, individualized feedback during group activities (which is much easier in person, e.g., taking someone to one side to adjust their movement, and not so feasible in an online setting). Smaller groups of patients were also preferable with remote delivery, as it was harder to monitor multiple patients' movement via a screen.

Over time, the format of the digital course can be tweaked based on further feedback from patients and the unique experience and expert knowledge of the contributing health care professionals. Economic evaluations could also be useful to determine the cost-effectiveness of digital versus in-patient rehabilitation. Future wider implementation of digital rehabilitation for axial SpA could be critical in terms of relieving pressure from the health services, reducing wait times, and reducing travel burden for patients. However, we foresee that some form of in-person, supervised delivery will still be vital, particularly for those individuals who are newly diagnosed, fearful of movement, or who may have more severe disease and need closer supervision to prevent injury during exercise. Future studies to identify those patients who may most benefit from an in-person versus virtual rehabilitation program will be useful to refine these parameters, as will collaborations between patients, health care professionals, and researchers from multidisciplinary fields (biomechanics, human–computer interaction, health psychology) to assess the impact of such interventions and the best way to implement them. An initial in-person first-contact visit should also be considered to fully triage a patient's capabilities before prescription.

The immersive element of the 2-week inpatient program may also have greater benefits in terms of improving or maintaining motivation for exercise in the long term. Spurring or maintaining motivation may be more difficult when being guided over a monitor versus an immersive experience with peers and physical therapists who are living and breathing the rehabilitation together in a socially supportive environment away from other commitments and worries in day-to-day life. Even in terms of the pandemic, many of us have experienced dull motivation and focus, described as languishing (29), when attempting to work from home all day behind a monitor; similar feelings could be experienced with the virtual course. It must therefore be ensured that we do not simply abandon invaluable in-person follow-up visits and rehabilitation completely, as certain aspects simply cannot be replicated virtually. Furthermore, loss of in-person follow-up or initiation of patient-initiated, in-person follow-up may be particularly detrimental to those patients who are more stoic in nature. Indeed, in a clinic, it is not unusual for a physician to notice a sign or symptom that has not otherwise been raised by a patient. In a recent service evaluation in Bath involving interviews with rheumatology patients and clinicians at the RNHRD, the importance of in-person interaction for reassurance was highlighted (both for patients, that they have been assessed holistically, and for staff, that they have not missed key signs of disease progression) to build patient trust in what was going to be a long-term therapeutic relationship.

While digital interventions such as virtual rehabilitation potentially offer an array of benefits in terms of accessibility, relieving pressure on health services, and economic implications, digital exclusion is another key factor that must be considered. The term digital exclusion refers to those who lack the access, capacity, skills, motivation and/or trust to confidently go online (30). Indeed, digital exclusion exists at the intersection of multiple inequalities, whereby studies have shown that nonusers of the internet, devices, and online services are increasingly in vulnerable groups and may be older, less educated, and more likely to be unemployed, disabled, or socially isolated (31). In a recent study of 548 rheumatologists from 64 countries, although 82% of rheumatologists had switched to telehealth video during the pandemic, 17% estimated that approximately one-fourth of patients did not have access to telehealth video, especially those patients living below the poverty line (32). Respondents expressed a concern

for these more socially and economically vulnerable patients, whereby wide implementation of telehealth could further widen existing health inequalities and differences in health literacy. During the pandemic, interruption of disease-modifying antirheumatic drugs without recommendation by a physician was also shown to be associated with lower socioeconomic status (33). The identification of vulnerable patients at risk of digital exclusion should be considered when beginning to implement telehealth. These patients should perhaps be prioritized for in-person, face-to-face health care delivery. In the context of rehabilitation, however, for individuals who may be more economically vulnerable and unable to take considerable time off work for an immersive rehabilitation program such as the 2-week course at the RNHRD, an online course to complete around other commitments may be preferable if provided with the appropriate resources and support.

Other considerations are provision of digital education and optimization of health services, which will be critical for suitable implementation. In a recent survey of patients and clinicians, although >70% of patients and rheumatologists believed that digital health applications were useful in the management of RMDs, patients and rheumatologists respectively highlighted lack of information on suitable applications (58.5% of patients; 41.9% of rheumatologists) and poor usability (42.1% of patients) as key barriers to implementation (34). Rheumatologists also highlighted the importance of research evidence to support the implementation of such digital services.

In the UK, a survey study of patients with axial SpA and rheumatologists during the pandemic highlighted some key areas requiring urgent attention, including upskilling of digital service provision (embedding good digital practice) and addressing gaps in digital infrastructure and staff skills (15). For example, in terms of patient coding, just 58% of health care professionals surveyed in the aforementioned study were able to identify the cohort of patients at high-risk of COVID-19 under their care in 2 weeks or less. Furthermore, 10% of respondents were still unable to identify high-risk patients 4 months after shielding guidance was first issued by the UK government. Coding challenges were often the cause of these delays and the huge variation in times to identify high-risk patients. Interestingly, similar coding concerns throughout other rheumatology services prompted in Leeds the development of a strategy to communicate with patients online and enable them to self-assess their COVID-19 risk (35). The authors described the flexibility and agility of the NHS in the UK for introducing drastic change rapidly when pressured on such an unprecedented scale, in addition to describing the encouraging level of engagement of patients when it came to self-assessment and self-education.

Conclusions

Physical therapy and rehabilitation are key in the management of axial SpA. Despite the challenges faced, the pandemic has also fostered an environment for adaptation and development of creative solutions to provide continued care. Indeed, all services have been tested and as such have been propelled into a new era of digital service provision. We have witnessed the launch of online virtual physical therapy and education in addition to an emphasis on remote monitoring. Not only has this provided a temporary stop-gap in treatment for some patients, but in the future, it may allow for a wider reach and provision of care and resilience of vital services. Unique collaboration between patients, health care professionals, and researchers will be key to fostering relationships and trust and facilitating wider evaluation and implementation of digital services at each stage in a patient's journey (from diagnosis to rehabilitation and long-term condition management), which are imperative to relieve pressure from health care providers. Despite the potential of such digital interventions, it is important to highlight the maintained critical need for face-to-face services, particularly during diagnosis or during a flare of symptoms. We must ensure that digital interventions are evaluated rigorously before widespread implementation in clinical practice. It is also vital that we remain vigilant regarding digital exclusion and that we avoid a further widening of existing health inequalities. Optimization of digital infrastructure, staff skills, and digital education alongside promoting accessibility, engagement, and building trust among communities will be vital as we enter this new age of blended in-person and digital service provision.

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AUTHOR CONTRIBUTIONS

Both authors were involved in drafting the article or revising it critically for important intellectual content, and both authors approved the final version to be submitted for publication.

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